Walking in Your Patient's Shoes: An Investigation of Genetic Counselor Empathy in Clinical Practice

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Juihsien H. Kao

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Dr. Patricia McCarthy Veach, Adviser

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Dedication

This dissertation is dedicated to my parents; my husband, *Yenpin Kao*, and our daughter,

Hannah.

Abstract

Empathy is defined as "... [the ability] to perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the 'as if' condition" (Rogers, 1957, p.210). It is an important genetic counselor attitude and skill that is effective in establishing rapport with patients and providing them with psychosocial support (Kessler, 1999; McCarthy Veach, Bartels & LeRoy, 2007). Yet there is a dearth of empirical studies concerning how genetic counselors conceptualize and use empathy in their clinical practice. Furthermore, genetic counselors' empathy tendency, or ability to experience empathy, has not been examined. Accordingly the present study investigated genetic counselors' empathy tendency, their empathic responses to patient statements in five hypothetical genetic counseling scenarios (cancer, cleft palate, Fabry disease, Long QT syndrome, and Huntington Disease), and their personal successes and challenges in engaging empathically with their patients. Two hundred ten genetic counselors responded to an anonymous online survey posted to the National Society of Genetic Counseling (NSGC) listserv, and of these respondents, 143 completed the entire survey. Their empathy tendency was assessed with the Interpersonal Reactivity Index (Davis, 1983). Results indicated that participants had the highest mean empathy scores on the Empathic Concern Scale, followed by the Perspective-Taking Scale, Fantasy Scale, and Personal Distress Scale. Content analysis of written responses to the five genetic counseling scenarios revealed that, within and across scenarios, participants' responses to patient statements varied markedly. They included concise summaries of content and reflections

of patient feelings, and lengthy, complex responses containing open and closed questions, information, self-disclosure, advice, counselor opinions, and/or nonverbal behaviors. Participants' use of empathy in their responses to the patients were not significantly related to their scores on any of the four empathy tendency scales. Analysis of empathy successes revealed three major themes: Exploring Psychosocial Issues and Providing Psychosocial Support, Information Provision, and Facilitating Patient Coping. Analysis of empathy challenges also revealed three major themes: Counselor Factors, Nature of Genetic Counseling Sessions, and Patient Factors. Implications for practice and research are presented.

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Chapter 1

Introduction

In his historical paper entitled "The Necessary and Sufficient Conditions of Therapeutic Personality Change," the founder of the Person-Centered Theory, Carl Rogers, defined empathy as "…[the ability] to perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the 'as if' condition" (Rogers, 1957, p.210). In the same paper, Rogers also advocated empathy as one of the "necessary and sufficient" conditions for therapeutic changes.

Rogers' paper sparked numerous endeavors to investigate the construct of empathy in the field of counseling psychology (cf. Bohart & Greenberg, 1998; Bozarth, 1998; Wispe, 1987). Although empathy is defined differently in other counseling theories, and not every theorist endorses such a strong therapeutic effect of empathy as does Rogers, empathy is generally acknowledged as an important counseling element. Specifically, the counseling and psychotherapy literature suggests that the empathic understanding expressed by therapists during the counseling process may enhance understanding of clients' issues/situations, deepen clients' experiences of their feelings, and in general, establish rapport within counseling dyads (Clark, 2007; Galdstein, 1983; Hill & O'Brien, 1999).

Not only is empathy a significant construct in counseling psychology, but its importance has been increasingly recognized in other human service professions. For instance, in the medical field, many professional programs are developing training

activities that aim to enhance medical trainees' empathy levels toward patients (e.g.,

Deloney & Graham, 2003; Shapiro, Rucker, Boker, & Lie, 2006). In genetic counseling,

increasing attention has been given to helping genetic counselors express empathy in

order to help them establish an emotional bond with their patients (cf. Kessler, 1999;

McCarthy Veach, LeRoy, & Bartels, 2003).

The current study investigated genetic counselors' self-perceived empathy

tendency and their use of empathy in response to hypothetical genetic counseling patient

scenarios. In the following sections, the definition and nature of genetic counseling and

the use of empathy in genetic counseling practice are described. Finally, the significance

of the present study is articulated.

Genetic Counseling Defined

Genetic counseling is a relatively new profession; the term *genetic counseling*

was coined by Sheldon Reed only about 50 years ago (Resta, 1997). In creating the term,

Reed hoped to remove the eugenic connotations generally ascribed by the public to

genetic counselors' work. Reed believed that most patients seek genetic counseling to

obtain relevant medical information regarding genetic conditions, rather than for eugenic

purposes. In addition, he advocated that psychological factors be incorporated into the

process of delivering medical/genetic information in order to empower patients in their

decision-making.

More recently, the National Society of Genetic Counselors (NSGC)

commissioned a task force to develop a definition of genetic counseling. The task force

defines genetic counseling as "the process of helping people understand and adapt to the

medical, psychological, and familial implications of the genetic contributions to disease"
(NSGC, 2006, p. 79). They identified three activities as major components of genetic
counseling process, including "interpretation of family and medical histories 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 adaptation to the risk or condition" (p. 79).

<u>Nature of Genetic Counseling: Genetic Counseling Models of Practice</u>

Given its relatively short existence, genetic counseling is still evolving as a
profession, and concomitant with that evolution is the development of models for practice
(McCarthy Veach et al., 2007; Weil, 2003). When Reed coined the term, *genetic
counseling,* he referred to it as a kind of genetic social work that integrates the provision
of medical information and psychological support. Many after Reed, including the NSGC
(2006), agreed that genetic counselors should provide medical/genetic information and
emotional support to patients (Biesecker, 2001; Evans, 2006; Kessler, 1997; McCarthy
Veach et al., 2007). However, although patients' psychological needs seem to be
acknowledged, some recognized genetic counselors' tendency to over-emphasize
information-delivery while overlooking psychological/emotional elements in practice
(Kessler, 1999; Marks, 1993). This tendency to focus on educational goals may result in a
failure to address the pain, anguish, and emotional distress patients experience in their
decision-making. Opportunities to empower patients and to enhance their self-esteem are
often missed when the focus is solely on information-provision (Kessler, 1999; McCarthy
Veach et al., 2007).

Kessler (1997) describes the disparity between an educational or *teaching model* and a *counseling model* of genetic counselor practice. The teaching approach stresses the importance of delivering medical/genetic information to patients, with the assumption that human beings make rational decisions based on the information they receive. In contrast, the counseling approach recognizes information-seeking may only be one patient goal for seeking genetic counseling and that it is important to address patients' emotional reactions in order to alleviate their distress and increase their control. Kessler believes that most genetic counselors strive to incorporate both approaches in practice, but they are seldom able to successfully combine them. Thus, he argues that genetic counselors tend to emphasize one model or the other.

In their attempt to articulate a unique model of genetic counseling practice, McCarthy Veach et al. (2007) invited 23 genetic counseling program directors or their representatives from 20 genetic counseling graduate programs in North America to identify the fundamental tenets, goals, strategies, and behaviors of genetic counseling. Their participants identified five tenets (fundamental assumptions): (1) genetic information is key; (2) relationship is integral to genetic counseling; (3) patient autonomy must be supported; (4) patients are resilient; and (5) patient emotions make a difference. They also identified 17 corresponding goals. Some examples of these goals include: empowering patients; genetic counselor and patient establish a bond, and patient self-esteem is increased. Because time limitations precluded the development of strategies and behaviors corresponding to these tenets and goals, McCarthy Veach et al. called for further research to identify those components of what they termed the "Reciprocal-

Engagement Model" (REM) of genetic counseling practice. Nevertheless, their model describes a blend of biomedical information provision/education with attention to the psychosocial aspects of genetic risk. One element that receives a strong emphasis in their model is counselor empathy.

Empathy in Genetic Counseling Practice

Definitions of empathy in genetic counseling. Some authors have theorized about empathy specific to genetic counseling settings. Kessler (1997) discusses empathy in a general manner, referring to its functions. Specifically, he regards empathy as a way to clarify patients' issues and to empower patients in their decision-making. Baker (1998) describes empathy as having "both affective and cognitive functions" (p. 133). Weil (2000) defines empathy as "…an understanding, insofar as possible, of the counselee's lived reality. This includes his or her past and present experiences, emotions, and perceptions of the world, and the role these play in shaping behavior" (p. 54). McCarthy Veach et al. (2003) defined empathy as a fundamental genetic counseling skill that requires a counselor to put himself/herself in patients' shoes to relate to (*experience*) their feelings and thoughts and then to convey (*communicate*) to patients the counselor's understanding of their experiences.

Role of empathy in genetic counseling. Given the emphasis on patient psychological needs, as reflected in the REM tenets and goals, McCarthy Veach et al. (2007) argued that it is important for genetic counselor to have strong empathy skills. Empathy appears to be a particularly salient construct since Carl Rogers' Client-Centered Therapy formed a foundational basis of the first graduate program in genetic counseling.

Indeed, Marks (1993), who developed the curriculum for that program, discusses the necessity of integrating Rogers' facilitative conditions in order to establish therapeutic relationships with patients. She further maintains that this emphasis would bridge the gap between the educational model and psychosocial models of genetic counseling practice. Specifically, she regards Rogers' ideas of empathic understanding, unconditional positive regard, and non-directive counseling as powerful and significant for addressing patients' emotions and creating strong relational bonds.

Other scholars, in addition to Marks (1993), advocate empathy training in genetic counseling. For example, Baker (1998) states that, "Empathic attunement is a learned skill. The learning occurs within our own life experiences and relationships. For many counseling professionals, empathy is explored and developed during case supervision" (p. 134). Kessler (1999) endorses training in the use of empathy to empower patients and to enhance genetic counselors' understanding of patients' situations. McCarthy Veach et al. (2003) propose that genetic counselors receive practice in using primary empathy and advanced empathy skills in order to facilitate genetic counseling processes and outcomes. Furthermore, in their article describing the REM, McCarthy Veach et al. (2007) say that Marks "got it right"—yet another testimony to the relevance and necessity of Rogers' facilitative conditions such as empathy.

Purpose and Significance of the Present Study

A number of authors argue that genetic counselors need to address patients' psychological/emotional needs in order to provide relevant services (Biesecker, 2001; Kessler, 1999; NSGC, 2006; McCarthy Veach et al., 2003). They contend that focusing

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on delivering medical information alone is insufficient for addressing patients' emotional reactions such as anxiety, grief, frustration, and distress. Although the mental health literature is replete with theory and research concerning the role and effects of empathy (cf. Clark, 2007; Duan & Hill, 1996; Gladstein, 1983), presently there is considerably less empirical attention to empathy in genetic counseling. There are few empirical data describing what empathy should and does "look like" in genetic counseling practice.

Accordingly, the present study was an investigation of genetic counselors' empathic responses to hypothetical patient scenarios and the extent to which their responses are related to their self-perceived empathy tendency. It was hoped that the results of this study would: (1) aid in further operationalization of empathy as it is used in genetic counseling practice, and (2) provide guidance regarding genetic counselors' and genetic counseling students' training needs vis a vis their empathy skills.

Chapter 2

Literature Review

This chapter contains three sections: Definitions of empathy according to two major counseling approaches – (1) Person-Centered Theory and psychoanalytic approaches; (2) review of operational definitions of empathy and related empathy measures; and (3) critical review of empirical studies of empathy in genetic counseling and other medical settings.

Empathy in the Person-Centered Framework

Carl Rogers is widely acknowledged as the most important advocate of the significance of empathy in therapeutic settings (Bohart & Greenberg, 1998; Teich, 1992; Wispe, 1987). Numerous empirical studies investigating empathy's therapeutic effects have been conducted since Rogers (1957) proposed that empathy is one of the "necessary and sufficient" conditions for therapeutic changes (cf. Bohart& Greenberg, 1998; Bozarth, 1998; Wispe, 1987). Moreover, at least two prominent empathy measures, the Barrett-Lennard Relationship Inventory (Barrett-Lennard, 1962), and the Truax Accurate Empathy Scale (Truax & Carkhuff, 1967), have their conceptual roots in Rogers' perspectives on empathy.

Rogers first defined empathy as "… [the ability to] perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the 'as if' condition (1957, p. 210). This definition speaks to both the cognitive and affective nature of empathy (Duan & Hill, 1996; Gladstein, 1983). Moreover, by stressing the "as if"

condition, Rogers distinguished empathy from the idea of identification or "losing one's self" (Bozarth, 1998; Teich, 1992).

More than a decade later, Rogers (1975) presented a second definition of empathy in his article entitled "Empathic understanding: An unappreciated way of living," stating that empathy involves:

> "… entering the private world of the other and becoming thoroughly at home in it. It involves being sensitive, moment to moment, to the changing felt meanings which flow in this other person… It means temporarily living in his/her life, moving about in it delicately without making judgments, sensing meanings of which he/she is scarcely aware, but not trying to uncover feelings of which the person is totally unaware, since this would be too threatening. It includes communicating your sensings of his/her world as you look with fresh and unfrightened eyes at elements of which the individual is fearful. It means frequently checking with him/her as to the accuracy of your sensings, and being guided by the responses you receive. … (p.4)"

In addition to being richer and more comprehensive, this second definition is distinctive from Rogers first definition in several ways. First, Rogers emphasizes that the individual (being empathized with) is the judge of the accuracy of empathy, and that constant checking on the accuracy of empathy should occur in the relationship. Furthermore, Rogers urges that one refrain from making judgments in the process of empathizing with another person. Finally, the second definition explicitly states that the content of empathy stays within conscious levels and does not extend to unconscious levels; this is an important conceptual distinction from a psychoanalytic perspective on empathy (Kohut, 1959), described later in this chapter.

It is necessary to understand the basic premises of Person-Centered theory in order to more fully appreciate how Rogers views empathy functions in therapy. In his article entitled "The necessary and sufficient conditions of therapeutic personality change" (1957), Rogers contends that empathy, genuineness/congruence and unconditional positive regard, are the three essential elements of a positive therapist attitude. He believes these attitudinal elements are indispensable for establishing rapport in counseling dyads and for promoting positive therapeutic changes. Specifically, receiving therapists' positive attitude (empathy, genuineness, and unconditional positive regard) not only allows clients to develop the same positive attitudes toward themselves, but it also nurtures their self-actualization tendency for personal growth and healing, a tendency Rogers believes to be inherent in every individual.

Rogers' ideas of empathy not only spurred much research interest in its therapeutic effects, but also stimulated the creation of numerous training activities designed to develop empathy (Bohart & Greenberg, 1998). Most of these training activities appear to focus on specific techniques such as restatement, reflection of feelings, and/or empathic reflection (Bohart & Greenberg, 1998; Teich, 1992). Unfortunately, the enthusiasm about training individuals in empathic skills led to conceptual confusion within the psychotherapy community, as many individuals confused Rogerian empathy with the above mentioned micro-skills. In fact, Rogers' Person-Centered theory and therapy and his view of empathy became somewhat caricatured because many people simplistically equated Rogerian empathy with restatement of feelings.

Rogers (1975) himself strongly refutes that empathy can be equated with any micro-skill. He contends that the essence/spirit of empathy is for building positive relationship and that empathy should be viewed as a "process" instead of a "state" (p. 4). Rogers does not oppose the use of techniques to express empathy or genuineness and unconditional positive regard. However, he believes that skills only comprise "channels" of empathy; they do not fully reflect the other two attitudinal dimensions of his definition. In other words, an extreme focus on microskills is too reductionistic and thus fails to capture the rich essence of Roger's definition.

Empathy in Psychoanalytic Theory

Unlike the important role empathy clearly holds in Person-Centered theory (Rogers, 1959, 1975), no apparent consensus regarding a definition of empathy and its status in therapy exists within the psychoanalytic community (Basch, 1983; Eagle & Wolitzky 1998; Lichtenberg, Bornstein, & Silver, 1984; Teich, 1992). Indeed, some theorists consider empathy pivotal to effective therapy, while others maintain a more reserved attitude toward its role in psychotherapy.

Heinz Kohut's perspective on empathy (1959) generally is acknowledged as the most significant work by a psychoanalyst (Teich, 1992). Yet, few recognize that the creator of psychoanalysis theory, Sigmund Freud, addressed the concept of empathy in his writing before Kohut (Eagle & Wolitzky, 1998). In his *Group Psychology and the Analysis of Ego* (1967, p.66), Freud says that empathy "plays the largest part in our understanding of what is inherently foreign to our ego in other people." He also believes that empathy is a "prerequisite for analysis" as clients need to receive empathy from

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therapists (Eagle & Wolitzky, 1998). Unfortunately, Freud seems to discuss empathy only in the context of identification and analysis; he did not fully develop his perspective on the construct (Basch, 1983; Wispe, 1987).

Inspired by his clinical work with his patients, Kohut regarded understanding clients' situations correctly in psychotherapy as therapeutically important (MacIssac, 1998). Contending that empathy is the key to accurate understanding of other's mental state, he wrote extensively on the topic. According to Kohut (1959), the inner world, unlike the physical world, cannot be perceived or understood through our sensory system. Instead, it can only be recognized and studied through introspection and empathy, defined by Kohut as *vicarious introspection*. Specifically, introspection is the means for understanding one's own inner world, whereas empathy is the method for understanding others' inner world. Furthermore, it is through introspecting one's own inner state that one becomes capable of vicariously introspecting other's inner world (i.e., to empathize).

Having defined empathy as a tool or method for collecting mental data for the purpose of understanding human minds correctly, it seems reasonable that Kohut (1959) describes empathy as value free. In his later writing, Kohut further defines empathy as "… the capacity to think and feel oneself into the inner life of another person" (1984, p.82). However, he also stresses that empathy differs from identification, as one does not lose oneself in the process of empathy. Kohut's distinction appears to be similar to Rogers' (1959, p.210) idea that one does not lose the "as if" stance in the process of empathy.

In addition to Freud and Kohut, many other psychoanalysts propose different

perspectives of empathy. Eagle and Wolitzky (1998) summarized the various empathy definitions proposed within the psychoanalytic community. One definition refers to empathy as a mode of listening (e.g., Schwaber, 1979), and it concerns understanding clients' subjective experiences. Another definition conceptualizes empathy as an essential developmental need (e.g., Beebe & Lachmann, 1988) and the therapist's job as fulfilling clients' needs for empathy. The confusion arising from various empathy definitions within the psychoanalytic community can be summarized in Theodore Reik's (1948) statement on empathy:

> "I note with a certain envy that my difficulty in describing the process of psychological comprehension adequately does not exist for many psychologists. Faced with my problem, the expression 'empathy' readily occurs to their minds and flows from their pens. Indeed, this expression sounds so full of meaning that people willingly overlook its ambiguity. To speak of empathy has on occasion been as senseless as to discuss sitting in a box without distinguishing whether one means a compartment in a theater, the driver's seat, or a big case. The word empathy sometimes means one thing, sometimes another, until now it does not mean anything (pp. 356-357).

Operational Definitions of Empathy

This section reviews several operational definitions of empathy. Major empathy theorists' (i.e., Rogers, 1959, 1974; Kohut, 1959) perspectives are reviewed first to discern whether they provide any operational definitions, followed by several significant operational definitions of empathy developed by other theorists and researchers.

Although Kohut's (1959) perspective on empathy (i.e., vicarious introspection) is the most widely discussed among psychoanalytic views on empathy, he does not elaborate regarding an operational definition. His (1984) idea of empathy appears to

consist of two steps - understanding and interpreting. Similar to Kohut's perspective, Carl

Rogers' Person-Centered theory lacks a precise operational definition of empathy (1959,

1974). This is not surprising given Rogers' strong stance that empathy reflects counselor

attitude, rather than a specific counseling micro-skill. Despite the very limited operational

implications of Rogers' writing about empathy, and without suggesting that empathy is a

counseling technique, it seems fair to state that Rogerian empathy can occur through

living "as if" one is in another person's life and conveying one's understanding of those

"as if" experiences to the person.

Conceptually rooted in Rogers' (1959, 1975) Person-Centered theory, Barrett-

Lennard's (1981) model offers a more comprehensive operationalization of empathy. His

3-phase empathy cycle delineates the process of how empathic understanding occurs and

is conveyed within interpersonal dyads. He contends that empathy happens within the

empathizer, even without the presence of the recipient of empathy, (e.g., empathizing

with figures in movies or novels). However, in order for the receiver to be able to

experience empathic understanding from the empathizer, the empathizer needs to express

it in some way.

The first phase of Barrett-Lennard's model consists of two steps. First, the

empathizer needs to be *attentive* to the receiver when the receiver shares his/her

experiences. Then the empathizer needs to experience *resonation* with the receiver's

experiences, whether they are directly or indirectly conveyed to the empathizer. The

second phase of the model involves only one step, during which the empathizer takes

actions (e.g., verbal or non-verbal) to express his/her empathy, (i.e., the resonation

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experienced in the first phase, toward the receiver). The third phase (2 steps) happens

subsequently when the *receiver attends* to the empathizer's empathy expressed in the

second phase and in return *provides feedback* regarding its accuracy. Barrett-Lennard

created the terms "expressed empathy" and "received empathy" to describe the two

distinctive kinds of empathy in the second and third phases, respectively. He notes that

the empathy cycle does not discontinue after the third phase. Instead, after the receiver

expresses feedback to the empathizer, another round of empathic understanding occurs

within the dyad. Indeed, empathy is a continuous process within dyads.

Similar to Barrett-Lennard's (1981) idea that empathizers need to express their

empathy in order for receivers to feel empathized with, Byland and Makoul (2005)

contend that it is important for physicians to communicate their empathy for patients,

rather than simply holding their "internal empathy" without expressing it. Furthermore,

they use several terms [from Suchman, Markakis, Beckman, & Frankel (1997)] to

describe: 1) situations when patients share personal/emotional information during which

it may be appropriate for physicians to show their empathy (also known as *empathic

opportunity or potential empathic opportunity*); and 2) different physicians' reactions that

convey empathy or "no empathy" to patients (e.g., *empathic response*, *empathic

opportunity terminator*).

Byland and Makoul's definitions of empathy is best described in their Empathic

Communication Coding System (ECCS) that differentiates 7 levels of empathic

communication. The lowest level of empathy is called *denial/disconfirmation*, referring

to physicians conveying no empathy to patients by discounting their emotional needs.

Perfunctory recognition (level 2) and *implicit recognition* (level 3) are the next two higher empathic levels, and they refer to physicians' providing "scripted-type" answers and their attending to peripheral issues of patients' concern, respectively. The next two higher levels are *acknowledgment* (level 4) and *pursuit* (level 5), which involve physicians' recognizing the main issue of patients' concern, and their further efforts to explore the main issue, respectively. Finally, the next higher level (Level 6: *confirmation*) specifies that physicians recognize the legitimacy of patients' concerns, while the highest level (Level 7: *shared feeling or experience)* refers to physicians' using self-disclosure or expressing explicitly that patients' struggles are understood.

After reviewing the empathy literature in counseling psychology, social psychology and developmental psychology, Gladstein (1983) proposes defining empathy as a multistage interpersonal process, involving emotional contagion, identification, and role-taking. Emotional contagion refers to a state in which one is able to receive and experience another person's emotions and feelings, while role-taking specifies one's capacity to cognitively comprehend others' situations. Distinct from the psychoanalytic concept of identification, in Gladstein's model identification is similar to Rogers' (1959) idea of living "as if." Gladstein recognizes the importance of further research to test the validity of his model.

Measures of Empathy

Chlopan, McCain, Carbonell, and Hagen (1985) trace the idea of assessing empathy to social intelligence tests in the early 20th century. These authors note that social intelligence tests assess abilities that share conceptual similarities with empathy.

For example, the George Washington Social Intelligence Test (cited in Chlopan et al., 1985), one of the most popular social intelligence tests, includes items assessing areas such as humor, social judgment, and social memory. Another example is the Chapin Social Insight Test (Chapin, 1942), which measures individuals' capacity to recognize social stimuli, such as group conflict or tension. In their review of the above measures, however, Chlopan et al. note that they have been criticized as testing verbal ability, rather than social intelligence, and as lacking sufficient empirical support for their validity.

Various inventories have been developed to measure empathy (e.g., Bachelor, 1988; Barrett-Lennard, 1962; Berger, 1962; Carkhuff, 1969; Cochrane, 1974; Davis, 1980; Elliott, Filipovich, Harrigan, Gaynor, Reimschuessel, & Zapadka, 1982; Hargrove, 1974; Hogan, 1969; Truax & Carkhuff, 1967). Many authors (Chlopan et al., 1985; Duan & Hill, 1996; Gladstein, 1983) attribute the variety of empathy inventories to the lack of consensus regarding the definition of this construct. For example, Davis (1983) views empathy as a multi-dimensional construct, and therefore, his *Interpersonal Reactivity Index* includes four subscales that measure the various dimensions. Mehrabian and Epstein (1972) define empathy as experiencing another's affect, and accordingly, their *Questionnaire Measure of Emotional Empathy* focuses on vicarious emotional experience alone, without addressing cognitive experience. Six of the more widely used measures of empathy are discussed in greater detail next. They were selected based on their significance, as suggested in the literature, and also because they illustrate the variety/diversity among extant measures.

Hogan's (1969) *Empathy Scale,* a 64-item, self-report measure, is one of the few

empathy measures developed before the 1970's that has sound demonstrated reliability

and validity (Chlopan et al., 1985). Hogan defines empathy as the capacity to mentally

comprehend others' situations, and he believes that empathy skills are an important index

for one's interpersonal acuity and social relationships. Hogan constructed the items in his

Empathy Scale by comparing the responses of individuals with low and high levels of

empathy, as measured by the combined item pool of the California Psychological

Inventory (CPI; Gough, 1964) and the Minnesota Multi-Phasic Personality Inventory

(Hathaway & McKinley, 1943). The reported average correlation between Hogan's

Empathy scale and other empathy scales is .62; and its reported internal consistency is

.80. A sample item is: "As a rule I have little difficulty in putting myself into other

people's shoes."

