

Who should I bring? A qualitative examination of the role of the support person in the  
cancer genetic counseling appointment

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## **Dedication**

This dissertation is dedicated to my loves, Jason and Addie.

## Abstract

Perceived social support positively predicts healthcare outcomes (cf. Codori, Slavney, Young, Miglioretti, & Brand, 1997). Yet, only one study specifically examines the role of the support person in genetic counseling sessions (for Huntington's Disease; Williams et al., 2000). The present study investigated the role of the support person in cancer genetic counseling from the perspective of practicing genetic counselors. There were three major research questions: (1) In what ways do cancer genetic counselors involve the support person in patients' genetic counseling sessions? (2) What variables do cancer genetic counselors believe contribute to successful and unsuccessful support person performance? and, (3) How can cancer genetic counselors help patients construct the best psychosocial support within genetic counseling sessions and after the genetic counseling relationship ends? Fourteen cancer genetic counselors engaged in semi-structured, phone interviews exploring their: approach to talking with patients about bringing a support person to session(s), impressions of patients' decision-making process with regard to choosing a support person, examples of successful and unsuccessful support person involvement, and perceived obligations to the support person. Using grounded theory analysis (Glaser, 1978; Strauss & Corbin, 1990) data were organized into themes supporting a *core category* (general theory). The derived core category is consistent with major tenets of Relational Regulation Theory (Lahey & Orehek, 2011): social support buffers against negative patient reactions, and perceived support comprises the mechanism through which buffering occurs. Specific to the present study, findings indicate support persons achieve the most success when three core conditions are met: 1)

perceived as supportive, 2) matches the patient's needs, and 3) is emotion-based, information-based, focused on decision-making, or a combination of the three. Additional findings regarding successful and unsuccessful support person qualities, patients' decision-making process while selecting a support person, and genetic counselor strategies for facilitating positive support person experiences during and after sessions are presented.

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## **Chapter 1: Introduction**

Similar to many complex medical processes, genetic counseling for cancer conditions is a process that can yield myriad reactions from the individual patient and the patient's family (Bonadona et al., 2001; Freyer, 1999; Watson et al., 1999). Given the sensitive nature of cancer genetic counseling, a patient may approach the appointment wondering, "Who should I bring?" This qualitative study investigated cancer genetic counselors' perspectives on patients' decisions to include a support person in the counseling process. Chapter 1 contains essential definitions of relevant variables, a description of the significance of this study, and a summary of the primary goals of this investigation.

### **Definitions**

"Support person(s)," "support individual(s)" and variations on these two terms will be used to refer to the individual personally selected by the genetic counseling patient to accompany the patient to cancer genetic counseling sessions. Though there is no formal definition of "support person" in the genetic counseling literature, this term is generally used by authors to refer to an individual who accompanies the patient to sessions and is expected to serve in the following capacities: 1) Supplements or provides genealogical information [National Society of Genetic Counselors (NSGC) SGC FAQ 2013]; 2) Provides support to the patient during times of stress particularly during test disclosure (Williams, Schutte, Holkup, Evers, & Muilenburg, 2000) and engages in other capacities yet undocumented in the literature.

Broadly defined, “social support” is the acquisition of “resources provided by others” (Cohen & Syme, 1985, p. 12). The specific types of support, or “resources,” however, are defined widely and are contingent upon theoretical understandings of social support (Cohen & Wills, 1984; House, Landis & Umberson, 1988; Lakey & Orehek, 2011). Commonly cited functions of support include emotional support (e.g., empathy), informational support (e.g., providing a medical history), and instrumental assistance (e.g., making a decision) (House, Kahn, McLeod, Williams & Cohen, 1985).

Genetic counseling is defined as “the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease” (Resta, 2006, p. 79). This definition does not apply exclusively to the processes of the individual patient. Indeed, genetic risk and genetic disease impact entire families (Bylund, Galvin, & Gaff, 2010) including communication patterns among family members, genetic information available to other family members, and perceptions or “narratives” families hold of themselves. As genetic counseling for individuals impacts these (and other), it seems intuitive that family members may be interested in the testing process and the results. Additionally, because the results of genetic counseling can have serious and life-altering implications for the patient, it also seems intuitive that patients would seek psychosocial support to aid them through the process.

Results of many studies suggest a second individual, who is not the proband (identified patient), often attends the genetic counseling session. For instance, the inference that a second person is present is derived from literatures underscoring the notion that genetic counseling is grounded in family systems (Galvin & Young, 2010),

family narratives (Trees, Kellas & Roche, 2010), and family communication (Koerner, LeRoy & Veach, 2010). Moreover, some researchers recommend that disclosures to family members take place during the consultation session (Forrest, Delatycki, Skene, Aitken, 2010). Despite frequent indications that a second person, or support person, is present in the room, research has yet to document who the support person is, the nature of their functions and needs, and how the genetic counselor interacts with the support person.

### **Significance of the Present Study**

The present study is a first step toward elucidating the identities and role of the support person in the genetic counseling appointment. This study was designed to develop insight into the motivations, expectations, and decision-making processes of cancer genetic counseling patients' decisions to bring a support person to their appointment. By drawing information directly from a sample of cancer genetic counselors, the collective experiences of these participants were expected to provide significant insight into a broad spectrum of genetic counseling patients. In addition to obtaining information about the experiences of patients, the present study sought to develop insight into the specific practice of genetic counselors with regard to the support person. Results of this study were intended to provide preliminary information about: 1) the identities and functions of the support person, 2) the impact of the support person on the genetic counseling appointment, 3) and genetic counselors' perceptions of their role with regard to the support person. It was thought the results of this study would

contribute to preliminary recommendations for genetic counselors regarding how to help patients recruit the best support person possible.

There were three major research questions investigated using qualitative, semi-structured telephone interviews: (1) In what ways does the cancer genetic counselor involve the support person in the patient's genetic counseling appointment and process? (2) What variables do cancer genetic counselors believe contribute to successful and unsuccessful support person performance? and, (3) In what ways can cancer genetic counselors help patients construct the best psychosocial support within the context of the genetic counseling appointment and following termination of the genetic counseling relationship?

## **Chapter 2: Literature Review**

The scope of this study is framed by the review of literature contained in this chapter. This section provides a brief overview of genetic counseling to acquaint the reader with its history as well as to provide a foundation for the tasks and issues involved in cancer genetic counseling. Additionally, current models of genetic counseling practice are reviewed and critiqued. A summary of social support focuses on discussing the positive and negative impact of social support on health and on psychological well-being. Theories of social support are reviewed and critiqued. A final section contains a summary of research examining social support within the context of genetic counseling.

### **A Brief Introduction to Genetic Counseling**

Since the discovery of DNA in in mid-19<sup>th</sup> century, the notion that physical and behavioral traits may be inherited has led to a rapidly increasing awareness of personal health and genetic information. In the late 1950's researchers at the University of Minnesota acknowledged that information about human genetics posed unique questions that required careful and specialized answers. In response to this issue, human genetics



professor Sheldon Reed established the term “genetic counseling.”

In 1969 the field of genetic counseling was formally established at Sarah Lawrence College with the opening of the first genetic counseling training program by Melissa Richter, a dean and former professor of psychology and biology, and later directed by Joan Marks following Richter’s death. Richter’s conception for the program was grounded in the idea that “Researchers are making new breakthroughs in genetics all the time...but there is nobody to pass these services on to patients. There is a tremendous gap at this point between knowledge and service” (Happenings, 1971, p. 5). Richter’s goals for genetic counseling- a focus on helping an autonomous patient make informed choices about reproduction and inherited disease- set a tone for the field that emphasized a patient-centered approach.

**Who are genetic counselors?** The purpose of this section is to acquaint the reader with a basic profile of a genetic counselor including educational requirements, specific training, and personal demographic information. The majority of genetic counselors in North America graduate with a master’s-level degree from a genetic counseling program. The SLC program for genetic counseling began by offering students a master’s degree, and the Master’s in Science (MS) continues to be the terminal degree in genetic counseling today. According to a Professional Status Survey conducted by the National Society of Genetic Counselors (NSGC, 2012), the professional organization and accrediting body for genetic counselors, 73% of genetic counselors have a master’s level degree in genetic counseling, 24% have a master’s level degree in

genetics, 6% have a master's degree in a related field, 9% have an advanced degree in another field, and 2% have a PhD (these statistics account for individuals with multiple degrees). Genetic counseling programs accredited by the Accreditation Council for Genetic Counseling provide specialized training in human genetics, sciences related to medical genetics, clinical practice, and psychosocial interventions (American Board of Genetic Counseling, 2010). Thus, it can be inferred from the above statistics that at least 73% of genetic counselors have received training to use basic counseling skills in their genetic counseling sessions.

The racial ethnic representation of genetic counselors is grounded in the feminist movement of the 1960's, where the initial genetic counseling cohort at SLC was composed of white, middle-class women. Richter strongly encouraged women to pursue an advanced degree and actively recruited women, typically housewives over the age of 30 with some college education, into the first cohort of genetic counselors. Some speculate these roots have shaped the field's racial and ethnic representation of genetic counselors, though the mechanism for how or why this may have happened is unclear (Stern, 2009). In 2014 the NSGC published the results of a professional survey designed to ascertain demographic information about genetic counselors in the United States. The results indicate that, in 2007, 91% of genetic counselors identify as Caucasian, 5% as Asian, 1% African American, and 2% Hispanic. The results also indicated that 96% of genetic counselors identify as female and 4% as male. The study did not identify the presence of any transgendered or other-gendered genetic counselors (NSGC, 2014).

**Models of Genetic Counseling.** NSGC members identify the following as a comprehensive definition of the tasks and processes of genetic counseling (Resta et al., 2006, p. 79): “The NSGC definition of genetic counseling states that genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease. This process integrates:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources and research.
- Counseling to promote informed choices and adaptation to the risk or condition.”

Models for the practice of genetic counseling have been proposed to describe the ways in which genetic counselors perform the three major tasks of genetic counseling consistently and effectively. Historically, there were two general models of genetic counseling practice - teaching and counseling. Practitioners who employ a teaching model (Hsia, 1997) base their work on the assumption that patients are rational decision-makers who are primarily seeking information from the genetic counseling appointment. Alternatively, practitioners who employ the counseling model base their work on the assumption that patients will make better decisions if their strengths, needs, limitations and values are incorporated into the decision-making process (Kessler, 1997). More recently, the Reciprocal Engagement Model (McCarthy Veach, Bartels & LeRoy, 2007) proposed a model that blends information-giving with psychosocial support. It is necessary to review these models because each one provides a unique framework from which to understand the counselor’s perception of the support person as a valuable contributor to the counseling appointment.

Two models from medical practice that have been adapted to genetic counseling practice are the Mutual Participation Model and the Life History Narrative Model. The Mutual Participation Model is adapted from a philosophical perspective on medical practice that emphasizes patient autonomy and deemphasizes disease and diagnosis (Kenan & Smith, 1995; Szasz & Hollender, 1956). This model emphasizes the importance of equality between patient and counselor and interdependence (both parties having their needs satisfied). This model also suggests genetic counselors should not act as authorities in the relationship, rather, the counselor should work as an equal with the patient to make decisions that are consistent with the patient's cultural, value, family, and personal preferences. Though the Mutual Participation Model espouses ideals that many genetic counselors support (such as autonomy), it suffers from a lack of practical recommendations for the practice of genetic counseling.

The Life History Narrative Model (Mischler, 1986), similar to the Mutual Participation Model, strives to empower the patient by shifting the control, pace, and content of the genetic counseling session from the counselor to the patient. This model suggests that allowing patients to speak in stories, rather than answers, allows them to share their values, cultural traditions, and the status of their relationships with family members in a unified, flowing manner. The Life History Narrative model encourages genetic counselors to listen more than talk, avoid interrupting the patient, and pay attention to the nuances of the patient's story. The genetic counselor, when listening carefully, should be able to ascertain the patient's beliefs about genetic testing, risk, and heredity.

Both the Life History Narrative Model and the Mutual Participation Model share the value of equalizing power in the counselor-patient relationship by deemphasizing the authority of the counselor. This quality is a valuable component of any genetic counseling setting, but because genetic counseling is a careful balance between education, interpretation and counseling, both the Life History Narrative Model and the Mutual Participation Model may be most valuable during the information gathering and decision-making components of the session.

McCarthy Veach et al. (2007) developed the Reciprocal Engagement Model (REM) based on a consensus conference convened with 23 genetic counseling program representatives from 20 North American genetic counseling programs. The purpose of this study was to harness the voices of genetic counselors toward defining a model of practice specific to genetic counseling, independent from other fields' models of practice. Participants were directed to provide a descriptive, not proscriptive, definition and explanation of the current model of genetic counseling practice. The researchers transcribed and analyzed data using qualitative methods to extract major themes for tenets (underlying assumptions), goals, strategies, and behaviors.

The authors concluded the model of practice that guides genetic counselors is strongly rooted in both the psychosocial tradition, where psychosocial processes play out in the context of providing genetic information and education. The REM builds on a traditional biopsychosocial model by emphasizing psychosocial components of positive regard, empathy, respect for the patient, respect for cultural differences and a process that is heavily centered in the patient-counselor relationship. Overall, the model places an

emphasis on the engagement between the counselor and client as well as the reciprocity between the counselor's characteristics, information-provision, and the patient's characteristics. According to the REM, the genetic counselor's role is to carefully attend to the psychosocial context that mediates the objective information provided in sessions. This model is limited by the fact that due to time constraints, strategies and behaviors are less fully developed than tenets and goals. There is, however, preliminary evidence supporting the validity of the REM tenets and goals (Hartmann, McCarthy Veach, MacFarlane, & LeRoy, 2013).

**Summary.** The REM model is a particularly compelling model of practice because it was developed through discussion and process with practicing genetic counselors and, for that reason, is a reflection of the collective voice of the field. The REM model strikes a balance between a philosophy of practice that emphasizes information-giving and education as the primary task of genetic counselors with a philosophy that emphasizes the psychosocial factors as the primary focus of genetic counselors. From the perspective of REM, a counselor's perception of the role of the support person would likely be one that follows the lead of the patient in a collaborative manner. A critique of the model (Fox, Weil & Resta, 2007) reflects the value of REM as a conduit that allows decision-making to fall to a combination of the patient, family, and healthcare provider.

### **Cancer Genetic Counseling**

There are a number of genetic counseling specialties. Most prevalent are: pediatrics, prenatal and cancer genetics (NSGC Professional Status Survey, 2012). The

present study focuses exclusively on cancer genetic counselors and their patients. Cancer genetic counseling is a subset of genetic counseling that centers on a patient's risk for developing inherited forms of cancer (Schneider, Shannon, Chittenden, Hiller & Kieffer, 2002). Approximately 25% of all genetic counselors provide cancer-related services as a primary professional role (NSGC, 2012). Cancer genetic counselors receive training to assess the risk for inherited cancer, to accurately interpret genetic results, and to provide emotional support around the psychological and decision-making implications of genetic testing. Patients who have been diagnosed with cancer at a young age, have had multiple cancers, or have multiple family members with a cancer diagnosis are prime candidates for cancer genetic counseling (Genetic Alliance, 2008). This section contains a review of information about the cancer genetic counseling session. Additionally, because specific cancers are referenced throughout the literature review, results and discussion chapters, this section includes a brief introduction to common cancers in the genetic counseling setting.

Cancer genetic counseling sessions include several standard components based on practice guidelines developed by the NSGC (Trepanier et al., 2004). Trepanier et al. developed the practice guidelines through a systematic literature review based on the following key-words: cancer genetics, genetic counseling, psychosocial assessment, and gene testing. They categorized the studies into tiers based on the quality of the analysis, where evidence derived from randomized controlled trials was tier one and "opinions based on respected authorities" was the final tier (p. 85).

The authors concluded that an initial cancer counseling session should involve the following: The risk assessment process and counseling process in cancer genetics begin with an intake emphasizing a personal medical history, and a family history, resulting in the development of a genetic pedigree. Next the genetic counselor conducts a psychological assessment of a patient's motivations for seeking out genetic information and risk. This assessment focuses on several psychological variables including motivation for seeking genetic counseling, beliefs about cancer, perceptions of risk, ethno-cultural information, socioeconomic and demographic information, psychosocial factors, cancer screening, health behaviors and coping strategies. While interviewing patients about their psychological history, the authors recommend a pace that is conversational and emphasizes a Person-Centered approach (Rogers, 1951). In addition to providing a cancer risk assessment, genetic counselors may offer an option of molecular testing for hereditary cancers, assist patients in a decision-making process regarding genetic testing, subsequently discuss the test results with the patient in a disclosure session, and finally, provide as-needed, follow-up and surveillance. Depending on the specific circumstances of the patient, the counseling process may include just an initial session with a telephone follow-up, an initial session with a results disclosure session, or multiple sessions.

Trepanier et al. (2004) summarized and made recommendations concerning the standard processes involved in cancer genetic counseling based on empirical evidence. Their intent was to provide broad practice-based guidelines, and for that reason they did not delve into particular information about any given topic. Specifically, the authors



recommended genetic counselors invite the patient to “bring a support person (spouse, relative, friend) with them to their genetic cancer risk assessment sessions” (p. 93). It is unclear, however, whether that recommendation is based on empirical evidence or because it appears intuitively useful. Examination of the individual articles included in the authors’ review suggests the latter, which would mean this recommendation lacks empirical data validating the practice as useful.