The *Barrett-Lennard Relationship Inventory* (BLRI; Barrett-Lennard, 1962) is

one of the most widely used measures for assessing counseling relationships (Duan &

Hill, 1996; Watson, 1998). Borrowing from ideas in Carl Rogers' (1957) Person-

Centered theory, the BLRI is a paper and pencil measure that assesses therapists' levels

of empathic understanding, regard, unconditionality of regard, willingness to be known,

and congruence toward clients. Barrett-Lennard defined empathy as therapists' capacity

to fully understand clients' experiences, both affectively and cognitively. Furthermore,

the empathic process consists of two steps: empathic recognition and empathic inference.

The former refers to the understanding of meaning *directly conveyed by clients,* and the

latter refers to the understanding of meaning *indirectly expressed by clients*. Two parallel

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forms of the BLRI (one for clients and one for therapists) are used when studying

therapeutic relationships. The author reported a split-half reliability coefficient of .86 for

the Empathy Scale. Although he claimed that the inventory has good validity, he

provided no specific empirical data to that effect. A sample item is "There are times when

I feel that this outward response is quite different from his inner reaction to me."

Another commonly used empathy measure is the *Truax Accurate Empathy Scale*

(Truax & Carkhuff, 1967), developed initially for research purposes. The authors defined

accurate empathy as therapists' capacity to understand clients' behaviors and to

communicate their understanding to clients accurately. Although this scale was

conceptually rooted in Roger's (1957) Person-Centered theory when initially developed,

the psychoanalytic perspectives of empathy, which went beyond simply understanding

clients' frames of reference, to interpretation of information, were included in later

versions of the measure. A nine-point scale assesses levels of empathy, with the lower

levels focusing on grasping clients' meanings/feelings accurately, and the higher levels

emphasizing accurate interpretation (in addition to accurate understanding) via therapists'

verbal and non-verbal language. The scale was designed to be used with tape recordings

or live observations of therapy sessions. Trained observers rate therapists' levels of

empathy based on the 9-point scale. Moderate reliability and validity were reported by

the authors.

In contrast to the more quantitatively-focused methods used in the previous three

measures, Bachelor (1988) used a qualitative method to assess empathy. In order to fill

the void with respect to measures of *clients'* perspectives of counselor empathy, Bachelor

attempted to assess clients' experiences of receiving empathy. Bachelor asked a group of

clients who received therapy during the time of the study, and a group of lay persons (as a

comparison group), to describe a situation during which they received empathy from their

therapist (or friend, for the lay person group). Each participant was provided with this

definition of empathy: "when you felt that he or she demonstrated the ability to put

himself or herself in your place" (Bachelor, 1988, p. 229). Participants' written

descriptions were then analyzed by two raters using content analysis procedures. The

author reported four kinds of perceived empathy extracted from participants' responses

(both the client-group and the lay-person-group): cognitive empathy, affective empathy,

sharing empathy, and nurturant empathy. He defined *cognitive empathy* as accurate

identification and recognition of clients' inner experiences, with the information overtly

conveyed by clients or covertly expressed. *Affective empathy* was received by clients

when their therapists were able to accurately identify and share their (clients') feelings

with them. *Sharing empathy* was experienced by clients when their therapists self

disclosed their personal perspectives or experiences spontaneously and appropriately.

Finally, *nurturant empathy* was defined as therapists' general warm, supportive, and

attending presence with their clients. The author concluded that received empathy should

be considered a multidimensional construct, instead of a global, uni-dimensional

construct.

Similar to Bachelor (1988) who views empathy as a multidimensional construct,

Davis (1983) posits that empathy consists of several sub-constructs. His Interpersonal

Reactivity Index (Davis, 1980) is a self-report measure that assesses levels of empathy

within four different sub-constructs: perspective taking, fantasy, empathic concern, and personal distress. *Perspective taking* refers to individuals' capacity of "putting themselves in others' shoes," while *fantasy* is about individuals' ability to understand the perspectives and experiences of fictitious characters, such as novel figures or TV/movie characters. Whereas *perspective taking* and *fantasy* address the cognitive dimensions of empathy, *empathic concern* and *personal distress* pertain to the affective dimensions. Both *empathic concern* and *personal distress* tap into the capacity for experiencing the feelings of those in emotional distress. However, the former refers to other people's feelings, while the latter deals with one's own emotions when one is in distress. Two sample items from the measure include: "I sometimes try to understand my friends by imagining how things look from their perspective" (from the *perspective taking* scale) and "I often have tender, concerned feelings for people less fortunate than me" (from the *empathic concern* scale).

More recently, Dziobek and colleagues (Dziobek, Rogers, Fleck, Bahnemann, Heekeren, Wolf et al., 2008) developed the Multifaceted Empathy Test (MET). Based on the authors' belief that cognitive empathy and emotional empathy are different and separable from each other, the MET measures these two kinds of empathy separately. The MET consists of 23 pairs of stimuli, with each pair of stimuli consisting of a context picture and a person picture (including a person in the same context).

When administering the MET, the context pictures are presented to participants first. After seeing the context pictures, participants are asked to rate their level of arousal, using the Self Assessment Manikin (SAM; Lang et al., 1997, cited in Dziobek et al.,

2008). Following the context pictures, person pictures are shown to participants, who are then asked to make inferences about the mental state of the person in the picture (cognitive empathy). In addition, participants are required to rate their level of arousal and their level of empathic concern for the person in the picture (emotional empathy). Internal consistencies of the subscales of MET reportedly ranged from .71 to .92. Furthermore, construct validity scores were computed by correlating the scale scores of MET (of both cognitive empathy and emotional empathy) with the scale scores (perspective taking scale, personal distress scale, and empathic concern scale) of the Interpersonal Reactivity Index (Davis, 1980). The results indicate that MET emotional empathy scores were significantly correlated with the IRI emotional empathy scores; however, the MET cognitive empathy scores did not correlate significantly with the IRI cognitive empathy scores.

Summary. It appears that empathy is construed and assessed in a variety of ways by different authors. For instance, Hogan's Empathy Scale is a self-report measure while Truax's Accurate Empathy Scale (Truax & Carkhuff, 1967) is an observer-report inventory. Bachelor (1988) adopted a qualitative method to assess perceptions of received empathy, while the Barrett-Lennard Relationship Inventory (Barrett-Lennard, 1962) is a quantitatively-based measure of both given and received empathy. Furthermore, most of the inventories described in this literature review either measure general empathy (e.g., Hogan's Empathic Scale, 1969; Davis' Interpersonal Reactivity Index, 1980; and Dziobek et al's Multifaceted Empathy Test, 2008) or therapeutic empathy (e.g., Barrett-Lennard's BLRT, 1962 and the Truax's Accurate Empathy Scale, 1967), with the

exception of Bachelor's (1988) inventory which measures received empathy in both

therapy and non-therapy settings. Finally, empathy is defined as a multidimensional

construct in the Interpersonal Reactivity Index (Davis, 1980), the Multifaceted Empathy

Test (Dziobek et al., 2008), and Bachelor's (1988) qualitative measure. In the rest of the

measures (Barrett-Lennard, 1962; Hogan, 1969; Truax & Carkhuff, 1967), however,

empathy is viewed as a global, uni-dimensional construct. These themes are coherent

with the conclusions made by Gladstein (1983) and Duan and Hill (1996) in their review

of empathy literature. These authors elaborated on the variety and diversity of definitions

of empathy and empathy measures in their articles. They also unanimously attributed the

existence of different empathy measures to the various definitions of empathy found in

the literature.

Empathy in Genetic Counseling/Medical Settings

As mentioned in Chapter 1, genetic counselor empathy has received theoretical

attention since the profession's inception (cf. Baker, 1998; Kessler, 1999; Marks, 1993;

McCarthy Veach, LeRoy, and Bartels, 2003, 2007; Reed, 1975; Weil, 2000). In addition

to the theoretical literature, a handful of studies have investigated behavioral indications

of genetic counselor empathy in clinical practice. These studies typically involve small

sample sizes and often include a variety of genetics professionals (e.g., geneticists,

genetic counselors) in the United Kingdom, and Australia.

Duric and colleagues (Duric, Butow, Sharpe, Lobb, Meiser, Barratt and Tucker, et

al.,2003) explored the relationship between genetic counselors'/clinical geneticists'

communication in genetic consultations and patients' levels of emotional distress. Study

participants were 111 women from high risk breast cancer families in Australia. Their

levels of psychological distress were measured by the Hospital Anxiety and Depression

Scale (HADS; Zigmond and Snaith, 1983) two weeks before, and three to four weeks

after their first genetic consultation. Five clinical geneticists and 2 genetic counselors

provided the 111 genetic consultation sessions. All of the consultations were audiotaped

and transcribed for analysis. Patients' emotional cues of distress, defined as any patient

messages that contained emotional content, were identified in the transcripts.

Consultants' (both genetic counselor and clinical geneticist) comments made

before, and after each patient emotional cue were also identified and categorized based on

the dimensions of *form* (e.g., open question), *content* (psychosocial content or not), and

level of empathy in response to the patient. Four levels of empathy were identified

(Carkuff & Pierce, 1975): level 1) delay or ignore; level 2) responds to content; level 3)

respondes to feeling; level 4) did level 3 and invites elaboration. The results indicated

that consultants' empathic responses to patients' emotional cues led to additional

patients' emotional cues. Further results showed significant reduction in patients' post-

consultation depression scores, when consultants used more empathic responses.

However, no significant relationship was found between the number of empathic

responses and patients' post-consultation anxiety scores.

Lobb and colleagues (Lobb, Butow, Barratt, Meiser, & Tucker, 2005) explored

the relationship between genetic consultants' (2 clinical geneticists, 2 genetic counselors,

and 1 oncologist) communication in genetic consultations and patients' levels of distress.

Participant included 150 Australian women from high risk breast cancer families

attending their first genetic consultation. Participants' levels of psychological distress

were measured two weeks before, and three to four weeks after, the genetic consultation,

using the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983).

Their satisfaction with the genetic consultation was assessed after the consultation was

completed. All of the genetic consultation sessions were audiotaped and transcribed for

analysis. The results indicated significant differences among consultants in the following

behaviors: addressing emotional concerns, facilitating understanding, active involvement,

partnership building, and discussing prophylactic mastectomy. Additional results

revealed that greater manifestation of these behaviors was related to greater improvement

in patients' depressive symptoms four weeks after the consultation. However, the authors

indicated that limitations in the statistical analysis did not allow the determination of

which specific communication behavior (e.g., addressing emotional concern or

facilitating partnership building) contributed to the improvement in patients' depressive

symptoms.

Michie, Bron, Bobrow, and Marteau (1997) investigated the relationship between

11 genetic counselors' directiveness and counseling process. Participants included 131

patients attending routine genetic consultations at a regional genetics center in the United

Kingdom. All genetic consultations were audiotaped and transcribed for analysis.

Counselor directiveness included counselor behaviors of providing advice, evaluation, or

reinforcement. *Advice* was defined as suggesting the best option for clients. *Evaluation*

referred to counselor provision of his/her perception of the client's situation. Finally,

reinforcement was defined as counselor reflection or acknowledgment of clients'

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feelings, perspectives, or behaviors. Counseling process was measured by five aspects of the consultation: the length of consultation, number of emotional issues raised by the counselor or the counselee, number of social issues raised by the counselor or counselee, number of concerns not followed up on by the counselor, and blocks of uninterrupted speech (defined as 10 transcript lines of uninterrupted counselor talk). The results indicated that counselor directiveness was associated with longer consultations (in all three directiveness areas), more blocks of uninterrupted speech (in evaluation and reinforcement), more social and emotional issues being raised (in all three directiveness areas), and fewer patient concerns being followed up on by the counselor (in evaluation only).

Summarizing the above studies, only Duric et al.'s (2003) study clearly demonstrated the effect of empathy on genetic counseling processes and outcomes. Specifically, their results showed a positive correlation between counselors' empathic responses and the number of emotional cues given by patients and the intensity of patients' depressive symptoms. Specifically, greater use of empathic responses by the counselors tended to be related to a greater number of patient emotional cues and reduced depressive symptoms. In contrast, Lobb et al. (2005) investigated the effects of empathy-related behaviors (e.g., addressing emotional concerns) and Michie et al. (1997) investigated "non-empathy" responses (e.g., advice, reinforcement) on genetic counseling outcome and process. In these latter two studies, the effects of specific counselor behaviors are unclear. Furthermore, two of the studies (Duric et al., 2003; Lobb et al., 2005) are limited to genetic counseling for breast cancer. Finally, as stated previously,

two of the studies included clinical geneticists in addition to genetic counselors, and none of these studies were done in the U.S.

Purpose of the Present Study

Empathy is believed to be an important component of genetic counseling (e.g., Marks, 1993, 2003; McCarthy Veach et al., 2007). A limited number of studies have investigated genetic counselors' empathic behavior. Results of these studies provide preliminary evidence of the positive effects of empathy on genetic counseling outcomes. No published research has examined genetic counselors' empathic tendencies. Therefore, the current study was designed to investigate genetic counselors' empathy tendency and the use of empathy in genetic counseling practice. There were five major research questions: 1) What level of empathy tendency do genetic counselors self-report? 2) How do genetic counselors respond empathically to patients in hypothetical clinical scenarios? 3) What are genetic counselors' experiences of being empathic with their patients (both successes and challenges)? 4) Are genetic counselors' demographic characteristics significant predictors of their empathy tendency? and 5) What are the relationships between genetic counselors' empathy tendency, demographic characteristics, and their empathic responses to patients?

Chapter 3

Methodology

Participant Recruitment and Data Collection

Upon approval from a University of Minnesota institutional review board
(Appendix A), an email invitation in the form of a cover letter soliciting participation in
the current study (Appendix B) was sent to the estimated 1,177 full members of the
National Society of Genetic Counselors who subscribed to the listserv on August 16,
2009. The same email invitation was sent as a follow-up reminder for participation on
September 23, 2009. Both email invitations carried a link to an online survey tool
(www.surveymonkey.com) that allows for respondent anonymity. In addition to a letter
soliciting participation, the survey included a demographic information sheet (Appendix
C); a question asking participants to evaluate a definition of empathy (Appendix D), a
self-report empathy instrument (the Interpersonal Reactivity Index; Davis, 1980, 1983,
Appendix E); a series of five hypothetical genetic counseling patient scenarios for which
respondents were asked to provide an empathic response (Appendix F), an open-ended
question asking respondents to describe an experience of being empathic with a patient
(Appendix G), and an open-ended question asking about respondents' difficulty in using
empathy in their clinical practice (Appendix H).

Sample

Two hundred ten genetic counselors (203 females, 7 males) responded to the
survey, resulting in an estimated response rate of 17.8%. Their demographics are
summarized in Table 1 and reported in the Results chapter.

Demographic Information Sheet

Ten questions were developed by this investigator to elicit information about

respondents' gender, age, racial/ethnic background, relationship status, number of years

practicing as a genetic counselor, primary area of specialty, primary work setting,

whether they were seeing patients currently or within the past two years, average number

of patients seen per week, and length of their typical genetic counseling session.

Empathy Definition

Rogers' (1975) definition of empathy was included on the survey, as follows:

> "… entering the private world of the other and becoming
> thoroughly at home in it. It involves being sensitive,
> moment to moment, to the changing felt meanings which
> flow in this other person… It means temporarily living in
> his/her life, moving about in it delicately without making
> judgments, sensing meanings of which he/she is scarcely
> aware, but not trying to uncover feelings of which the
> person is totally unaware, since this would be too
> threatening. It includes communicating your sensings of
> his/her world as you look with fresh and unfrightened eyes
> at elements of which the individual is fearful. It means
> frequently checking with him/her as to the accuracy of your
> sensings, and being guided by the responses you receive.
> … (Rogers, 1975, p.4)"

This definition was selected because genetic counseling historically has been

grounded in Rogerian theory, and current models of practice incorporate Rogers' views

on empathy (cf. McCarthy Veach, LeRoy, & Bartels, 2007). Respondents were asked to

read the definition and then choose the number that best describes the degree to which

they agree/disagree with the definition (1 = Strongly Disagree; 2 = Disagree; 3 = Agree; 4

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= Strongly Agree). They were also given an option to provide narrative comments.

The Interpersonal Reactivity Index (IRI; Davis, 1980, 1983)

The Interpersonal Reactivity Index (IRI, Davis, 1980, 1983) is a 28-item, self-report measure of empathy. Due to the paucity of paper and pencil measures of empathy (Davis, 1980; Mehrabian and Epstein, 1971), the IRI was chosen to assess genetic counselors' empathy tendency in this study because it has demonstrated psychometric properties. Based on the idea that empathy is a multifaceted construct, the IRI consists of 4 subscales: perspective taking, fantasy, empathic concern, and personal distress. *Perspective taking* refers to individuals' capacity to see things through others' perspectives, while *fantasy* refers to individuals' ability to identify with fictitious characters, such as characters in novels, television, movies, and plays. Both *empathic concern* and *personal distress* tap into an individual's capacity for experiencing the feelings of those in emotional distress. However, the former involves other people's feelings, while the latter deals with one's own emotions when one is in distress. Whereas *perspective taking* and fantasy emphasize the cognitive dimensions of empathy, *empathic concern* and *personal distress* emphasize its affective dimensions. Sample items from the measure include: "I sometimes try to understand my friends by imagining how things look from their perspective" (from the *perspective taking* scale); "I really get involved with the feelings of the characters in a novel" (from the *fantasy* scale); "I often have tender, concerned feelings for people less fortunate than me" (from the *empathic concern* scale); and "Being in a tense emotional situation scares me" (from the *personal distress* scale).

Each item on the IRI is rated on a five-point scale (0 = Does Not Describe Me Well to 4 = Describes Me Very Well). " Eight items on the IRI are reverse scored. Each subscale consists of 7 items. Sub-scale scores can range from 0 to 28, with higher scores indicating stronger capacity to empathize.

Davis (1980) reported the psychometric properties of the IRI. The internal consistency reliabilities (standardized alphas) of the four subscales ranged from .68 to .79, and test-retest reliabilities of the four scales ranged from .61 to .81. The IRI also positively and significantly correlates with two existing empathy measures, the Mehrabian and Epstein Emotional Empathy Scale (Mehrabian & Epstein, 1972), and the Hogan Empathy Scale (Hogan, 1969), thus supporting the construct validity of the measure.

Hypothetical Genetic Counseling Patient Scenarios

Five hypothetical genetic counseling patient scenarios were developed by this investigator to solicit participants' empathic responses. The scenarios consist of slightly modified excerpts from actual patient statements reported in five selected qualitative studies published in the *Journal of Genetic Counseling* during 2007 and 2008. Patient statements were chosen to reflect a variety of genetic disorders and clinical richness. Their statements were slightly modified to make them easy to read and comprehend, and sufficient information was provided so that respondents could understand the background/context of each patient statement. Respondents were asked to read each scenarios, to pretend that they were the genetic counselor in the scenario, and to provide an empathy response as if they were actually speaking to the patient. Scenarios were

standardized with respect to patient gender (female patients). Each scenario is described

next:

Scenario One: Cancer. A woman spoke about the process of undertaking genetic

assessment for familial breast/ovarian cancer risk.

> She said:

> *"Why does it take so long to assess? … When am I likely to hear
> anything? If risk is great, how soon for surgery? … I am not
> getting any younger and need to get this sorted ASAP…"(Phelps et
> al., 2007, p.509)*

> You say:

Scenario Two: Clefting. A mother described the experience of finding out at birth

that her baby was diagnosed with clefting.

> She said:

> *"The first words I heard from him (the doctor) (…) were, "Oh,
> my"…. They said it was something that was fixable and not
> something to be majorly worried about. I didn't quite like it at all.
> I heard the 'Oh my', my husband fainted and I thought something
> was majorly wrong. I actually thought maybe the baby was dead or
> something. …" (Nusbaum et al., 2008, p.340)*

> You say:

Scenario Three: Fabry Disease. A woman with Fabry disease described her

experience of the disease.

> She said:

> *"The episodes of pain in hands and feet are impossible to describe
> because the pain is so personal and out of control when it comes… The
> severe abdominal cramping is a sudden onset pain that is scary and
> something you're not sure you can survive. It actually feels like it might
> kill you [sic] many times I have passed out – I just hope and pray if I*

pass out the pain will be over when I come back… if I come back."
(Gibas et al., 2008, p.531)"

You say:

Scenario Four: Long QT Syndrome. A young woman diagnosed with Long QT

Syndrome was talking about wanting to have a baby.

She said:

"And I want to give birth to at least one child. I want to have the opportunity to do that, then later I can adopt and all those things (…) you know you have a life today and you can in a way survive. (…) When you think about having a child, it is very frustrating not to get a clear answer as to whether you might die or not (…). If I choose to take the risk, because it is a hard burden on the heart, it is entirely up to me. No one can say whether it will work out well or not." (Andersen et al., 2008, p.494)

You say:

Scenario Five: Huntington Disease. A woman at risk of developing Huntington

disease talked about concealing from her children information about her risk.

She said:

"That's one area [telling the children] where we've made some really bad decisions. We haven't really had too many discussions about it. (…) They know that my brother [who has HD], comes to visit usually twice a year for a week. They know that he, you know, that he has problems with his balance and they can't jump on him and play. And there's certain things that they can't do with him, and they know that he doesn't work because of his balance and stuff like that. They know that my father died of Huntington's disease. They know that my brothers and my sister were sick. They don't know that I'm at risk for Huntington's disease. And they know the name of it and we've, we have been I guess a little bit evasive about it because we're, I'm afraid that as soon as we say Huntington's disease they're going to think "death" you know. They're going to jump to that and I don't think my youngest son could understand that. He's very young…."(Quaid et al., 2008, p.122)

You say:

Open-ended Items

Two items asked respondents to describe their personal experiences with empathy in their clinical practice. The first item asked: "Please describe a genetic counseling session in which you were being particularly empathic with your patient. Please describe the patient's issue/situation, how you responded, and the patient's reaction to your empathy." The second item asked: "Please describe the challenges you experience in attempting to engage empathically with patients in your genetic counseling sessions."

Research Questions

The purpose of this study was to examine the use of empathy in genetic counseling settings and its relationship to genetic counselors' empathy tendency. Five research questions were investigated: 1) What level of empathy tendency do genetic counselors self-report? 2) How do genetic counselors respond empathically to patients in hypothetical clinical scenarios? 3) What are genetic counselors' experiences of being empathic with their patients (both successes and challenges)? 4) Are genetic counselors' demographic characteristics significant predictors of their empathy tendency? and 5) What are the relationships between genetic counselors' empathy tendency, demographic characteristics, and their empathic responses to patients?

Data Analysis

Several analyses were conducted in this mixed method study.

Descriptive Statistics

Means, standard deviations, n's, and ranges were calculated for responses to the

four subscales of the Interpersonal Reactivity Index. Means, standard deviations, *n*'s and percentages were calculated, as appropriate, for responses to the demographic questionnaire items.

Qualitative Analysis

    Written responses to hypothetical scenarios. Domains (rationally-derived topics) and categories (more specific topics within domains) were extracted from the content of the genetic counselors' responses to the patient scenarios (e.g., which aspects of the patients' situation the counselors address in their responses). This analysis was informed by the Helping Skills Verbal Response System (HSVRS) (Danish, D'Augelli & Brock, 1974). Given the variability in written responses, the HSVRS was used as a preliminary method for classifying different types of statements. The HSVRS operationally defines 8 types of helper responses: Continuing Responses (affect, content), Leading Responses (influence, advice, open questions, closed questions) and Self-Referent Responses (self-disclosure, and self-involvement). In addition to the 8 types of responses from the HSVRS, two types of responses were added: a non-verbal response, and an "information" response, given the emphasis on information provision/education in genetic counseling (cf. McCarthy Veach et al., 2007).

    Frequencies for each domain/category were tabulated, and verbatim quotations that illustrate each domain/category were selected. The analysis was conducted by this investigator and then reviewed by a data auditor, a licensed psychologist experienced in using the HSVRS. Disagreements were discussed until a consensus was reached.

    Responses to open-ended items. Responses to the two open ended items regarding

empathic connection and empathic challenges with one's own patients were analyzed

using an interpretive content analysis method (Giarelli and Tulman, 2003). This method

allows responses with similar conceptual themes to be categorized. One volunteer

researcher from a master's counseling program analyzed the content of responses to each

question and grouped them based on their conceptual similarities. Next, she reviewed

each grouping and labeled it with a name that represents the major theme underlying the

responses in that grouping. After the themes were identified, coding was done

inclusively, allowing a response to be coded under multiple themes/categories.

Frequencies for each theme were tabulated and verbatim illustrative quotations were

selected. Her analysis was reviewed by this investigator and a licensed psychologist, and

disagreements were discussed until a consensus was reached.

Quantitative Analyses

     Multivariate analysis of variance (MANOVA): Empathy tendency and

demographic factor (years of experience). To determine the relationship between years of

experience and scores on the four IRI subscales MANOVAs were conducted. The

dependent variables were scores on the four IRI subscales, and the independent variable

as years of genetic counseling experience (< 5 years versus ≥5 years).

     Multivariate analysis of variance (MANOVA): Empathy tendency and empathy

responses. To determine the relationship between empathy responses (whether one did or

did not provide an empathy response) for each of the hypothetical clinical scenarios and

scores on the four IRI subscales, a series of MANOVAs were conducted. The dependent

variables were scores on the four IRI subscales, and the independent variables were the

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empathy/no empathy responses for each of the five scenarios. Note that participants whose responses were categorized into the "Content" domain and/or the "Affect" domain were in the "Empathy" group, whereas those whose responses were not categorized in either domain were in the "No empathy" group.

Chi-square analyses: Demographic variable (years of experience) and empathy response. Five chi-square analyses were conducted to determine the relationship between years of genetic counseling experience (< 5 years versus ≥ 5 years) and counselor responses ("Empathy" versus "No empathy") for each of the five scenarios.

Chapter 4

Results

This chapter begins with a description of the sample's demographic characteristics, reactions to the definition of empathy provided on the survey, and responses to the Interpersonal Reactivity Index. Results of quantitative analyses are reported first, followed by results of qualitative analyses of responses to the hypothetical clinical scenarios and responses to questions about empathy challenges and successes.