The particular issues that cancer genetic counselors address in session include three primary sub-divisions of cancer, hereditary breast and ovarian cancers (HBOCs), prostate cancer, and colorectal cancer, although cancer genetic counseling involves other types of cancers as well [e.g., familial medullary-thyroid carcinoma (Freyer, 1999)]. Participants in the present study discussed specific cancers during their interview; for that reason a brief overview of hereditary cancers follows.

The American Cancer Society (ACS, 2013) developed estimates of cancer incidence by sampling 70 national population-based cancer registries representative of 93% population coverage in the United States and Canada. Their sampling method accounted for regional, racial, and age-related diversity within both countries. Results indicated that 1 in 3 people will develop cancer in their lifetimes. For those adults who do develop cancer, the ACS estimates 10-15% of those cases are due to a dominantly inherited gene mutation.

***Hereditary Breast and Ovarian Cancers.*** The ACS prevalence study estimates that 5-10% of breast and ovarian cancers are inherited. Hereditary breast and ovarian cancers (HBOC) are linked to mutations on the *BRCA1* and *BRCA2* genes, which are

responsible for repairing cells that have been damaged. Mutations on one or, less commonly, both of these genes lead to the on-going division of mutated cells, possibly leading to a cancer diagnosis.

Genetic counselors use a variety of tools to assess risk for gene mutations including family history, molecular genetic testing, and probability models. Probability models are designed to provide patients with the most accurate estimate of their risk for developing cancer (Euhus et al., 2002) and, more specifically, to distinguish between patients whose cancer is inherited and those whose cancer developed for other reasons. Common models include the Myriad Prevalence Tables (Frank et al., 2008), the BRCAPRO model (Parmigiani et al., 1998; Katki, 2007), the BOADICEA model (Antoniou et al., 2004), and the Tyrer-Cuzick model (Tryer et al., 2004). Every model has demonstrated validity, suggesting that they are equally able to distinguish between patients with HBOC and those with breast and ovarian cancer with other etiologies (Antoniou et al., 2008).

The four listed probability models have two major limitations. First, they primarily focus on HBOC and do not test for prostate and colorectal cancer. Second, these models are limited by their dependence on accurate and thorough family histories. For instance, Weitzel (2008) sampled 1543 women in high-risk cancer genetics clinics who were being tested for *BRCA* mutations. Of these women, 153 reported a limited family structure, defined as less than 2 first or second degree relatives represented on a family history. Results indicate that probability models were significantly less successful in predicting risk for women with limited family structure compared with women who

reported adequate family structure. These results are particularly relevant to the present study because they strongly suggest patients who have access to accurate family information or have access to a family member's knowledge about family history are more likely to receive accurate *BRCA* risk assessment in a genetic counseling session.

***Prostate cancer.*** The ACS prevalence study estimates that 5-10% of prostate cancers are hereditary. Increased risk for prostate cancer in men has recently been linked to mutations on the *BRCA-2* gene (Kirchhoff, 2004). Though there are no tests that can predict the disease onset based on a specific gene mutation, patients with a family history of prostate cancer can be screened using the prostate-screening antigen (PSA) test that determines the extent to which proteins produced by the prostate are present in the patient's blood.

***Colorectal cancer.*** The ACS prevalence study estimates that 5-10% of colorectal cancers are inherited. The major subtypes of heredity colorectal cancers include Lynch Syndrome and familial adenomatous polyposis (FAP). Lynch syndrome is associated with mutations on the *MLH1* and *MSH2* genes, which are primarily responsible for repairing damage when errors are created in the genetic code. If a mutation occurs on either of these genes, the DNA code may develop a multitude of errors resulting in cancer.

FAP is a condition characterized by the development of thousands of polyps in the colon which, if left untreated, can lead to cancer. FAP is associated with heritable mutations on the *APC* gene which accounts for 75% of the incidence of FAP; the remaining 25% of cases are thought to have developed by as a result of non-genetic

factors. Risk for both Lynch Syndrome and FAP are assessed using gene sequencing and probability modeling.

**Summary.** Genetic counseling for hereditary cancers involves a holistic assessment of the patient, including an assessment of both the family's cancer history and the patient's historical and current psychological status. A summary of the primary types of cancer for which patients can receive testing and/or screening suggests that the best risk assessment results from the most accurate family history pedigree. Recommendation made by the NSGC (Trepanier, et al., 2004) to bring a support person to cancer genetic counseling sessions may be based on the likelihood that a supportive individual can contribute to both the family history assessment and the psychological assessment. Due to the dearth of research related to the use and purpose of a support person in the genetic counseling appointment, this hypothesis warrants empirical investigation.

### **Psychological Reactions to Receiving Information about Genetic Risk**

This section contains a review of three studies examining patients' psychological reactions to receiving cancer risk information or receiving a cancer diagnosis. These studies focus on emotional and quality of life response to receiving test results in a cancer genetic counseling environment.

In a mixed-methods study designed to evaluate patient reactions to the disclosure of a positive test result, Bonadona et al. (2001) interviewed 23 cancer patients identified as carriers of a mutation for either hereditary breast and ovarian cancer or nonpolyposis colorectal cancers. Patients were primarily female (female,  $n=17$ ; male  $n=6$ ) with a median age of 47-years. Patients were interviewed one month after the disclosure of a

positive test result and completed a self-report inventory to assess their anxiety and depression. The semi-structured interview addressed four major topics: (a) the patients' personal feelings and reactions before and after the disclosure of the result; (b) the meaning they give to the result for themselves and their family; (c) their opinion about the pros and cons of genetic testing; and (d) the communication of information about genetic testing as well as the effects the communication has on other family members. Thematic analysis indicated eight patients expressed distress reactions regarding their diagnosis one month following results disclosure. Additionally, 14 patients expressed at least one negative feeling about the disclosure including: worried ( $n=10$ ), surprised ( $n=9$ ), unhappy ( $n=7$ ), dissatisfied ( $n=5$ ), discouraged ( $n=5$ ), and shocked ( $n=3$ ). Eight of the fourteen patients reported the disadvantages of learning about their risk outweighed the advantages. Finally, the results indicated that all of the patients ( $N=23$ ) disclosed their risk to at least one close relative.

These results suggest many cancer genetic counseling patients experience distress reactions and other negative emotional responses to a positive test. Moreover, the findings demonstrate the negative emotions are not simply reactive, rather patients may continue to explain them upon a one-month reflection. Though this study revealed patients disclosed information about risk to a family member(s), it did not examine the role of a support person as a variable that may mediate the relationship between risk disclosure and psychological response.

In an earlier study, Freyer (1999) recruited 77 patients (44% women, 56% men) from two French cancer genetic counseling institutions to evaluate the psychosocial

impact of genetic testing in familial medullary-thyroid carcinoma. Patients had a median age of 45.2-years (Range:11-77 years). They completed two self-report measures to assess anxiety and depression and quality of life. Correlational analysis indicated that individuals who carried the mutation reported tended to reported significantly lower levels of quality of life, less life satisfaction, and lower expectations about future life satisfaction. These findings suggest that individuals who are carriers of genetic mutations may experience higher levels of overall frustration as a direct result of becoming aware of their carrier status.

This study is limited by the inclusion of such a large age range, where the youngest participant was 11-years-old and the oldest was 77-years-old. Because coping mechanisms, social networks, cognitive development, and emotional literacy vary greatly throughout the lifespan, the data acquired from these vastly different age groups as a whole may not be representative of any one particular developmental phase (e.g., young adults). Additionally, the anxiety and depression inventory is normed for adults ( $\geq 18$ -years; Hinz, 2011), and therefore is not an appropriate measure for many participants.

In a study designed to evaluate the psychological impact of risk perception in women with a family history of breast cancer, Watson et al. (1999) recruited 282 women, who were first-time genetic counseling patients and had a history of family breast cancer, to assess the intersection between their perceptions of genetic risk and the psychological effects of prospective genetic counseling. Participants received a pre- and post-assessment with follow-up at 1, 6, and 12 months at four South London genetic counseling centers. Self-report measures evaluated general health, state-trait anxiety,

helplessness, worry, and perceptions of the impacts of events. Additionally, the participants were asked to assess their perceptions of their individual risk of developing breast cancer based on family history as well as their risk of developing breast cancer relative to other women. Results indicate that 28% of women with a family history, but who had not been through genetic counseling, experienced high levels of cancer-specific distress. Additionally, 18% of all respondents reported experiencing worry about developing breast cancer “frequently or constantly.” Following a genetic counseling session, participants reported slightly more accurate predictions of their own risk, their perception of anxiety was still present, though interfered less in their daily functioning. The results indicated that for women who continued to over-estimate their risk for developing cancer, even after receiving information, levels of anxiety remained high.

This study suggests that women’s worry about developing breast cancer is not always proportional with their risk for developing hereditary breast cancer. Moreover, the results of this study suggest genetic counseling is unsuccessful 20% of the time in helping women reduce their anxiety about developing breast cancer. The authors did not discuss alternative interventions for these women whose anxiety was not alleviated by the genetic counseling session. Additionally, a discussion regarding variables that may moderate the relationship between anxiety and the diagnosis is lacking.

**Summary.** The findings of these three studies provide some evidence to suggest that genetic counseling patients experience distress, decreased quality of life, and worry related to the anticipation of developing cancer as well as in reaction to received risk or diagnosis of cancer. Furthermore, emotional reactions may be stronger one-month post-

results session compared with reactions observed during the results session. These findings are related directly to the cancer risk or diagnosis and therefore were not defined as characterological. Therefore, it may be beneficial for genetic counselors to discuss long-term emotional reactions with their patients during the initial session and/or results session.

**Recommendations for Bringing a Support Person.** To counteract the stressful impact of genetic counseling/genetic testing, genetic counseling clinics often recommend that patients bring a supportive person with them to the genetic counseling session. For some genetic conditions, such as Huntington disease (HD), most genetic counseling centers require patients to bring a support person with them throughout the counseling and testing process (Williams et al., 2000). As mentioned previously, the NSGC meant practice guidelines (Trepanier, et al., 2004) contain a one-line recommendation that genetic counselors can suggest the inclusion of a support person for the risk assessment session. There are no published protocols, however, to assist patients in deciding who to bring or how to invite and prepare that person.

One study compared the general (i.e., not cancer-specific) genetic counseling practice guidelines of multiple, international genetic counseling organizations using 56 documents from 29 organizations (Rantanen, et al., 2008). The researchers qualitatively analyzed the data, organizing them into themes using grounded theory methods. They extracted a total of nine themes, including: “Education and training of professionals,” “Content of information to be provided,” “The counsellee’s understanding of genetic



information,” “Psychological Support,” “Confidentiality,” “Implications for the family,” “Autonomy of the counsellee,” “Genetic discrimination,” and “Informed consent.”

Specific results regarding “Psychological support” indicate that guidelines commonly recommend patients bring a support person with them to the appointment when a test result is disclosed, regardless of whether the test is positive or negative. The “support person” was described as a “relative,” “friend” or “support group” in the corpus of documents. The guidelines cited a support person as a valuable source of emotional support because “...a test result-whether positive or negative- may alter the patient’s self-concept (p. 448).” This study did not obtain empirical evidence to validate the claim that a support person would positively mediate the relationship between a negative test result and patient stress, however.

No additional studies were identified that address the methods genetic counselors use to invite, involve, and/or educate the support person within an appointment. For this reason, this investigator reviewed literature published on genetic counseling websites for content related to recommendations regarding the support person in lieu of the dearth of scientific literature in this area.

Listed next is a non-exhaustive summary of literature published by various, national cancer genetic counseling clinics. A Google search using the following search terms yielded the literature on which these results are based: “genetic counseling support person,” “Support genetic counseling appointment,” cancer genetic counseling support person.”

“You are welcome to invite anyone to come with you (family, friend, etc.) to your appointment, but you will be the main focus of the consultation. If you bring a friend or family member with you and they have specific questions or concerns, it may be necessary to schedule a separate appointment for them (*MD Anderson Cancer Center, University of Texas*).”

“If you have a spouse, family member or close friend that you would like to have with you for support, you are more than welcome to have them with you doing your evaluation. Also, if several members of your family are affected with, or are at risk for, the same condition, then it might be helpful for those individuals to accompany you to your appointment as well. However, if a family member would like to be fully evaluated, he/she will need to schedule a separate appointment (*Cleveland Clinic*).”

“We encourage you to bring a support person(s) with you. Many people find it very helpful to have an “extra set of ears” present during the initial appointment. Family members may also benefit from the information provided, and they may be able to help with providing family history information. However, if some issues in your medical history are highly private and not known to your relatives, you may want to come alone (*Cancer Genetics at the University of Chicago*).”

These quotations summarize the types of statements typical of many cancer genetic counseling websites. All of these quotations suggest that bringing a support person is a valuable practice for multiple reasons including emotional support, informational support, and assistance with providing a family history. The Cleveland Clinic’s quotation alludes to the different reasons a patient may choose to bring a second person to the appointment; in addition to providing support, this clinic acknowledges that the invited-person may be present for reasons related to their personal health status. Though these statements may be intuitively or anecdotally accurate, there is no research supporting these recommendations.

### **Social Support**

Social support has been linked to better health and health care maintenance in a variety of medical contexts (Lakey & Orehek, 2011; Wills & Ainette, 2012). This section contains a discussion of the role of social support in the context of physical and psychological health and wellness. First, theories of social support are reviewed toward the goal of identifying the mechanisms that link social support with positive outcomes. Next, research from multidisciplinary medical professions that link social support with increased health and wellness are discussed. Finally this link is discussed within the context of genetic counseling.

Over 30 years of empirical evidence demonstrates a causal and positive impact of social support on psychological health, physical health, and longevity (House, Landis & Umberson, 1988). It is clear that social relationships impact perceptions of stressful events, generally leading to a reduction in stress. Three major theories explain the interaction between social relationships and stress/psychological well-being, including the Stress-Buffering Theory, The Main Effect Theory, and Relational Regulation Theory. Each theory is reviewed in this section.

**Stress-Buffering Hypothesis.** Stress-Buffering Hypothesis (Cohen & Hoberman, 1983) proposes an explanation of stress mitigation that identifies social support as a “buffer” against stress. The theory furthers states that an individual’s perception of “support” may be a mechanism that attenuates a physiological stress response. “Stress” is broadly defined as the state in which an individual perceives a large demand and insufficient resources to satisfy that demand (Lazarus & Launier, 1978).

In their seminal work on the topic, Cohen and Wills (1985) conducted a meta-analysis ( $N=18$ ) of studies that exclusively used quantitative designs to measure the interaction between stress and social support. They evaluated the evidence that supported the Buffering Hypothesis model of social support, compared with a second prevailing model, the Main Effect Model, which is discussed in turn below. In particular, the authors hypothesized the best type of social support is a kind that is specifically tailored to the stressor, a model of support that could be described as stress-support matching.

The authors concluded results provided compelling evidence to support both theoretical explanations of social support, though each model appears to explain different facets of the interaction between stress and social support. Regarding the Buffering Hypothesis specifically, the results did not support the hypothesis that the best support is perceived when it specifically matches the type of stress. Instead, the authors concluded that stress is successfully buffered when the responses of the support person match the emotional needs of the recipient. These results emphasize the idea that the *quality* of social support is more important than other characteristics of support, such as accuracy of information provided, availability, or support that is matched with the stressor.

Turner-Cobb et al. (2006) conducted a cross-sectional, exploratory study to examine the relationship between family history of breast cancer and psychological distress. Using the California Breast Cancer Registry, they recruited 45 female relatives of female probands diagnosed with breast cancer. Using a survey-driven design, they assessed the women's coping styles, social support, state-trait anxiety, and family relations using validated measures. Data were analyzed using Pearson's  $r$  correlational

co-efficients and a one-way analysis of variance (ANOVA). Results support the buffering hypothesis of social support as a variable that moderates the relationship between distress and losing a loved one to breast cancer. For those individuals who had positive and strong networks of social support, the death or multiple deaths of loved ones to breast cancer resulted in lower distress compared to participants who experienced the death of loved ones but had poor social support. These results indicate that positive, strong networks of support can reduce perceived distress about the prognosis regarding one's cancer diagnosis and future risk.

In summary, the Buffering Hypothesis proposes a model of stress mitigation that highlights social support as a mediator of the relationship between an antecedent and perception of stress. Specifically, the research reviewed indicates that stress is successfully buffered when the type of social support is of high quality and matches the emotional needs of the recipient. Additionally, perceived emotional support is thought to be the most protective of health outcomes, whereas availability and information-giving functioned less successfully as a buffer (Lakey & Orehek, 2011).

The Stress Buffering Hypothesis is supported primarily through correlational studies and abundant theoretical papers. However the availability of controlled, empirical research examining this model is limited. It is likely that the Buffering Hypothesis provides a good explanation for one component of adjustment to stressful events, however, the Buffering Hypothesis does not provide a complete theory of how social support reduces stress perceptions, as evidenced by the lack of interventions using the

model in controlled environments as well as the limited empirical literature (Cohen & Pressman, 1994).