Demographic Characteristics

The total sample consisted of 210 individuals. Everyone in the sample completed the Demographic Sheet. One hundred twenty-three individuals (hereafter referred to as the *completers*) completed the whole survey [i.e., the Demographic Sheet, the Interpersonal Reactivity Index (IRI), and the Hypothetical Clinical Scenarios]. The remaining 87 individuals completed parts of the survey, but not all three main sections. For various analyses that involve only parts of the survey, data for every individual who completed those parts are included.

Responses to the Demographic Sheet and ratings of agreement/disagreement with Roger's definition of empathy for the total sample and the completers are summarized in Table 1. Those data for individuals who partially completed the survey are provided in Appendix I. As shown in Table 1, the vast majority of participants in the total sample were female ($n = 203$, 96.7 %), they identified themselves as Caucasian/white ($n = 193$, 91.9 %), and they were either married ($n = 121$, 57.6 %) or single ($n = 62$, 29.5 %). The most prevalent age range was "25-29" ($n = 67$, 31.9 %), and the most prevalent range for years of practice was "< 5 years" (n = 107, 51.0%). These percentages of novice and

experienced counselors reflect the general population of genetic counselors (Smith, Freivogel, & Parrot, 2009). Almost all (n = 198, 94.3 %) were seeing patients at the time of the survey. They saw an average of 11.85 patients per week (SD = 7.67), and the average length of their genetic counseling sessions was 52.87 minutes (SD = 19.50). The most prevalent genetic counseling specialties were: prenatal counseling (n = 119, 56.7 %), Cancer Genetics (n = 66, 31.4 %), and pediatric counseling (n = 61, 29.0 %). Most participants either agreed (n = 144, 68.6%) or strongly agreed (n = 45, 21.4%) with Carl Rogers' definition of empathy.

Differences Between Total Sample and Completers

A series of one-way analyses of variance (ANOVA's) and chi-square analyses were conducted to determine whether there were significant differences between the total sample and the completers with respect to demographic variables for which there was sufficient variability. There was no statistically significance difference between the total sample and the completers for the number of patients seen per week, *$F(1,289) = 0.058$, p = 0.89* (M = 11.85, SD = 7.67 versus M = 11.63, SD = 7.12, respectively). There also was no statistically significant difference between the total sample and the completers for the average length of genetic counseling sessions, F(1, 311) = 0.452, *p = 0.502* (M = 52.87, SD = 19.50 versus M = 54.45, SD = 21.11).

Responses for several categorical variables were regrouped in order to obtain the minimum cell number of five to run the chi-square analyses. Responses for *Age* were combined into three groups: 20-34 years (n= 144 versus n = 85); 35-49 years (n = 50 versus n = 30); and 50-64 years (n = 16 versus n = 8). Responses for *Race/Ethnicity* were

regrouped into Caucasian/White ($n = 193$ versus $n = 114$); and Non-White ($n = 17$ versus $n = 9$). Responses for *Years of Genetic Counseling Experience* were regrouped into less than 5 years ($n = 107$ versus $n = 67$), and greater than or equal to 5 years of experience ($n = 102$ versus $n = 56$). Chi-square analyses showed no significant differences between the total sample and the completers on any of these three variables: *Age* [X^2 (2, $N = 333$) = 0.148, $p = 0.929$]; *Race* [X^2 (1, $N = 333$) = 0.065, $p = 0.798$]; and *Years of Experience* [X^2 (1, $N = 332$) = 0.333, $p = 0.564$].

Reaction to Rogers' Definition of Empathy

The vast majority of participants either agreed ($n = 144$, 68.6%) or strongly agreed ($n = 45$, 21.4%) with Carl Rogers' definition of empathy. Thirty-five individuals provided comments about Roger's definition. Their comments are listed in Appendix J. About two-thirds of the comments indicated agreement with the definition. Some comments referred to difficulty with certain aspects of empathy. For instance, some participants commented about the difficulty "to be thoroughly at home in the other's world." Some identified time limitations in genetic counseling as a challenge for achieving the type of empathy implied by Rogers' definition. Among the participants who disagreed with Rogers' definition, some mentioned that empathy can only be achieved when two individuals share similar personal experiences, and some believed that counselors should try to uncover feelings of which the patient is unaware of, something Rogers considered unhelpful to do.

Table 1: Demographic Characteristics of Participants

	Completers (*n*= 123)			Total Sample (*N*= 210)		
Variable	*n*	%	M	*n*	%	M
Gender						
Female	118	95.9	-	203	96.7	-
Male	5	4.1	-	7	3.3	-
Age						
20-24	8	6.5	-	13	6.2	-
25-29	43	35.0	-	67	31.9	-
30-34	34	27.6	-	64	30.5	-
35-39	15	12.2	-	26	12.4	-
40-44	5	4.1	-	12	5.7	-
45-49	10	8.1	-	12	5.7	-
50-54	4	3.3	-	8	3.8	-
55-59	2	1.6	-	5	2.4	-
60-64	2	1.6	-	3	1.4	-
Race						
African American	1	0.8	-	1	0.5	-
Alaskan Native	0	0	-	0	0	-
Asian American	2	1.6	-	7	3.3	-
Biracial	1	0.8	-	3	1.4	-
Caucasian	114	92.7	-	193	91.9	-
Chicano/Hispanic	1	0.8	-	2	1.0	-
Other	4	3.3	-	4	1.9	-
Relationship						
Single	40	32.5	-	62	29.5	-
Engaged	5	4.1	-	9	4.3	-
Married	70	56.9	-	121	57.6	-
Partnered	6	4.9	-	15	7.1	-
Separated/Divorced	0	0	-	0	0	-
Widowed	0	0	-	0	0	-
Other	1	0.8	-	1	0.5	-
Missing	1	0.8	-	2	1.0	-
Years of Practice						
< 5 years	67	54.5	-	107	51.0	-
6-10 years	28	22.8	-	54	25.7	-
11-15 years	14	11.4	-	24	11.4	-
16-20 years	3	2.4	-	6	2.9	-
Greater than 20 years	11	8.9	-	18	8.6	-
Missing	0	0	-	1	0.5	-
Currently Seeing Patients						
Yes	120	97.6	-	198	94.3	-
No	3	2.4	-	12	5.7	-

Table 1 Continued: Demographic Characteristics of Participants

	Completers (*n*= 123)			Total Sample (*N* = 210)		
Variable	*n*	%	M	*n*	%	M
Primary Specialty						
Adult Counseling	19	12.4	-	26	12.4	-
Cardiology	2	2.4	-	5	2.4	-
Cancer Genetics	42	31.4	-	66	31.4	-
Infertility, ART/IVF	7	5.7	-	4	5.7	-
Molecular/Cytogenetics/ Biochemical Test	8	8.1	-	5	8.1	-
Neurogenetics	1	1.4	-	3	1.4	-
Pediatric Counseling	36	29.0	-	61	29.0	-
Prenatal Counseling	72	56.7	-	119	56.7	-
Psychiatric Disorder	1	1.4	-	3	1.4	-
Public Health/ Newborn Screening	5	4.3	-	9	4.3	-
						-
Screening	9	5.7	-	12	5.7	-
Specialty Disease	9	7.1	-	15	7.1	-
Teratogens	5	3.8	-	8	3.8	-
Other	3	3.8	-	8	3.8	-
Work Setting						
University Medical Center	44	35.8	-	73	34.8	-
Private Hospital/ Medical Facility	28	22.8	-	42	20.0	-
Public Hospital/ Medical Facility	23	18.7	-	41	19.5	-
Diagnostic Lab	5	4.1	-	11	5.2	-
Physician's Private Practice	14	11.4	-	27	12.9	-
Federal/State/ County Office	3	2.4	-	4	1.9	-
Other	4	3.3	-	10	4.8	-
Missing	2	1.6	-	2	1.0	-
No. of Patients/Week	109	-	11.63	182	-	11.85
Length of Session (min)	118	-	54.45	195	-	52.87
Roger's Definition						
Strongly Disagree	4	3.3	-	4	1.9	-
Disagree	2	1.6	-	5	2.4	-
Agree	91	74.0	-	144	68.6	-
Strongly Agree	26	21.1	-	45	21.4	-
Missing	0	0	-	12	5.7	-

Genetic Counselors' Empathy Tendency

Mean Scores on the IRI Subscales

One hundred sixty-seven individuals completed the Interpersonal Reactivity Index (IRI; Davis, 1983). Table 2 contains a summary of the means, standard deviations, and ranges for the four IRI subscales. The possible range for each IRI scale is *0 – 28*. As shown in Table 2, genetic counselors had the highest mean score on the Empathic Concern Scale (M = 21.32, SD = 3.75), followed by the Perspective-Taking Scale (M = 19.40, SD = 3.85), the Fantasy Scale (M = 17.92, SD = 4.67) and the Personal Distress Scale (M = 10.12, SD = 4.17). Davis (1983) administered the IRI to 53 female and 56 male undergraduate students. He found that female students had significantly higher scores than males on all four IRI subscales. Comparing the scores for the present sample to those of Davis' male and female samples, the genetic counselors' mean scores appear to be higher than the males in Davis' study. Compared to Davis' female sample, the genetic counselors' mean scores seem to be fairly comparable for Empathic Concern, lower for Fantasy and Personal Distress, and higher for Perspective-Taking. The scores for these three groups are as follows: Empathic Concern Scale (Males: 19.04, Genetic Counselors: *21.32*, Females: 21.67); Fantasy Scale (Males: 17.53, Genetic Counselors: *17.92*, Females:18.75); Personal Distress Scale (Males: 9.46, Genetic Counselors: *10.12*, Females: 12.28); Perspective-Taking Scale (Males: 16.78, Females: 17.96, Genetic Counselors: *19.40*).

Relationships Between Demographic Factors and Empathy Tendency

One of the major research questions investigated was whether empathy tendency

would vary as a function of genetic counselor characteristics. A multivariate analysis of variance (MANOVA) was conducted to determine whether there were significant differences in scores on the four subscales of the IRI due to genetic counselor years of experience. No other demographic variables were appropriate to be included in the analysis due to the uneven numbers of participants in specific levels of variables and/or lack of variance in responses (e.g., participants were predominantly Caucasian and female).

Responses to the *Years of Genetic Counseling Practice* item were regrouped into Novice: less than 5 years ($n = 83$) and Experienced: greater than or equal to 5 years" ($n = 84$). This regrouping was done to avoid the drastic difference in number of participants across the original 5 levels of the variable. Means and standard deviations for scores on the IRI subscales for novice versus experienced genetic counselors are summarized in Table 3. The results of the MANOVA yielded no significant main effect for experience on any of the four IRI scales [Wilks' lambda = 0.973, $F(4,162) = 1.137$, $p = 0.341$].

Empathy Responses and Empathy Tendency

For each hypothetical clinical scenario, participants were divided into two groups based on their written responses: "Empathy" versus "No Empathy." Roger's (1975) definition of empathy was used as the criterion for evaluating whether or not participants' expressed empathy to the patient in each scenario. Specifically, the "Empathy" group included individuals whose responses included at least one reflection of the patient's experience (content response) and/or the patient's feelings (affect response). In contrast, the "No Empathy" group included individuals whose responses did not include at least

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Table 2: Means, Standard Deviations, and Ranges for the Interpersonal Reactivity Index (IRI) Subscales ($n = 167$)

Subscales	M	SD	Range
Empathic Concern (EC)	21.32	3.75	7-28
Perspective-Taking (PT)	19.40	3.85	7-28
Fantasy (FS)	17.92	4.67	4-28
Personal Distress (PD)	10.12	4.17	0-20

Note. Scores for each subscale can range from 0 to 28, with higher scores indicating higher levels of the respective empathy dimensions.

one content or affect response, based on Rogers' definition. For each scenario, a multivariate analysis of variance (MANOVA) was conducted to determine if the two groups ("Empathy" vs. "No Empathy") differed in their mean scores on the four IRI scales.

For Scenario One, the MANOVA results showed no significant main effect for the groups ["Empathy" ($n = 110$) vs. "No Empathy ($n = 12$)] on the four IRI scales, [Wilks' lambda = 0.986, $F_{(4,117)} = 0.407$, $p = 0.804$]. Therefore, there were no significant differences between the two groups on Empathic Concern, Fantasy, Personal Distress, or Perspective-Taking.

For Scenario Two, the MANOVA results showed no significant main effect for groups ["Empathy" ($n = 110$) vs. "No Empathy" ($n = 13$)] on the four IRI scales, [Wilks' lambda = 0.953, $F_{(4, 118)} = 1.442$, and $p = 0.224$]. Therefore, there were no significant differences between the two groups on the four IRI scales.

For Scenario Three, the MANOVA results showed no significant main effect for groups ["Empathy" ($n = 71$) vs. "No Empathy" ($n = 49$)] on the four IRI scales [Wilks' lambda = 0.991, $F_{(4, 115)} = 0.258$, and $p = 0.904$]. Therefore, there were no significant differences between the two groups on the four IRI scales.

Table 3: Means and Standard Deviations for Scores on the Interpersonal Reactivity Index (IRI) Scales for Novice (*n* = 83) versus Experienced (*n* = 84) Genetic Counselors

	Empathic Concern Scale		Fantasy Scale		Personal Distress Scale		Perspective-Taking Scale	
	M	SD	M	SD	M	SD	M	SD
Novice	21.71	3.59	18.35	4.49	10.55	3.69	19.39	3.61
Experienced	20.94	3.88	17.50	4.84	9.69	4.58	19.40	4.10

Note. The Novice group consists of genetic counselors with less than five years experience providing genetic counseling to patients. The Experienced group consists of genetic counselors with greater than five years experience providing genetic counseling to patients.

For Scenario Four, the MANOVA results showed no significant main effect for groups ["Empathy" (*n* = 89) vs. "No Empathy" (*n* = 31)] on the four IRI scales, Wilks' lambda = 0.960, F (4, 115) = 1.187, and *p* = 0.320]. Therefore, there were no significant difference between the two groups on the four IRI scales.

For Scenario Five, the MANOVA results showed no significant main effect for groups ["Empathy" (*n* = 92) vs. "No Empathy" (*n* = 27)] on the four IRI scales, [Wilks' lambda = 0.977, F (4, 114) = 0.673, and *p* = 0.612]. Therefore, there were no significant differences between the two groups on the four IRI scales.

To further understand the relationship between empathy tendency and empathy responses, this investigator contrasted the content of written responses of participants who scored the highest (top five scorers or more if more than one person had a similar score) and the lowest (lowest five scorers or more if more than one person had a similar score) on each of the IRI scales. For instance, empathy responses of participants who scored the highest (*n* = 6) on the Empathic Concern Scale were compared to empathy

responses of those who scored the lowest ($n = 5$) on the same scale. The same comparison was also conducted for the other three IRI scales: the Perspective-Taking Scale, the Fantasy Scale, and the Personal Distress Scale.

There were no discernible difference in response content for the four comparisons. The responses of both high and low scorers on the four scales were congruent with the themes/domains identified for the empathy responses of all participants (presented in the next section). Specifically, written responses of participants in both groups included short and lengthy statements, statements that were exclusively empathy (i.e., content or affect statements) and statements that reflected multiple domains (e.g., advice, influence, self-disclosure). Finally, both groups appeared to provide accurate empathy responses; none of their responses appeared to be "off-the-mark."

Examination of the demographic characteristics of high versus low scorers indicated that they were similar demographically. They were predominantly female, white, young (most prevalent age range being "25-29") group, married or single, and a novice-practitioner (most prevalent years of practice being "< 5 years") group. Finally, most participants in both groups either "agreed" or "strongly agreed" with Rogers' definition of empathy, sharing a similar perspective to the majority participants in the current study.

Empathy Response and Genetic Counseling Experience

A series of Chi-Square analyses were conducted to determine possible relationships between participants' written responses in the five hypothetical clinical scenarios and one selected demographic variable – years of experience. Participants were

divided into two groups based on their written responses (as described in the previous section): "Empathy" versus "No Empathy."

For scenario One, Chi-Square analysis showed no significant difference between the two groups for *Years of Experience* [X^2 (1, N = 122) = 0.251, *p* = 0.114].

For scenario Two, Chi-Square analysis showed no significant difference between the two groups on *Years of Experience* [X^2 (1, *N* = 123) = 0.406, *p* = 0.524].

For scenario Three, Chi-Square analysis showed no significant difference between the two groups on *Years of Experience* [X^2 (1, *N* = 120) = 2.866, *p* = 0.09].

For scenario Four, Chi-Square analysis showed no significant difference between the two groups on *Years of Practice* [X^2 (1, *N* = 120) = 1.365, *p* = 0.243].

For scenario Five, Chi-Square analysis showed a significant difference between the two groups on *Years of Experience* [X^2 (1, *N* = 119) = 4.357, *p* = 0.037]. Scenario Five involved a woman at risk for Huntington Disease who was concerned about when and how to explain her risk to her children. For this scenario, within the individuals who provided an empathy response, novice counselors had a significantly higher percentage (*n* = 55, 59.78%) than experienced counselors (*n* = 37, 40.22%). Within the individuals who provided a no-empathy response, experienced counselors had a significantly higher percentage (*n* = 17, 62.96%) than novice counselors (*n* = 10, 37.04%).

Genetic Counselors' Empathic Response to Hypothetical Clinical Scenarios

The number of participants who responded to each of the five hypothetical clinical scenarios ranged from 139 to 144. Many of their responses were complex and therefore were classified multiple times in domains and/or categories. In this section,

each scenario is presented, followed by each domain and illustrative examples. In

addition, Tables 4 - 8 contain one example from each domain for each of the Scenarios in

order to demonstrate "at a glance," the wide range of responses provided by participants.

<div align="center">Scenario One: Cancer</div>

A woman is speaking to you about the process of undertaking genetic assessment for
familial breast/ovarian cancer risk (Phelps et al., 2007, p.505). She says to you: "Why
does it take so long to assess?... When am I likely to hear anything? If the risk is great,
how soon can I have surgery? … I am not getting any younger and need to get this sorted
ASAP." You say (your empathic response):

For Scenario One, 142 participants wrote responses that were classified into 10

domains. The number of different domains reflected in their individual responses ranged

from 1-6.

Affect Domain (n = 94)

Ninety-three participants wrote responses that reflected the patient's feeling(s)

about various aspects of her situation. There are 7 categories.

Category 1. Patient anxiety/nervousness (n = 45). One genetic counselor said, "I

can see that you are very anxious to figure out what your cancer risk is…" Another

genetic counselor expressed, "I can see that you are anxious about a timeline for this

testing…" Yet another responded, "It seems to me that you are feeling anxious to get an

answer soon."

Category 2. Patient frustration (n = 18). Several participants reflected that the

patient was feeling frustrated over various aspects of her situation, including the time

interval required to receive a test result and over the ambiguity of her situation. For

instance, one genetic counselor replied, "It seems like you're frustrated about the time it

takes to wait for an answer…" Another said, "You're frustrated that you don't have a definitive plan."

Category 3. Advanced empathy (n = 11). Ten counselors identified possible latent feelings the patient was experiencing. One genetic counselor said, "You're really anxious about your cancer risk and want to feel that you can control some aspect of it?" Another replied, "While you seem most anxious about the timing of results could you also be anxious about what those results might tell you?"

Category 4. Patient concern/worry (n = 10). A number of participants reflected the patient's concern. One genetic counselor commented about the time interval, "Sounds like you are concerned about moving on with the process as soon as possible." Another expressed, "It sounds like you are pretty worried about all of this."

Category 5. Patient stress (n = 9). One genetic counselor referred to the waiting period, "I can imagine that it's too stressful to have to wait." Another identified the stress involved in post-test result decisions, "It must be very stressful feeling like so many large decisions hinge on these test results."

Category 6. Patient fear (n = 7). One genetic counselor said, "I can only imagine how scary it is to wait on this information…" Another responded, "I am sure this feels very scary to you."

Category 7. Patient feels overwhelmed (n = 4). One genetic counselor replied, "It sounds like you're feeling overwhelmed by the implications of this testing and the potential results."

Content Domain (n = 56)

Fifty-six participants wrote responses that reflected or summarized the essence of the patient's statements. There are 7 categories.

Category 1. Acknowledging the difficulty of waiting (n = 22). Many counselors commented on the difficulty posed by waiting for results. One genetic counselor responded, "It is so hard to wait for information like this…" Another wrote, "… I understand that every week feels like an eternity…"

Category 2. Recognizing patient's desire to receive results/answers ASAP (n = 16). One genetic counselor replied, "It sounds like you would like to have a definite answer as quickly as possible so that you may make the decision to have surgery…" Another responded, "It sounds to me like you would like this information as quickly as possible…"

Category 3: Recognizing patient's need to move ahead/make plans (n = 12). One genetic counselor expressed, "… you are ready to get the ball rolling." Another said, "…It sounds, too, like you really just want to have a plan in place for this process over the next few weeks."

Category 4. Expressing the significance of the test results (n = 3). One genetic counselor responded, "I understand that this information will be very important for your decision in the future…" Another wrote, "… It sounds like you feel like your life depends on these results…"

Category 5. Acknowledging patient questions (n = 2). One genetic counselor said, "I understand that you have a lot of questions…" Another replied, "…You are in a

situation where you have a thousand questions, some of which we can answer, some which we cannot…"

 Category 6. Appreciating patient's thoughts/efforts put into the process (n = 2). One genetic counselor said, "It sounds like you have really been thinking about what these results will mean for you…"

 Category 7. Miscellaneous (n = 2). Two content responses could not otherwise be classified: "… You've seen all these people in your family who have cancer and you don't want to go through that…"; and "… It sounds like you would be willing to undergo prophylactic surgery if the risk is high…"

Influence Domain (n = 56)

Fifty-six participants wrote personal opinions expressing either support or disagreement with the patient's thoughts, feelings, and/or behaviors. There are 9 categories.

 Category 1. Normalizing that waiting is difficult (n = 24). One genetic counselor replied, "…Waiting and anticipation are often the most difficult part of this process…" Another said, "…Waiting is hard for everyone."

 Category 2. Rationalizing why assessment takes time (n = 21). One genetic counselor replied, "…The laboratory needs to do the test twice to ensure that the results are accurate so this takes some time…" Another said, "… unfortunately, the testing process is quite complicated and takes some time to perform…"

 Category 3. Normalizing patient's general feelings about the situation (n = 8). One genetic counselor expressed, "… I understand your concern and urgency given that

cancer can be a very scary illness…" Another responded, "… it is normal to feel like we are in an emergency situation…"

       Category 4. Reinforcing uptake of counselor advice (n = 6). A few participants offered suggestions (advice) to the patient. Several suggested ways to proceed in a planful manner, and they followed those suggestions with an influencing response supporting the utility of their advice (likely to increase the chance the patient would comply with their suggestions). For instance, one genetic counselor replied, "… (Perhaps we can sit down and sort out pro's and con's to having surgery and give you something to think about while the testing is being performed [advice]) That way hopefully by the time your results have come back you will have thought everything through and can make a well-informed decision." Another genetic counselor expressed, "(We can discuss all of your options for your future healthcare now [advice]) - so that as soon as the results return we can begin to implement which ever option you choose."

       Category 5. Providing a "reality check" (n = 6). Six influence responses attempted to correct the patient's perspective. One genetic counselor said, "… I think that right now you're thinking several steps ahead of where we are right now, which is the initial assessment phase…" Another expressed, "… (You are in a situation where you have a thousand questions, some of which we can answer, some which we cannot.) That is exactly why you and I are here right now…"

       Category 6. Normalizing patient's need to move on (n = 4). One genetic counselor said, "…It is certainly understandable that you will want to get this sorted ASAP…" Another responded, "…I think a lot of people in your position want to just get

done with this and feel like they can move on with their lives."

Category 7. Expressing counselor's medical opinion (n = 4). One genetic counselor replied, "… Having surgery is a big step that may or may not be appropriate, and it is not a decision that should be made rashly…" Another said, "… (Everyone on the team is interested in getting you the medical care you need.) It is as important to go about this in an orderly fashion as it is to do everything quickly."

Self-Disclosure Domain (n = 39)

Thirty-nine participants shared personal information in responding to the patient. There are 2 categories.

Category 1. Counselor assurance about facilitating the process (n = 26). Many of these participants stated that they would contact the patient as soon as her results are available. For example, one genetic counselor said, "…Be assured that the *moment* we hear something we will call you…" Another genetic counselor expressed, "…I promise though, I will call you with the results as soon as they get faxed over…" Other participants verbally committed to do what they could to expedite the process. One genetic counselor replied, "…I assure you that I'll do everything I can to make the process go as quickly and smoothly as possible…" Another genetic counselor said, "…We will try to get everything done as soon as we can…"

Category 2. Counselor describing own role and approach (n = 13). One genetic counselor responded, "…We need to take everything one step at a time.…" Another genetic counselor expressed, "…I'll be here to help you put that information into context as you make your surgery decision…"

Information Domain (n = 28)

Twenty-eight participants provided information to the patient. There are 4 categories.

Category 1. Information about time frame of genetic testing (n = 19). One genetic counselor said, "…It takes two to three weeks to get back the results of the test…" Another responded, "…Testing typically takes x long…"

Category 2. Information about treatment options/procedures (n = 13). One genetic counselor replied, "…As far as surgery, if you do have a change in your DNA sequence and the risk is great, you and the surgeon can discuss when the best time for you to have surgery is…" Another expressed, "Surgery may not be something you need to face, but if you decide you would like to proceed with surgery based on a positive test result, we can set up an appointment for you to meet with Dr. John Doe."

Category 3. Information about how test results will be handled (n = 5). One genetic counselor responded, "…… Results will be given to you and your doctor as soon as they are received." Another replied, "…When the results come back we will sit down and talk more in-depthly about what those mean for you…"

Category 4. Information about breast cancer risk (n = 4). One genetic counselor said, "…I spoke earlier about the fact that women with a BRCA gene mutation have a 60-80% lifetime risk of breast cancer, but this risk accumulates over time…"

Advice Domain (n = 21)

Twenty-one participants provided advice to the patient. There are 5 categories.