**The Main Effect Model.** The Main Effect Model of social support hypothesizes a positive correlation between social support and well-being (Cohen & Wills, 1985), regardless of the presence or absence of stress. This model suggests the level of integration an individual has within a social network will impact their overall well-being, including economic, psychological and social well-being. The meta-analysis study conducted by Cohen and Wills (1985), outlined above in the “Stress Buffering” section, generated evidence that an overall integration in a social network can improve well-being. However, results of this meta-analysis indicate that while the Main Effect Model explains the interaction between the social network and well-being, *integration* in social network does not appear to protect against stress. In other words, simply being involved in a social network does not appear to function as a coping mechanism. Instead, the authors suggested that being involved in a rich social network protects well-being via sociological forms, such as socio-economic predictability or by engaging in predictable traditions and cultural rituals. The authors speculated that specific, high quality support such as that proposed by the Buffering Hypothesis, is necessary to actively protect against the detrimental impacts of stress.

The Cohen and Willis (1985) meta-analysis could be improved by the inclusion of a discussion of the extent to which both of these processes, stress buffering and main effects, occur simultaneously. Additionally, the researchers included a number of studies that defined social support differently, some using family support, community

involvement, marital status, or other social identifiers as a marker of social involvement. Identifying a consistent definition of social support could strengthen the results of this study and assist in future replications and extensions of extant research.

A second study yielded support for the Main Effect model by examining the relationship between social support and post-traumatic stress disorder. Brewin et al. (2000) conducted a meta-analysis of 14 distinct risk factors for PTSD. They analyzed data using chi-square tests and converted results into correlational coefficients to yield an effect size for each study. Results for individual risk factors suggest that factors at play during the trauma itself, such as the severity of the trauma, other life stress factors, and low social support, yielded significant  $p$ -values. The authors concluded that individuals who demonstrated perceived integration in social networks were at significantly less risk for developing PTSD symptoms compared with their socially less-integrated peers. These results support the Main Effect hypothesis, indicating that simply being integrated into a social network may have positive effects on mental health. The authors concluded that a social network protects mental health, and particularly protects against PTSD symptoms, but they did not provide speculate about the mechanism(s) that may be responsible for this effect.

**Relational Regulation Theory.** Relational Regulation Theory (RRT) was developed to provide an explanation for the mechanism that supports the main effect *and* the buffering effects between perceived social support and mental health (Lakey & Orehek, 2011). RRT asserts that “perceived” support is a better indicator of significant effects than “received” or “available” support, or support that objectively meets the

recipient's apparent needs. This hypothesis was substantiated by Wethington and Kellser (1986) who conducted a study of the effects of perceived support compared with received support. Using survey methods, the authors recruited a national sample of participants ( $N = 1,269$ ) between the ages of 21 and 65. Participants responded to questions about their perceived support availability, received support, psychological distress, and life events. Multiple regression analyses indicated that stress is buffered by social support because of the recipient's perceptions that the support is available, and not because of the recipient's evaluation of the actual support behaviors provided. This study is limited by its cross-sectional design that may have lacked sensitivity to cohort effects, that is, the unique social and life events particular to different age groups. This study is unique, however, as it is one of the first investigations to demonstrate a specific mechanism (i.e., perceived support) mediates the relationship between social support and psychological distress.

Recently, Haber, Cohen, Lucas and Baltes (2007) conducted a meta-analytic study designed to provide a quantitative point estimate of the relationship between perceived and received support. The authors analyzed the effects sizes of 23 individual studies and used Pearson's coefficients to develop an average correlation. Results demonstrate a moderate relationship ( $r = .35, p < .001$ ) between perceived and received support, suggesting there is significant disagreement between perceptions of support and the actual support being provided. Because perceived support has been documented as paramount to the recipient's successful buffering of stress, providing information about variables that moderate the relationship between perceived and received support could have strengthened this study.



RRT proposes a theory for why people perceive support in ways that differ from received support, or objectively supportive actions (Lakey & Orehek, 2011). This theory proposes eight key principles that, when considered together, postulate that people regulate themselves primarily through social interactions. In other words, RRT suggests that both main and buffering effects occur because the social relationship facilitates healthy regulation of thoughts, actions, and feelings. A summary of RRT's key principles, as well as the research that supports them, is as follows:

*Principle 1:* RRT proposes that people regulate their thoughts, emotions and affect primarily through interacting with other people. This claim is rooted in Bowlby's theory of attachment (1969) which stated that emotion regulation is established in infancy and is based on the quality of the relationship an infant has with his primary care-giver.

*Principle 2:* The extent to which social interaction successfully helps recipients to regulate their thoughts, emotions, and actions depends on the relational characteristics of the dyad. In other words, the recipients' personal tastes - a preference for extroverted or stoic support, for example - will act as a moderator for the success of the social support. This principle supports the notion that perceived support, as opposed to received support, is what determines successful stress buffering.

*Principle 3:* RRT proposes people are most likely to perceive effective support, and will thereby more effectively regulate their thoughts, emotions and behavior, when they are doing ordinary activities together, rather than directly discussing the stress or ways to manage the stress. For example, Lakey and Orehek (2011) state:

“When awaiting news of the outcome of a relative's surgery, people will rely

heavily upon the ordinary social interaction that helps regulate them in non-stressful situations (e.g., discussing family members' exploits, work, or sports). Thus, in surgery waiting rooms, one should observe large amounts of ordinary talk as well as troubles talk (p. 487)."

*Principle 4:* RRT proposes that relational regulation occurs through conversation about shared activities and contexts. The theory purports that conversational partners who understand each other's interests, activities, and cognitive contexts are more likely to perceive each other as supportive. Further, the authors argue that these positive links become associated with the cognitive representation each partner has of the other, thereby laying the groundwork for relationship regulation in future conversations.

*Principle 5:* Perceived support, then, occurs when recipients find they are able to regulate their thoughts, affect, and behaviors through engagement with the relationship. RRT proposes that perceived support tends to occur through ordinary interactions (e.g., the surgery example above), but sometimes occurs through enacted support (e.g., intentionally discussing a stress response).

*Principle 6:* RRT asserts that relational regulation is a dynamic process, where the recipient shifts her or his perceptions of the support provided by any one individual over time. The authors argue that as support person's shift in their own personal dynamics, their support will be perceived as more or less helpful over the course of time. This leaves the patient to shift relationship partners as a means to finding the most effective regulation.

*Principle 7:* The authors argue that social support will be the most effective when it harnesses relational regulation. Therefore, the authors argue that the ideal form of social support is the kind that is 1) perceived to be supportive by the recipient, 2) intimate

and represents companionship, 3) and represents a positive emotional attachment.

*Principle 8:* RRT proposes that individuals who have an array of persons they perceive to be supportive are the most likely to effectively regulate their thoughts, emotions and behaviors. This principle alludes to the conclusions from Main Effects research, that is, individuals with a rich and large social network are more likely to experience wellness, regardless of their level of stress. This principle states that main effects emerge from ordinary interactions where there exists a diverse array of individuals who help the individual regulate their thoughts, emotions and behaviors.

The RRT model is limited primarily by its novelty. RRT lacks empirical validation through controlled studies. Additionally, RRT lacks specificity in some of its central concepts. In particular, the theory does not explain how individuals who demonstrate psychopathology or struggle to engage in relationships perceive social support. Finally, RRT proposes a directional hypothesis explaining the role of the relationship as a moderator between social support and well-being. However, it may be difficult to decipher the directionality of this hypothesis given the support person, recipient, and the relationship are highly inter-connected, potentially inextricably. Future research on RRT should focus on isolating each of these three variables to provide empirical validation for this directional hypothesis.

**Summary.** In this section, the intersection between social support and well-being was evaluated according to three predominant theories, the Stress Buffering Hypothesis, the Main Effect Hypothesis, and Relational Regulation Theory. Cohen and Wills (1985) demonstrated the Stress Buffering and the Main Effect models appear to explain two

different aspects of social support, such that the stress buffering explains the way social support can buffer particular examples of stress and the main effect model generally equates more social support with more psychological well-being. RRT proposes that neither the Stress Buffering Hypothesis nor the Main Effect model sufficiently explain the mechanism by which social support improves well-being. RRT states that perceived support moderates this relationship and is only successful when the relationship helps recipients regulate their thoughts, emotions, and behaviors. According to RRT, relational regulation provides both buffering against specific stressors as well as a main effect.

**The impact of social relationships on health outcomes.** With a theoretical understanding of the impact of social support on well-being in hand, this section contains a review of the intersection between social support health outcomes within a health care setting. Prospective populations studies have demonstrated a relationship between measures of social support (or social capital) and mortality, disease, and recovery from chronic disease. In this section, includes a review of these studies of the relationship of social relationships to health outcomes, including disease onset, mortality, and psychological health.

House, Landis, and Umberson (1998) conducted a meta-analysis to examine the impact of social capital on lifespan and mortality. They drew upon three primary areas of research: 1) theoretical models of a causal relationship between social capital and health, 2) empirical evidence supporting the hypothesis that social support is a predictor of health outcomes, and 3) experimental and quasi-experimental evidence demonstrating a causal link between social relationships and human/animal physiological and

psychological wellness. Results indicated there are sufficient data supporting a strong and consistent causal link between social relationships and positive health. Results point to the Stress Buffering Hypothesis (Cohen & Wills, 1985) and biopsychosocial theories of social support as explanatory models. The authors' main conclusion is that lack of social support appears to be a risk factor for mortality and morbidity. Those individuals with a small amount of social support in conjunction with a poor quality of social support were at increased risk for death. This study is limited, however, by an inadequate description of the analysis methods used to evaluate the meta-analytic data size.

In a meta-analysis designed to explore the impact of social relationships on the development of dementia and Alzheimer's disease, Fratiglioni, Paillard-Borg, and Winblad (2004) reviewed seven longitudinal studies with an average sample size of 30. Results indicated that the size of an individual's social support network acts as a buffer against the development and progression of dementia. Additional social variables that correlated with reduced risk for dementia include high levels of empathy from others, high quality social support, and regular engagement in any type of activity. The results of this study are limited by the same variables that limit the Main Effect hypothesis, namely this meta-analysis is not sensitive enough to address confounding variables such as lifestyle or genetic risk factors, to name just two. Additionally, the authors did not identify an underlying mechanism for the impact of social support on disease progression.

Brummet et al. (2001) conducted a five-year longitudinal study evaluating social isolation as a predictor of morbidity. They recruited patients ( $N=433$ ) from a large

university hospital where they were receiving treatment for cardiovascular disease. In addition to a thorough assessment for characteristics indicative of the quality of their social support network, patients were assessed for social isolation at the time of their assignment to the study; they were assessed again at one-month, three-months, 6-months, one-year, and then annually following the initial meeting. Chi-square tests indicated mortality rates were significantly higher ( $p = .001$ ) for individuals who had three or fewer individuals in their support networks.

The researchers concluded that isolated adults are 2.4 times more likely to die from cardiac-related incidents than their socially connected peers. This study is limited by the fact that, similar to other studies reviewed in this section, a mechanism(s) that contributes to the significant results was not identified. In addition to this meta-analysis, other investigations that use death as an outcome-measure suggest individuals who have small social networks and identify themselves as lonely have a 2-4% increased risk of death compared with individuals who have medium or large-sized social networks (Bowling & Grundy, 1998; Ceria et al., 2001). These data suggest that social support has a direct impact on physical health and may lead to earlier deaths.

**Summary.** Combined, these results suggest a strong causal relationship between social support and health outcomes. Consistent with RRT, these studies also suggest that certain characteristics of social support seem to moderate its relationship to health outcomes. These include the size of the support network, the quality of the support provided, and the types of support provided (e.g., empathy). Because several of the studies listed are prospective population studies and meta-analyses which reviewed a

range of morbidities, once can conclude that social support appears to be beneficial for general health outcomes, regardless of the specific form of disease or disorder.

**Social Undermining.** Despite the vast literature validating the relationship between social support and positive psychological and physical outcomes, the outcomes of social support are not always positive. Social undermining is a construct defined as social support that leads to unhelpful outcomes, increased stress, and poor psychological well-being (Vinokur & van Ryn, 1993). Additionally, despite the robust literature that has defined a strong and consistent relationship between social relationships and health, not all support that is presumed to be beneficial is actually linked to better health (Umberson & Montez, 2010). Research has documented variables that moderate the relationship between social relationships and health outcomes, including marital strain and relational stress.

Regarding marital strain, Kiecolt-Glaser and Newton (2001) conducted a meta-analysis to evaluate 64 published studies exploring the interaction between marriage and health outcomes. The authors concluded that marital functioning has a significant impact on both partners' health, though women appear to be more impacted by negative marital relationships than men. Indirect consequences include depression and poor eating habits, while physical systems that are directly and negatively impacted by poor marital functioning include the cardiovascular, endocrine, immune, and neurosensory systems. The results of this study are limited by the studies selected for the meta-analysis. Many of the studies used recruited couples who had experienced previous distress or were in current distress, a characteristic that may have biased the outcome of this meta-analysis.

A large body of literature also highlights the impact low-functioning marital relationships can have on physiological and psychological systems. In a study examining care-giver (i.e., support person) stress for patients diagnosed with Rheumatoid Arthritis Bediako and Friend (2004) recruited 39 women and their spouses from a large university hospital. They completed questionnaires designed to assess patient expectations of the spouse, spousal perceptions of the patient's expectations, and patient perceptions of positive and negative social support from the spouse. Pearson's  $r$  correlations and regression analyses were used to analyze the questionnaire data. Results indicate that patients were significantly negatively impacted by care-givers who exhibit signs of stress ( $r = .83$ ). Patients who felt unable to articulate their needs when a care-giver exhibited signs of stress reported feeling misunderstood and having less perceived support. This study is significantly limited by a low sample size and by the fact that the sample only included heterosexual, legally married couples.

In an effort to distinguish the positive and negative impacts of social relationships on stress and well-being, Rook (1984) recruited female senior citizens ( $N=120$ ) from senior living centers in a large, urban area. In this mixed-methods design, participants completed an interview in which they discussed both positive and negative social ties in their life. Each participant then completed several inventories designed to assess their psychological well-being and social support and social networks. Qualitative research methods and multiple regression analyses were used to evaluate the data.

Results showed that negative social relationships have a greater impact on psychological well-being than positive social relationships. Additionally, participants



reported that 36% of problematic relationships were those with family members or close friends. These results indicate the importance of avoiding conflating “social support” with “social interaction,” making it clear that not all social support is positive. This study controlled carefully for confounding variables in demographics within the sample.

However, The generalizability of the findings are is severely limited, however, by the overall sample. As the social needs of the aging are unique, these results may not reflect the general population.

**Summary.** The concept of “social undermining” refers to situations where received social support is not perceived as helpful or supportive. Within the context of the healthcare setting, variables that contribute to social undermining include situations where the stress of the support person is highly perceptible to the patient, the patient feels misunderstood by the support person, the social support is being provided in the context of an existing dysfunctional relationship, and the patient lacks a sufficient or rich social support network. This research has implications for the genetic counselor’s conceptualization of the contributions the support person to the overall progression of the genetic counseling appointment.

**Social Support within context of the genetic counseling appointment.**

Currently the presence of a support person in a genetic counseling session is frequently recommended by genetic counseling clinic websites, the National Society for Genetic Counselors (NSGC) and genetic counseling literature as a standard recommendation. Very little research exists, however, to answer basic questions about this presumably helpful recommendation. Basic questions about the characteristics of an

ideal support person, how the counselor should talk with the patient about the inclusion of a support person, the role of the patient in the appointment and after the appointment, and ways to manage an unsupportive “support person” remain unanswered. This section, contains a summary of research that addresses the role of the support person within the context of all sub-specialties of genetic counseling.

Williams et al. (2000) explored the perceived psychological impact of serving in a support person role for patients undergoing predictive testing for Huntington disease. Using a mixed-methods design, support persons ( $N=18$ ) completed self-report measures of state-trait anxiety and of current distress. They also participated in semi-structured interviews designed to elicit their personal experience with regard to the predictive testing process. The quantitative data were analyzed using independent t-tests and, the interview data were transcribed and analyzed using an unspecified qualitative method.

Results indicate that support persons experienced significant anxiety in this role, regardless of whether the test was positive or negative. When the patient’s test was positive, support persons reported that they required more support and direction from the genetic counselor, felt they were bound to function in a care-giver role following the appointment, and felt that they did not have enough knowledge about how to care for the person with the gene mutation. Finally, results from this sample strongly indicate that family members who are also at-risk for developing HD are the least able to provide support for the patient.

This study has several implications. First, based on participant feedback that the results left them feeling a heightened sense of anxiety, support persons may need more

guidance about how to bridge their support from the appointment to the post appointment care-giving role. Second, based on participants' experience of feeling unprepared to provide on-going support to the patient, additional counseling of some kind may be appropriate for patients and families to aid in decision-making following the final genetic counseling session. Finally, this study's findings suggest the role leads to significant anxiety for the support person, and that individuals for whom the results have health implications experience the most anxiety and feel least able to be supportive to the patient. Though participants report feeling unable to provide support, there is no empirical research that identifies the impact of this anxiety on the overall appointment or the ability of the support person to engage in effective supportive behaviors.