Category 1. Advising about assessment-related issues (n = 7). One genetic

counselor said, "… Let's take one step at a time, and talk first about the testing and how it works, which may answer your questions as to why it takes a bit to get results…" Another genetic counselor suggested, "… really internalize what these results would mean for you whether they are positive or negative."

Category 2. Advising patient to seek support (e.g., from counselor, family, friends) (n = 5). One genetic counselor replied, "… You can take my card if you'd like to call me to check up as well…" Another genetic counselor said, "… I would recommend in the meantime to discuss this information with your friends and family and really internalize what these results would mean for you whether they are positive or negative

Category 3. Advising about treatment options/procedures (n = 5). One genetic counselor replied, "… Perhaps we can sit down and sort out pro's and con's to having surgery and give you some things to think about while the testing is being performed…" Another genetic counselor expressed, "…Let's wait to discuss surgery options until we know what your risks are…"

Category 4. Advising patient to be planful (n = 5). One genetic counselor said, "… Would it be helpful if we think of ways to feel prepared for when the assessment is complete so you will know what you would like to do when we know what your risk is?"

Category 5. Miscellaneous (n = 1). One advice responses could not otherwise be classified: "… Let's try to explore your feelings to try to relieve some of your anxiety."
Self-Involvement Domain (n = 17)

Seventeen participants responded with their "here and now" personal reactions to the patient and/or her behavior. There are 4 categories.

Category 1. Expressing counselor's wish for an alternative situation (n = 6). One genetic counselor said, "… I wish that I was able to give the results to you more quickly…" Another genetic counselor said, "…I wish I had some way to make it happen faster!"

Category 2. Expressing sympathy toward the patient (n = 5). One genetic counselor replied, "…I'm sorry we can't sort everything out for you as fast as you'd like…" Another said, "I'm sorry that you have to wait longer than you'd like…."

Category 3. Acknowledging counselor's understanding of patient's feeling (n = 5). One genetic counselor responded, "… and of course I can understand why you might be anxious…" Another genetic counselor said, "(It sounds like you're nervous about your risks), and I can understand that"

Category 4. Expressing counselor's willingness to be helpful (n = 3). One genetic counselor responded, "…If there's any other questions you have about the testing, however, I would be happy to answer them."

Open-ended Question Domain (n = 14)

Fourteen participants wrote open-ended questions in response to the patient. There are 3 categories.

Category 1. Assessing patient's sense of urgency (e.g., about the waiting, having a surgery) (n = 5). One genetic counselor said, "…Tell me what you are thinking about and why three weeks seems long to you." Another responded, "…Can you share with me why you may be feeling a sense of urgency to get this done??"

Category 2. Assessing causes of patient's fear or anxiety (n = 4). One genetic

counselor asked, "…Would you share with me some of the thoughts or issues that are causing you anxiety?" Another said, "…Can you help me understand what your greatest fear is?"

Category 3. Assessing patient's perspective of having high risk/cancer (n = 4). One genetic counselor asked, "Tell me more about your concerns about being at greater risk." Another replied, "can you talk a little more about what "high risk" means for you?"

*Category 4. Miscellaneous (n =1).*One open-ended question could not otherwise be classified: "…What questions can I answer right now?"

Close-ended Question Domain (n = 6)

Six participants wrote close-ended questions in response to the patient. There are 3 categories.

Category 1. Assessing patient's needs (n = 2). One genetic counselor asked, "… Is there anything I can do for you right now?" Another genetic counselor said, "… Is there something specific that is bothering you about the situation that we can address?"

Category 2. Questions attempting to reach an agreement between counselor and patient (n = 2). One genetic counselor said, "… (I think that right now you're thinking several steps ahead of where we are right now, which is the initial assessment phase.) Do you agree?"

Category 3. Miscellaneous (n = 2). Two close-ended questions could not otherwise be categorized: "… (Simply because of your age and that fact that you are a woman, your risk of breast cancer within the next year is [information].) Do those

numbers make you feel any differently?" "…is there something that happened recently that made you decide that now is the time to pursue this testing?"

Non-Verbal Behavior Domain (n = 2)

Two participants used non-verbal behaviors in response to the patient. Their responses included "nodding" and "silence."

Table 4 contains an example of a response from each domain for Scenario One.

<div align="center">Scenario Two: Clefting</div>

A woman is describing to you her experience of finding out at birth that her baby was diagnosed with clefting (Nusbaum et al., 2008, p.340). She says to you: "The first words I heard from the doctor were, 'Oh, my'… They said it was something that was fixable and not something to be majorly worried about. I didn't quite like it at all. I heard the 'Oh, my', my husband fainted, and I thought something was majorly wrong. I actually thought maybe the baby was dead or something." You say (your empathic response):

For Scenario Two, 144 participants wrote responses that were classified into 9 domains. The number of different domains reflected in their individual responses ranged from 1 - 5.

Affect Domain (n = 89)

Eighty-nine participants wrote responses that labeled the patient's feeling. Many connected the patient's feelings (and at times, her husband's feelings as well) to the way in which she learned about her child's condition. There are 9 categories.

Category 1. Patient fear (n = 55). More than half of the participants who wrote an affect response acknowledged the patient's fear. One genetic counselor said, "Of course! That must have been so scary…" Another expressed, "…How scary!

Table 4. Domains, Prevalence, and Example Responses for Scenario One: Cancer

Domain	Participant Responses
Content (*n* = 56)	*It sounds like you would like this information as soon as possible.* Can you share with me why you may be feeling a sense of urgency to get this done?
Affect (*n* =94)	*You're tired of being so uncertain with your future. You're frustrated that you don't have a definitive plan.*
Open-Ended Question (*n* =14)	It sounds like you are feeling very overwhelmed right now. *What is your main concern?*
Close-Ended Question (*n* =6)	It sounds as though you are very anxious about getting these results - *is there something that happened recently that made you decide that now is the time to pursue this testing?*
Advice (*n* =21)	I understand you are anxious for these results as they have a huge impact on your care and your everyday life. Unfortunately, DNA analysis is a lengthy process so it does take 2-3 weeks for results. *I would recommend in the meantime to discuss this information with your friends and family and really internalize what these results would mean for you whether they are positive or negative.*
Influence (*n* =56)	*It's a normal reaction to be nervous when waiting for results.* We should hopefully have results in _____ (days/weeks) and I will call you as soon as I get your results to set up a return appointment. Let's wait to discuss surgery options until we know what your risks are. I don't want to overwhelm you with information that may not be relevant for you.
Information (*n* =28)	You're anxious about getting answers -- we will let you know as soon as we know something. *Typically this takes about xxx weeks.*
Self-Disclosure (*n* =39)	I understand this is stressful. We want to be giving you correct information and guidance, so we need to do this carefully and thoroughly. We will try and be as quick as we can while being careful.
Self-Involvement (*n* = 17)	*I'm sorry that the process takes a long time.* I can see why you would be anxious.
Non-Verbal Behavior (*n* =2)	Correct me if I am wrong, but it seems to me like you are very anxious about today's assessment. *(Silence)*

 Note. Examples are provided verbatim. For those examples which involve more than one domain, italics indicate the portion of the response that represents the domain in question.

Category 2. Patient distress (n = 12). Twelve genetic counselors reflected the patient's distress, that is, feeling stressed or upset. One genetic counselor said, "It sounds like you were upset by the way the news of this condition was broken to you…" Another genetic counselor expressed, "How stressful that sounds!..."

Category 3. Patient shock (n = 9). One genetic counselor said, "Sounds like the doctor's response was startling for you." Another genetic counselor replied, "…That must have been quite a shock for the doctor to present it like that…"

Category 4. Patient worry/concern (n = 5). One genetic counselor responded, "Hearing the words that the doctor said really made you feel concerned." Another genetic counselor expressed, "…It must have been very worrisome to hear the doctor say words that indicated something was different with no explanation of what was seen…"

Category 5. Advanced empathy (n = 6). Six genetic counselors identified possible latent feelings the patient was experiencing. One genetic counselor said, "…I can imagine that you must have felt angry too when they said it was nothing to worry about…" Another genetic counselor expressed, "…Even if it is 'fixable' it can still be overwhelming and sad to hear that the baby will experience surgeries and has a cleft…"

Category 6. Patient dissatisfaction (n = 4). Four genetic counselors reflected that the patient was feeling displeased or unhappy about the situation. One genetic counselor said, "It sounds like you weren't happy with the way the information was presented to you." Another genetic counselor replied, "It sounds like you and your husband were not very pleased by the way the diagnosis was communicated to you."

Category 7. Patient feeling traumatized (n = 2). One genetic counselor said, "It

sounds like the way you found out about the cleft was pretty traumatic…"

Category 8. Patient anxiety (n = 2). One genetic counselor replied, "…That must have been extremely anxiety-provoking, to say the least…"

Category 9. Miscellaneous (n = 2). Two affect responses could not otherwise be classified: "…You must have been so worried and then so relieved" and "It sounds like there was some conflicting information that you were receiving at first, which I'd imagine was quite confusing…"

Content Domain (n = 52)

Fifty-two participants wrote responses that reflected or summarized the essence of what the patient said. There are 6 categories.

Category 1. Acknowledging patient's difficult experience (n = 16). About one-third of genetic counselors who wrote content responses acknowledged that patient had a difficult experience. One genetic counselor said, "…That sounds like it was a really bad experience…" Another genetic counselor replied, "That must have been a very difficult time for you."

Category 2. Acknowledging patient's difficulty in experiencing others' reactions (n = 11). Eleven genetic counselors acknowledged patient's difficulty in experiencing other's reactions. One genetic counselor said, "…Hearing those words from the mouth of the doctor must have been awful." Another genetic counselor responded, "When you heard that initial reaction from the doctor, it made you feel something was very wrong…"

Category 3. Recognizing patient's difficulty with not knowing what was happening (n = 10). One genetic counselor expressed, "… It must have been hard to hear

something was wrong, but not know what was wrong…" Another genetic counselor responded, "…It must have been difficult to hear that reaction from your doctor and not understand what was happening with your baby…"

Category 4. Advanced empathy (n = 10). Ten counselors reflected latent content, that is, issues somewhat below the surface of what the patient stated. One genetic counselor said, "… Hearing the 'oh, my' must have made it very difficult to listen to anything else until you got to hold your baby and know they would be okay." Another genetic counselor responded, "… And once you hear that something's wrong, it's hard to hear anything else, like the fact that it can be repaired…"

Category 5. Recognizing patient's difficulty in receiving the diagnosis (n = 5). One genetic counselor responded, "That must have been a difficult way to hear about your baby's cleft…" Another genetic counselor said, "… Although clefts are repairable this was not what you and your husband expected…"

Category 6. Restating patient's belief that her baby might be dead (n = 2). Two genetic counselors restated the patient's initial thoughts that the baby might be dead. One genetic counselor replied, "Wow, that must have been difficult to start thinking it was so bad that the baby might be dead." Another genetic counselor said, "… It must have been so difficult to think that maybe your precious baby was dead for even a second."

Influence Domain (n = 37)

Thirty-seven participants expressed personal opinions intending to support or disagree with the patient's thoughts, feelings, and/or behaviors. There are 5 categories.

Category 1. Normalizing patient's reactions (n = 23). One genetic counselor

expressed, "…Although it is true that clefting is fixable (the surgeons can do an amazing job), of course parents worry when they find out that anything is not what they expected, especially when the first words you hear are 'Oh, my'…" Another genetic counselor said, "…of course you would think the worst when a doctor says something like that and you can't see what is happening…"

   Category 2. Criticizing medical staff/others (n = 14). Fourteen genetic counselors criticized medical staff or family members. One genetic counselor responded, "The doctor unfortunately did not express himself appropriately…" Another genetic counselor replied, "…Your husband's reaction and the physician's words didn't match the idea that it was "fixable"…"

   Category 3. Expressing opinions about labor/delivery (n = 5). One genetic counselor expressed, "Delivery is always an emotional time…" Another genetic counselor replied "(It's hard to hear any words of surprise, shock when giving birth.) It's already such an emotional time!"

   Category 4. Justifying the doctor's/husband's reactions/opinions (n =4). One genetic counselor replied, "…We're all human, and I suppose the doctor was taken by surprise as well…" Another genetic counselor said, "…(The appearance can initially be striking until everything registers and is put into perspective), and I suppose your doctor's and husband's were responding to those very initial impressions, before an understanding of what they were viewing had clicked into place."

   Category 5. Miscellaneous (n = 2). Two responses could not otherwise be classified: "…But luckily we have figured out that it isn't going to be a major problem

for you and the baby." "…It is good that the surgical repair of clefting is so successful, and seeing before and after photos of babies having this is often very reassuring…"

Self-Involvement Domain (n = 35)

Thirty-five participants responded with their "here and now" personal reactions to the patient and/or the patient's behavior. There are 4 categories.

Category 1. Expressing general sympathy (n = 19). A number of counselors offered sympathy without articulating any specifics of the patient's situation. One genetic counselor replied, "Oh no, I'm sorry!" Another genetic counselor responded, "… I'm so sorry you had that experience…" A third genetic counselor replied, "…I'm sorry you had to go through that experience…"

Category 2. Expressing specific sympathy (n = 13). Several counselors expressed sympathy because of specific factors of the patient's situation. One genetic counselor said, "I am sorry that you learned about your son's birth defect in such a difficult manner…" Another genetic counselor replied, "…but I'm sorry that he (the doctor) expressed himself the way he did…" A third genetic counselor responded, "I am so sorry that you had to go through that experience at a time that was to be so happy."

Category 3. Expressing sympathy for the couple (n = 3). One genetic counselor replied, "… I'm sorry that the news came to both of you that way…" Another expressed, "… I'm really sorry that you and your husband had to go through that experience…"

Category 4. Miscellaneous (n = 3). Three self-involving responses could not otherwise be classified: "… I'm glad that you didn't also faint!..." "I appreciate your telling me how you felt when you found out…" "…I can't imagine what it's like to hear

something like that when you have just had your baby…"

Open-ended Question Domain (n = 25)

Twenty-five participants wrote open-ended questions in response to the patient. There are 7 categories.

Category 1. Assessing patient's feeling/reaction about the diagnosis (n = 8). One genetic counselor said, "…What did you feel when they told you the baby had a cleft…?" Another responded, "…How do you feel now about your baby's problem?"

Category 2. Collecting more details about the situation (n = 6). Six genetic counselors asked questions to further understand the moment when the situation occurred . One genetic counselor asked, "…What happened next?" Another genetic counselor said, "… Can you tell me what happened next?"

Category 3. Assessing patient's first interaction with the baby (n = 5). One genetic counselor asked, "…How did things go once you held the baby?..." Another responded, "… Once you saw your baby, how did you feel?"

Category 4. Assessing patient's feeling during the situation (n = 4.) One genetic counselor asked, "…Can you tell me more about how you were feeling at the moment?" Another responded, "…How did you feel when that happened?"

Category 5. Assessing patient's adjustment to the situation (n = 2). One genetic counselor asked, "…How have you been feeling now that you know what the doctor saw?" Another responded, "…How have things been since then?"

Category 6. Assessing other parties' adjustment to the situation (n = 2). One genetic counselor asked, "…how is your child doing now?" Another responded, "…How

did your husband do?"

Category 7. Miscellaneous (n = 1). One response could not otherwise be

categorized: "…What do you think would have been the appropriate words from your

doctor?"

Close-ended Question Domain (n = 10)

Ten participants wrote close-ended questions in response to the patient. There are

3 categories.

Category 1. Assessing patient's present reaction to the situation (n = 5). Five

genetic counselors inquired about the patient's reaction to or perception of the moment

when the scenario happened. One genetic counselor asked, "That sounds like it was a

very powerful moment, do you still think about that often?" Another genetic counselor

said, "… Is it difficult for you to think about those moments?"

Category 2. Assessing patient's understanding of clefting (n = 2). One genetic

counselor replied, "…Did they take the time to talk with you and explain your baby's

diagnosis?" Another genetic counselor expressed, "… Were you able to get a clear

idea of what the doctor had meant by his/her reaction?

Category 3. Miscellaneous (n = 3). Three responses could not otherwise be

classified: "…Would you say that you tend to think of 'worst case scenarios' when

hearing bad news?" "…Did your child have the surgery and is he/she doing well now?..."

"…Were you able to see and hold your baby soon after the comments?..."

Information Domain (n = 4)

Four participants provided information in response to the patient. There are no

separate categories. Three counselors offered information about the diagnosis/prognosis of clefting. For instance, one genetic counselor said, "… many people born with clefting do very well – have their repair, go to school, grow up, work, get married, have families…" Another genetic counselor expressed, "Clefting can be difficult to see before birth, so it's often diagnosed after delivery, and can be shocking to parents, especially if they aren't expecting it…" A third genetic counselor replied, "…Cleft lip and/or palate is a common birth defect that can easily be fixed through surgery and many individuals don't even know they were born with it." A fourth counselor indicated that s/he would outline next steps: "(I am sorry that your child's diagnosis was presented to you in this way. You are completely correct that the cleft is treatable) and these are the steps that we will take…"

Self-Disclosure Domain (n = 3)

Three participants revealed personal information in response to the patient. There are no separate categories. These counselors variously wrote: "…In this type of situation, my imagination always works overtime…"; "… I can imagine that I would feel the same way…"; and "…I see it all the time…I will definitely provide that feedback to Dr. X so that they are more careful with other patients in the future."

Non-Verbal Behavior Domain (n = 1)

One genetic counselor included a nonverbal behavior (silence) in response to the patient: "It sounds like you were upset by the way the news of this condition was broken to you (silence)."

Table 5 contains an example of a response from each domain for Scenario Two.

Table 5. Domains, Prevalence, and Example Responses for Scenario Two: Clefting

Domain	Participant Responses
Content (*n* =52)	*When you heard that initial reaction from the doctor, it made you feel something was very wrong.* Hearing the news that way was upsetting.
Affect (*n* =89)	*You were really scared to find out what the doctor was talking about.*
Open-Ended Question (*n* =25)	That must have been difficult, *tell me what happened next.*
Close-Ended Question (*n* =10)	That sounds like it was a very powerful moment, *do you still think about that often?"*
Influence (*n* =37)	*Sometimes doctors and those present in the room react to what they are seeing without thinking about how their reactions will affect you.*
Information (*n* =4)	I'm sorry that was the way the situation panned out. The physician should not have expressed himself that way. He most likely was just surprised because your baby looks healthy everywhere else. *Cleft lip and/or palate is a common birth defect that can easily be fixed through surgery and many individuals don't even know they were born with it.*
Self-Disclosure (*n* =3)	From what you shared, it sounds like everyone else in the room was surprised and concerned and you didn't know what was going on. *In this type of situation, my imagination always works overtime.* Do you think that is what you were doing?
Self-Involvement (*n* =35)	*I'm so sorry that you had that experience with the birth of your child.* Hearing those words from the mouth of the doctor must have been awful.
Non-Verbal Behavior (*n* =1)	It sounds like you were upset by the way the news of this condition was broken to you. *(silence)*

 Note. This scenario does not have advice responses. Examples are provided verbatim. For those examples which involve more than one domain, italics indicate the portion of the response that represents the domain in question.

Scenario Three: Fabry Disease

A woman with Fabry disease describes to you her experience of the disease (Gibas et al., 2008, p.531). She says to you: "The episode of pain in my hands and feet are impossible to describe because the pain is so personal and out of control when it comes… The severe abdominal cramping is a sudden onset pain that is scary, and something you're not sure you can survive. It actually feels like it might kill you. Many times I have passed out – I just hope and pray if I pass out the pain will be over when I come back… if I come back." You say (your empathic response):

For Scenario Three, 140 participants wrote responses that were classified into 8 domains. The number of different domains reflected in their individual responses ranged from 1 - 4.

Influence Domain (n = 53)

Fifty-three participants wrote personal opinions expressing either support or disagreement with the patient's thoughts, feelings, and/or behaviors. There are 3 categories.

Category 1. Normalizing/Acknowledging difficulty experiencing the pain (n = 44). Many counselors normalized/acknowledged the difficulties the patient experienced living with the pain. One genetic counselor responded, "We go through life wanting to live and be happy, but this can be a very complicated thing to do when we are suffering through chronic and intense pain…" Another genetic counselor replied, "… Pain is one of those things that you can't accurately imagine experiencing until it happens to you… " A third genetic counselor expressed, "I think it's very normal to feel scared of the pain and to not know what will happen after you pass out…"

Category 2. Appreciating patient's resiliency (n = 4). One genetic counselor said, "… It really is an act of bravery to get through it each and every time you have an

episode of pain." Another genetic counselor replied, "You must be a very strong person to be able to endure that kind of pain…"

Category 3. Complimenting patient's ability to describe the pain (n = 2). Two genetic counselors complimented the patient on their ability to describe the pain. One genetic counselor said, "… You have actually done a very good job of explaining the pain…"

Affect Domain (n = 53)

Fifty-three participants wrote responses that reflected patient feelings which she had not directly expressed. There are 6 categories.

Category 1. Patient fear (n = 32). One genetic counselor said, "… It sounds like you are afraid that you may die during one of these episodes…" Another expressed, "…It sounds like it is terrifying when it happens, " A third genetic counselor responded, "That sounds like it is very frightening for you."

Category 2. Advanced empathy (n = 12). Twelve genetic counselors identified possible latent feelings the patient was experiencing. One genetic counselor said,"It seems like you are in a constant state of fear because of your pain." Another expressed, "You feel scared about getting through the next episode of pain." A third genetic counselor replied, "…But even though I know you're aware you're not alone, it must feel that way at times, especially when it feels like such a personal pain, as you said…"

Category 3. Patient worry (n = 4). One genetic counselor said, "… It sounds like you are worried the pain may actually kill you at some point." Another responded, "You seem very worried that the pain is eventually going to be too much for your body to

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bear…"

Category 4. Patient overwhelmed/stressed (n = 3). One genetic counselor replied, "It must feel emotionally overwhelming not be able to know when the pain is going to strike and for it to be so consuming when it happens."

Category 5. Patient frustration (n = 2). One genetic counselor said, "… And it sounds like no one can really understand your experience, which must also be frustrating."

Category 6. Patient feeling alone (n = 2). One genetic counselor said, "… You feel alone because no one understands the pain you are going through…

Content Domain (n = 46)

Forty-six participants wrote responses that reflected or summarized the essence of what the patient said. There are 4 categories.

Category 1. Acknowledging difficulties experiencing the pain/symptoms (n = 23). Many of the content responses acknowledged the patient's difficulties experiencing the pain/symptoms. One genetic counselor said, "It sounds like these episodes of pain are quite unbearable for you…" Another genetic counselor replied, "I imagine your experience with constant pain has been difficult and scary" (Note, this response is not an affect response because it does not reflect a feeling that the patient did not express. In other words, the patient used the word "scary"). A third genetic counselor expressed, "Oh my goodness… it must be very difficult for you not knowing if one of these attacks is going to come on…"

Category 2. Advanced empathy (n = 14). These counselors reflected latent

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content, that is, issues somewhat below the surface of what the patient stated. One genetic counselor said, "… And it must be very difficult when your friends and family can't really relate to what you're going through." Another genetic counselor responded, "… I wonder if you have days where you just wish it was all over so you didn't have to be in pain anymore." A third counselor expressed, "… It sounds like the pain is not just excruciating on a physical level, but it is excruciating on a psychological level as well…"

Category 3. Recognizing nature of the patient's pain (n = 10). One genetic counselor responded, "Wow, it sounds like in your case the pain episodes are very severe…" Another genetic counselor said, "From your description, it sounds like the pain is incredibly intense…"

Category 4. Restating patient's comment (n = 3). Three genetic counselors restated part of the patient's comments. One genetic counselor replied, "… You said that it is personal and impossible to describe…" Another said, "…You express that you hope you will come back from the pain…"

Self-Involvement Domain (n = 44)

Forty-four participants responded with their "here and now" personal reactions to the patient and/or the patient's behavior. There are 5 categories.

Category 1. Expressing difficulty imagining patient's situation (n = 22). One genetic counselor replied, "I can't imagine what it must be like to live day to day with this illness, and wonder when the next pain attack will be…" Another said, "… It's hard for me to imagine these episodes that you describe…."

Category 2. Expressing sympathy for patient (n = 14). One genetic counselor

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responded, "… I am so sorry you experience theses episodes and the agony they bring."

Another expressed, "I'm so sorry to hear that the symptoms have been so severe…"

Category 3. Expressing one's attempt to imagine the patient's situation (n = 6).

One genetic counselor replied, "I can only imagine how painful that must be for you…"

Another expressed, "I can only imagine how powerless you must feel when this pain

happens…"

Category 4. Expressing a desire to take away patient's pain (n = 5). One genetic

counselor replied, "…I wish that you didn't have to endure that torture – ever!" Another

said, "…I hope there is something we can do to lessen your pain."

Category 5. Appreciating patient's disclosure (n = 2). One genetic counselor

replied, "Thank you for sharing that with me…" Another expressed, "I appreciate you

sharing that with me…"

Close-ended Question Domain (n = 34)

Thirty-four participants wrote close-ended questions in response to the patient.

There are 5 categories.

Category 1. Assessing patient's coping mechanisms (n = 8). One genetic

counselor replied, "… Is there anything you do when you know that the pain is

beginning?" Another said, "… When you have an attack, is there anything you do to try

to get yourself through it, like medication or prayer?"

Category 2. Assessing patient's social support (n = 6). One genetic counselor

asked, "… Who do you turn to for support when you are experiencing so much pain?"

Another responded, "… Do you have someone you can talk to about these

experiences?..."

Category 3. Assessing patient's medical support (n = 6). One genetic counselor Said, "… Have you talked with your doctor about the severity of this pain?..." Another replied, "… Are your doctors aware and understanding of your symptoms?"

Category 4. Questions about patient's symptoms (n = 6). One genetic counselor asked, "…How long do the pain episodes last?..." Another responded, "…How often does it happen?"

Category 5. Questions about patient's experience with the disease (n = 3). Two counselors asked for details about the patient's experience with the disease. One asked, "… Do you live in fear of the next painful episode?" Another said, "… Are you constantly waiting for the sudden onset or have you learned to not think about it?..." A third counselor asked, "…Does anyone else in your family have Fabry disease?..."