This study is seminal to the present investigation because it is the only empirical research to examine the role of the support person during the actual process of genetic counseling (as opposed to research that focuses on disclosing results to family members after the session, or research that focuses generally on family communication). The study is limited by its sole focus on Huntington disease, which because of the complete penetrance of a positive test result, adds an element of severity that cancer genetic counseling does not always include. Additionally, generalizability of the findings are limited by the small sample size.

Greene et al. (2009) explored information-based support provided by family members in a cancer genetic counseling session. The purpose of their study was to determine what individual characteristics of family members led them to gather genetic information, disseminate information, or block the movement of information. The

sample consisted of 183 female patients from 124 families with a known history of BRCA1/2 mutations. A Colored Eco-Genetic Relationship Map (CEGRM), which is a visual representation of the relationships and social interactions between patients and their social network, was used to assess roles, communication patterns and social ties between the patient and family/non-family supports. Data were analyzed using descriptive statistics and hierarchical non-linear modeling. Results indicate that support network members who provide and disseminate information tended to be female ( $p < .001$ ), have had a cancer history ( $p < .001$ ), were in an older or the same generation as the patient ( $p < .001$ ), were female parents ( $p < .001$ ), and were emotional providers ( $p < .001$ ). Those individuals who tended to block the movement of information were spouses ( $p < .001$ ) and male relatives ( $p < .001$ ).

These results provide some insights to genetic counselors and patients about the characteristics of support persons who tend to provide the most valuable information-based support during the cancer genetic counseling appointment. They specifically indicate that the most successful information-providers tend to be mothers and those individuals who the patient perceives as emotionally supportive. These data have implications for patients as they make decisions about who to bring to the genetic counseling appointment. The data provided about the type of support person who disseminates information to others may be helpful to patients as they consider their ideal support person following the final genetic counseling appointment. This study is limited by its lack of focus on the way genetic counselors can facilitate decision-making regarding patients' choice of information provider and/or disseminator.

**Summary.** The research that addresses the experience and role of the support person within the genetic counseling appointment is limited. The two studies reviewed in this section suggest the support person engages in emotional, informational, and decision-making roles simultaneously throughout the appointment. Moreover, they suggest the support person who provides information often has a close, emotional relationship with the patient and tends to be a female parent (i.e., mother). The research also indicates the support person's emotional experience might be supported by the genetic counselor, specifically through provision of support and guidance to the support person, as well as being mindful of relationship dynamics between the support person and the patient.

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

It has been established that perceived support is a significant predictor of a patient's ability to psychologically adjust to information about risk (Codori et al., 1997). When the literature on Relational Regulation Theory (RRT) is combined with the small body of literature on social support within the general context of health care as well as the literature on social support within genetic counseling, the following variables seem to be central to a successful supportive dynamic: Social support for genetic counseling patients involves a person with whom the patient feels an intimate connection, has a developed attachment, whose own health is not directly impacted by the results, and is willing to follow-through with the provision of additional support following the testing appointment.

The present study was designed to develop insight into the motivations, expectations, and decision-making processes of genetic counseling patients' decision to

bring a support person to their appointment. This study indirectly explored those experiences by drawing upon the clinical experiences of cancer genetic counselors. The target population was cancer genetic counselors who provide services for a variety of types of cancer, a condition that does not have complete penetrance, and therefore is likely to yield a broad spectrum of responses by genetic counseling patients. This study also explored genetic counselor perceptions of their role with regard to facilitating the process of involving a support person, including that person in the session, and providing guidance to that person about their role.

There were three major research questions investigated using qualitative, semi-structured telephone interviews: (1) In what ways does the genetic counselor involve the support person in the patient's genetic counseling appointment and process? (2) What variables do genetic counselors believe contribute to successful and unsuccessful support person performance? and, (3) In what ways can genetic counselors help patients construct the best psychosocial support within the context of the genetic counseling appointment and following termination of the genetic counseling relationship? It was thought the results of this study would contribute to preliminary recommendations for genetic counselors regarding how to help patients recruit the best support person possible.

## Chapter 3: Methods

### Participant Recruitment

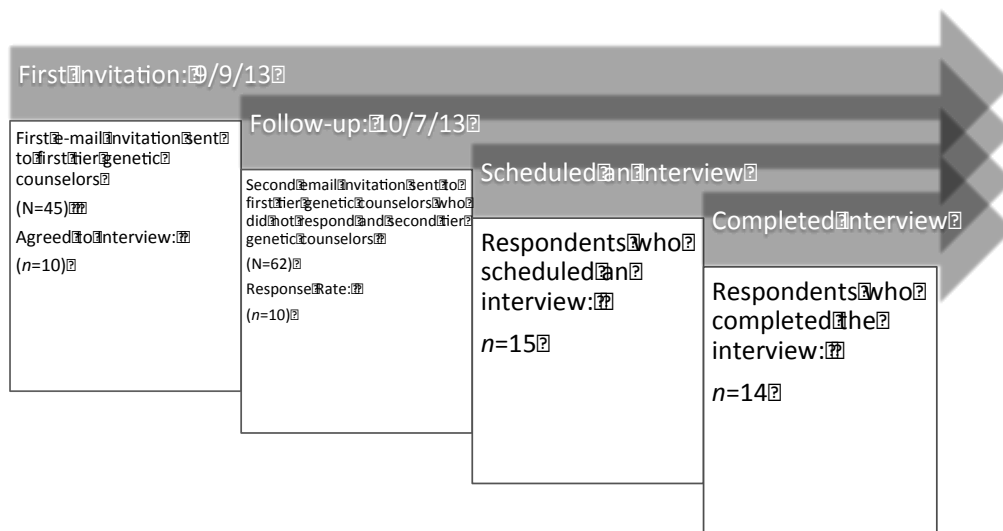
Upon approval from the University of Minnesota's institutional review board (IRB) (See Appendix A), recruitment for this study began by determining the following eligibility criteria for participants: a certified genetic counselor; at least five years of experience working in cancer genetic counseling, with a preference given to individuals with 10+ years working in cancer genetic counseling; currently see cancer patients at least part time. Finally, any genetic counselors working in a commercial setting were not invited to participate in this study. Next this investigator purposely sampled eligible participants from the National Society of Genetic Counselors (NSGC) website's public registry. The search box "Search for a counselor" was used to screen listed practitioners according to the eligibility criteria. Participants were sent an email invitation (see Appendix B) on September 9<sup>th</sup>, 2013 that included information regarding the purpose of the study, eligibility criteria, informed consent, and data confidentiality.

Potential participants were told the purpose of the study was to explore the nature of the support person chosen by the cancer genetic counseling patient from the perspective of the genetic counselor. Specifically, the study invitation asked participants to focus on their beliefs about the role of the support person, clinical examples of cases in which the support person seemed particularly impactful, and the variables the counselor believes contributed to that impact. A total of 72 participants were identified from the NSGC's public registry. The flowchart below (Figure 1) outlines the recruitment history.





Figure 1. Study Recruitment Flowchart



**Participants.** Potential participants identified were grouped into two categories: first tier ( $n=45$ ) and second tier ( $n=27$ ) genetic counselors, for a total of 72 genetic counselors. All 72 genetic counselors met the study eligibility criteria. Those in the first tier had worked in the field for 10+ years and demonstrated professional contributions to the field (e.g., publications). Those in the second tier had worked in the field for 5+ years and may or may not have demonstrated professional contributions to the field. For the Tier One recruitment, the response rate was 22.2% with 10 participants successfully recruited from a pool of 45. For Tier Two, the response rate was 37% where 10 additional participants were recruited from a pool of 27. Due to a low tier one response to the first email invitation, a follow-up invitation was sent to all of the remaining tier one genetic counselors as well as the tier two genetic counselors on October 7<sup>th</sup>, 2013. Of the 20 total

individuals who responded to the invitation email, fifteen individuals agreed to participate in an interview. Of these, 14 completed an interview. One participant selected out of the study and did not re-schedule the interview due to a scheduling conflict. Thus, the final sample included a total of 14 genetic counselors (13 women, 1 man). Additional demographic data for the sample are summarized in Chapter 4.

**Sample Size.** Determinations about sample size were made based on the following criteria proposed by Morse (2000). For research methods that are designed around clear (i.e., non-abstract) concepts and a straightforward scope, fewer participants may be required to reach saturation. An additional variable that may impact sample size is the use of shadowed data, or data that are intended to convey the experiences of others. Finally, study designs that incorporate multiple voices in one interview (e.g., a family interview) will produce more complex data, which may require a larger sample size to reach saturation. The present study investigated clear concepts organized around a straightforward scope and did not involve multiple voices per interview. This research did use shadowed data, however, a quality that may increase the number of participants required to reach data saturation. Recommendations for determining sample size in grounded theory research range from 6-12 (Bernard, 1995), to 12-15 (Creswell, 2002), to 15-30 (Morse, 2000). Because the shadowed data add one element of complexity to this design, the Creswell's (2012) moderate recommendation of 12-15 participants was used to guide sample size.

### **Instrumentation**

The primary investigator developed a semi-structured interview protocol containing 15 structured questions (see Appendix C) and as well as demographics questions. This instrument was based on consultation with genetic counseling professionals and faculty members. Questions were also developed based on extant literature. The results of Williams et al. (2000), which outlined implications for the support person, were particularly influential in the development of these items.

This 15-item protocol was organized around six central themes: 1) Information about the support person: when a support person is brought and what relationship exists between the proband and the support person, 2) Discussing a support person with the patient: language used, the extent to which it is discussed, situations where it is discussed, 3) Genetic counselors' perceptions about how patients make a decision regarding who to bring to the session, 4) Positive and negative clinical examples of cases involving the use of a support person, 5) Counselors' beliefs about what characteristics contribute to successful support, and 6) Perceptions regarding the role of the genetic counselor with regard to the inclusion of the support person during the appointment.

To test for clarity, this investigator piloted the interview with one practicing cancer genetic counselor at the University of Minnesota, Twin Cities campus. She engaged in a mock-interview with each pilot participant at a cancer genetic counseling clinic. Based on their feedback, she made revisions to the protocol to improve clarity and maximize efficiency. The genetic counselors who engaged in the pilot interviews were then ineligible for the participation in the study.

Because the nature of this study is interdisciplinary, and because the primary investigator has no formal education in cancer genetic counseling, she observed several cancer appointments with consenting patients prior to conducting this study. This observation provided the investigator with an *in-vivo* understanding of the genetic counseling appointment structure, tone, and information. Additionally, this opportunity provided the investigator with consultation regarding the project's scope and objectives.

### **Data Collection**

Interview data were collected between September, 2013 and December, 2013. All interviews were audio recorded and conducted by phone by the primary investigator. The primary investigator also recorded memos during the interview itself, noting issues related to scheduling, the participant's level of engagement, and the participant's adherence to the questions. Phone interviews were expected to take between 30 minutes and one hour. Genetic counselors were emailed the interview protocol at least one week prior to the phone interview to allow them time to reflect on the prompts and prepare answers.

The use of a semi-structured interview format ensures that all participants receive the questions and related prompts in approximately the same order, but also allows for follow-up topical trajectories. Additionally, the use of a semi-structured interview allows for replication of the interview with other participants while still allowing for individualized responding. Demographic information was collected at the beginning of each interview. Each participant was given the opportunity to specify relevant demographic information that was not addressed in the protocol.

## **Data Analysis**

The research team consisted of the primary investigator (and advanced doctoral student in counseling psychology) and one master's-level research assistant (a female student in a counseling program). The research assistant was trained in grounded theory analysis by the primary investigator through the use of face-to-face didactic training, assigned readings, and the provision of studies of exemplary grounded theory publications. The primary investigator completed all phone interviews (data collection) and transcribed all interviews verbatim. Any identifiers were removed from the transcripts. The primary investigator and research assistant completed the data analysis.

Data were analyzed using a grounded theory method with constant comparison (Glaser & Strauss, 1967; Strauss and Corbin, 1990), a method designed to aid in the systematic collection of qualitative data toward the goal of developing a theoretical model (Strauss & Corbin, 1990). Grounded theory is particularly well suited to uncovering the beliefs, values, and perceptions people assign to their experiential reality. Additionally, grounded theory is particularly valuable for exploring relationships between people in social settings, particularly when those relationships have not been explored previously (Crooks, 2001). For this study, the use of grounded theory allowed genetic counselors to narrate their professional understanding of and experience with the support person in the cancer genetic counseling appointment.

The data analysis was based on transcriptions from each interview, the typed notes taken by the primary investigator during each interview, and hand-written memos written during analysis. The data corpus consisted of approximately 150 pages of

transcriptions, memos, and notes, and 17 hours of audio recordings that documented 14 interviews.

Data analysis began with open coding, a process designed to develop initial categories by examining words, phrases and sentences. During this process the researchers independently developed code and category labels based on their impressions of the data. Following open coding, codes and categories were organized using axial coding, a process designed to develop structure and relationships within the data. Following axial coding, selective coding, or the integrative process of “selecting the core category, systematically relating it to other categories, validating those relationships [by searching for confirming and disconfirming examples], and filling in categories that need[ed] further refinement and development” was used to develop themes (Marrow & Smith, 1995; Strauss & Corbin, 1990, p. 116). Following the organization of themes, a theoretical model was developed to address proposed hypotheses regarding the nature of support persons within the genetic counseling appointment.

The qualitative analysis team met six times over the course of four months to discuss the transcripts, identify emerging themes, and develop a narrative of the data. Both analysts analyzed each transcript independently then collaboratively developed themes until consensus was achieved. Consistent with LeCompte and Goetz (1982), regular meetings enhance the research process by reducing the incidence of selective inattention, increasing sensitivity to data, and noting personal biases. A licensed psychologist with experience in genetic counseling research served as data auditor. Disagreements in data coding were resolved through discussion to reach consensus.

**Bracketed Biases on Reflective Research.** The process of identifying the researchers' biases in a qualitative manuscript is a necessary component that contributes to the validity of the results and strengthens the impact of those results. Drew (2004) stated that bracketing is "the task of sorting out the qualities that belong to the researcher's experience of the phenomenon" (p. 215). Creswell and Miller (2000) discuss the importance of researchers noting social, historical, cultural, and value-based biases during the early phases of research and including a summary of those biases early in the research manuscript.

For the present study, biases were tracked using computer and hand-written memos as well as reflective journaling. They were then organized into groupings based on similar themes. The following biases were noted in memos prior to analysis of the data: beliefs, values, hypotheses, preconceptions, presuppositions and assumptions. Consistent with Glaser's (1978) research on bracketing in qualitative research, biases and preconceptions were identified prior to analysis. See Chapter 4 for a summary of bracketed biases.

## Chapter 4: Results

This chapter will first review the documented biases that were recorded by both the primary investigator and the master's level research assistant (Table 1). Next, demographic information for the sample of genetic counselors will be presented (Table 2). The next section will review interview characteristics that were noted during data collection. Finally, the qualitative results will be presented according to each research question by presenting domains, sub-themes, and relevant quotations.

### Bracketed Biases

Prior to analysis, this research and the master's student identified and documented their biases. Table 1 contains a list of their biases, arranged according to three predominant themes about: the role of the genetic counselors, the patient's choice of support person, and beliefs about the positive impact social support has on the appointment or patient.

Table 1: Bracketed Biases on Reflective Research

<b>Role of Genetic Counselors</b>	Genetic counselors have the potential to influence patients' psychological reactions through the interaction with the patients and their best psychological mechanism for coping (the support person).
	Genetic counselors have a direct interface with the primary source of each patient's social support system.
<b>Patients' Choice of SP</b>	Some genetic counseling patients need help managing their psychological reaction to receiving information about genetic risk.



	Genetic counseling patients receive little to no direction about choosing a successful support person.
<b>Positive Impact of Social Support</b>	Social support is a good way to help genetic counseling patients brace for and manage information, particularly difficult information, about their genetic risk.
	The most likely source of social support for genetic counseling patients is the person they bring with them to the appointments.

### Participant Demographic Information

Fourteen genetic counselors were interviewed for this study. They provided demographic data verbally at the beginning of each phone interview. Their demographic data are summarized in Table 2.

Table 2: Participant Demographic Information

Variables	Genetic Counselors (N=14)	
<b>Age (years)</b>	Median= 44 Range= 32-65	
<b>Gender</b>	<i>n</i>	%
Female	13	93
Male	1	7
Other	0	0
<b>Years of Professional Experience</b>	<i>n</i>	%
0-5	0	0
6-10	3	21
11-15	4	28
16-20	5	37
21+	2	14
<b>Ethnicity</b>	<i>N</i>	%
Caucasian	12	85
Ashkinasi Jewish	2	15

	<i>n</i>	%
<b>Professional Degrees/Certifications</b>		
Master's in Genetic Counseling	14	100
Certified Genetic Counselor	14	100
Marriage and Family Counselor	1	7
<b>Current Practice</b>	<i>n</i>	%
Clinical	8	57
Clinical/Research Combined	6	43
<b>Work Setting</b>	<i>n</i>	%
Clinic	3	21
Private/State Hospital	3	21
University Hospital	2	14
Research Institute	1	7
Combined	5	37
<b>NSGC Region of Practice</b>	<i>n</i>	%
<u>Region I</u> (CT, MA, ME, BH, TI, VT, Canadian Maritime Provinces)	3	21
<u>Region II</u> (DC, DE, MD, NJ, NY, PA, VA, WV, Quebec, Puerto Rico, Virgin Islands)	1	7
<u>Region III</u> (AL, FL, GA, KY, MS, NC, SC, TN)	1	7
<u>Region IV</u> (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario)	5	37
<u>Region V</u> (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan)	3	21
<u>Region VI</u> (AK, CA, HI, NV, OR, WA, British Columbia)	1	7

As shown in Table 1, the sample was primarily female ( $n=13$ ) and most identified as Caucasian ( $n=12$ ). The participants varied in age (range = 32-65 years-old) as well as years of professional experience (range = 7-40 years). Everyone had a master's' degrees

in genetic counseling and was an American Board of Genetic Counseling (ABGC)-certified genetic counselor. One individual held an additional degree in marriage and family counseling. The participants reported working in a variety of settings, and all were providing cancer genetic counseling services to patients at the time of the interview. Finally, the participants represent a national sample, as evidenced by their NSGC region of practice.

### **Interview Characteristics**

This investigator recorded her impressions about participant demeanor during the interviews in the form of memos and notes. All participants demonstrated openness to the interview. Many indicated they had reviewed the protocol prior to the phone interview and had given prior thought to their answers. Additionally, many of the genetic counselors stated they were viewing the interview protocol throughout the interview. This process appeared to allow participants to relate their answers from one question to their answers to another question. For example, one individual said, “I am thinking about my answer to this question and also the one after it. I have a good answer to the second question, but I have to think about this first one.” It was this researcher’s impression that viewing the protocol throughout the interview allowed the participants to structure their answers within the broader context of the full protocol. Additionally, it seems clear this approach helped to reduce redundancy in the content of answers. For example, one participant who was about to elaborate on an answer saw that she would be in fact answering the subsequent question and said, “Oh, I will wait and save that until the next question.”

Participants demonstrated a strong grasp of the content of the protocol and answered questions with authority and confidence, as evidenced by quick and articulate responses without verbal indications of uncertainty (e.g., I'm not sure, maybe, perhaps, I don't know). They asked for clarification at times when a question or follow-up question was unclear. Additionally, many genetic counselors demonstrated interest in the topic as indicated by statements such as, "This is an important topic," "I haven't thought about these questions before, but I will now," and "These are good questions." A handful of participants demonstrated interest in the topic by sharing information, relevant published studies, or insight about the research process. One individual asked to vet her responses to the interview questions prior to publication. This request will be honored when the manuscript is written for publication. Additionally, all of the interviewees asked to receive a link to the manuscript once it has been published.

For each of the interviews, the use of technology was successful; therefore, the results were not impacted by any technological failures, disrupted interviews, or lost phone connections. Actual interview times varied between 20 minutes and 90 minutes (Median= 27.31 minutes).

### **Qualitative Analysis of Interview Protocol Responses**

The results in this section are organized according to each of the three major research questions. Individual interview questions are included under the sub-heading of the relevant research question. Finally, themes and domains follow interview questions, along with illustrative, verbatim quotations. Often the participants' responses were multifaceted and included answers to multiple prompts, resulting in their classification

into multiple domains. For this reason the domain total  $n$  will refer to the number of classifications and will frequently be larger than the total sample size (i.e., larger than  $N = 14$ ). (Summarize the three research questions)

**Research Question 1: In what ways do you involve the support person in the patient's genetic counseling appointment and process?**

Genetic counselors were asked to respond to five questions regarding their perceptions of the support person's involvement in the genetic counseling session. (Question 1) "Do your patients tend to bring a support person to their genetic counseling appointment?" Those participants who answered "yes" or "sometimes" to this question, were asked a follow-up question, "To which session(s) do patients tend to bring a support person?"; (Question 2) Participants were asked to speculate about their patients' motivations for bringing a support person with them to the session: "Why you think patients bring a support person?"; (Question 3) Next, they were asked to discuss the extent to which they talk with their patients about bringing a support person: "Do you talk with your patients about bringing a support person to their appointment?" Regardless of their response, all participants were asked this follow-up question: "Can you say more about why you do or do not talk about this with your patients?"; (Question 4) Those individuals who responded "yes" or "sometimes" were asked to discuss the language they use to discuss the choice to bring a support person to the session: "If you do discuss this, tell me about how you typically approach your patients about bringing a support person and what language you use?"; (Question 5) Finally, the genetic counselors were asked to assess clinical situations where they would feel more or less inclined to

discuss the involvement of a support person in the session: “Are there cases where you would encourage the use of a support person more so than others? Are there cases where you would discourage the use of a support person more so than others?” For those participants who responded in the affirmative to either or both questions, they are asked a follow-up question: “Can you provide an example of that kind of situation?”

### **Inclusion of a Support Person in Appointments**

The genetic counselors’ comments regarding the ways they believe support persons are involved in the genetic counseling appointment yielded two domains: Quantitative estimations provided estimates of the number of patients who bring a support person, and the identities of support persons (Domain 2) and qualitative estimations described the type of support person a patient tends to bring (Domain 1).

*Domain 1: Identities of Support Persons (n=14).* Many of the participants described the relationship the patient has with her or his chosen support person. Commonly, counselors identified family members as the most frequent visitor to the appointment. Multiple counselors noted family member tends to be female, most commonly including sisters, daughters, and mothers. Additionally, several counselors noted that spouses commonly serve in the role of support person. There are two categories.

#### *Category 1: Specific Relationships between the Support Person and Patient (n = 14)*

- “I do find that when people bring a support person it tends to be a family member.”

- “So, if somebody is eligible to come in for the study, typically we might bring them in a family sort of way, say, an affected 30-year-old and her children and maybe parents, maybe siblings, so the family constellation is common.”
- “If it qualifies as a support person, and it could be anybody, it could be a spouse, it could be a friend, it could be a mother or some other relative, and just really varies.”
- “A friend or a spouse- usually fulfills that role. I would say those are the two most common.”

*Category 2: Gender of Support Person (n=6).*

- “And it typically consists of either a spouse, a sibling, or likely to be a female sibling...”
- “Yeah, so let’s say a patient testing of breast cancer will bring their daughters along because they know that this is something inherited that their daughters may need to be concerned about.”
- “A lot of times someone brings their mom, for example. It’s because their mom had cancer, mom’s been through this journey, so now she is helping her daughter or son through the process.”

**Domain 2: Quantitative estimations (n=11).** A majority of the participants approached this question by first providing a quantitative estimation of the number of their patients who bring a supportive person with them to the appointment. There are three categories.

*Category 1: Half of all Patients (n=6)*

- “I would say roughly half of the patients bring a support person to the visit.”
- “I would say probably at most ½ of them do. A good percent come alone.”

*Category 2: Less than Half of Patients Bring a Support Person (n=3)*

- “It depends. The people that most often have someone with them are those who have a cancer diagnosis. But there are other people who do bring sometimes a parent or child or family. But, it certainly [is] not even all of them or even most. If I had to guess, maybe 20-25% of people bring someone to the first appointment without specifically being prompted to do so.”

*Category 3: More than Half of all Patients (n=2)*

- “People are more likely to have a support person with them if a diagnosis of cancer is new, but if this is an old diagnosis, not so likely. I would say 75% of patients have at least someone with them.”
- “Okay, yes, my patients do tend to bring a support person to their appointment. I very rarely see someone by themselves.”

### **Motivations for Bringing a Support Person to the Appointment**

The interviewees were asked to speculate about their patients’ decision to bring a support person to the session. Six domains pertain to descriptions of their perceptions of the reasons patients bring a support person: Provide information, Help with decisions, Help collect information, Double reason, Emotional support, and Practical reasons.

***Domain 1: Help collect information (n=14).*** In addition to helping patients construct a family history by providing information, participants also spoke to the role a support person plays in helping the patient to collect and retain information. They mentioned the value of having a “second set of ears” in the room as well as various ways support persons help the patients in sessions. There are three categories pertaining to reasons patients may struggle to remember information after the appointment.

*Category 1: Second set of ears (n=8).*



- “To have an extra ear in the room.”
- “I think most people are wanting a second set of ears in the room.”
- “Sometimes they are just another set of ears... a family member or spouse usually fills that role.”

*Category 2: To help remember information (n= 5).*

- “So sometimes we will have the support people with a note book, and they are the ones doing the note-taking.”
- “And sometimes there is a support person who will ask a question when the primary person isn’t thinking of it at that time, sometimes they will bring up other questions or have a different grasp on the overall issue- to help remember the information.”
- “Sometimes the spouses help remember the information and pass it on to others.”

*Category 3: Why patients can be challenged to remember information (n=3).*

- “Patients receiving chemotherapy have a hard time remembering everything in session.
- “We give so much information in a session and patients can get overwhelmed, especially if it’s a new diagnosis.”
- “I don’t see many of those [cases], but cognitive impairment would definitely be an instance where I would need someone else present.”

**Domain 2: Emotional support (n=7).** Several genetic counselors noted they believe a support person serves as an emotional support for the patient. A handful of genetic counselors noted that simply having someone present in the room appears to be beneficial to the patient. Others described the benefit of emotional support in more detail. There are no separate categories.

- “I think that they [patients] are not sure what to expect and they want someone to be there, just in case.”
- “Seems like it’s primarily for emotional support.”
- “In some cases it’s for emotional support, or having someone to bounce things off of.”
- “I think sometimes they are nervous and just want someone there.”
- “Having the security of company when you are coming to a strange place.”

**Domain 3: Provide information (n=5).** Many genetic counselors expressed a belief that patients invite a support person, in part, to provide information about the family’s medical history as well as to use their knowledge of the history to help the patient make decisions. There are no separate categories.

- “If it’s a family member, they are often there to help provide family history information.”
- “I think in part especially when patients are bringing mothers with them to the appointment, I think they are wanting their input regarding the family history and think they will be able to provide additional information beyond what the patient may recollect.”

**Domain 4: Help with decisions (n=4).** Several genetic counselors pointed out the value their patients place on having a support person present for the purpose of making a decision together. There are no separate categories.

- “We are open to the notion that patients can bring another person to the appointment whether it’s a family member or a friend, um, somebody that helps them make medical decisions.”
- “Gosh, there are a lot of reasons- shared decision-making, probably.”

- “I am thinking of a patient I had last week who brought her husband. This was the third time we met in person. She brought him because she really needed him to support her decision-making. I think that was a great use of a support person.”

**Domain 5: Double reason (n=4).** Some of the participants shared their perception that the support persons sometimes are present in the appointment because the information provided by the genetic counselor will impact their own medical decisions. One participant referred to this situation as a “double reason,” highlighting the fact that the support person is sometimes there to provide support, but may also have a personal investment in the results. There are no separate categories.

- “In some cases, they are a family member and could be impacted by the results of the session- children or siblings.”
- “...it could also be because they are a family member and they would be able to benefit from the information for themselves.”
- “If there was something found on the testing, they want their daughter or sister to get the information and do the test, too.”
- “So, the daughters are there probably not only for support but also because it is information that can benefit them too. So it’s kind of a double reason.”

**Domain 6: Practical reasons (n=4).** A few counselors described practical advantages for bringing a support person to the appointment. These include transportation reasons and habitual practices. There are no separate categories.

- “I think sometimes they just need a ride.”
- “I think honestly, it’s just habit. They [the support persons] go to all of their appointments with them if it’s cancer related.”

### ***Discussing the Inclusion of a Support Person with the Patient***

Participants were asked to reflect on whether or not they discuss the option to include a support person in the session with their patients. There are domains of action regarding their approach to this discussion: Initiation of conversation with patients, Selective and Routine recruitment of support person, and Neither counselors nor staff speak with patients.

***Domain 1: Initiation of conversation with patients (n=7).*** Many participants described an active approach, speaking with patients directly regarding their option to bring a supportive person to their appointment. The majority of these counselors actively spoke with all of their patients as a component of their practice. One individual stated that she only actively talks with patients about the value of a support person when they are at 50/50 risk. There are two categories.

*Category 1: Routine recruitment of support person (n=5)*

- “Actually I do all of my own scheduling, so I tell people that they are welcome to bring somebody. I always encourage that.”
- “Specifically for cancer, yes. When I started doing this years ago, the scheduler used to always encourage the patient to bring someone with them to help with information and decisions. When a patient has a support person with them, they will make a decision they are more comfortable with.”
- “I’ve always invited [that they could have] somebody to come with [them]. Two sets of ears are better than one.”

*Category 2: Actively speak to high-risk patients only (n=2)*

- “For individuals who are at 50/50 risk with known mutations, if they don’t bring someone with them to the first session, I encourage them to think about whether or not they want to have someone with them when they learn the result.”

- “If the likelihood that they are going to be having something will be higher, then I might mention it.”

**Domain 2: Selective recruitment of support person (n=4).** A few genetic counselors endorsed the value of talking with patients about the inclusion of a supportive person, but noted they make this recommendation passively, only when the opportunities presents itself or if a patient specifically asks to bring someone.

*Category 1: Only if patient specifically makes a request (n=3).*

- “We open that up as a possibility. Let’s say the patient calls and has questions regarding their upcoming appointment and at that juncture our staff typically introduces the notion that if they want to bring somebody with them they we welcome to do so, and it doesn’t need to be limited to just one person. If they want to bring more than one person, that is fine as well.”

*Category 2: If the opportunity presents itself (n=1).*

- “I do not have contact with them prior to the appointment; the only person they have talked with is my scheduler. Once in a while I will bring it up, but it’s not something that I routinely mention. If a daughter says, ‘Oh, I wonder if I should bring my mother,’ I encourage it.”

**Domain 3: Neither counselors nor staff speak with clients (n=4).** A handful of counselors said they talk with patients about this choice very rarely or not at all. Some stated that they do not have the opportunity to make this recommendation because of scheduling constraints.

*Category 1: Rarely (n=2)*

- “You know, I don’t always do that. No, I don’t do that. Usually not.”
- “Not typically. Sometimes it’s helpful, but I don’t typically bring it up on my own.”

*Category 2: Lack opportunity (n=2)*

- “We don’t speak with everyone ahead of time, though they are welcome to bring someone.”
- “I don’t. I don’t usually talk to patients prior to their scheduling their appointments. So I don’t have the opportunity.”

***Language Used to Discuss the Inclusion of a Support Person***

Genetic counselors who affirmed having conversations with their patients about the utility and value of bringing a supportive person with them to their appointments ( $n = 7$ ) were asked a follow-up question about the language they use in that situation. Their examples of concrete language they use to address this issue resulted in two domains: Recommendation based on practical benefits, and Recommendation based on multiple forms support .

***Domain 1: Recommendation based on practical benefits (n=7).*** Two categories pertain to language that either mentions a specific benefit or language of a more general nature.

*Category 1: Bring someone to help you remember all of the information (n=6).*

- “Another person will provide a second set of ears, and it helps to just have a person there.”
- “Two sets of eyes are better than one. I say, ‘You might want to bring somebody with you- we cover a lot of information. It’s helpful to have somebody to help think of questions. After you go out the door, it’s somebody to bounce things back and forth with.’ This recommendation has been my practice.”

*Category 2: A general invitation to bring someone (n=4).*

- “I ask if they plan to bring anyone to the appointment if they haven’t brought it up themselves. If they say ‘Yes,’ then I say ‘You are certainly welcome to; we are glad to have others come.’ If they say, ‘I haven’t thought about that,’ I say, ‘If there is anyone you can think of that you’d like to bring along, we’re fine with having more than one person in the room,’ just leaving it open.”
- “I tell people they are welcome to bring someone. A lot of times people will ask if their sister could come or something like that, and I always encourage that.”

***Domain 2: Recommendation based on multiple forms support (n=2).***

Two participants stated that they identify multiple ways that a support person can be helpful when brought to the appointment. There are no separate categories.

- “I would say that ‘It’s helpful for you, and you may find it helpful to bring someone with you. There is a lot of information we will go over, and it’s good to have a second pair of ears, and it’s best to bring someone along for moral support.’ And that’s exactly how I would phrase it.”
- “I say to people, ‘It’s 50/50 risk; it may be helpful when you learn of the result to have that person with you and to either celebrate with or to make sure you ask all the questions that you need to. And I might say to them ‘It helps you because you don’t have to be the one absorbing and then trying to relate this information to a spouse, for example, who is going to have a lot of questions’.”

***Encouraging or Discouraging the Involvement of a Support Person***

Genetic counselors were asked to reflect on their clinical experience to determine if there are cases where they would encourage the involvement of a support person more so than others, and alternatively, if there are cases where they would discourage the involvement of a support person. There are two domains: Discouraging the involvement of a support person, and Encouraging the involvement of a support person.

***Domain 1: Discouraging the involvement of a support person (n=12).***

Almost every participant identified several instances where they would recommend a patient's support person either leave the appointment room or avoid coming to the clinic altogether. These counselors stated that they would discourage a patient from bringing a disruptive support person, a coercive support person, or a person who would be unable to give support, such as a child. Additionally, two individuals stated they were unable to identify a situation where they would discourage a support person. Several genetic counselors noted that, though they would prefer discouraging certain types of support persons from joining the session, they often do not know that until after the initial appointment. There are four categories.