Open-ended Question Domain (n = 16)

Sixteen participants wrote open-ended questions in response to the patient. There are 3 categories.

Category 1. Assessing patient's coping mechanisms (n = 12). One genetic counselor asked, "… How do you manage to get through each episode?" Another responded, "… What kind of techniques do you use to help with the pain?"

Category 2. Questions about patient's experience with the disease (n = 2). One genetic counselor asked, "…Please tell me how that affects your day-to-day life." Another responded, "… Can you tell me more about the average day of having these symptoms?"

Category 3. Miscellaneous (n = 2). Two open-ended questions could not otherwise be classified: "…What do you mean by if I come back?..." "… Can you tell me what treatments or steps you have taken?..."

Advice Domain (n = 8)

Eight participants provided advice to the patient. There are 3 categories.

Category 1. Advice about managing pain episodes (n = 4). Four genetic counselors provided advice about managing the pain. One suggested, "… Do you feel it might help to have a plan to deal with the pain and the potential to be unconscious?" Another responded, "… Would you be interested in learning how to better manage the pain when it hit so it might not seem so tarrying?"

Category 2. Advising patient to get social or medical support (n = 3). One genetic counselor suggested, "… Do you think talking with other women who have Fabry's disease would help?..." Another said, "… I would like to try to help you find a physician/pain management group to help you."

Category 3. Miscellaneous (n = 1). One response could not otherwise be classified: "… Prayer may be a way for you to help deal with some of this pain, not just physical but also emotional."

Self-Disclosure Domain (n = 7)

Seven participants revealed personal information in response to the patient. There are 2 categories.

Category 1. Personal experience with the disease (n = 5). One genetic counselor replied, "…I have a family member that suffers from sudden painful events…" Another

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said, "…I know a little about this kind of pain, from knowing people with sickle cell…"

Category 2. Hypothetical reaction to having the disease (n = 3). One counselor

responded, "(I can't imagine dealing with that. It sounds like it affects every part of your

life.) I would be so afraid and worried about when it was going to happen." Another said,

"…I think I'd be constantly be worrying about whether I'd have an attack during work, or

while driving, or while I am alone and no one is there to take care of me…"

Table 6 contains an example of a response from each domain for Scenario Three.

Scenario Four: Long QT Syndrome

A young woman diagnosed with Long QT Syndrome is talking to you about wanting to
have a baby (Andersen et al., 2008, p.494). She says to you: "And I want to give birth to
at least one child. I want to have the opportunity to do that, then later I can adopt and all
those things. You know, you have a life today and you can in a way survive. When you
think about having a child, it is very frustrating not to get a clear answer as to whether
you might die or not. If I choose to take the risk, because it is a hard burden on the heart,
it is entirely up to me. No one can say whether it will work out well or not." You say
(your empathic response):

For Scenario Four, 141 participants wrote responses that were classified into 9

domains. The number of different domains reflected in their individual responses ranged

from 1 - 5.

Content Domain (n = 75)

Seventy-five participants wrote responses that reflected or summarized the

essence of what the patient said. There are 6 categories.

Category 1. Acknowledging the difficulty of uncertainty (n = 32). Many counselors

commented on the lack of sufficient information and/or the uncertainty of

the situation. One genetic counselor responded, "It must be frustrating that there is no

Table 6. Example Responses for Scenario Three: Fabry Disease

Domain	Participant Responses
Content (*n* =46)	*It sounds like the pain associated with this condition has had a severe impact on your life and it is something that you think about very often....*
Affect (*n* =53)	*It sounds like your pain makes you feel out of control and helpless.*
Open-Ended Question (*n* =16)	That sounds like it must be really difficult to cope with. *What kinds of techniques do you use to help with the pain?*
Close-Ended Question (*n* =34)	That type of pain must be very difficult to live with and to never know when it may come, that must very unsettling. *Are there times you just wish you'd pass out?*
Advice (*n*=8)	Oh my goodness... it must be very difficult for you not knowing if one of these attacks is going to come on. The uncertainty along with being afraid of the pain must make things difficult for you. Do you have enough time or warning to get somewhere safe when that starts to occur? *would it help if we could come up with a way to give you more warning or make it safer for you?*
Influence (*n* =53)	*Pain management can be quite difficult, especially when you don't know when the pain will start, or where it will be.* It must make your life very difficult and unpredictable.
Self-Disclosure (*n* =7)	Pain can be very overwhelming. *I have a family member that suffers from sudden painful events. Even though I have witnessed it, the degree of the pain is hard for me to imagine. But I see the suffering and I understand its power.*
Self-Involvement (*n* =44)	*I'm very sorry to hear that you are in such pain. It's hard for me to imagine these episodes that you describe.* I would like to try to help you find a physician/pain management group to help you.

 Note. This scenario does not have information responses and non-verbal behavior responses. Examples are provided verbatim. For those examples which involve more than one domain, italics indicate the portion of the response that represents the domain in question.

clear answer for what you should do." Another wrote, "You wish you had a clear answer, to know what will happen…" And a third genetic counselor said, "… it must be difficult to be left with so much uncertainties…"

Some counselors connected insufficient information or uncertainty to the difficulty of making a decision. One counselor replied, "It sounds like this is a really difficult decision for you, given the uncertainty of the results…" Another stated, "It must be difficult to feel like you are making personal health and life decisions without the most complete information."

Category 2: Advanced empathy (n = 25). These counselors reflected latent content, that is, issues somewhat below the surface of what the patient stated. One genetic counselor expressed, "… it must be really important to you to have children of your own to love and watch them grow." Another said, "… I'm also hearing that it's important to you that the decision be yours, and not the doctor's or specialist."

Category 3. Recognizing patient desire to experience a pregnancy/have a biological child (n = 20). These responses reflected the patient's desire to experience a pregnancy or to have her own biological child. One genetic counselor replied, "It sounds like the act of childbirth is something that you cherish and really wish to experience…" Another responded, "Having your own child seems to be a very important part of what you want your life to be."

Category 4. Expressing the patient's dilemma (n = 9). Some participants identified the dilemma the patient is dealing with in this ambiguous situation. One participant reported, "… Your desire to have a baby is shadowed by the real concern that

not all the risks are known with Long QT and pregnancy…." Another stated that, "… it sounds like you are caught between whether to have a child which has a risk involved in it, or whether not to take that risk…"

Category 5. Articulating the difficulty of not knowing the impact of a pregnancy (n = 4). Four genetic counselors recognized the difficulty the patient experiences in not knowing the effect of a pregnancy. One participant responded, "It sounds like it is very hard not to be sure how a pregnancy will affect your health."

Category 6. Miscellaneous (n = 2). Two content responses could not otherwise be classified: "… You want to take advantage of the life you have now, and live life to the fullest…"; and "…It sounds like you are aware of the risks that a pregnancy would pose to your health…"

Influence Domain (n = 63)

Sixty-three participants expressed personal opinions intending to support or disagree with the patient's thoughts, feelings, and/or behaviors. There are 9 categories.

Category 1. Normalizing difficulties posed by uncertainty (n = 23). One genetic counselor replied, "… Uncertainty is extremely tough to deal with…" Another said, "…It's one of those unknowns, and that's so hard to deal with…"

Category 2. Reinforcing it is the patient's own decision (n = 20). Twenty genetic counselors wrote responses acknowledging that it's the patient's decision to make. One genetic counselor replied, "… Ultimately, this is your decision, and no one else…" Another said, "You are right, in the end it is your choice to make."

Category 3. Validating the decision-making is difficult (n = 18). Some genetic

counselors expressed their opinion that the decision-making is difficult. One genetic counselor said, "You are faced with one of the most difficult decisions a woman has to make…" Another responded, "It can be very difficult to make such difficult choices and to have such few guarantees."

Category 4. Normalizing patient's desire for pregnancy (n = 13). One genetic counselor responded, "The desire to have a baby is such a natural part of life for most people…" Another said, "Many women want to have the experience of pregnancy and becoming a mother…"

Category 5. Complimenting patient's thorough consideration of the situation (n = 6). One genetic counselor replied, "You have apparently [have] given this lots of thought…" Another expressed, "… I'm sure you've given a lot of thought to the pros and cons of a pregnancy…"

Category 6. Expressing counselor's opinion about pregnancy/childbearing (n = 4). One genetic counselor said, "…Childbearing is a scary time for any woman…" Another responded, "…There are never any guarantees with a pregnancy."

Category 7. Expressing counselor's medical opinion (n = 4). One genetic counselor replied, "… (You mentioned the option of adoption, but have you considered the option of a surrogate?) That way, you can use your own egg and have a biological child without having the risks to your body?" Another said, "… I do not think it is possible for a condition like LQT to give a clear answer for any one individual."

Category 8. Stating counselor's perspective about human existence (n = 3). Three genetic counselors stated their philosophical views. One genetic counselor replied, "All

anyone can do is live their life the way they feel is best for them…" Another said, "I

think you're exactly right, and that's really what life is made up of, right?... (decisions

about things that we have no idea how they will turn out.)"

Category 9. Miscellaneous (*n* = 4). Four influence responses could not otherwise

be classified: "(It is your decision,) but is the experience of giving birth really worth the

possibility that you will not survive?"; "You seem to have a good grasp of the risks

involved."; "… All anyone can do is give you their best guess as to what your risks

would be, which I'm sure you will listen to very carefully…"; and "I can see not wanting

to sacrifice the chance to give birth to a child."

Affect Domain (n = 50)

Fifty participants wrote responses that identified the patient's feeling. There are 6

categories.

Category 1. Patient frustration (n = 29). One genetic counselor said, "… I hear

frustration in your voice…" Another expressed, "Wow, it sounds like you're dealing with

a lot of emotions, especially frustration with your decision to have a baby or not…" Yet

another responded, "It must be frustrating having to balance your deepest desire, to be

pregnant and have a child, with the fears and concerns about your heart condition…"

Category 2. Patient fear (n = 11). One genetic counselor replied, "It must be

scary, not knowing how a pregnancy would affect you." Another said, "It's a scary thing

to think of – the desire for a child, yet the fear of what might happen."

Category 3. Advanced empathy (n = 5). Five counselors identified possible latent

feelings the patient was experiencing. One genetic counselor said, "… It also sounds like

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you may be feeling alone in your decision to try to become pregnant or not…" Another expressed, "… and you are worried if you will be there for the child…"

Category 4. Patient feels overwhelmed (n = 3). One genetic counselor replied, "You're feeling overwhelmed by making the decision."

Category 5. Patient worry (n = 2). One genetic counselor said, "… You not only have to worry about your baby but also about your health…"

Category 6. Miscellaneous (n = 2). Two affect responses could not otherwise be classified: "…I can feel the pain in your voice…"; and "It sounds like you are between a rock and a hard place, very much wanting a baby of your own but uncertain as to the severity of the consequences to you and your family."

Close-ended Question Domain (n = 18)

Eighteen participants wrote close-ended questions in response to the patient. There are 5 categories.

Category 1. Questions about the decision-making process (n = 7). One genetic counselor asked, "… Does it seem like this is your decision alone?..." Another said, "… Have you thought about who else may want to have a say in your decision (spouse? partner? parents?)?"

Category 2. Assessing patient's attitude/reaction about the risk (n = 3). One genetic counselor said, "… (It also sounds as though maybe you're hearing from some people that that it's too risky)--is that true?"

Category 3: Exploring patient's emotions about the situation (n = 3). One genetic counselor asked, "… Is there anything that scares you…?" Another said, "… (I hear

frustration in your voice) – is 'it' connected with your situation or with your doctor's

uncertainty of what might happen?"

Category 4. Assessing patient's social and medical support (n = 3). Three

responses asked about support the patient was receiving from others, including health

care providers. One genetic counselor said, "… Do you have people other than doctors

you can talk with about taking that risk?" Another replied, "… Have you discussed your

desire to have a baby with your cardiologist? Is your OB/GYN aware that you have been

diagnosed with Long QT?"

Category 5. Miscellaneous(n = 3). Three close-ended questions could not

otherwise be classified. They include: "Whose input has meant the most to you?"; "Is

there anything that scares you, or are there specific questions I can answer for you."; and

"Have you thought about what it is about having a baby that you really desire?"

Open-ended Question Domain (n = 12)

Twelve participants wrote open-ended questions in response to the patient. There

are 3 categories.

Category 1. Assessing a third party's perspective of the pregnancy (n = 6). One

genetic counselor said, "… How does your husband feel about you being pregnant?"

Another responded, "… How does your family feel about you possibly [being]

pregnant?"

Category 2. Assessing patient's desire or perspective about being pregnant

(n = 3). One genetic counselor asked, "…Can you describe why it is important to you to

give birth to a child?" Another said, "… What do you envision happening if you do get

pregnant?"

Category 3. Miscellaneous (n = 3). Three open-ended questions could not otherwise be classified: "(It sounds like this is a really difficult decision for you, given the uncertainty of the results.) What is most important to you?"; "…How does that risk make you feel?..."; and "…Knowing that we can't predict the outcome, what information would be most helpful for us to give to you today?"

Advice Domain (n = 12)

Twelve participants provided advice to the patient. There are 5 categories.

Category 1. Advising patient to explore different options (n = 5). One genetic counselor said, "… What we can do is talk about all of the possibilities and options that are available to you, to help you make the right decision for you." Another genetic counselor suggested, "… Let's talk about all the options more…"

Category 2. Advising patient to make her own decision (n = 2). One genetic counselor replied "… You have to decide how you need to live yours (your life)."

Category 3. Advising patient to get medical or social support (n = 2). One genetic counselor replied, "…Planning ahead and having a doctor who specializes in the condition…" Another genetic counselor said, "Would it help you to talk to someone about your decision-making and how it makes you feel?"

Category 4. Advising informed decision-making (*n* = 2). Two counselors advised the patient to make an informed decision: "… the better prepared you are might help for a better outcome…"; and "I would encourage you to learn what you can and make an informed decision."

Category 5. Miscellaneous (n = 2). Two responses could not otherwise be classified: "… Let's talk more about that (patient's frustration)."; "… But please understand our point of view as health professionals to make you aware of the pros and cons of you getting pregnant and giving birth due to your genetic syndrome."

Self-Involvement Domain (n = 11)

Eleven participants responded with their "here and now" personal reactions to the patient and/or the patient's behavior. There are 4 categories.

Category 1. Expressing own wish for greater certainty for the patient (n = 4). One genetic counselor replied, "…I wish there were more clear-cut answers…" Another said, "… I wish we had a window into knowing for you if it would all work out fine…."

Category 2. Expressing difficulty imagining patient's situation (n = 3). One genetic counselor responded, "I can't even imagine what that must feel like for you."

Category 3. Expressing that counselor shares a similar understanding of patient's situation (n = 3). One genetic counselor expressed, "I understand what you're saying…" Another responded, "I can see your point of view…"

Category 4. Miscellaneous (n = 3). Two self-involving responses could not otherwise be classified: "Wow. I really feel for you…"; "…I'm impressed with how you have thought it through…"; and "It is hard because we want to take care of you physically but understand the emotionality of having a child."

Information Domain (n = 7)

Seven participants provided information to the patient. There are 3 categories.

Category 1. Information about the risk (n = 3). One genetic counselor said, "…

and then there are couples with risk factors like Long QT where everything is fine and they don't have complications…"

Category 2. Information about resources (n = 3). One genetic counselor replied, "… [it] is possible to put you in contact with other women with Long QT who have had successful pregnancies."

Category 3. Miscellaneous (n = 1). One information response could not otherwise be classified: "Unfortunately, this is one of those things that there is not consensus about…"

Self-Disclosure Domain (n = 6)

Six participants revealed personal information to the patient. There are 3 categories.

Category 1. Describing counselor's role (n = 2). Two counselors described their involvement in providing help, support, and/or information to the patient. One genetic counselor said, "… I am here to give you as much information as I can in order to help you make your decision."

Category 2. Revealing one's support for patient's decision (n = 2) One genetic counselor replied, "… We will support your decision."

Category 3. Acknowledging own limitation in providing a definite answer (n = 2). One genetic counselor responded, "… and so we aren't going to be able to give you an answer either…"

Table 7 contains an example of a response from each domain for Scenario Four.

Table 7. Domains, Prevalence, and Example Responses for Scenario Four

Domain	Participant Responses
Content (_n_ =5)	It sounds like having a child of your own is very important to you.
Affect (_n_ =50)	You feel frustrated because there is no way to predict what would happen to you if you got pregnant.
Open-Ended Question (_n_ =12)	It sounds like having a child is very important to you. *What do you envision happening if you do get pregnant?*
Close-Ended Question (_n_ =18)	You are right that it is frustrating not to have clear answers. *Can you tell me about who you have consulted in talking about this? Whose input has meant the most to you?*
Advice (_n_ =12)	*I would encourage you to learn what you can and make an informed decision*, but only you can decide what is right for you.
Influence (_n_ = 63)	Many woman want to have the experience of pregnancy and becoming a mother. It is especially hard for you when you have additional medical concerns. Yes, this is your decision along with your partner, but there are many people that can help inform your decision and provide support. There are never any guarantees with a pregnancy.
Information (_n_ = 7)	It sounds like the act of childbirth is something that you cherish and really wish to experience. I think you're right in that it is such a unique experience that we can have as women. It also sounds that you are frustrated because people are trying to deprive you of this experience because of your personal risk during childbirth due to your heart condition. You are right in that no one can really say whether it will work out well or not, and that is extremely frustrating. Uncertainty is extremely tough to deal with. However, I can reassure you that the doctor's do have your best interest in mind when giving you advice. *There is a risk there and that risk is real, and they are looking out for you from that perspective.*
Self-Disclosure (_n_ = 6)	I think you just painted a really clear picture of what many people go through when thinking about getting pregnant and I am impressed with how you have thought it through. Yes, it is true that there are some serious issues you and your partner and your medical team need to think about before you get pregnant. *Hopefully I can help in anyway that I can with your decision and is possible put you in contact with other women with Long QT who have had successful pregnancies.*
Self-Involvement (_n_ =11)	I can't even imagine what that must feel like for you.

Note. This scenario does not have non-verbal behavior responses. Examples are provided verbatim. For those examples which involve more than one domain, italics indicate the portion of the response that represents the domain in question.

Scenario Five: Huntington Disease

A woman at risk of developing Huntington disease is talking to you about concealing from her children information about her risk (Quaid et al., 2008, p.122). She says to you: "Telling the children is one area where we've made some really bad decisions. We haven't really had too many discussions about it. They know that my brother who has HD comes to visit, usually twice a year for a week. They know that he, you know, that he has problems with his balance and they can't jump on him and play. And there's certain things that they can't do with him, and they know that he doesn't work because of his balance and stuff like that. They know that my father died of Huntington's disease. They know that my brothers and my sister were sick. They don't know that I'm at risk for Huntington's disease. And they know the name of it and we've, we have been I guess a little bit evasive about it because we're, I'm afraid that as soon as we say 'Huntington's disease' they're going to think 'death' you know. They're going to jump to that, and I don't think my youngest son could understand that. He's very young." You say (your empathic response)"

For Scenario Five, 139 participants wrote responses that were classified into 9 domains. The number of different domains reflected in their individual responses ranged from 1-5.

Content Domain (n = 77)

Seventy-seven participants wrote responses that reflected or summarized the essence of what the patient said. There are 8 categories.

Category 1. Reflecting patient's desire to act in her children's best interest (n = 27). One genetic counselor replied, "It sounds like you're really trying to do the best thing for your children…" Another expressed, "It sounds like your [sic] really trying to protect your children from the knowledge of the risk of losing their mother…"

Category 2. Expressing patient's difficulty discussing the issue with children (n = 22). Many counselors commented on the patient's difficulty communicating about their situation with their children. One genetic counselor responded, "It sounds like talking to

your children about Huntington's disease has been challenging…" Another genetic

counselor reflected more specifically that the difficulty involved how to have that

discussion and how much to disclose, "It sounds like you're really struggling with how,

and how much, information to reveal to your children…"

Category 3: Identifying patient's dilemma about sharing information with her

children (n = 16). One genetic counselor expressed, "… I can see the conflict in you

between being honest and sparing them from worrying about you and ultimately

themselves." Another genetic counselor said, "… You feel that you want to protect them

from this scary information, and yet, there is the burden of feeling as though they have a

right to know what you and they might be facing…"

Category 4. Advanced empathy (n = 16). Eleven genetic counselors reflected

latent content, that is, issues somewhat below the surface of what the patient stated. One

genetic counselor speculated, "Do you think if they knew you were at risk that they

would treat you differently, like they treat your brother?" Another genetic counselor

interpreted, "It must be very difficult to conceal these concerns from your child, when

you probably think about these concerns more often than your children know…"

Category 5. Reflecting children's awareness/knowledge about the disease (n = 4).

One genetic counselor replied, "It sounds like your children already know a lot about the

condition and understand to at least some degree that it is something that affects multiple

family members…" Another genetic counselor expressed, "It sounds like your children

have some awareness of HD - the name, that it is in the family, some of the symptoms…"

Category 6. Articulating the stressful nature of the patient's situation (n = 4). One

genetic counselor responded, "…It seems like there's a lot going on in your life right now..." Another genetic counselor replied, "… I can see that your concerns about your children are weighing on you…"

Category 7. Expressing patient's efforts put into the process (n = 3). Two genetic counselors said "… It sounds like you have been thinking a lot about this though…" A third counselor said, "(It sounds as if you've thought of some reasons to postpone telling your children about Huntington's), but that you have thought about it quite a bit…"

Category 8. Miscellaneous (n = 1). One content response could not otherwise be classified: "… you're very aware of what they've seen in your family related to HD."

Influence Domain (n = 72)

Seventy-two participants expressed personal opinions that either supported or disagreed with the patient's attitude (thoughts, feelings, and/or behaviors). There are 10 categories.

Category 1. Normalizing the difficulty discussing HD with children (n = 36). About half of the genetic counselors who provided an influencing response, stated that parents generally would have difficulty discussing an issue such as HD with their children. One genetic counselor replied, "Most parents find it very difficult to provide information about the HD…" Another genetic counselor said, "Figuring out when and how to tell your children about Huntington's disease is difficult for many people with the condition…"

Category 2. Reinforcing patient's desire to protect her children (n = 19). One genetic counselor replied, "I think it's perfectly natural that you've wanted to protect your

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children from this information -- that's part of what it means to be a parent…" Another genetic counselor said, "… It's natural to want to protect them from information that may be scary to them."

Category 3. Pointing out children's capacity to comprehend/seek information (n = 15). One genetic counselor expressed, "… (You're doing what many good moms do - we want to protect our children as long as we can.) The trouble is that kids usually figure it out on their own eventually…" Another genetic counselor responded, "… I think you might be surprised that your children can handle the information better than you think…"

Category 4. Complimenting patient's communication with her children (n = 10). One genetic counselor responded, "You probably made decisions that seemed best at the time…" Another genetic counselor said "I don't know that I would call those bad decisions. I think you have so much to think about when it comes to talking about Huntington's disease with your kids!"

Category 5. Agreeing that children may have difficulty comprehending the issue (n = 7). One genetic counselor replied, "This can be a very hard for younger children to comprehend…" Another genetic counselor said, "Information, especially complicated information like that about Huntington's can be difficult for anyone, but especially children, to really understand…"

Category 6. Reinforcing patient autonomy about sharing information with her children (n = 6). One genetic counselor said, "It is a very personal choice of when and how to tell your kids about your risks…" Another genetic counselor responded, "You have to make your own decision about when your children are ready to hear about your

risk and how it may relate to their risk…"

Category 7. Acknowledging the importance of age-appropriate information (n = 4). One genetic counselor replied, "… And you have to say what is appropriate for their age." Another individual said, "… Age-appropriate information is very important for children…"

Category 8. Appreciating patient knows her children best (n = 3). One genetic counselor replied "(It is really difficult to know when and how to tell your children.) You know your children well, and will be the best judge of that…"

Category 9. Acknowledging patient's personal experience with HD (n = 2). One genetic counselor responded "… But I bet you remember being a child and seeing Huntington all around you in your family…" Another genetic counselor replied "…As a child of your father with Huntington disease, you also know first hand that what you understand about the family history and the disease as you age into maturity is a very progressive process…"

Category 10. Miscellaneous (n = 4). Four influence responses could not otherwise be classified: "Being a parent is so hard…" "… you must know that your decision about whether to tell your children stems from your love for them…" "You are going to know the best time to talk to them about your healthcare and their future…" "… Fortunately although their grandfather passed away of the condition, they have seen your uncle and hopefully are not afraid of him and see how he manages with the condition. That may help in their realization that although HD will eventually lead to death, it is just one of many things we can die of…"

Affect Domain (n = 51)

Fifty-one participants wrote responses that identified the patient's feelings. There are 7 categories.

Category 1. Patient worry (n = 16). These responses focused on the patient's worry about her children. One genetic counselor said, "It sounds like you're very worried about the impact this news will have on your children…" Another expressed, "It sounds like you are worried about how your children might react."

Category 2. Patient fear (n = 13). One genetic counselor replied, "It's very scary to think about frightening your children." Another genetic counselor said, "it sounds like the prospect of telling your children is pretty scary…"

Category 3. Patient concern (n = 7). One genetic counselor responded, "… It sounds like you are really concerned about doing the right thing for your children…" Another genetic counselor expressed, "You are concerned about your children's reaction to your risk for this disease."

Category 4. Advanced empathy (n = 8). Eight counselors identified possible latent feelings the patient was experiencing. One genetic counselor said, "… It sounds like they might not relate HD to death, but it is more of something that you are afraid of." Another genetic counselor replied, "I understand that you want to protect your children from being scared or hurt... things that you may have felt growing up in a family with relatives how have Huntington's disease."

Category 5. Patient's love for her children (n = 3). One genetic counselor responded, "It sounds like you really love your children and don't want to scare them…"

Another genetic counselor expressed, "It sounds like you have a lot of love for your children and are trying to protect them…" Yet another counselor replied, "…It's clear that you love and care about them in your statements…"

Category 6. Patient guilt (n = 2). One genetic counselor said, "… but on the other hand you kind of feel guilty about not being completely honest with them…" Another genetic counselor responded, "You feel guilty for not being more straightforward with your children about the potential for you to develop HD."