*Category 1: Discouragement of a support person who is negatively impacting the session (n=5)*

- “If someone is going to be distracting. Of if I’ve met with them already and I’ve learned that there is a person who has created a barrier to a good genetic counseling relationship. Then I suggest [the patient and I] meet one-on-one.”
- “If it’s undue burden on the family, I guess that would be the main thing.”

*Category 2: No cases where a support person would be discouraged (n=3)*

- “I can’t imagine discouraging a support person.”
- “Oh, nooooo. I have never done that. No.”
- “Oh, that’s a really good question. I don’t think so. People make a choice to bring someone with them for a reason and I am not the kind of person who is going to intervene in that relationship.”



*Category 3: Discourage a support person who is being coercive (n=2).*

- “There are times where you feel that someone else has a different agenda they are pushing. For example, ‘Oh, my mom is really pushing that I be tested.’ I talk that through if I have a sense that that is going on. I say, ‘Do you feel like you would be able to do what you need to do if she were not here?’”
- “I’ve felt uncomfortable about the autonomy or the voice of the patient being heard- that they are there willingly or their needs are addressed versus the needs of the support person becoming dominant during the session.”

*Category 4: Discouragement of specific types of support persons (n=1).*

- “If someone asked me about bringing minor children to a session, I would have a discussion with them about their expectations about that to make sure we were on the same page.”

***Domain 2: Encouraging the involvement of a support person (n=11).*** A

large majority of the participants provided at least one example of a situation where they would provide a particularly strong recommendation for the inclusion of a support person. These cases include situations where the patient’s psychosocial needs are high or dysregulated, where the presented concern was unique or severe, and where the patients appeared to have very little information about their family history. Additionally, two counselors denied instances where they would place a heavier emphasis on a recommendation to bring a support person. There are four categories.

*Category 1: Encouragement of support person for severe cases (n=6).*

- “When someone is quite ill it can be hard. For someone who has just received a diagnosis or is quite sick, it’s hard for them to process much of anything, not an ideal time to be coming in. They need the information, so I recommend a support person.”

- “This is a great question. I guess my initial response would be that the individuals who have the highest probabilities of pursuing genetic testing and the highest probability of testing positive are the ones who often get the most benefit. Patients don’t necessarily know that upfront, so I’m not sure if there is a good way of capturing that population in advance.”

*Category 2: No cases where a support person would be encouraged more so than others (n=2).*

- “I like to think the answer is no. I always encourage people to bring whoever they want.”
- “I encourage everyone to bring a support person, and none more so than others. I think the earlier and the more integrated and involved and active we can make the support person from the get-go, the earlier the better.”

*Category 3: Encouragement of a support person for a patient with high psychosocial needs (n=2).*

- “If they had questions that could wait and were overly anxious or whatever, I would definitely encourage. This is a situation where I would be more assertive in encouraging someone to bring a support person with them [to the next session].”
- “Yes, absolutely. There are some patients who come in and if they do not have a support person with them and I can tell they are overwhelmed I will say, ‘I’m not really okay with you going ahead with this right now, why don’t you go home, come back again with someone else, talk to whoever you talk to, and come back after you’ve had a conversation and we can work through this together.’”

*Category 4: Recommendations based on need for accurate family history (n=1)*

- “With some patients I talk to ahead of time, I get the sense that they really don’t know much about their family history. I might mention if it is possible for your mother to attend the appointment with you to help you address some of these questions? If they can’t

give me accurate family history information, it's hard for me to give them appropriate recommendations.”

**Research Question 2: What variables do genetic counselors believe contribute to successful and unsuccessful support person performance?**

The interviewees were asked to discuss variables they believe contribute to the successful involvement of a support person as well as unsuccessful involvement of a support person. As the success of support person's performance may lie, at least in part, in the choice of support person, genetic counselors were asked their impressions about how patients choose which person(s) they will bring with them to the appointment:

“From your experience, how do patients choose whom they will bring to the appointment?”

Next, participants were asked to provide clinical examples from their cancer genetic counseling practice. The counselors were asked to reflect on both positive and negative instances of support person performance through these questions: “In what ways does bringing a support person benefit the patient?” “Can you provide an example(s) of a case where the inclusion of a support person seemed beneficial to the patient?” “In what ways can bringing a support person adversely impact patients?” “Can you provide an example(s) of a case where the inclusion of a support person seemed detrimental to the patient?”

***Variables that Influence Patients' Choice of Support Person***

Participants were asked to use their clinical experience to comment on their patients' processes with regard to choosing a support person. Specifically, they were

encouraged to identify specific variables that enter into the patients' decision-making process. There are three domains: Choice is based on who can provide the best support to the patient, Choice is based on who could benefit from the information, and Choice is based on reasons unknown to genetic counselor.

***Domain 1: Choice is based on who can provide the best support to the patient*** ( $n=11$ ). The majority of participants stated that one variable contributing to a patient's decision-making process is the extent to which the patient will feel supported during the process. Four categories variously reference spouses, a previous family member who had been diagnosed with cancer, (sources of emotional support, and sources of practical support.

*Category 1: Patients bring their spouse because they are their closest relation* ( $n=5$ )

- "I think it's basically out of habit, like who has gone to previous appointments. It's usually a spouse."
- "I think a lot of people in cancer bring their spouses. They choose them because it's [prophylactic measures] a very sexual thing, and they need their partner there to validate their decision about that. I think most men come in with their wives, more because the wives are prodding them in and not because it's an act of choice."
- "Especially for spouses who accompany, that they are choosing somebody for emotional support, and I would suspect the spouse is there for any of their oncology appointments, not just the genetic counseling appointment."

*Category 2: Patients bring a source of emotional support* ( $n=3$ )

- "I think it's often someone they feel close to. I have had sometimes men come with women, maybe a boyfriend. They may just 'be

there,' they may not be very verbal, their hats are down over their eyes. But they are there.”

- “In this case, the patient was not close to her family. Her best friend was going to visit from the east coast, so we arranged [the appointment] to give her the results while her friend was in town. It is the person the patient perceives is going to be helpful to her.”
- “There are probably emotional reasons the patient would want to bring someone not obvious, even though they have a spouse or sibling there. But I don't know that people actually see it as a decision-making process. I think it's [choosing a support person] almost automatic.”

*Category 3: Patients bring a support person who has had a cancer diagnosis (n=2).*

- “If someone has not had cancer but their mother had cancer say, they will bring her there because they think that their mother knows which questions to ask or is familiar with the system, so [if] they start talking about seeing a surgeon [the support person] will know what that's all about.”

*Category 4: Patients bring a support person who provides practical support (n=1)*

- “Sometimes it's transportation based- who is giving them a ride.”

***Domain 2: Choice is based on who could benefit from the information (n=7).***

Several genetic counselors indicated patients sometimes make a decision to bring individuals who can benefit from the information that will be provided in session. Two categories reference that patients will bring a blood relative who may also be at risk for developing inherited cancer, and there are cases where patients seek testing for the sole benefit of the patient's family, rather than to themselves.

*Category 1: Blood relations (n=5).*

- “A lot of sisters come in together. It’s always the worst situation for me to be in. Bringing your sister is the worst. They have their own agenda [that is they] are at the same genetic risk, but are carrying two agendas.”
- “I think sometimes patients will make the choice based on information that is relevant to ‘my sister,’ for example, ‘So I think it would be helpful for her as well, because she is also thinking about pursuing genetic testing’.”
- “People were bringing people who would also benefit from hearing the information, like sisters, brothers, children, blood relations because genetic[s] of cancer would also have an effect on them.”

*Category 2: Patients pursue genetic testing at the request of a family member (n=2).*

- “Patients that are farther out from their diagnosis and have put off genetic testing and are getting pressure from family members are ones that often bring children or siblings with them who have a vested interest in those results. These are people who are trying to make those decisions for other people’s benefit or believe that it doesn’t have any benefit [for] them at that point in time. That’s a really common thought process.”

*Domain 3: Choice is based on reasons unknown to genetic counselor (n=2).*

Two participants stated they felt unable to provide a response to this question because they had never discussed this topic with their patients (i.e., they do not ask patients, and patients do not volunteer this information). One participant laughed as she answered this question, possibly implying that asking a patient about their decision-making process in this regard would be unusual. There are no separate categories.

- “I don’t [have a sense for how people make the decision to choose a support person]. That’s a good question. That’s not something I talk about.”

- “Honestly I don’t know because I don’t think I’ve ever spoke with a patient about ‘Why did you choose to bring your daughter or your mother?’ (*laughs*), um, so I can’t speak to that one.

***Advantages and Benefits of Including a Support Person in the Genetic Counseling Appointment.***

Participants were asked to identify their perceptions of positive effects that can result from including a support person in a genetic counseling appointment. Specifically, they were asked to comment on positive impacts directly for the patient as well as effects on the overall counseling process and outcomes. Participants who endorsed positive effects were asked to provide examples from their clinical work. All 14 participants endorsed positive impacts, and 12 of these participants were able to generate at least one example. There are three domains describing support person behaviors that may result in positive effects for both the patient and the session outcomes: Provision of psychosocial support, Giving and receiving information, and Maintenance of a broad perspective during the appointment.

***Domain 1: Provision of psychosocial support (n = 14).*** The majority of participants reported that support persons who demonstrate emotional support are particularly helpful to patients. Additionally, a handful of counselors stated that support persons who are able to sustain a non-judgmental perspective throughout the appointment help to facilitate the patients’ processes. Counselors stated that this type of non-judgmental support is more helpful than biased support or feedback that reflects the support person’s personal agenda. Additionally, many participants noted that friends are often better candidates for the role of support person because they have less investment in

the outcomes, and are thereby more emotionally available to patients. Finally, several participants shared that support persons with a previous cancer diagnosis often provide hope and comfort to the patient. There are four categories.

*Category 1: Support persons are helpful when they are emotionally supportive (n=10).*

- “Also, psychosocial support - to help when someone is having a hard time. [Support persons] help me with a lot of counseling elements in a lot of ways. They help with re-phrasing and analogies and give me insight into how to provide information in a meaningful way.”
- “There is a group called ‘Angel Care,’ and if people don’t have a close person to talk through diagnosis, these people are available to come to your appointments and be supportive. Her only role was to be a supportive person- their purpose is emotional support”
- “It helps carry [patients] through emotionally. And with that usually people are able to function more easily in terms of process.”

*Category 2: A support person with a previous diagnosis of cancer provides comfort and hope (n=5).*

- “I had a patient who brought a friend who had had breast cancer herself. That was a nice dynamic. Here’s my friend who has been through this process a little bit and has some insight.”
- “I had two sisters in a room, they both had had breast cancer and one had already done genetic testing and was found to carry the mutation, and had already been through the process herself. So before even seeing me, the patient had a heads up about the appointment and the information we were going to review. So my patient had her sister there, and it was nice for emotional support because the sister had already been through it, and the sister did preventative surgery so my patient could refer to her and understand that- her sister was doing fine even though it’s scary information. I think that really helped her out.”



*Category 3: Friends have unique ability to be supportive (n= 3).*

- “I think being her friend, she could not only have more insight into figuring out where the patient was struggling with decisions, but was also, I would imagine, a much more trusted person to have the conversation with than I would be.”
- “I had a wonderful, wonderful experience the other day where a woman brought her friend to the appointment. I’ve never seen anything like it in my life. They were both so supportive of each other and really friendly.”
- “Where people bring a friend- this is more often the case, but it can happen with family members as well. They are very supportive and are really there for the person.”

*Category 4: Non-judgmental support is the most helpful (n=2).*

- “I remember a situation recently where the patient would try to decide about whether or not to have a genetic test and the support person was almost like a ‘co-counselor.’ When the patient was deliberating, she would ask questions. ‘What do you think you would do with that information?’ ‘Would you consider changing your surgery because of this?’ This was a really nice dynamic- not coercive. It’s recognizing that ‘This has to be my [the patient’s] journey’.”

**Domain 2: Giving and receiving information (n=9).** Many genetic counselors stated the inclusion of a support person can be beneficial to the outcomes of the appointment because patients more readily accept information from a loved one than from a medical professional. Additionally, multiple participants stated that support persons can be helpful by providing the family history or by collaborating with the patient to provide the most accurate family history. There are two categories.

*Category 2: Support persons as historians (n=5)*

- “I see the support people providing all kinds of supports- remembering the facts, family history, providing information to use, or clarifying.”
- “History taking. I have had many occasions where a support person corrects a patient. They figure out the most accurate part of the family history.”

*Category 1: Patients are more willing to accept information from a loved one than from a genetic counselor (n=4)*

- “I was posing scenarios and questions. Dad was doing the same thing. It’s different coming from someone supporting you than from a health-care professional.”
- “The lady I saw last week. She did not want to get her blood drawn. Having her husband there to say ‘It’s okay,’ was really helpful to her.”
- “I think in instances where patients are coming in and they have a family member who has been diagnosed with cancer, but the patient has been resistant, they may be more open because some of the misconceptions that they had regarding ‘How is this really going to help me?’ [have been dispelled].”
- “Family members know each other better than I know the family, so they help each other make decisions.”

***Domain 3: Maintenance of a broad perspective during the appointment (n=12).***

Participants reported that support persons can be particularly helpful with decision-making by maintaining a broader perspective or “big picture” while the patients manage their reactions. Additionally, the vast majority of counselors referred to the value of “having a second set of ears” in the room. Finally, a handful of participants stated a

support person can be particularly helpful to clients by managing the social and familial implications of the results. There are three categories.

*Category 1: Support person hears information the patient cannot or does not hear (n=11).*

- “Another set of ears is really important in a lot of cases. Genetics isn’t something that most people have a strong familiarity with. So, where you are dealing with complicated issues or decisions it is helpful to have someone else to listen to the same information and to be able to act as a sounding board to ask additional questions during session.”
- “I think it’s always helpful to have an extra set of ears, to make sure they understood everything.”
- “It’s also very helpful to have that extra set of ears. When patients walk out, they did not hear everything that I said. It’s nice to have someone to fill in the holes.”

*Category 2: Support persons can help to facilitate decision-making (n=4).*

- “The benefit of bringing a support person is mostly for validation- that the support person is making a decision that is comfortable for them.”
- “Where you are dealing with complicated issues or decisions it is helpful to have someone else to listen to the same information and to be able to act as a sounding board to ask additional questions during the session.”
- “Having that support person there helped them to think things through, what it is they really wanted to do. So, that is the most helpful.”
- “A lot of times they help facilitate decision-making- I do a lot of it, but family members know each other better than I know the family.”

*Category 3: Support person can be more aware of broader social/familial context (n=2)*

- “The person who is going through cancer treatment, so thinking about chemo and what their surgery is, and rightfully so they are focused on their own care, whereas their support person is coming in and they hear the potential impact on the family as well as other things. Their minds are a little bit more free.”
- “... I think it also benefits the family communication setting it around the family. So, if the person has cancer, they are pretty focused on that, but if their support person comes with them, they are very focused on the family aspect.”

***Disadvantages and Adverse Effects of Including a Support Person in the Genetic Counseling Appointment***

The participants were asked to reflect on clinical cases where the support person was in some way detrimental to the genetic counseling process and outcomes, to the patient, or to both. They shared that most support persons are generally positive contributors to the session, but there are times when the support person’s presence and behavior can be damaging. There are three domains: Support person and patients have separate agendas, Specific effects unsuccessful support persons have on the patients, and Genetic counselors manage difficult support persons differently.

***Domain 1: Support persons and patients have separate agendas (n=14).*** The majority of genetic counselors identified conflicting agendas as a source of discord between the patient and support person. Specifically, they described cases where the support person acted in coercive ways or attempted to pressure the patient to do something with which she or he was uncomfortable. Also, the counselors cited as

problematic, situations where the patient brings a support person whose agenda is to receive information about their own family history.

*Category 1: Support person acts in coercive ways or pressures the patient*

(n=5).

- “The daughter, from the viewpoint of her mother, it’s clearly the insistence of the mother for the daughter to be tested, but the daughter was clearly not engaged in the session at all.”
- “It can affect the patient where there is pressure from the support person to make a decision that goes against what the patient wants. For example, for the mother-daughter pair I worked with, mom had a Li-fraumeni mutation, the daughter did not want to know. The pressure was there – ‘It was mom’s dying wish.’ I felt like that was one of the worst situations I have ever been in.”
- “I’ve had a couple of instances where someone brought a family member and the family member either really pushed them into something they didn’t want to do or persuaded them into not doing something they did want to do. Sometimes you do feel as if the patient is kind of being put on the spot in front of me and with their family members and making decisions that they are not comfortable with.”
- “The situations that come to mind are when the support person has their own agenda that takes away from the patient’s consult. They overshadow the appointment because they are a stronger personality. I’ve felt uncomfortable about the autonomy or the voice of the patient being heard- that they are there willingly or their needs are addressed versus the needs of the support person becoming dominant during the session”

*Category 2: Support persons seeking information for their own medical*

*purposes (n=5)*

- “Family members ask ‘What about me?’ and friends will then start talking about ‘What about me and my family history?’ and you sort of rein that in and talk generally about ‘As we just discussed, this is not a problem if, etc.’”

- “I had one last week where there were five people in the room. Two siblings and two parents; they were divorced and one had the condition. Every person in that room had a different agenda and their own issues that needed to be addressed. It made focusing on the patient difficult.”

*Category 2: Support persons assert their own emotional needs over the patients emotional needs (n=5).*

- “Support people do things that are distracting. Perhaps from their own emotional neediness. SO, those are the ones that don’t work quite as well.”
- “You have times when the patient is incredibly anxious and the husband was sitting there rolling his eyes at her. And it was maybe not disruptive, but just ineffective and you almost want to say, “Why are you here?”
- “Sometimes when a support person is there, you then have to deal with two people falling apart.”

***Domain 2: Genetic counselors manage difficult support persons differently***

**(n=10).** In addition to sharing clinical experiences about unsuccessful support persons, several genetic counselors identified methods they have used to manage these situations. A handful of counselors stated they try to re-focus the session back on the patient once they’ve realized the support person is monopolizing the time. Conversely, two counselors stated that they do not intervene in these dynamics. Other genetic counselors discussed difficult situations where they’ve deferred to the support person because the patient did not make her wishes and preferences clear. Finally, one genetic counselor stated that she appreciates when conflict unfolds in the session because it allows them to make progress more efficiently and meaningfully. There are four categories.

*Category 1: Re-focusing the session on the patient (n=5)*

- “When that does happen, we try to focus it back on the person who is the patient at the time. Occasionally we try to separate people out if it’s not working at all.”
- “You get sidelined especially with something like a daughter when it becomes more about them. The ‘What if?’ and then ‘What does that mean about me?’ I think it’s easy to contain in terms of ‘Focus on the patient’.”
- “And so it ended up being that I was almost trying to counsel two different things at once because it was hard to just ignore her [the support person’s] questions because I didn’t want to be rude. I did address her questions, I tried to move on after addressing her questions and tried to address the support person’s questions with closed rather than open-ended questions.

*Category 2: Avoid intervening in the disruptive dynamic (n=2).*

- “I’m not a marriage counselor; I’m just trying to help them make a decision. But she chose to bring him and incorporate his thoughts into the decision, so who am I to judge?”
- “Usually I don’t say a lot. I try to sometimes address it a little bit. I have the mentality that they brought that person with them, and so they knew that person’s personality and what they were probably pushing for or not pushing for in the beginning.”

*Category 3: Giving preference to the support person’s wishes because the patient’s wishes are unclear(n=2).*

- “I worked with a family that has hereditary colon cancer history; the mom has a known mutation, daughter is 19. It was appropriate for the daughter to consider testing. The daughter was primarily on her iPhone when asked direct questions, shrugging and looking to mom. The mom cancelled the follow-up appointment and asked me to call her- the mom- as soon as we have the results. But I needed to hear from the daughter; as she is of age, it is her decision for how this handled. So the daughter calls and says it’s okay. Somehow I feel we have done a disservice to this daughter in terms

of helping her to manage her own health care because that's what she will have to do. And it's okay to have this be a little bit of transition, but it's more extreme, and I wonder if we had some intentional time alone with the daughter if that would help that transition happen."

- "I worked for a hospital that had a lot of Arabic speaking individuals and they would come, the husband and wife. The wife would wear a burqa; I could only see her eyes. The husband would be the interpreter. In those situations, you really wish that guy would leave the room. It's very difficult to get a sense of the patient, and in those cases the woman would really hide what she really wanted versus what her husband wanted.

*Category 4: Using conflict to improve the counseling (n=1).*

- "The conflict came out between them in counseling. And I actually feel happy when that comes out in a verbal way that we can work within the session as opposed to being one of those elephants in the room that doesn't get talked about. I don't think that's a bad thing to come out during the counseling."

***Domain 3: Specific effects unsuccessful support persons have on the patients***

**(n=7).** Genetic counselors identified several specific effects an unsuccessful support person can have on directly on the patient. Additionally, two counselors added that negative experiences with support persons are rare, though when they occur they tend to be memorable. Two categories reflect these perspectives.

*Category 1: Negative patient reactions during session (n=5)*

- "If the patient is getting teary and the stress is coming from the other person, we might offer that they [the patient] have some time on their own.
- "I think it [support person's comments] came as criticism, and she felt not understood."
- "It took away from my patient probably feeling like she was the patient.



- “I’ve had people shut down because the support person is there.

*Category 2: Unsuccessful support person experiences are rare (n=2).*

- “Horrible support persons are the exception.”

### ***What are the Characteristics of an Ideal Support Person?***

Participants were asked to describe their perceptions of specific characteristics that “ideal” support persons possess. There are three domains: Emotionally supportive, Provide tangible support, and Provide support around decision-making.

***Domain 1: Emotionally supportive (n=14).*** A majority of participants mentioned emotional support is a key characteristic of successful support person. Specifically, they noted that being a good listener, showing empathy to the patient, just being “supportive,” and having a strong attachment were the primary characteristics of a person who is emotionally supportive of the patient. Most counselors said an ideal support person usually has some combination of these characteristics. There are four categories.

*Category 1: An ideal support person is a good listener (n=7).*

- “They would be a good listener.”
- “They just need to listen without judging.”
- “Someone who lets the patient talk first.”

*Category 2: An ideal support person is empathic (n=7).*

- “A person who is very empathic, I don’t think they need to know the person intimately, but to be able to listen and be almost very Rogerian, just sort of echoing back what she is saying.

- “That would be a person who is very empathic, who is sort of grounded in their thought processes and they are not intrusive and where they have their own personal experiences that they can bring to help the patient. And some insight, basically.
- “I think my ideal support person is tuned into or understanding the needs of the individual at that time.”
- “They don’t try to make it about themselves and they make it about the person who is the patient. I guess somebody that ultimately has the idea that the reason they are there is to benefit the patient, not to benefit themselves.”

*Category 3: An idea support person is actually “supportive” (n=5)*

- “‘Supportive’ sounds like a no-brainer, but I keep going back to that. What’s another word? Maybe positive or open-minded. That is the one that seems most important.”
- “A ‘support’ person who is supportive.”
- “The most important thing is that their agenda is to be supportive of the patient.”
- “I want them to be generally supportive, how you would picture a support person for any appointment.”

*Category 4: An idea support person has a secure attachment with the patient (n=1).*

- “Ideally, I’d love the securely attached mother-type with a securely attached adult patient; they have an adult-kind of relationship that is warm but not co-dependent. Predictable, reliable but not intrusive. Actively interested and actively active within the session, but not taking over.”

**Domain 2: Provide tangible support (n=13).** In addition to providing emotional support, the participants stated that ideal support persons also provide practical or tangible support. Three categories describe being able to speak to the patient’s medical

history, acting as a scribe or note-taker, and asking good questions during the appointment.

*Category 1: The ideal support person knows the patient and his/her medical history well (n=6).*

- “Someone who can help out with the family history information, will put in details, but will not take over, ‘cause I’ve had that happen too.”
- “It’s ideal to have a relative in some ways who the information affects, because I think it’s helpful when they go through it together, depending on the family, and they know the history.”
- “And so the support person needs to recognize that background and experience of the patient - they don’t have the same cancer the patient has.”

*Category 2: The ideal support person acts as a scribe (n=4).*

- “The ideal person does what that person needs for them to do, whether it be a scribe or recording.”
- “They are taking notes, they’ve got their binder, you know, of stuff to collect for their patient.”

*Category 3: The ideal support person asks good questions (n=3).*

- “Someone who asks appropriate questions”
- “Asking them [the patient] good questions about why they want to do it, knowing their personality, those are the things.”
- “They would ask questions that perhaps the patients forget to ask because they are so anxious, and they talk about it ahead of time [discuss their questions with the genetic counselor at the beginning of the session] and they make sure the patients gets all of the information.”

***Domain 3: Provide support around decision-making (n=11).*** Many genetic counselors stated that an ideal support person should also be able to help the patient make a decision with which he or she feels comfortable. The participants stated that support persons who avoid taking over the session help to facilitate the patient's decision-making process. Several other counselors made general comments about the utility of a support person who can help the patients make decisions. Finally, one counselor said that support persons who can remain "objective" are particularly helpful during session. Two categories reflect these perspectives.

*Category 1: The ideal support person does not monopolize time (n=8).*

- "Someone who understands that he or she is the secondary person, they are not the primary focus of attention."
- "Different from a family member, sometimes you need someone who is not directly affected by the information who can truly support you and has no vested interest in the actual genetics. So you can't beat that."
- "It's helpful to have someone that would be able to dissociate her own experience from the patient's experience. That is one thing we will tell patients is to recognize that it's great to hear other stories about how they made decisions, but everyone has their own cancer, and what is right for one person is not right for another"

*Category 2: The ideal support person is helpful with decision-making (n=2).*

- "They would be able to reflect back [reflect the patient's thoughts and feelings back to the patient] with the patient to help facilitate decision-making."
- "Helping her make the decision by reflecting back what she is saying. A 'support' person who is supportive."

**Research Question 4: In what ways can genetic counselors help patients construct the best psychosocial support within the context of the genetic counseling appointment and following termination of the genetic counseling relationship?**

*What do genetic counselors believe their perceived role is with regard to talking to patients about choosing a support person?*

In addition to asking participants if they discuss the possible inclusion of a support person with their patients, they were also asked to describe their perceptions about the extent to which they feel it is their role to do so. In total, 11 participants responded “yes,” they do feel it is their role to discuss this topic with patients. In addition to the word “role,” participants used the words “responsibility” and “obligation” to describe their affirmative stance on this question. One genetic counselor said “yes and no,” indicating the approach should be tailored to individual patient needs. Finally, two participants said t they do not feel it is their role to talk with patients about the inclusion of a support person in the appointment. Domains and categories are used in this section to elaborate on the participants’ responses to this question. There are three domains: Yes, it is the genetic counselor’s role to provide guidance; No it is not the genetic counselor’s role to provide guidance, and The counselor’s decision to provide guidance is patient-dependent.

***Domain 1: Yes. It is the genetic counselor’s role to provide guidance (n=12).***

The majority of participants said that they do believe it is the role of the genetic counselor to provide guidance to the patient regarding their choice of support person. All of these counselors elaborated on their affirmative answer with supportive reasons for their

opinion. Several said they encourage patients to bring a support person who will actually be perceived as supportive to the patient. Others talked about their preference to provide this guidance prior to the appointment in the form of a letter, a brochure or via the appointment scheduler. Others said they talk with patients about carefully choosing their support person. Finally, several participants stated they encourage their patients to bring someone who might benefit from the information provided in the session. There are four categories. Many counselors provided an answer that reflected a combination of these categories, but all affirmed that importance of talking with their patients about this choice.

*Category 1: Encourage patients to bring someone with supportive qualities (n=6).*

- “When someone asks ‘Who should I bring’ we might say, ‘Who do you feel comfortable with? Who would be there to help you through this process?’ So suggesting qualities that might be helpful.”
- “I would say, ‘Do you think it might be nice to have a support person with you? We usually encourage that, if you can, [it] might be a good approach.’ you know, and explain why because maybe the person just never thought about it before.”
- “I would say yes [it is our role], or just validating that this is the kind of person you want to bring. When I suggest someone bring someone, I try to validate that that person would be someone good to have present for them while they are learning about the testing or the results.”

*Category 2: Encourage the patient to bring a support person prior to appointment (n=6).*

- “You’d want it to happen before the appointment- how practically would that take place? I suppose you could do it in an introductory appointment letter and you had some section about who to bring with you. And some kind of introduction of ‘Often patients benefit from having someone else come to the appointment’ and give a list of things that would help them bear some things in mind.”
- “Some centers do standard contact ahead of time to get information. That would be a place to do it.”
- “I don’t talk to all of my patients before they come in, so if you have a brochure mention it there, or when things are being scheduled, say something simple, ‘Bring whoever you want’.”

*Category 3: Encourage patients to think carefully about who to bring (n=3).*

- “I think counselors do this by rote, sometimes, and maybe the first obvious choice is not the always the best choice. Just a little bit of prompting, ‘Oh, do you think your husband is the one who you are going to talk to about this?’ So to help them think these things through. Some probing might be good.”
- Sometimes there is already a discussion about the family/family structure, and it becomes apparent that there would be someone who would be a particularly strong support person, but ultimately it’s the patient’s decision about what to do. So, some guidance there.”

*Category 4: Encourage the patient to bring someone who might benefit from the information (n=2)*

- “When it comes to a positive result within the family, I think I should definitely guide them about bringing what relative or at least blood relative that could benefit from listening in.”
- “It might not hurt to also mention if they want to bring any support people, especially family members, who might also benefit from hearing this information as well as to help provide information on your family history. Because I have heard patients say, ‘Oh, I wish I would have brought my mom because she knows all this information.’ If she would have known maybe she would have invited her.”

***Domain 2: No. It is not the genetic counselor's role to provide guidance (n=2).***

A few genetic counselors stated that they do not talk with their patients about bringing a support person to the session. Two categories reflect their comments. Some of these individuals affirmed the importance of talking with patients about a support person, but they also conflated the idea of “guiding” a patient through this decision with “telling the patient what to do” and said they would never do the latter. Other participants said that they do not have this conversation because it is not practical conversation to do so.

*Category 1: Conflating “guidance” with “telling the patient who to bring” (n=3).*

- “I don’t think that’s our role- to tell them who to bring to session. But I think that if they posed the question to us, I think I would ask them if there are particular individuals who would be helpful to bring with them to the visit and if so if they wouldn’t mind telling me about them and maybe we can work together to decide what would be the best bet for the individual to choose.”
- “No, because I don’t think any of understand the family dynamics well enough to [do so] - I try to encourage them and let them pick the person most, that they feel is the best person. I think you have to assume that the patient knows best. I would encourage bringing someone, which I wouldn’t pick who.”

*Category 2: Genetic counselor cannot provide guidance around this issue because it is not practical (n=2).*

- “It’s not practical to have a long discussion before everyone comes in on who you are going to bring. I don’t talk to all of my patients before I come in. It’s not practical for it to be a thought-out discussion.”
- “I think they know their relationships better than a two-minute scheduling conversation can provide me about who to bring.”



***Domain 3: The counselor's decision to provide guidance is patient- dependent***

**(n=4).** A handful of participants stated there are certain conditions where they would choose to have this conversation with the patient. Two counselors stated they only talk with patients about this topic if the patient initiates the conversation. An additional two participants stated that they initiate this conversation primarily when the patient's results are positive or when they are at 50% or greater risk. Two categories reflect this perspective.

*Category 1: Provide guidance only if the patient asks (n=2).*

- “If they have a question about [it], I usually say something.”

*Category 2: Provide guidance only if the patient is at 50/50 risk or greater (n=2).*

- “[I would suggest] Bring a person if the patient is at 50% risk or greater, but don't bring another person with 50% risk.”

***The genetic counselor's responsibility with regard to providing guidance to the support person about their supportive role***

Participants were asked to discuss the responsibility they believe genetic counselors should have in providing guidance to the support person about their supportive role in the appointment. Reactions varied and the sample was fairly divided on this issue. There are three domains: Generally, yes. It is the responsibility of genetic counselors to provide guidance to the support person, Generally, no. It is not the responsibility of genetic counselors to provide guidance, and Never considered this before.

***Domain 1: Generally, yes. It is the responsibility of genetic counselors to provide guidance to the support person (n=6).*** Two categories indicate either general agreement with providing guidance or agreement with doing so in certain situations.

*Category 1: It is always appropriate to guide the support person (n=4)*

- “Yes, during this time we could make it explicit that the support person isn’t there to just listen but to contribute as well. And that this person’s views are important to the whole process, and set up processed expectations. And then a lot of times, and I’m guilty of this too, I would say that you do a whole session that is pretty information dense, and then you are talking alone, and then at the end say, ‘And what do you think?’ And it’s like, oh my god, how could I have let this happen? I think that the process - to get more GCs to pay more attention to the process - is an on-going issue.”
- “Yes, I do. But I think you have to do it in a sensitive way. It’s part of what we do - it’s a part of our job when we are there.”
- “Yes, it’s best when it [the guidance] comes from the genetic counselor just because we can speak anecdotally if the patient asks something confusing my scheduler does not know. And our scheduler has a template to tell them what happens during the appointment they could also add that into their template to discuss that information with them about bringing somebody and what it could do for them.”

*Category 2: There are certain cases where guiding the support person would be appropriate (n=4).*

- “Well, I think if the support person is turning to us and asking ‘Are there ways that I can be of assistance to the patient?’ then yes, in that particular instance it would be an appropriate dialogue to have.”
- “Yes, you’d want to be careful. Supposedly in a lot of cases the patients are bringing with [them] someone they trust and have a relationship [with] and you don’t want to violate that trust by saying, ‘You’re not being helpful here’ because the counselor is the outsider in the situation. If clearly a support person is not being

helpful, then guiding how the support person can be helpful would be appropriate.”

- “Yes and no. I think there are different purposes for different support people. But if we recognize the support person is not being supportive, it’s our job to intervene.”

***Domain 2: Generally, no. It is not the responsibility of genetic counselors to provide guidance (n=5).*** There are no separate categories.