Category 7. Miscellaneous (n = 2). Two affect responses could not otherwise be classified: "You are feeling torn between wanting to protect your children and wanting to provide them with the information you need." "So, you are not satisfied with the decision you've made not to tell the children you're at risk?"

Advice Domain (n = 22)

Twenty-two participants provided advice to the patient. There are 4 categories.

Category 1. Recommendation to work with the counselor or other professionals (n = 11). One genetic counselor suggested, "…We can talk and brainstorm ideas about how to share information with them, and maybe role-play a bit so you can see how it might go…" Another counselor said, "…Maybe a family counselor could help you find the right time and way to discuss this with your children…"

Category 2. Advising how and when to talk to the children about HD (n = 9). One genetic counselor replied, "…Maybe discussing the other aspects of your siblings' lives before they were severely affected with the disease would be beneficial…" Another said, "… Another idea is that you can have periodic discussions with them as they grow older,

and explain more and more as they will understand it or if they have questions…"

Category 3. Advising patient to trust herself (n = 2). One genetic counselor replied "…but try not to be so hard on yourself…" Another said "… You need to do what feels most comfortable for you…"

Category 4. Miscellaneous (n = 1). One advice responses could not otherwise be classified: "… (Children understand things differently at different ages) and so it is important to plan ahead…"

Close-ended Question Domain (n = 22)

Twenty-two participants wrote close-ended questions in response to the patient. There are 9 categories.

Category 1. Assessing patient's communication with her children (n = 5). A few genetic counselors asked questions assessing the patient prior and/or prospective communication with her children about HD. One counselor asked, "… Have you thought about how and when you might tell them?" Another said, "Have you talked to your children about how they see their (aunts, uncles, etc)?..."

Category 2. Assessing children's ages (n = 3). Three genetic counselors asked "… How old are your children?"

Category 3. Exploring patient's desire/motivation to share more details with her children (n = 3). One genetic counselor said, "…Is giving them more details something you want help pursuing?" Another genetic counselor asked, "…do you think that giving them more information will help them better understand your risks?"

Category 4. Assessing factors affecting communication with her children (n = 3).

One genetic counselor replied, "… At what age do you think that they will be ready to understand the information?..." Another asked, "… Do you feel like you're waiting on something before you talk about it more? ...like the results of testing or for them to get older?..."

Category 5. Assessing the nature of the patient's concern for her children (n = 2). One genetic counselor said "… but are you more worried about them finding out in another way, rather than from you?..." Another expressed "…. (You appear to be concerned that the children may hear HD but equate that with dying, and that, in the future, if you have the condition, perhaps they may think that way then.) Is that something that goes through your mind as well?"

Category 6. Assessing children's understanding about the situation (n = 2). One genetic counselor said, "… Have they been asking you any questions about others in your family with HD?" Another expressed, "… Do you think they've done any research on their own about Huntington disease or have an idea that you might be at risk as well?..."

Category 7. Assessing patient's perceptions of her decision (n = 2). One genetic counselor asked, "… is there something you wish you hadn't said?..." Another replied, "… Is there some reason you think you've made some really bad decisions about this?"

Category 8. Assessing patient's desire to receive resources/support (n = 2). One genetic counselor responded, "… (Sometimes people talk to a therapist about their family dynamics and the age of their children.)… Would you find that helpful?" Another said "… have you spoken to other families with HD for support and guidance?" This two examples might also imply advice to the patient to speak with a therapist and to

speak with other families, respectively.

Category 9. Miscellaneous (n = 3). Three close-ended questions could not otherwise be categorized: "… Did anyone ever explain anything to you in such a way, when you were a kid, or even as an adult, that helped you understand and not become overwhelmed by it?" "… Did your siblings have any children that they told or didn't tell?" "… Does the name Huntington's make you think of death?..."

Open-ended Question Domain (n = 21)

Twenty-one participants wrote open-ended questions in response to the patient. There are 4 categories.

Category 1. Assessing patient's perceptions of her decision (n = 11). One genetic counselor said, "what makes you say you've made bad decisions in the past about talking to your children?..." Another responded, "…Can you explain more about the 'bad' decisions you have made in this context?"

Category 2. Inquiring about children's likely reactions to receiving the information (n = 5). One genetic counselor asked, "…How do you think it will affect them, knowing that you are at risk?" Another said, "…How do you think each child will comprehend the information?"

Category 3. Assessing patient's perceptions of ideal communication with her children (n = 2). One genetic counselor asked, "… What do you feel would be best the way to discuss this information with them…" Another said, "…What do you think they should know?"

Category 4. Miscellaneous (n =5). Five open-ended questions could not otherwise

be classified: "…(But I bet you remember being a child and seeing Huntington all around you in your family.) I wonder what ideas did you had [sic] about it before anyone explained anything…"; "…What would you want them to associate with "HD"?..."; "…How do they act around your brother?..."; "…How does your husband feel?..."; and "…What do you think would be helpful?..."

Self-Involvement Domain (n = 11)

Eleven participants responded with their "here and now" reactions to the patient and/or the patient's behavior. There are 3 categories.

Category 1. Expressing personal understanding about the patient's concerns (n = 9). One genetic counselor expressed, "…I can understand the desire to protect your children from the worries that you have had to face…" Another genetic counselor said, "… I can understand your reluctance to open the door into the realm of Huntington's disease to your children…"

Category 2. Expressing personal reaction to the struggle of discussing the issue (n = 2). One genetic counselor replied "…I can't imagine having to talk to my children about a topic like this…" Another said "…I can see why it would be difficult to know what is the right amount of information to give your children…"

Category 3. Miscellaneous (n = 1). One response could not otherwise be classified "… If the question arises through them about your risk/future, I hope that you would continue to be as honest with them as possible…"

Self-Disclosure Domain (n = 5)

Five participants revealed personal information in response to the patient. There

are 3 categories.

Category 1. Counselor expression of willingness to help (n = 2). One genetic counselor said, "… (But it also sounds like you're ready to start bringing them in a little more), and that's something we can definitely help you with." Another genetic counselor expressed, "…However, we could help you find the best way to provide this information to your children"

Category 2. Counselor revelation of clinical experience dealing with HD (n = 2). One genetic counselor replied, "…In my experience, the children often know more than parents realize and at a pretty young age…" Another genetic counselor said, "Whenever I see someone to talk about HD, the difficult decision about how and when to tell children is one of the greatest struggles they face …"

Category 3. Miscellaneous (n = 1). One response could not otherwise be classified: "…I would think that if so many people in my family were affected with Huntington's disease that I would be a little afraid to talk about it too…"

Information Domain (n = 2)

Two participants provided information to the patient. There are no separate categories. Both of these genetic counselors offered information regarding resources for discussion with children. One individual said, "… There are certainly resources available that can help with such a discussion…" Another expressed, "… There are resources available to help with age appropriate ways to explain Huntington's disease with children…"

Table 8 contains an example of a response from each domain for Scenario Five.

Table 8. Domains, Prevalence, and Example Responses for Scenario Five: Huntington's Disease

Domain	Participant Responses
Content (*n* = 77)	*It sounds like it is really hard to know when the right time is to discuss this disease with your children.*
Affect (*n* = 51)	*You feel frustrated because there is no way to predict what would happen to you if you got pregnant.*
Open-Ended Question (*n* = 21)	Every family experience is different, and it sounds like your children are already gathering information without formally discussing HD. *You say that you've made bad decisions, tell me more about that.*
Close-Ended Question (*n* = 22)	So, you sound concerned about the information they have received so far about Huntington's Disease. *At what age do you think that they will be ready to understand the information?*
Advice (*n* = 22)	It can be very scary discussing illness with your children. I think you might be surprised that your children can handle the information better than you think. How do they act around your brother*? Maybe a family counselor could help you find the right time and way to discuss this with your children.* It sounds like you would like to find a good way to do that.
Influence (*n* = 72)	What you're telling me is very common in families with a history of Huntington's Disease - and that basically is how to tell the next generation what the real issues and risks are. However, it does seem as though your children know a bit more about it than you realize and when you and your husband feel that it is the right time to discuss this with them, that knowledge of theirs combined with a child's natural strengths will help them greatly.
Information (*n* = 2)	Information, especially complicated information like that about Huntington's can be difficult for anyone, but especially children, to really understand, and I can understand your reluctance to open the door into the realm of Huntington's disease to your children. But children often guess more that we give them credit for, and may start asking questions. *There are certainly resources available that can help with such a discussion,* and present age-appropriate information in a way that is easy for kids to understand and will help facilitate discussion.
Self-Disclosure (*n* = 5)	This is tough. Each family has to decide when and how to share the information with children. There probably isn't one right way to do so. *In my experience, the children often know more than parents realize and at a pretty young age.* Have you considered asking your son or daughter what they understand? Then you can slowly fill in the blanks.
Self-Involvement (*n* = 11)	*I can't imagine having to talk to my children about a topic like this.* It sounds like you have been thinking a lot about this though. How old are your children?

Note. This scenario does not have non-verbal behavior responses. Examples are provided verbatim. For those examples which involve more than one domain, italics indicate the portion of the response that represents the domain in question.

Genetic Counselors' Experiences of Being Empathic with Patients: Empathy Challenges

Participants were asked to respond to the following question: *Please describe the challenges you experience in attempting to engage empathically with patients in your genetic counseling sessions.* One hundred twenty-one individuals responded, describing their perceptions of various factors that hinder or inhibit their ability to engage empathically with patients. Many of their responses were classified multiple times into themes, domains, and/or categories. There are 3 themes, 6 domains, and 18 categories. The three themes are: Counselor Factors, Nature of Genetic Counseling Sessions, and Patient Factors. In the following sections, themes, domains, and categories are described, and illustrative examples are provided.

<center>Theme I: Counselor Factors (<u>n</u> = 70)</center>

This theme includes responses describing counselor characteristics, behaviors, attitudes, beliefs, and/or feelings that limit their empathic engagement. There are two domains: Counselor characteristics, and Counselor feelings and beliefs.

Domain 1: Counselor Characteristics (n = 47)

Forty-seven participants wrote responses describing personal characteristics that affect their use of empathy with patients. There are 3 categories.

Category 1. Lack of perspective-taking/insight about patient's experience (n = 24). Some participants commented on the difficulty they sometimes face in understanding a patient's experience, primarily due to differences in life experiences. One genetic counselor responded, "… My patients are usually much older (I'm only in my mid 20s) and this makes it a lot harder to empathize with them, as well." Another genetic

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counselor said, "… Sometimes the patients are very unlike me – especially mental illness and incarcerations – that I am only connecting with the human, not the specifics." A third genetic counselor expressed, "My biggest challenge is simply that I've never been in their situation or even close to it. Not having ever been pregnant, I don't know the anticipation, fear, or any other emotion associated with being pregnant nor the affect [sic] of the hormones on those emotions."

Category 2. Challenges using empathy skillfully (n = 21). A number of participants described themselves and/or counselors in general as not being able to fully empathize with patients due to personal characteristics or behaviors, including their empathy skills. One genetic counselor commented, "…I am also still working on expressing my empathy which leads to my own barriers." Another genetic counselor said, "I think the biggest challenge with empathy is not to react too soon to what a patient is saying and assume you know what they are feeling…" A third genetic counselor replied, "I am not always right when I respond to patient emotions (ie: I may attribute their outward reaction to the wrong underlying emotion)…" A fourth counselor expressed, "… I have to fight the desire to 'fix' the problem and remind myself to listen and mirror the patient's emotions."

Others mentioned how they had difficulty using empathy effectively when there were cultural/language differences between themselves and their patients. One genetic counselor said, "People who's [sic] backgrounds are very different than mine. Particularly if the patient or mother is from a culture where other family members make the medical and other decisions and they don't answer any questions, other family

members do." Another genetic counselor replied, "For me the biggest challenge is with patients from backgrounds very different from mine who tend to keep their thoughts and emotions very private (both spoken and non-verbal)." A third genetic counselor expressed, "Language barrier is certainly a challenge."

Category 3. Over-identifying with the patient (n = 8). A few genetic counselors talked about the challenge of over-identifying with the patient. One genetic counselor responded, "Occasionally, it seems that I am more concerned about the child's diagnosis than the parent is." A second genetic counselor expressed, "… I suppose it's really counter-transference, but those times when a client is in a situation that evokes such fear in me (ie typically developing child who slowly, inexorably, starts to lose skills and declines in cognitive function/physical health) that I don't think I'm really being empathic to the pain that they're feeling. I'm really feeling more of my pain and fear about the possibility."

Domain 2: Counselor Feelings and Beliefs (n = 27)

Twenty-seven participants talked about personal feelings and beliefs that interfered with being empathic toward patients. There are 3 categories.

Category 1. Counselor judgmentalness (n = 16). Sixteen genetic counselors commented on the difficulty they experience being empathic when they feel critical or disapproving about their patients' situation and/or behavior. One genetic counselor said, "If I am morally or ethically conflicted in some way about the situation, I find it more difficult to engage empathically." Another genetic counselor expressed, "Sometimes it can be hard for me to empathize with someone who I see making bad choices over and

over again (drug during pregnancy, abusive relationship, etc). In those cases, I sometimes try to forget the past history that I am aware of and pretend that I am talking to a girlfriend."

Category 2. Counselor frustration (n = 7). Seven genetic counselors described how their frustration at times interfered with their empathy. One individual said, "I find it challenging when patients have unrealistic expectations of genetics and the medical community. This usually arises after many interactions when I have repeatedly explained limitations, validated frustration, and apologized that we are not able to give the patient what he or she wants. I find it difficult at this point to empathize with someone who continues to demand more than I or my profession can give." Another genetic counselor replied, "Frustration if I feel like the patient's point of view or feelings come from a faulty understanding of the facts of a situation…"

Category 3. Counselor compassion fatigue (n = 6). Compassion fatigue is the physical and emotional distress experienced by care-givers through their repeated empathic engagement with patients (Figley, 2002). Predictors of genetic counselors' compassion fatigue include burnout, coping with their distress by using self-criticism and giving up, experiencing a variety of distressing clinical cases, and having larger caseloads (Udipi et al., 2008). A few of the present participants described empathy challenges that reflect possible compassion fatigue. One genetic counselor said, "Depending on the number of patients seen in the practice, I can easily experience burn out quickly in my attempts to engage empathically with every patient." Another genetic counselor expressed, "I often feel that I take my emotions home with me, and have a hard time

feeling relaxed after a particularly emotional day."

<div align="center">Theme II: Nature of Genetic Counseling Sessions (*n* = 54)</div>

Theme II includes responses describing factors that involves certain inherent features of genetic counseling sessions. There are two domains: Time, and Mediating services/presence of others.

Domain 1: Time (n = 45)

Forty-five participants mentioned time as a factor that limits their empathic engagement with patients. There are 3 categories describing time constraints, time management issues, and the limited nature of typical genetic counseling sessions/relationships.

Category 1. Time constraints (n = 31). Thirty-one genetic counselors attributed their challenges with using empathy to the limited amount of time in a genetic counseling session. One genetic counselor commented, "In some situations, the patient has so many feelings that it can be challenging to address all of them. Time is the major limiting factor in a session that requires empathy for multiple feelings that the patient shares with me…" Another genetic counselor said, "… Length of session, you just get the rapport going and it's time to wrap it up. If you did get into deep discussions, don't have time for the patient to talk & 'fall apart' and 'pull it back together'." A third genetic counselor responded, "Time is one of the biggest challenges on a busy day. Sometimes you know that you need to delve deeper, but unfortunately don't have the time…"

Category 2. Time management: Prioritization (n = 15). All but one of the genetic counselors whose responses are classified in this category described having to assign

greater priority to tasks other than empathy, given the limited amount of session time. In particular, information gathering and provision took precedence over empathy. One genetic counselor expressed, "The amount of technical information to cover in the course of a session often makes it difficult to spend a lot of time engaging empathetically…" A second individual responded, "Time constraints make it difficult to engage empathically but also provide and gather all of the necessary information to best provide genetic counseling."

One genetic counselor described leaving empathy until the end of the session, which meant that it did not always occur: "…Empathy usually left to the end of session and run out of time to really engage a patient beyond a couple of brief questions…"

Category 3. Brief/short term nature of genetic counseling (n = 9). Nine genetic counselors indicated that the brief/short-term nature of genetic counseling and lack of follow-up with most patients make it difficult to connect empathically with them. Their responses variously suggest a certain amount of rapport is necessary in order for empathy to occur, and/or that one's empathic engagement can only increase over time. One genetic counselor said, "Usually only meet with patients one time, so any building of substantial rapport is difficult…" Another expressed, "The biggest challenge is the length of time spent with the patient. Often I will not be able to see them again and that can be difficult interacting as empathetic [sic] as possible." A third genetic counselor responded, "My biggest challenge is the fact that my interactions with the patients can sometimes be very brief. I sometimes do not see the patient's once a genetic diagnosis is made, it is frustrating to be unable to use the skills I learned from my GC training program…"

Domain 2: Mediating Presence of Others During Counseling Session (n = 17)

Seventeen participants wrote responses describing how the presence of others (health care providers, other family members) and services provided by others during counseling sessions (specifically, interpreters) inhibit their use of empathy with patients. There are 2 categories.

Category 1. Disruptive presence of others (n = 11). Eleven genetic counselors described how the presence of medical staff and/or the patient's family members pose challenges for empathic connection, including lack of privacy, distractions, and conflicts regarding to whom one should respond empathically. One genetic counselor identified as a challenge, "… lack of privacy (multiple family members and other providers in the room)." Another responded, "… In pediatric clinic, the presence of noisy children can get in the way of a real connection." A third participant replied, "… GC sessions often involve multiple family members with competing needs and issues. It can be quite a challenge to engage empathically with any one individual to a satisfying extent."

Category 2. Language interpretation hinders empathic connection (n = 6). A few genetic counselors reported that the presence of a language interpreter made it more difficult to build empathic connection with patients. One genetic counselor said, "1/2 my pts are Spanish speaking, so engaging empathically with a more reserved client is even more difficult through an interpreter…" Another genetic counselor responded, "… My difficulty is that I see many patients through a language interpreter and these sessions are difficult for me with regard to empathic statements as the sincerity feels lost at times. This is when I tend to rely heavily on body language and tone of voice."

Theme III: Patient Factors ($n = 38$)

Theme III includes responses that identify various patient-related factors. There are three domains: Patient characteristics, Patient feelings, and Miscellaneous.

Domain 1: Patient Characteristics (n = 29)

Twenty-nine participants wrote responses describing patient characteristics that are challenging with respect to counselor empathic engagement. There are 3 categories.

Category 1. Patient disinterest in discussing feelings (n = 23). Twenty-three genetic counselors indicated that patients' lack of interest in or motivation to discuss feelings interfered with their expressions of empathy. One counselor commented, "Some patients do not like to talk about their feelings…" Another said, "Patients come in expecting a procedure, not expecting to be asked to open up regarding historical events. Sometimes not responsive to emotional reflections or questions, just want to 'get on with it'…"

Category 2. Patient demographics (n = 5). Five genetic counselors mentioned patients' demographic backgrounds (e.g., age, gender, socioeconomic status) as a barrier to empathy. One genetic counselor said, "resistance to discussing their emotions (especially men)…" Another genetic counselor expressed "… I personally have a harder time engaging teenagers, getting them to tell me how they are feeling…"

Category 3. Patient's culture does not support sharing feelings (n = 4). Four genetic counselors described how a patient's cultural values/practices might not be supportive of discussing feelings. One individual wrote, "… Also, pts often deny certain feelings/emotions/topics due to strict catholic/religious background which makes it

difficult to take some conversations to a deeper level (ie Down syndrome, birth defects, etc)…" Another genetic counselor said, "…Also, we have a very diverse ethnic population here, and not all are open to empathy and volley [sic] of conversation that needs to happen for it to be most effective."

Domain 2: Patient Feelings (n = 16)

Sixteen participants described certain patient feelings and beliefs that challenge their use of empathy. There are 3 categories.

Category 1. Patient anger/aggression (n = 8). Eight genetic counselors talked about their difficulty being empathic toward patients who are angry or aggressive. One participant said, "Sometimes if a patient is rude and aggressive, I am able to 'manage' them, but I'm probably not as empathetic as usual because I feel defensive…" Another genetic counselor expressed, "… I find that patients who are angry require even more empathy since they have focused their sadness and grief into anger which can result in isolation. It is hard to be around an angry person. But these are the patients who really need someone to recognize their anger as part of the grieving process."

Category 2. Patient distrust/skepticism (n = 5). Five genetic counselors described their difficulty being empathic when their patients did not trust or were suspicious of them. One genetic counselor commented, "There are occasional patients that are surprised and skeptical that a busy professional is really interested in their feelings…" Another said, "… Some people are quite skeptical of 'genetics' in general, and hesitant to open up."

Category 3. Patient shock/denial (n = 5). Five genetic counselors identified

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difficulty connecting to patients who were in shock and/or coping by using denial about their situation. One genetic counselor responded, "I have a harder time when patients are in denial…" Another expressed, "… some patients have a strong defense mechanism in the early phase of dealing with a crisis and they choose to focus on the practical side of their situation (information gathering, decision making) and will not respond to attempts to engage the more emotional aspects of the situation…"

Domain 3: Miscellaneous (n = 7)

Seven responses could not otherwise be categorized into domains: (1)"… The offices in which I work are also not set up to allow me to be physically close to the patient. I'm stuck behind a large desk separating me from the patient, which decreases the level of comfort and lessens the degree to which we can connect." (2)"…There's a fine line with maintaining your professionalism, but being real. Also, with people so quick to sue or get offended, that can be a challenge. For example, when I feel the session has been particularly emotional, I always ASK the patient if I can give them a hug b/c I'm afraid they would take it the wrong way if I just hugged them unannounced." (3)"… Most of my patients have already had problems, as well as life-saving surgeries, so they are usually very upbeat and thankful for the information that I can provide (which doesn't necessitate a ton of empathy)…" (4)"I sometimes wonder just how often patients want to hear or experience empathy, and how often they just want someone to listen…" (5)"… Have trouble when patients give misinformation about what has been said." (6)"…Often they seem 'talked out' by the time they get to me. We have the luxury of excellent social work, child life, behavioral medicine, and other staff who meet with many of our patients

for more direct discussion of their coping." (7)"I usually engage empathically with my patients, and am guided to some extent by them as to the level to which they wish me to take this."

Genetic Counselors' Experiences of Empathy with Patients: Empathy Successes

Participants were asked to respond to the following questions: *Please describe a genetic counseling session in which you were being particularly empathic with your patient. Please describe the patient's issue/situation, how you responded, and the patient's reaction to your empathy.* Ninety-seven individuals responded, describing their empathy (verbal responses and/or non-verbal behaviors) and their patient's reactions. Descriptions of their own empathy were categorized into 3 themes, 9 domains, and 4 categories. The three themes are: Exploring Psychosocial Issues and Providing Psychosocial Support, Information Provision, and Facilitating Patient Coping. In the following section, themes, domains, and categories are described, and illustrative examples are provided.

Theme I: Exploring Psychosocial Issues and Providing Psychosocial Support (*n* = 94)

Theme I includes descriptions of empathic behaviors that involve exploring the patient's psychosocial issues and providing psychological and social support. There are five domains: Verbal behaviors, Counselor validating/normalizing patient's feelings/needs, Non-verbal behaviors, Counselor empowering and/or encouraging patient, and Patient advocacy.

Domain 1: Verbal Behaviors (n = 84)

Eighty-four participants wrote responses that involved verbally empathizing with the patient. There are 4 categories.

Category 1. Primary empathy (n = 50). Some participants provided examples of actual responses they made to their patients. Their responses consisted of primary empathy statements that reflected details of the patient's situation and/or the patient feelings. One genetic counselor described a session in which the patient was dealing with "…test results of uncertain significance in a child with developmental issues." The counselor said to her patient, "It must be extremely frustrating that nobody can tell you what this means." Another genetic counselor described her empathic response to a 20-year old patient who was at 50% risk for Lynch syndrome. The patient "…had not understood the purpose of her visit to genetics…[and I]…had to tell her of her risk for the condition and what this risk meant." The counselor said to this patient, "… it must be very difficult to hear this information. Especially when you didn't know that this was what we were going to be discussing today. No one wants to hear that they may be at risk of developing cancer."

A third genetic counselor had a couple who "…just learned that their unborn baby had a severe skeletal dysplasia that would likely not be compatible with life after birth… [and they were]…angry at the way in which the diagnosis had been delivered by a physician at another clinic." The counselor "…acknowledged that they wished the news had been delivered differently and asked how they would have preferred it had been done." The counselor also "…reflected the overwhelm, shock, and grief they (patients) were feeling, and their need for more sensitive and thorough communication from their

health care providers."

Category 2. Reinforcement/Influence (n = 32). Some participants described sharing their personal opinions in an attempt to support their patient's perspectives. One genetic counselor counseled a couple "…in their second pregnancy…[The couple]…ended the first pregnancy because of fetal anomalies and now seeing me during their second pregnancy in which fetal anomalies have been detected and are considering ending the pregnancy." The counselor responded to the couple by saying, "It is not your fault…[and] There is nothing wrong with you." Another genetic counselor described a situation in which the patient "…had a child with a severe form of epidermolysis bullosa and the child was palliative at the time of our meeting…She (The child) was clearly in a great deal of pain…the patient was speaking about the fact that her daughter was not going to survive for much longer and expressed a lot of ambivalence about wanting her daughter to survive but also hoping that it might be over soon." The counselor said to the patient, "It's ok to feel conflicted. I'm hearing that you love your daughter very very much and while you have been strong and kept hope for a long time, you're feeling like now may be the time to let her go. It's because you love her so much that you're feeling that it may be time to say goodbye."

Category 3. Further exploring patient's situation or feeling (n = 27). Some genetic counselors generally described how they engaged empathically through further exploration of the patient's situation or feelings. For example, one genetic counselor described a prenatal session in which the pregnancy was affected with triploidy. The counselor reported spending "…the rest of the time talking with her about how she felt

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about her circumstances," after having presented the patient with scientific/medical information. Another genetic counselor had a patient who called about her miscarriages (she had 2 or 3), and the counselor had evaluated one of her children because he has Klinefelter syndrome. The patient "…wanted to know as much info as possible since she really wanted more kids." The counselor described "…discussing patient's desire for a big family but also their anxiety of having a child with a problem."

Category 4. Self-Disclosure/Self-Involvement (n = 17). Some genetic counselors shared personal information or "here-and-now" feelings in response to their patient. One genetic counselor had a patient "…whose brother has Duchenne muscular dystrophy. Sequencing was not covered with their insurance and paying for it was financially not possible. Linkage studies determined the woman is a carrier and her male fetus is affected with 80% accuracy." The counselor replied to the patient, "… You know that I will support whatever decision is right for you. I am just so sorry that you are faced with making these difficult decisions." Another genetic counselor had a patient who "…was afraid that genetic testing would not reveal a mutation that would provide answers to her family, especially her children. She wanted to have something black and white to give them, so they would be protected from the unknown (in the event we could not identify why she had early onset cancer)." The counselor replied by saying, "I had also had early onset cancer, and when I did genetic testing, it was negative." The counselor also shared "how it was so unexpected, and how much I had wanted to have information for my children."

Domain 2: Counselor Validating/Normalizing Patient's Feelings/Needs (n = 38).

Thirty-eight participants talked about validating or normalizing patient's feelings. There are no separate categories. For example, one genetic counselor had a patient with "…possible Cowden syndrome having to wait a year for the PTEN gene test results." The counselor empathized with her distress as she "… Normalized her feeling of frustration…" Another genetic counselor had a patient who "…has had breast cancer and BRCA testing… [The patient's test was negative and she was] really looking for more information on her risks and if she has made the proper medical decision." The counselor described the patient as very nervous and "…when she goes to the doctor she feels like she gets 10 minutes and then a brush off of her concerns." The counselor reported "…validating the patient's need for answers and more specific information, as she (the patient) is stuck in a bit of a grey zone with her cancer and her negative genetic results."

Domain 3: Non-Verbal Behaviors (n = 19)

Nineteen participants wrote responses that involved the use of various non-verbal behaviors to empathize with patients. There are no separate categories. *Listening* was mentioned by a few counselors. One said, "I listened, and listened, and listened…" Another replied, "… I listened to her story…" A third genetic counselor responded, "I let her tell the story of how this all unfolded…"

Other genetic counselors described a variety of non-verbal behaviors. For example, one individual wrote, "I stayed near her, and stroked her hair…" Another responded, "I gave her a hug…" A third genetic counselor said, "… I did get some tears in my eyes when talking to her and seeing her pain and sadness."

Domain 4:Counselor Empowering and/or Encouraging Patient (n = 14).

Some participants empathized with patients by providing encouraging or empowering statements. For example, one genetic counselor described a situation in which she was with a patient "… who was undergoing a 22 week induction of labor for a baby with trisomy 13…[The patient] delivered the baby, and the baby was gasping for air, and clearly still alive." The patient then "…began sobbing, thinking about how she was killing her child, and when he shuddered, she put a blanket over his head and looked away, shaking with grief." The counselor responded to the patient by "… talking about how she was so brave and so selfless - she was willing to give up this very wanted pregnancy to protect her child from what she felt would be a life of suffering."

Another genetic counselor described a situation when "A patient came in for Lynch syndrome testing after her mother had both endometrial and colon cancer and ultimately died from her colon cancer in her 50s…[The patient's] only maternal uncle also died from colon cancer at age 32…[and] both patient's maternal grandparents died in their 40s-50s of colon cancer…The patient has little to no support system due to family being deceased and her losing contact with her two half siblings. She is also raising two young children on her own." The counselor "…reassured her that this information is hard to take in but would get better with time and that the goal of knowing this information was so that she could be around to see her kids grow up and so she could stay cancer free…"

Domain 5: Patient Advocacy (n = 6)

Six participants described advocating for their patients. In these situations, advocacy refers to providing concrete assistance for patients. There are no separate

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categories. One genetic counselor described a session in which "…an unusual anomaly was detected via the amniocentesis result. The patient was very upset and decided to terminate. She has the termination at the same institution as my workplace. She wanted a baptism and funeral service ASAP." The counselor described advocating for the patient through "…helping her schedule a baptism, setting up a service in the hospital chapel, and assisting with getting a casket, etc."

<div align="center">Theme II: Information Provision (n = 41)</div>

This theme includes responses that involve providing information to patients. There are two domains: Information to enhance understanding of biomedical issues, and Facilitating decision-making process.

Domain 1: Information to Enhance Understanding of Biomedical Issues (n = 31)

Thirty-one participants described providing biomedical information to their patient. There are no separate categories. Five genetic counselors talked about following up with patients after a genetic counseling session in order to provide information. One genetic counselor told her patient that he/she would "follow up at regular intervals to provide information." Another genetic counselor "checked on her patient with the autopsy results…[and] followed up for a few months afterwards."

Additional examples of information provision include one genetic counselor who "briefly provided the relevant scientific/medical information…" to a patient experiencing a pregnancy with triploidy. Another genetic counselor had a patient who was referred for a workup for infertility. The counselor described "… walking through, step by step, her personal and family history, what is involved in an infertility workup, etc."

Domain 2: Facilitating Decision-Making Process (n = 18)

In this domain, participants described sessions in which they helped a patient with the decision making process, either through *anticipatory guidance* (i.e., exploring with patients how they thought they would feel, what they would do, how they would cope, and what they may need if pursuing a test or receiving an unwanted diagnosis) or by presenting to, or exploring options with, a patients. There are no separate categories.

One genetic counselor dealt with the following situation: "a woman who had 5 early miscarriages was finally pregnant and at 12 weeks - she'd never been that far along. she was really excited but then she found out, from first trimester screening, that her risk for Down syndrome was increased. she was anxious about the risk of CVS to a potentially healthy pregnancy." The counselor discussed with the client "the likelihood of Down syndrome vs. the likelihood of a miscarriage from the CVS and what the results of a CVS would mean to her…." Another genetic counselor had a patient who was "seeking carrier testing for hemophilia - came to clinic with mother." The counselor discussed the "what if" with the patient – what if the patient is not a carrier.

<div align="center">Theme III: Facilitating Patient Coping (n = 19)</div>

Theme III includes empathic behaviors that facilitate patient coping. There are three domains: Coping resources, Coping strategies, and Miscellaneous.

Domain 1: Coping Resources (n = 12)

Twelve respondents described helping their patients identify *coping resources*. There are no separate categories. For example, one genetic counselor described a session in which the patient was "…distressed regarding her pregnancy. Pt's previous child has

delays from CMV infection and pt very scared that would happen again. Pt also worried about balancing care for her child and the newborn. Pt was seen for integrated screening." The counselor and the patient discussed "… meeting with a counselor to discuss those stresses if she (the patient) is interested (which would be a free service for her)…[as well as] all the individuals able to assist her." Another genetic counselor dealt with a situation involving "Amnio diagnosed trisomy 18 in a 27 yo woman. It was her and her husband's first pregnancy and very much wanted and planned for. They were making the decision of whether or not to terminate." The counselor described giving the patients "…a book about dealing with the loss of a pregnancy."

Domain 2: Coping Strategies (n = 7)

Seven participants wrote responses that involve working with patients to build up *coping strategies*. There are no separate categories. For example, one genetic counselor had a patient "… from the middle east who had 2 female children and 8 pregnancy losses, all boys." The counselor and the patient talked about "… what would she (the patient) do if it was a girl." Another genetic counselor saw a couple "who were about my age who had recently miscarried a pregnancy." The counselor and the couple talked more about "their plans for future pregnancies, continued coping as the due date approaches, anticipatory guidance, etc..."

Domain 3: Miscellaneous (n = 3)

Three responses could not otherwise be classified within the domains in this theme: 1) "… I did not see the ultrasound report from China and did not know how strong the markers for Trisomy 18 were, but it sounded like the diagnosis was more likely

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than not…" ; 2) "… I walked with her to labor and delivery from our office in the

hospital and tried to prepare her for giving birth…"; and 3) "… She had already received

the diagnosis of cancer and was dealing with it with such strength for a person who is

young and still has so much to do in life…"

<div align="center">Summary of Research Findings</div>

This section contains a brief summary of the major research findings, presented in

the order of the major research questions investigated in the present study.

Research Question 1: What is genetic counselors' empathy tendency?

Results showed that on the Interpersonal Reactivity Index (Davis, 1983), the

participants had the highest mean empathy score on the Empathic Concern Scale,

followed by Perspective-Taking Scale, the Fantasy Scale, and the Personal Distress Scale.

These findings indicate that the genetic counselors were highest on the affective

dimensions of empathy, as defined by Davis. The range of scores for three of the

dimensions (Empathic Concern, Perspective-Taking, and Fantasy) suggests a possible

ceiling effect as a number of participants obtained the maximum subscale score of 28.

Research Question 2: How do genetic counselors respond empathically to patients in

hypothetical clinical scenarios?

Results showed that genetic counselors expressed empathy through a variety of

responses (e.g., summarizing the content of patient statements, reflecting patient affect,

asking questions, providing advice…, etc). Content and affect responses were the two

most prevalent types of responses for the cancer, clefting, and Long-QT scenarios and

they were first and third most prevalent, respectively, for the Fabry and Huntington's

scenarios. Thus, a majority of participants formulated responses reflecting empathy as operationalized by other authors (cf. Danish, D'Augelli, & Hauer, 1980; McCarthy Veach, LeRoy, & Bartels, 2003). For every scenario, some participants provided responses that have been defined as advanced empathy (cf. McCarthy Veach et al., 2003).

Research Question 3: What are genetic counselors' experiences of being empathic with their patients (both successes and challenges)?

Results indicated that genetic counselors perceived/defined empathy successes in different ways, suggesting the multidimensional nature of the construct. Their responses primarily are in accordance with Rogers' definition of empathy. Their descriptions of empathy challenges suggest the reciprocal influence of three major sources: counselor characteristics/behaviors, patient characteristics/behaviors, and nature of genetic counseling. Their challenges also are in accordance with Rogers' definition of empathy.

Research Question 4: Are genetic counselors' demographic characteristics significant predictors of their empathy tendency?

The results suggested that the demographic characteristic of years of experience as a genetic counselor was not a significant predictor of any of the four dimensions of empathy tendency as measured by the Interpersonal Reactivity Index.

Research Question 5: What are the relationships between genetic counselors' empathy tendency, demographic characteristics, and their empathic responses to patients?

Results showed that genetic counselors' empathic responses to patients (whether or not they responded empathically) were not significantly related to their scores on any of the four dimensions of empathy tendency. Furthermore, years of experience as a

genetic counselor was only significantly related to responses to one of the hypothetical

clinical scenarios (Scenario 5: Huntington Disease). For that scenario, experienced

genetic counselors were less likely to respond with empathy (content or affect response)

than were novice counselors.

Chapter 5

Discussion

Carl Rogers, the founder of Person-Centered Theory, defined empathy as " …
[the ability] to perceive the internal frame of reference of another with accuracy and with
the emotional components and meanings which pertain thereto as if one were the person,
but without ever losing the 'as if' condition" (Rogers, 1957, p.210). Although empathy is
defined differently in other theories, it is generally acknowledged as an important
counseling element. For instance, some theorists and researchers suggest that empathy
expressed by therapists may enhance their understanding of clients' issues/situations,
deepen clients' experiences of their feelings, and in general, establish rapport within
counseling dyads (Clark, 2007; Gladstein, 1983; Hill & O'Brien, 1999).

Not only is empathy widely recognized in counseling psychology, attention is
being given to the construct in other human service fields. In genetic counseling,
increasing efforts are being directed towards helping genetic counselors to be empathic
with their patients (cf., Kessler, 1999; McCarthy Veach, LeRoy, & Bartels, 2003). Yet,
little is known empirically about how empathy should be defined and practiced in a field
that aims to provide both medical/genetic information and psychosocial support to
patients (Biesecker, 2001; McCarthy Veach, Bartels & LeRoy, 2007).

Therefore, the present study involved an investigation of genetic counselors' self-
reported empathic tendency (a measure of one's ability to *experience* empathy) and their
written empathy responses to patients in hypothetical clinical scenarios (a measure of
one's ability to *express* empathy). Full members of the National Society of Genetic

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Counselors (NSGC) who subscribed to the online listserv were invited to participate in an anonymous online survey. Two-hundred ten individuals returned surveys, and of these, 123 completed the demographic items, the Interpersonal Reactivity Index, and provided responses to five hypothetical clinical scenarios. In the following sections, major results are discussed (beginning with results of quantitative analyses, followed by qualitative results), study limitations are delineated, and practice implications and research recommendations are provided. Furthermore, as literature (Barrett-Lennard,1981) suggests there are three dimensions of empathy: empathizers' ability to experience empathy, their capacity to express empathy verbally or non-verbally (expressed empathy), and how receivers experience the empathy (received empathy), major results will be discussed in relation to specific dimension/s of empathy.

Genetic Counselors' Empathy Tendency

One major research question investigated in this study involved the extent to which genetic counselors have an empathy tendency (i.e., ability to experience empathy). The participants' empathy tendency was measured by the Interpersonal Reactivity Index (IRI; Davis, 1983). The results showed that the current sample had the highest mean score on the Empathic Concern Scale, followed by the Perspective-Taking Scale, the Fantasy Scale, and the Personal Distress Scale. Their two highest scale scores reflect one affective dimension of empathy (the Empathic Concern Scale) and one cognitive dimensions of empathy (the Perspective-Taking Scale), as conceptualized by Davis (1983). One would expect helping professionals to have a strong ability to experience empathy in ways that allow them to understand their clientele (e.g., higher perspective

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taking) and to feel their emotional distress (e.g., higher empathic concern). In contrast, the lower personal distress score for the present sample suggests that they generally are able to maintain a certain amount of professional distance or objectivity; moreover they may be able to effectively manage compassion fatigue, which can result from continual empathic engagement with patients who are in distress (cf. Udipi, McCarthy Veach, Kao, & LeRoy, 2008). Furthermore, as these results indicate that genetic counselors as a group have high capacity to experience empathy and that they are able to maintain objectivity in distressing situations , it seems that the genetic counseling profession is effectively attracting, selecting, preparing, and retaining individuals for genetic counseling practice.

The genetic counselors' scores on the IRI are quite similar to those of an undergraduate female sample (Davis, 1983), with one exception - Davis' sample had a higher mean score on the Personal Distress Scale than on the Fantasy Scale. One might expect genetic counselors to have higher scores on the Empathic Concern and Perspective Taking scales than a "generic" sample of undergraduates, since individuals with high empathy tendency likely would gravitate to helping professions. As noted in Chapter 4, however, there was a possible ceiling effect for three of the four empathy subscales, thus possibly lowering the overall means for the sample. Moreover, the vast majority of the genetic counselors were female [which reflects the population of genetic counselors (Smith, Freivogel, & Parrot, 2009)]. Regardless of whether they are professionals or undergraduates, females in the U.S. tend to be socialized to be nurturing and emotionally expressive (Witt, 1997) and thus might be expected to report higher empathic tendency.

Results from the multivariate analyses of variance (MANOVA's) indicated that

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years of experience practicing in genetic counseling (< 5 years versus ≥ 5 years) had no significant main effect on scores for any of the four subscales of the IRI. In other words, the longer one practices as a genetic counselor does not necessarily result in higher empathy level in IRI. These findings lend further support to the speculation that females are socialized to experience empathy. One might conclude from these results that increased clinical experience does not increase one's empathy tendency. On the other hand, the possible ceiling effect for the IRI scales and the crude categorization of individuals into "less than five years" or "five or more years" of experience may have obscured any differences. The findings might also be interpreted as evidence that graduate programs are selecting applicants who have strong empathic tendencies.

Regardless of how these findings are interpreted, clinical experience alone likely would not account for all of the variance in genetic counselors' empathy ability. A growing body of literature suggests that in order for genetic counselors to develop professionally, they must engage in reflective practice (cf. Runyon, Zahm, McCarthy Veach, Macfarlane, & LeRoy, *in press*).

Empathy Tendency, Responses to Clinical Scenarios, and Counselor Demographics

Another research question explored the relationships between genetic counselors' empathy tendency and both their responses in hypothetical clinical scenarios and their genetic counseling experience. Genetic counselors' written responses for each hypothetical clinical scenario were coded either as "Empathy" or "No Empathy," based on Rogers' (1975) definition. For each scenario, a MANOVA was conducted to determine if the two groups ("Empathy" versus "No Empathy") differed in their scores

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on the four IRI subscales. The results suggested no significant main effects. Thus, the ways in which the genetic counselors responded to the hypothetical clinical scenarios were not significantly related to their empathy tendency scores on the IRI.

Rogers' definition of empathy (1975, p.4) includes cognitive and affective dimensions; and the four subscales of the IRI also tap into these dimensions. Therefore, it may seem counter-intuitive that no significant relationships were achieved between participants' empathy tendency scores and their responses in the clinical scenarios. However, several factors might have contributed to the lack of statistically significant results. First of all, one's ability to *experience* empathy does not necessarily equate to one's ability to *express* empathy. Second, as mentioned previously, categorization of the written responses into two groups (Empathy vs. No Empathy) provided a very crude differentiation. It is possible that subtle differences might have been detected if variables such as use of affect versus content responses, use of other types of responses (e.g., advice, influence, self-disclosure, etc.), and overall length of responses were analyzed. Sample size precluded these types of analyses, as there would have been insufficient statistical power. Third, reliance on written responses may have "leveled the field" to a certain extent, in that participants could take all the time they wished to formulate and revise their responses. There may have been more apparent differences if their responses were made in a face-to-face clinical situation (either real or simulated).

Furthermore, even though most participants reportedly agreed with Rogers' definition of empathy, their responses varied widely, and many clearly extend beyond what Rogers' defined as empathy (This point is elaborated on in the next section). Many

of the genetic counselors appeared to want to "cover it all," perhaps in an attempt to be maximally helpful to patients, even though they were instructed to only respond with empathy. Accordingly, the results may suggest that the manner in which empathy is practiced in genetic counseling differs from how it practiced in counseling and psychotherapy. Additional research is necessary to define the nature of empathy in genetic counseling.

The second part of this research question explored the relationship between genetic counselor years of experience and empathy responses for each of the five scenarios. There was only one statistically significant finding. Genetic counselors that had five or more years of experience were less likely to include empathy in their response to the patient in Scenario Five: Huntington scenario. In other words, a significantly higher percentage of novice genetic counselors expressed empathy (as defined in this study) than experienced counselors. Since the five hypothetical clinical scenarios deal with distinctive clinical issues, it is possible that this finding reflects the distinctive nature of Scenario five. For instance, the Huntington scenario was more complex than the other scenarios since it involved a patient who was herself at 50% risk for a lethal condition, issues about when and how to tell her children about her risk, guilt about not having had a conversation with her children, and fear that she carries the mutation. Perhaps the more experienced counselors viewed a content and/or affective response as insufficient for dealing with complex issues and therefore moved to more "action-oriented" types of responses. Further research is needed to determine whether and how clinical experience affects genetic counselors' empathy responses.

Genetic Counselors' Empathy Responses

Participants were asked to write an empathy response (i.e., expressed empathy) for each of five hypothetical clinical scenarios. Across all five scenarios, affect and content responses were among the most prevalent domains. Thus, many of their responses reflected feelings and/or content shared by the patients. Very few responses appeared to be "off the mark" (e.g., understating or discounting patients' feelings or the gravity of their situations). Thus, most individuals' responses contained empathy, as defined in this study. These results affirm Joan Marks' (1993) decision to base training philosophy of the very first genetic counseling program on Carl Rogers' (1975) facilitative conditions for therapeutic relationships (empathy, genuineness, and unconditional positive regard). Genetic counselors as a group appear to be doing what their training programs intend for them to do.

In addition to affect and content domains, *influence* comprised another prevalent domain. The vast majority of influence responses seemed to be attempts to validate or normalize the patient's experience and/or to instill hope. These goals are consistent with those identified in models of genetic counseling practice (cf. McCarthy Veach, LeRoy, & Bartels, 2007).

Across all five scenarios, a large number of participants' responses contained more than one domain (nine different domains were extracted), and many participants provided rather lengthy responses. It is unknown whether the genetic counselors viewed every part of their response as empathy. As suggested earlier in this chapter, their complex and lengthy responses might reflect a tendency to be comprehensive or to

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"cover it all" – even though they were asked only to provide an empathy response. Alternatively, some participants may believe that an empathy response is not sufficient, and they feel pressed to "do more."

Another possibility is that complex responses reflect the time-limited, decision-making focus of genetic counseling as well as a belief that empathy, in and of itself, does not lead to desired genetic counseling outcomes. In counseling/psychotherapy empathy may be used primarily to deepen clients' experiences of their feelings, and thus can often be a "stand alone" response (Clark, 2007; Gladstein, 1983; Hill & O'Brien, 1999). In contrast, within genetic counseling, empathy may be used to express counselor understanding, acceptance, and support, and to "diffuse" patients' affect so they can receive the medical/genetic information and move forward with their decision-making. Thus, empathy may "set the stage" for the counselor to follow-up with information, validation, questions, etc. Kessler (1997), in describing two genetic counseling models – an educational/teaching model and a counseling model - stresses the importance of incorporating empathy into both models in order to provide emotional support to patients. In their Reciprocal-Engagement Model (REM) of genetic counseling practice, McCarthy Veach et al. (2007) similarly propose that empathy is an important element of the genetic counseling process because it provides support to the patient.

Genetic Counselors' Empathy Experience

Empathy challenges. Participants were asked to describe their challenges and successful experiences in engaging empathically with patients. Three themes emerged from their responses about empathy challenges, including counselor factors, nature of

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genetic counseling sessions, and client factors. Within the counselor factors, many

individuals talked either about difficulty understanding patients' perspective or

challenges using empathy skillfully. Some shared that over-identifying with patients or

having feelings such judgmentalness posed challenges to their empathic engagement.

Consistent with empathy theory and empathy skills (cf. McCarthy Veach et al., 2003),

these responses suggest when genetic counselors focus on themselves, they have

difficulty fully taking on the patient's perspective.

Regarding the nature of genetic counseling sessions, many identified insufficient

time in a session as well as genetic counseling's typically short-term nature as challenges.

Some also talked mentioned the challenge of dealing with the presence of people other

than the patient, such as medical staff or interpreters. Time limitations may inhibit a

genetic counselor's ability to develop a deep understanding (experiencing) of the patient

and her/his situation. These limitations may further limit the time available to express

one's empathy. The presence of others may inhibit patient expression of personal feelings

and thoughts, which subsequently limits the counselor's ability to empathize. The

presence of other family members may further distract the genetic counselor, for instance,

by raising dilemmas about to whom one should express empathy.

Finally, many participants indicated that patients may be disinterested in empathic

interaction. Some also identified certain patients' feelings that make it difficult for

counselors to engage empathically with them, such as anger or hostility. One might

speculate that it is difficult for genetic counselors to avoid taking patient anger

"personally." Once again, counselors' focus on themselves may interfere with attention to

their patient (McCarthy Veach et al., 2003).

Overall, participants appeared to be open and transparent about their empathy challenges. Additionally, their empathy challenges appear to include both difficulties *experiencing* empathy and *conveying* empathy. The findings also suggest that the nature of genetic counseling presents certain challenges for empathic engagement. Despite the fact that most participants agreed with Rogers' conceptual definition of empathy, its operationalization in genetic counseling requires further articulation. Thus, researchers should continue to explore the nature and role of empathy in genetic counseling sessions and relationships.

Empathy successes. Participants were also asked to describe successful experience of empathic engagement with their patients. Consistent with their responses to the hypothetical clinical scenarios, participants described a variety ways to provide empathy to patients. Many described responses indicative of reflections of client feelings and/or situations. Also, prevalent, however, were reports of using personal opinions (e.g., influencing statements) to support their patients' perspectives as a way to show empathy. Some described using self-disclosure to engage empathically, and some counselors described their empathy as involving information provision or facilitating patients' coping. These results also support the need for research that further defines empathy in genetic counseling.

Comparison of Current Research Findings to Empathy Literature in Genetic Counseling/Medical Settings

In this section current research findings are compared and contrasted to those of

the studies reviewed in the "Empathy in Genetic Counseling/Medical Settings" section in Chapter 2 (i.e., Duric et al., 2003; Lobb et al., 2005; Michie et al., 1997). Several differences in methodology and findings exist between the current study and the reviewed studies. First of all, participants (service providers) in the reviewed studies generally included genetic counselors and other professionals, such as geneticists or genetic consultants, whereas all of the participants in the present study were genetic counselors. Furthermore, the main purpose of the reviewed studies was to explore the effects of empathy (expressed empathy) as well as other counselor behaviors on genetic counseling processes and counseling outcomes. In contrast, the current study focused mainly on genetic counselors' capacity for experiencing empathy and a demonstration of their expressed empathy. Neither the reviewed studies nor the current study investigated genetic counselors' (as well as geneticists' and genetic consultants') intentions or conceptualizations regarding empathy.

Regarding the differences in research findings, the reviewed studies showed mixed effects of expressed empathy on counseling process and counseling outcome. Specifically, Duric et al.'s (2003) study showed a positive relationship between counselors' empathic response and the number of emotional cues given by patients. However, Lobb et al.'s (2005) and Michie et al.'s (1997) findings revealed no significant relationships between expressed empathy and counseling process/outcome. The current study did not explore the effect of expressed empathy on counseling process or counseling outcome; it focused on genetic counselors' capacity to experience empathy and their expressed empathy. The results indicated that genetic counselors generally have

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a high capacity to experience empathy and that they are able to maintain objectivity in distressing situations. Many of their expressions of empathy correspond to the types of empathy behaviors described in the studies reviewed in Chapter 2.

Study Limitations

Several limitations of the present study suggest caution in drawing definitive conclusions about the results. An estimated 1,177 full members of the National Society of Genetic Counselors (NSGC) that subscribed to the listserv were invited to participate in the study. Only 210 individuals responded to the invitation, for an estimated response rate of 17.8%. This sample may not be representative of the total population of genetic counselors, although their demographic characteristics are quite representative of the population (Smith et al., 2009). Nevertheless, it cannot be determined whether responders differ from non-responders in salient ways, and therefore generalizability of the results may be compromised. Additional limitations concern the five hypothetical clinical scenarios used to explore genetic counselors' empathic responses. The scenarios were highly analogue (simulated) in nature. They represented a limited number of issues, a very small portion of patient dialogue, they included only female adult patients, and participants had an unlimited amount of time in which to formulate their responses. Studies involving face-to-face genetic counseling sessions of a longer duration would provide a more realistic context in which to assess genetic counselor empathy. Finally, it is possible that participants responded in socially desirable ways to the survey and thus their responses may not reflect their actual characteristics and/or their actual counseling behaviors.

Practice and Training Implications

Despite the limitations outlined in the previous section, the present results may be useful for genetic counselor training and practice. The written responses provided for the clinical scenarios provide a wealth of examples for use in genetic counseling curricula. The scenarios could be used for student practice; students could compare their responses to those provided by the present participants. In addition, the genetic counselors' responses could be stimuli for discussion of the meaning of empathy in genetic counseling. The challenges and successes identified in this study could be used to further educate students about the nature and role of empathy in genetic counseling.

The findings further support theoretical arguments (e.g., Kessler, 1997,1999; McCarthy Veach et al., 2007) concerning the role of empathy in genetic counseling. The overall pattern of results suggests that empathy plays an important role in genetic counseling practice and a large amount of the data are consistent with Roger's (1957) definition of empathy. The prevalence of content and affective responses also provides validation of a recently proposed model of genetic counseling practice, the Reciprocal-Engagement Model (REM; McCarthy Veach et al., 2007).

Research Recommendations

This study explored genetic counselors' empathy tendency and their empathy responses to hypothetical clinical scenarios. The results offer some insights about genetic counselor empathy, but further studies are needed. Specifically, although most genetic counselors were capable of crafting an empathy response and they generally agreed with Carl Rogers' (1975) empathy definition, their intentions and

conceptualizations regarding empathy are unknown. Therefore, in-depth interviews may be helpful in deepening the understanding of how genetic counselors conceptualize and practice empathy in genetic counseling.

Furthermore, as the current study did not explore "received empathy," surveys of genetic counselors, patients, and/or potential patients could be done to obtain their evaluation of the various types of responses provided in the present study (e.g., the extent to which they express empathy, their helpfulness, etc.). Ratings by patients or potential patients are important because they would provide insights on how genetic counselor empathy is received by patients. Finally, hypothetical scenarios similar to the ones used in this study could be developed to include some of the challenges identified by the participants (e.g., situations in which the patient is angry at the counselor, the counselor feels critical of the patient's decision, the patient expresses disinterest in exploring feelings, etc.). Hopefully such research will contribute to the existing knowledge base of genetic counselor empathy, resulting in enhanced genetic counselor professional preparation and clinical practice, and contributing to a high standard of patient care.

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Appendix A: IRB Approval

Juihsien Kao

TO : leroy001@umn.edu, hung0047@umn.edu,

The IRB: Human Subjects Committee determined that the referenced study is exempt from review under federal guidelines 45 CFR Part 46.101(b) category #2 SURVEYS/INTERVIEWS; STANDARDIZED EDUCATIONAL TESTS; OBSERVATION OF PUBLIC BEHAVIOR.

Study Number: 0907E68886

Principal Investigator: Juihsien Kao

Title(s):
Exploring the use of empathy in genetic counseling

_____

This e-mail confirmation is your official University of Minnesota RSPP notification of exemption from full committee review. You will not receive a hard copy or letter.
This secure electronic notification between password protected authentications has been deemed by the University of Minnesota to constitute a legal signature.

The study number above is assigned to your research. That number and the title of your study must be used in all communication with the IRB office.

Research that involves observation can be approved under this category without obtaining consent.

SURVEY OR INTERVIEW RESEARCH APPROVED AS EXEMPT UNDER THIS CATEGORY IS LIMITED TO ADULT SUBJECTS.

This exemption is valid for five years from the date of this correspondence and will be filed inactive at that time. You will receive a notification prior to inactivation. If this research will extend beyond five years, you must submit a new application to the IRB before the study?s expiration date.

Upon receipt of this email, you may begin your research. If you have questions, please call the IRB office at (612) 626-5654.

You may go to the View Completed section of eResearch Central at http://eresearch.umn.edu/ to view further details on your study.

The IRB wishes you success with this research.

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Appendix B: Cover Letter

Dear Genetic Counselor:

You are invited to participate in a study of genetic counselors' use of empathy in clinical settings. You were selected as a possible participant because you are a practicing genetic counselor and a member of the National Society of Genetic Counselors. We ask that you read the following information and contact us with any questions you may have before beginning the survey.

This study is being conducted by Juihsien Kao, M.A., a doctoral student in the Counseling and Student Personnel Psychology Program at the University of Minnesota, under the supervision of her faculty advisor, Patricia McCarthy Veach, Ph.D., LP. and in consultation with Bonnie LeRoy, M.S., CGC.

The purpose of this study is to investigate how genetic counselors define empathy, their empathy tendency, and how they would use empathy responses in several hypothetical client situations.

Relevant Background Information: Empathy is thought to be an important counselor attitude, and empathy responses to clients in genetic counseling sessions may be helpful for building rapport. However, the ways in which empathy is expressed in genetic counseling have not been studied widely. A better understanding of empathy as defined and used by genetic counselors will assist in training and supervision and promote empirically-based genetic counseling interventions.

If you agree to participate in this study, we would ask you to do the following: Complete the anonymous online survey that can be accessed through the link below. The survey consists of a brief Demographic Information Sheet, an Interpersonal Reactivity Index, one open-ended question asking you to define empathy, and five brief, hypothetical client statements for which you are asked to provide an empathy response. It should take approximately 20-30 minutes to complete.

This is a minimal risk study with the only perceived risk of your participation being the possible discomfort with reflecting on responses to difficult client situations.
There are no direct benefits to you for participating in this study.
The anonymous online survey does not connect your responses to any identifying information. 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. The records of this study will be kept private, stored in a password protected computer. Only researchers will have access to the records.

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

Contacts and Questions:
If you have any concerns or questions about this study, you may contact Juihsien Kao, M.A., a doctoral student in the Counseling and Student Personnel Psychology Program at the University of Minnesota by email hung0047@umn.edu or telephone at 612.205.4990. You may also contact Juihsien's faculty advisor, Patricia McCarthy Veach, Ph.D. by email at veach001@umn.edu or telephone at 612.624.3580.

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.

Juihsien Kao, MA	Patricia McCarthy Veach, Ph.D.,	Bonnie LeRoy, M.S.
Doctoral Candidate	Professor	Genetics, Cell
Educational Psychology	Educational Psychology	Biology and
		Development

Appendix C: Demographic Sheet

1. What is your gender?

____ female

____ male

2. What is your current age?

____ 20 - 24

____ 25 - 29

____ 30 - 34

____ 35 - 39

____ 40 - 44

____ 45 - 49

____ 50 - 54

____ 55 - 59

____ 60 - 64

____ 65 - 69

____ 70 - 74

3. Please check the racial or ethnic group with which you most strongly identify.
   (Please check only one option):
   ____ African American/Black
   ____ Alaskan Native/American Native
   ____ Asian/Pacific Islander
   ____ Biracial (Please specify) _____
   ____ Caucasian/White
   ____ Chicano/Hispanic/Latino
   ____ Other (Please specify) _____

4. Please check your current relationship status:
   ____ Single
   ____ Engaged
   ____ Married
   ____ Partnered
   ____ Separated/Divorced
   ____ Widowed
   ____ Other (Please specify) _____

5. Please estimate the number of years you have practiced as a genetic counselor.
   ____ < 5 years
   ____ 6-10 years
   ____ 11-15 years
   ____ 16-20 years
   ____ greater than 20 years

6. What is your primary area of specialty? Check all that apply.
   ____ Adult Counseling
   ____ Cardiology
   ____ Cancer Genetics
   ____ Infertility, ART/IVF
   ____ Molecular/Cytogenetics/Biochemical Testing
   ____ Neurogenetics
   ____ Pediatric Counseling
   ____ Prenatal Counseling
   ____ Psychiatric Disorders
   ____ Public health/newborn screening
   ____ Screening (Multiple Marker)
   ____ Specialty Disease
   ____ Teratogens
   ____ Other (Please specify) _____

.
7. Where is your primary work setting? Check only one of the following.
   ____ University Medical Center
   ____ Private Hospital/Medical Facility
   ____ Public Hospital/Medical Facility
   ____ Diagnostic Laboratory
   ____ Physician's Private Practice
   ____ Federal/State/County Office
   ____ Other (Please specify) _____

8. Have you seen patients in the past two years or do you see patients currently?
   ____ Yes
   ____ No (Please skip to the next page if you answered "no.")

9. If you answered "yes" to question #8, what is the average number of patients you see per week? _____

10. If you answered "yes" to question #8, what is the length of your typical genetic counseling sessions? _____

Appendix D: Definition of Empathy

The founder of the Person-Centered Theory, Carl Rogers, proposes that empathy be one of the essential counselor attitudes. Rogers' definition of empathy is widely accepted in the field of counseling psychology and his work has started to be recognized in genetic counseling. His definition of empathy is provided as below. Please write the number that best describes the degree you agree/disagree with his definition. Please add any comments if you'd like.

Roger's definition of empathy:

> "… entering the private world of the other and becoming thoroughly at home in it. It involves being sensitive, moment to moment, to the changing felt meanings which flow in this other person… It means temporarily living in his/her life, moving about in it delicately without making judgments, sensing meanings of which he/she is scarcely aware, but not trying to uncover feelings of which the person is totally unaware, since this would be too threatening. It includes communicating your sensings of his/her world as you look with fresh and unfrightened eyes at elements of which the individual is fearful. It means frequently checking with him/her as to the accuracy of your sensings, and being guided by the responses you receive. … (Rogers, 1975, p.4)"

_____	1	2	3	4
	Strongly disagree	Disagree	Agree	Strongly agree

Comments:

Appendix E: Interpersonal Reactivity Index

The following statements inquire about your thoughts and feelings in a variety of situations. For each item, indicate how well it describes you by choosing the appropriate letter on the scale at the top of the page: A, B, C, D, or E. When you have decided on your answer, fill in the letter on the answer sheet next to the item number. READ EACH ITEM CAREFULLY BEFORE RESPONDING. Answer as honestly as you can. Thank you.

ANSWER SCALE:

A	B	C	D	E
DOES NOT				DESCRIBES ME
DESCRIBE ME				VERY
WELL				WELL

_____ 1. I daydream and fantasize, with some regularity, about things that might happen to me.

_____ 2. I often have tender, concerned feelings for people less fortunate than me.

_____ 3. I sometimes find it difficult to see things from the "other guy's" point of view.

_____ 4. Sometimes I don't feel very sorry for other people when they are having problems.

_____ 5. I really get involved with the feelings of the characters in a novel.

_____ 6. In emergency situations, I feel apprehensive and ill-at-ease.

_____ 7. I am usually objective when I watch a movie or play, and I don't often get completely caught up in it.

_____ 8. I try to look at everybody's side of a disagreement before I make a decision.

_____ 9. When I see someone being taken advantage of, I feel kind of protective towards them.

_____ 10. I sometimes feel helpless when I am in the middle of a very emotional situation.

_____ 11. I sometimes try to understand my friends better by imagining how things look from their perspective.

____ 12. Becoming extremely involved in a good book or movie is somewhat rare for me.

____ 13. When I see someone get hurt, I tend to remain calm.

____ 14. Other people's misfortunes do not usually disturb me a great deal.

____ 15. If I'm sure I'm right about something, I don't waste much time listening to other people's arguments.

____ 16. After seeing a play or movie, I have felt as though I were one of the characters.

____ 17. Being in a tense emotional situation scares me.

____ 18. When I see someone being treated unfairly, I sometimes don't feel very much pity for them.

____ 19. I am usually pretty effective in dealing with emergencies.

____ 20. I am often quite touched by things that I see happen.

____ 21. I believe that there are two sides to every question and try to look at them both.

____ 22. I would describe myself as a pretty soft-hearted person.

____ 23. When I watch a good movie, I can very easily put myself in the place of a leading character.

____ 24. I tend to lose control during emergencies.

____ 25. When I'm upset at someone, I usually try to "put myself in his shoes" for a while.

____ 26. When I am reading an interesting story or novel, I imagine how I would feel if the events in the story were happening to me.

____ 27. When I see someone who badly needs help in an emergency, I go to pieces.

____ 28. Before criticizing somebody, I try to imagine how I would feel if I were in their place.

Appendix F: Hypothetical Genetic Counseling Patient Scenario

The following five hypothetical genetic counseling patient scenarios are excerpts from real patient conversations included in selected qualitative studies from the Journal of Genetic Counseling. Please provide your ***Empathic Response*** to the patient as if you were counseling him/her in a genetic counseling session.

a. Scenario One: Cancer

A woman spoke about the process of undertaking genetic assessment for familial breast/ovarian cancer risk.

She said:

"Why does it take so long to assess? ... When am I likely to hear anything? If risk is great, how soon for surgery? ... I am not getting any younger and need to get this sorted ASAP..."(Phelps et al., 2007, p.509)

You say:

b. Scenario Two: Clefting

A mother described the experience of finding out at birth that her baby was diagnosed with clefting.

She said:

"The first words I heard from him (the doctor) were, "Oh, my"…. They said it was something that was fixable and not something to be majorly worried about. I didn't quite like it at all. I heard the 'Oh my', my husband fainted and I thought something was majorly wrong. I actually thought maybe the baby was dead or something. ..." (Nusbaum et al., 2008, p.340)

You say:

c. Scenario Three: Fabry Disease

A woman with Fabry disease described her experience of the disease.

She said:

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"The episodes of pain in hands and feet are impossible to describe

because the pain is so personal and out of control when it comes… The severe abdominal cramping is a sudden onset pain that is scary and something you're not sure you can survive. It actually feels like it might kill you [sic] many times I have passed out – I just hope and pray if I pass out the pain will be over when I come back… if I come back." *(Gibas et al., 2008, p.531)"*

You say:

d. Scenario Four: Long QT Syndrome

A young woman diagnosed with Long QT Syndrome was talking about

wanting to have a baby.

She said:

"And I want to give birth to at least one child. I want to have the opportunity to do that, then later I can adopt and all those things (…) you know you have a life today and you can in a way survive. (…) When you think about having a child, it is very frustrating not to get a clear answer as to whether you might die or not (…). If I choose to take the risk, because it is a hard burden on the heart, it is entirely up to me. No one can say whether it will work out well or not." (Andersen et al., 2008, p.494)

You say:

e. Scenario Five: Huntington Disease

A woman at risk of developing Huntington disease talked about

concealing from her children information about her risk.

She said:

"That's one area [telling the children] where we've made some really bad decisions. We haven't really had too many discussions about it. (…) They know that my brother [who has HD], comes to visit usually twice a year for a week. They know that he, you know, that he has problems with his balance and they can't jump on him and play. And there's certain things that they can't do with him,

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and they know that he doesn't work because of his balance and stuff like that. They know that my father died of Huntington's disease. They know that my brothers and my sister were sick. They don't know that I'm at risk for Huntington's disease. And they know the name of it and we've, we have been I guess a little bit evasive about it because we're, I'm afraid that as soon as we say Huntington's disease they're going to think "death" you know. They're going to jump to that and I don't think my youngest son could understand that. He's very young…."(Quaid et al., 2008, p.122)

You say:

Appendix G: Genetic Counselors' Empathic Experience

Please describe a genetic counseling session in which you were being particular empathic with your patient. Please describe the patient's issue/situation, how you responded, and the patient's reaction to your empathy.

The patient's issue/the situation:

How you responded (what you said and/or did):

The patient's reaction to your empathy:

Appendix H: Challenge of Using Empathy in Genetic Counseling

Please describe the challenges you experience in attempting to engage empathically with patients in your genetic counseling sessions.

Appendix I: Demographic Characteristics of Participants (partial completers)

Variable	Demo + Scenarios (n= 144)			Demo + IRI (n= 167)		
	n	%	M	n	%	M
Gender						
Female	138	95.8	-	162	97.0	-
Male	6	4.2	-	5	3.0	-
Age						
20-24	10	6.9	-	9	5.4	-
25-29	49	34.0	-	54	32.3	-
30-34	40	27.8	-	51	30.5	-
35-39	18	12.5	-	21	12.6	-
40-44	6	4.2	-	9	5.4	-
45-49	11	7.6	-	11	6.6	-
50-54	5	3.5	-	6	3.6	-
55-59	3	2.1	-	4	2.4	-
60-64	2	1.4	-	2	1.2	-
Race						
African American	1	0.7	-	1	0.6	-
Alaskan Native	0	0	-	0	0	-
Asian American	4	2.8	-	3	1.8	-
Biracial	2	1.4	-	1	0.6	-
Caucasian	132	91.7	-	156	93.4	-
Chicano/Hispanic	1	0.7	-	2	1.2	-
Other	4	2.8	-	4	2.4	-
Relationship						
Single	42	29.2	-	52	31.1	-
Engaged	7	4.9	-	7	4.2	-
Married	85	59.0	-	94	56.3	-
Partnered	8	5.6	-	12	7.2	-
Separated/Divorced	0	0	-	0	0	-
Widowed	0	0	-	0	0	-
Other	1	0.7	-	1	0.6	-
Missing	1	0.7	-	1	0.6	-
Years of Practice						
< 5 years	78	54.2	-	83	49.7	-
6-10 years	33	22.9	-	43	25.7	-
11-15 years	16	11.1	-	20	12	-
16-20 years	3	2.1	-	6	3.6	-
Greater than 20 years	13	9.0	-	15	9.0	-
Missing	1	0.7	-	0	0	-
Currently Seeing Patients						
Yes	140	97.2	-	159	95.2	-
No	4	2.8	-	8	4.8	-

	Demo + Scenarios (n= 144)			Demo + IRI (n= 167)		
Variable	n	%	M	n	%	M
Primary Specialty						
Adult Counseling	20	13.9	-	22	13.2	-
Cardiology	3	2.1	-	4	2.4	-
Cancer Genetics	47	32.6	-	55	32.9	-
Infertility, ART/IVF	8	5.6	-	9	5.4	-
Molecular/Cytogenetics/ Biochemical Test	10	6.9	-	14	8.4	-
Neurogenetics	2	1.4	-	2	1.2	-
Pediatric Counseling	45	31.3	-	49	29.3	-
Prenatal Counseling	82	56.9	-	95	56.9	-
Psychiatric Disorder	1	0.7	-	2	1.2	-
Public Health/ Newborn Screening	5	3.5	-	8	4.8	-
						-
Screening	10	6.9	-	10	6.0	-
Specialty Disease	12	8.3	-	11	6.6	-
Teratogens	5	3.5	-	7	4.2	-
Other	5	3.5	-	5	3.0	-
Work Setting						
University Medical Center	50	34.7	-	59	35.3	-
Private Hospital/ Medical Facility	33	22.9	-	34	20.4	-
Public Hospital/ Medical Facility	28	19.4	-	31	18.6	-
Diagnostic Lab	7	4.9	-	9	5.4	-
Physician's Private Practice	17	11.8	-	20	12.0	-
Federal/State/ County Office	3	2.1	-	4	2.4	-
			-			
Other	4	2.8	-	8	4.8	-
Missing	2	1.4	-	2	1.2	-
No. of Patients/Week	128	-	11.34	145	-	12.03
Length of Session (mins)	138	-	53.62	158	-	53.92
Roger's Definition						
Strongly Disagree	4	2.8	-	4	2.4	-
Disagree	2	1.4	-	5	3.0	-
Agree	103	71.5	-	125	74.9	-
Strongly Agree	35	24.3	-	33	19.8	-

Appendix J: Comments on Rogers' definition

1. I think this is a very advanced definition of empathy, one that is very difficult to achieve in every counseling session or by an inexperienced or distracted counselor. A simpler definition of empathy, which would still be beneficial in a session, would be one that includes the first two phrases (i.e. the counselor is in tune with the clients feelings but not necessarily navigating so adeptly through them).
2. I think this defination of empathy is spot-on and really describes what we try to achieve when counseling our patients.
3. somewhat agree
4. The key aspects are "being sensitive......to changing felt meanings" and communicating your sensing...... and being guided"
5. I agree with the majority of this definition, except the phrase "thoroughly at home in it" - I don't think that an individual can ever truly by thoroughly at home in another person's private world, even if they know the person intimately and for a long time.
6. I agree with some of the thoughts expressed by Rogers, but not all. I do not feel that we can completely "enter the private world" of our patients to the degree Rogers visualizes during a 30 minute session. I feel that empathy does involve being sensitive to the changes you sense in another person and to their reactions about the information you are giving them, as Rogers states. I also agree that checking in to determine the accuracy of your impressions is important, though I do not feel this is empathy, just checking in. I feel that believing you can "be" in someone's life after only being with them for 20-30 minutes is presumptuous. All we can do is be attuned to our senses, read individuals to the best of our ability, and frequently ask good questions.
7. At first I thought I wouldn't put "strongly agree" when I read "...and becoming thoroughly at home in it." However, once I really read the explanation that followed, I strongly agree with the different components of being empathetic.
8. I believe that empathy is an essential counselor attitude.
9. This is empathy but to a much deeper degree than we can manage with our one time encounters and emphasis on many other issues
10. I agree with the last two sentences but I don't think empathy requires you "temporarily live thier life". I think you most genetic counselors don't have first hand experience of what our patients are experiencing, we just can appreciate the anticipated and expected emotions and reactions.
11. I think the general feel of this comment is accurate; however, I don't believe it is posible to truly enter the private world of another person, and to try to become at home in our pateints' world would make me more concerned about possible transferance/countertransferance issues.
12. I don't know if I agree with "thoroughly at home in it". I think we try to understand our patients by trying to understand their experience, but I'm not

sure what it means to be thoroughly at home in it. I don't feel it the way they feel their experience.

13. I think advanced empathy IS trying to uncover feelings which the person is unaware, but some of this definition I agree with

14. I hesitate to embrace this definition with strong agreement because it seems empathic responses and understanding do not need to exclude a counselors observations of feelings "of which the person is totally unaware". Dependant upon the relationship that a counselor has with a client/patient, such observations do not need to be "too threatening."

15. it is not always possible to be thoroughly at home in the other's world - though one tries. Uncovering feelings of which the other is unaware can be inadvertent - since empathy has an intuitive component and intuition is not 100%

16. I think empathy is important in connecting with a person, but I think when Rogers says, "...communicating your sensings of his/her world as you look with fresh and unfrightened eyes at elements of which the individual is fearful," I do not think of that as empathy. First you must communicate that you understand their feelings (empathy), and then you can move on from empathy to help them see them differently.

17. I think that it is impossible for anyone to "temporarily live" in another's life -- I think it imporant to understand that your own experiences impact your perceptions , weather we are aware of them or not.

18. This describes empathy in a certain therapist-client relationship. There is more depth to the meaning of this word, simply in considering it in all other relationships with other, including with one's self.

19. I don't agree completely because I think empathy involves some personal experience in the art of observing

20. I have always thought of empathy, in short, as imagining yourself in another person's shoes and trying to see life/their situation from their point of view.

21. Agree, but I think the statement "not trying to uncover feelings of which the person is unaware" is not entirely true. You are listening to the person, reflecting back to them what they are saying by paraphrasing and sometimes inadvertently or by subtly guiding them with careful word choices you can get a better therapeutic response and get to the heart of the matter.

22. However, in the world of prenatal dx I feel sometimes that you do have to delve into feelings/attitudes which the person may be unaware of in order to help them make decisions. In other words, sometimes bringig to light baises or inaccuracies is important for families to make decisions.

23. I don't feel that I become "thoroughly at home in it" because that is too much of an intrusion. I also don't feel that during a single GC session, it is very easy to determine to what level of understanding people have about these hidden feelings. I do agree that we are there taking a look at the scary bits, which are less scary to us because they are not happening to us, and in this way, we are able to not only be there with our patients, but help them find a way out. I very much like the last statement about checking in with the patient and allowing

them to guide the conversation
24. It's seems a little bit too extreme, it terms of becoming "at home" in the clients "private world"
25. I disagree that it includes "not trying to uncover feelings of which the person is totally unaware".   I think part of the job of a counselor is to help people recognize those feelings in a safe place and manner.
26. I agree with the definition in general. I don't think you can really turly "enter a person's private world and become at home in it". However, I do feel that trying to do this, trying to put a person's feelings into their appropriate context is critical to empathy. And I feel that the nonjudgemental aspect and frequently checking in with the client are key.
27. This is the definition I was taught and I agree with it.
28. The reason I don't strongly agree is due to the statement of "trying not to uncover feelings of which the person is totally unaware as this would be too threatening." I disagree with this statement as part of helping a patient cope and being empathetic is bringing things to their attention that they might not have thought of and it is not always threatening, it might actually be helpful.
29. I think of empathy as something that can only truly be achieved if you have had very similar experiences. e.g. only after I had my own pregnancies/children could I have true empathy for someone who is a parent.
30. I don't believe that a single session or the time limitations in a given genetic counselling session allow us to become "thoroughly at home in the priviate world of the other." I think we see snipets of what clients/patients are experiencing and try to put ourselves in their situation to empathize with what they are able to share with us.
31. There is a limit in the genetic counseling session to which we can "become thouroughly at home" in the client's private world; our counselor-client relationship is not always a relationship that can be developed over time.
32. No.
33. My experience has shown me that, as a counselor, when I am empathetic to how the client is receiving the genetic information, the client seems to have a better understanding of the information because he/she is able to engage in open and honest communication.
34. I, however, feel that this a definition about empathy from the perspective of a professional. I know many non-counselors who are empathetic and this definition does not apply as well to the average empathetic person.
35. You don't need to be as involved as the definition suggests to feel and express empathy toward another.