- “It could really impede the relationship if you try to step on those boundaries. There are cultural issues with support people. If we provided the guidance in an up - front manner, that wouldn’t be very culturally competent.”
- “In terms of really guiding the support person or asking ahead of the appointment, ‘Here’s what you need to do,’ I don’t think so, no, I’ve had a support person say, ‘Can I have a piece of paper and pencil?’ and I say that’s fine, I am always good about that sort of thing. We try to encourage participation, but not guide how they do it.”

***Domain 3: Genetic counselor has never considered providing guidance to the support person (n=3).*** There are no separate categories.

- “I hadn’t thought about giving guidance to the support person other than reining them in if they become inappropriate during the session.”
- “I’ve never thought to do this.”
- “Yes, that really could be useful. I haven’t thought about that.”

***The genetic counselor’s responsibility with regard to helping the support person prepare to continue their supportive role after the patient’s final appointment***

Participants were asked about the extent to which they believe it is their responsibility as professionals to provide guidance to the support person about their supportive role following the patient’s final appointment. All but two counselors

responded in the affirmative, stating they do believe genetic counselors should have this conversation with the patient and support person(s). Two themes reflect their conceptions of the process: Encourage the support person to provide psychosocial support after the final appointment, and Help patients utilize their support networks after the final appointment. Genetic counselors conceived of their role in the process in two ways. Two participants provided rationale for why they do not believe this conversation falls within the purview of the genetic counselor's role and their comments are reflected in a third domain: It is not the role of the genetic counselor to help the support person continue their supportive role after the patient's final appointment.

***Domain 1: Encourage the support person to provide psychosocial support after the final appointment (n=9).*** The participants' response to this prompt are separated into two main categories. First, genetic counselors stated that their role is to encourage the support person to continue to provide psychosocial support following the final appointment. Second, genetic counselors stated that that their role is to encourage the support person to provide information support, such as reminders, after the final session.

*Category 1: Genetic counselors encourage support persons to provide informational support (n=4).*

- "The support person can remember the information and talk with them about it later - they can remind them if they have to do this or that."

*Category 2: Genetic counselors encourage support persons to provide emotional support (n=3).*

- “I always talk about the emotional aspects of whatever we are talking about. I certainly think genetic counselors can say, ‘A lot of people have anxiety about this. If you are seeing that your daughter or sister is anxious, you might want to help them recognize it, and maybe get some help.’ I like to have little lines that I use, and I hope the support person will remember it and keep it in their pocket in case it comes up later.”
- “Yes, especially in the case where we find mutations. Then we know the patient is going to need that extra support. I feel like we should have a debriefing for the support person, ‘This person is going to be lean on you, but if you need to lean on me too, call me.’ This is going to be hard on you, too.’ I think that’s a part of what we do.”

***Domain 2: Help patients utilize their support networks after the final***

***appointment (n=5)***. Several participants stated their role is to help the patient best utilize their support network, for instance, by encouraging the support person to collaborate with the patient to create a plan of action. Additionally, some commented that genetic counselors can be helpful by preparing both the patient and support person for the future (e.g., by providing examples of common reactions and information about the future of the test or disease). There are two categories.

*Category 1: Genetic counselors encourage support person to help the patient prepare for the future (n=3).*

- “You can say, “You’ve helped them to this point, you need to have this colonoscopy every year, can you help remind them of that or work[-out] together, we really need to get this person to exercise.’ What you have there is evidence of the support system in the appointment, so you are helping your patient to utilize that existing support person moving forward.”
- “I think yes, in the sense that we may have something to offer with that. By discussing things that may come up in the future, helping the support person [anticipate] what will come up in the future.

And encouraging conversation with the patient there might be helpful.”

*Category 2: Genetic counselors encourage the patient and support person to develop a “plan of action” (n=2).*

- “If you’ve got a plan of action after the appointment for the patient, and if it includes the support person [who is] helping them already in in the process, then it seems like that could be a person to help them as they move forward with the plan together.”
- “I never thought to do this. But, yes, I’d say, ‘Let’s make a plan for this patient. It will help her decide how to disseminate this information and you can follow-up with her and encourage her and help her to remember’.”

***Domain 3: It is not the role of the genetic counselor to help the support person continue their supportive role after the patient’s final appointment (n=2).*** Two participants expressed ambivalence about this issue, indicating that they had not thought about it prior to the interview. Additionally, both counselors commented they would not feel comfortable initiating this conversation because it might appear invasive.

*Category 1: Expressed ambivalence about fulfilling this role (n=2).*

- “I’m not sure how I feel that that. I am not sure if that is a part of our purview.”
- “I never really thought of this, especially because of it being genetics.”

*Category 2: Exploring the support person’s role after the final appointment seems invasive (n=2).*

- “I would have a hard time stopping at the end of the appointment and mentioning these things to the support person with the patient there - it might make the patient feel like they are a child, like ‘Why are you thinking I need all of this after I leave...?’”

- “Because it’s more about how the patients feel comfortable about this, and how they want to handle that. Once they’ve been in our offices they can sort of figure out how they feel comfortable going forward. Unless they ask for a suggestion, that is a different story. I haven’t had that happen.”

***Additional information provides by the participants***

Genetic counselors were asked if there is anything else that would be helpful for this investigator to be aware of regarding their perspectives on this topic. Four domains, respectively, pertain to their comments about cultural contributors to the processes involved with the support person, the value of including a support person in session, future research directions, and perspectives on genetic counselor training: Cultural considerations, Overall genetic counselors highly recommended inclusion of a support person, and Research recommendations. There are no separate categories for these domains.

***Domain 1: Cultural considerations (n=4).*** Some participants remarked about the way specific cultural identifiers impact the role of the support person in session.

- “There are cultural groups, for instance, the Hutterite group, similar to a Mennonite or Amish equivalent, a religious organization that they live in colonies, and it’s a very male predominant group. So, the men in the colony have decision-making power, and the women aren’t allowed to make decisions without a male - either their spouse or a father or a male leader within the group to make those decisions. So, that definitely can play into the session, that they are not there necessarily for emotional support but because they are considered to have the decision-making authority. The other group that I see is the Native American population, and they very much incorporate extended family in health care matters. So, they are likely to bring large, extended groups of relatives with them. I had a woman bring in three of her aunts with her - so it’s a very family-centered

population. And so the support people often will be present during the session; that can change the dynamics of the session.”

- “We are not terribly culturally diverse, a lot of our patients are white middle class. In this state, Native Americans often aren’t referred to us - about 5% of our state is Native American. We don’t tend to see a lot of smaller population isolates. I would say generally our group is fairly casual and some are fairly salt-of-the-earth kinds of people, moderately well educated. Certainly have people at both ends of the spectrum, too. It would be hard to categorize. Often they will feel comfortable pulling in other people as a support.”
- “There are some cultures where, for one thing, the patient is not expected to be the decision-maker, and they bring a support person that they want to make a decision for them, and I respect that.”

***Domain 2: Overall, genetic counselors highly recommended inclusion of a support person (n=3).*** Several participants used their final comment to emphasize the perceived value of the support person in the genetic counseling appointment.

- “Here [at my current job] the support people are just more supportive because maybe I am directing them to bring somebody.”
- “I’ve had a really nice experience overall [with support people]. Very few exceptions. I’ve had really nice interactions most of the time with the support people that are here.”
- “I would say that overall, from my experience at least, that having a support person has actually been a positive experience in that it has enhanced the session in a number of different ways and I think that this one of the reasons why we, to the extent that we can, always try to encourage the patients to bring somebody with them. Because we do go through a lot of information in a short time frame, especially patients who are recently diagnosed with cancer, and they are already overwhelmed with the other information that is being thrown at them. Having a second set of ears in the room, somebody who might ask questions that they themselves might not think of and can then reiterate the information or clarify it for them, if they have some



misconceptions because they couldn't hear it, I think that could be very beneficial.”

***Domain 3: Research recommendations (n=2).*** Two participants provided citations for articles that they felt would enhance the present study.

- “Remember to look at the citation of the study for breast-ovarian cancer- inviting a female relative to come and do a series of questions.”

***Domain 4: Perspectives on genetic counselor training (n=2).*** Two participants commented on perceived differences between the emphasis placed on psychosocial training in genetic counselor training programs now, compared with 10-15 years ago.

- “I think its [psychosocial training for current trainees] is lacking. I didn't do my graduate work in the same area. I'm fairly certain that my program still has a similar robust background but programs around here could use more training in Roger [Carl Rogers].”
- “Back in the day training was more heavily focused on psychosocial training- I didn't do the genetic counselor and counseling combo, but a lot of our training had some social work underpinnings.”

## Chapter 5: Discussion

Research has demonstrated that perceived support is a significant predictor of a patient's ability to psychologically adjust to information about risk, to make medical decisions, and to provide an accurate family history to providers (cf. Codori, Slavney, Young, Miglioretti, & Brand, 1997). Additionally, research in the broader medical community clearly links perceived support with positive health outcomes (e.g., Lakey & Orehek, 2011; Wethington & Kellser, 1986). Despite investigations that implicate the quality of support as a significant contributor to the genetic counseling process (e.g., Cohen & Wills, 1985; Turnber-Cobb, et al., 2000), to date, only one study (Williams, Schutte, Holkup, Evers, & Muilenburg, 2000) has specifically examined the role of the support person in the genetic counseling appointment.

The current study was designed to develop insight into the motivations, expectations, and decision-making processes of cancer genetic counseling patients' decision to bring a support person to their appointment. The purpose of the present study was to address three major research questions using qualitative interviews: (1) In what ways do genetic counselors involve the support person in the patient's genetic counseling appointment and process? (2) What variables do genetic counselors believe contribute to successful and unsuccessful support person performance? and, (3) In what ways can genetic counselors help patients construct the best psychosocial support within the context of the genetic counseling appointment and following termination of the genetic counseling relationship?

Study participants were 14 cancer genetic counselors who provide services for a variety of types of cancer, a condition that does not have complete penetrance, and therefore is likely to yield a broad spectrum of responses by genetic counseling patients. Each participant engaged in a single individual, semi-structured interview designed to elicit their perspectives on their approach to talking with patients about a support person, their impressions of their patients' decision-making process with regard to choosing a support person, specific clinical examples of successful and unsuccessful support person involvement, and their perceived obligations to the support person. In the following section, discussion of significant research findings is organized within the context of each of the three major research questions. Next, consistent with grounded theory, a theoretical model based on the qualitative responses is proposed. Finally, study strengths and limitations, practice implications, and research recommendations are provided.

### **Involvement of the Support Person in the Genetic Counseling Process**

Five interview questions assessed participant perceptions of the involvement of the support person in the genetic counseling process (see Appendix C). Responses to these questions indicate that genetic counselors are very open to the involvement of a support person in the session. At least half of all genetic counseling patients bring someone with them either for the first session or for follow-up sessions. The support person is mostly likely to be a female family member such as a mother, daughter or sister. This finding is consistent with previous research outlining common characteristics of individuals who comprise cancer genetic counseling patients' primary social support (Greene, 2009). Additionally, many genetic counselors indicated one's spouse is a

commonly chosen support person. A few counselors mentioned the inclusion of friends as support persons but noted that friends are less likely companions than family members.

The participants provided impressions of their patients' motivations for wanting a support person present in the session. They identified four major reasons. First, everyone expressed a belief that patients bring a support person as a source of information, primarily in the form of providing a family history (i.e., pedigree) or assisting with decision-making. Second, all of the participants indicated patients bring a support person to assist in collecting information. Third, several participants noted the support person may have a personal investment in the results; this may be because the results have direct implications for the support person's cancer risk and/or because the support person is directly impacted by the impaired health of the patient. Finally, several participants identified emotional support as a primary motivation for including a support person in the appointment.

In practice, the genetic counselors identified "active" and "passive" attempts to discuss with their patients the inclusion of a support person. Active recommendations included outlining potential benefits of a support person, such as serving as a second set of ears or helping to track information. Passive recommendations generally involved making a vague invitation to bring a support person. Several participants stated that it is logistically difficult to make a recommendation prior to the first appointment, while others stated they include this information in their literature or have their schedulers discuss the inclusion of a support person with new patients.

Findings further indicate the genetic counselors were more likely to recommend a support person if the patient is at 50/50 risk, the patient asks to bring a support person, the patient has high psychosocial needs, and/or the clinical presentation is particularly complex or severe. Most of the genetic counselors expressed that they do not discourage the inclusion of a support person unless that person is coercive, is likely to negatively impact the session, and/or is a poor candidate for the role (e.g., is a child).


Overall, these results suggest that there is little agreement about when and how genetic counselors provide a recommendation to bring a support person to a cancer genetic counseling session. Additionally, these findings indicate that, at times, genetic counselors only provide this recommendation if the patient asks for it or if the support person is being disruptive to the counseling process. Most genetic counselors provide a general invitation to bring somebody along, a result that is consistent with the brief review of genetic counseling websites (described in Chapter 2). Thus, these results suggest genetic counseling patients do not uniformly receive guidance about their choice of support person in cancer genetic counseling sessions, and the guidance that is provided tends to be generic as opposed to being tailored to a patient's needs.

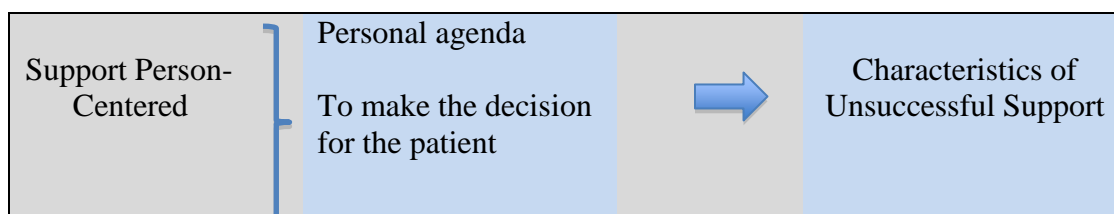
### **Variables Contributing to Successful and Unsuccessful Support Person Behavior**

This research question sought to determine factors that influence the extent to which support persons successfully provide support throughout the genetic counseling process. The present results indicate their success begins with the patient's choice of that individual. The majority of participants stated the primary variable contributing to a patient's decision of whom to choose is the patient's belief that the person will provide

the best relational and emotional support. This finding is consistent with Relational Regulation Theory (RRT) that asserts perceived support (e.g., the patient’s perception of the support) is more successful than enacted support (e.g., rote provisions of support that can be identified behaviorally) (Lahey & Orehek, 2011). In the case of genetic counseling, and illustrated in Table 3, findings indicate support can present itself in one of three ways: emotional support, informational support, and decision-making support. Consistent with RRT, successful support is likely perceived by the patient through one of these forms of support and is matches the needs of the patient. Contrarily, enacted support (e.g., providing rote or scripted support) is less likely to be successful when it does not match the person’s needs. Successful support is best characterized as “patient-centered” where the functions performed by the support person are driven by patient needs. Contrarily, unsuccessful support is best characterized as “support-person centered support” where the functions performed by the support person are driven by his or her needs and agendas.

Table 3. Patient-Centered Support vs. Support Person-Centered Support

Type of Support	Support Person Function		Outcome
Patient-Centered	Emotional support		Characteristics of Successful Support
	Information-based support		
	Decision-making support		



Participants were asked to identify characteristics they associate with an ideal support person. As shown in Table 4, the characteristics of an ideal support person closely resemble those of a genetic counselor. Indeed, one participant commented that an ideal support person functions as a “co-counselor” by facilitating decision-making, maintaining a patient-centered perspective, and providing emotional support. The fact that counselors value these characteristics in a support person strongly underscores the contributions support persons potentially make to the session. Additionally, this list might be useful for genetic counselors (or schedulers) to review with patients to help them make good decisions about choosing a support person.

Table 4. Characteristics of Successful Support, Unsuccessful Support and Ideal Support

	<b>Characteristics of Described Support Persons</b>	<b>Characteristics of Ideal Support Persons</b>
<b>Patient-Centered Support</b> <i>(Successful Support)</i>	<ul style="list-style-type: none"> <li>• Emotionally supportive</li> <li>• Shares experiences with cancer</li> <li>• Non-judgmental</li> <li>• Takes notes</li> <li>• Helps to make a decision</li> <li>• Provides information/family history</li> </ul>	<ul style="list-style-type: none"> <li>• A good listener</li> <li>• Empathic</li> <li>• Takes patient’s lead</li> <li>• Non-judgmental</li> <li>• Has a supportive attitude</li> <li>• Is securely, psychologically attached</li> <li>• Knows the patient well</li> <li>• Provides information about medical/family history</li> <li>• Takes notes</li> <li>• Advocates for the patient</li> </ul>

		<ul style="list-style-type: none"> <li>• Asks good questions</li> <li>• Can be objective</li> <li>• Helps the patient make decisions that are good for the patient</li> </ul>
<p><b>Support-Person Centered Support</b> <i>(Unsuccessful Support)</i></p>	<ul style="list-style-type: none"> <li>• Is coercive</li> <li>• Pressures the patient into a decision</li> <li>• Takes over the session</li> <li>• Is judgmental</li> <li>• Focuses session on self</li> <li>• Has a clear, personal agenda</li> <li>• Prioritizes personal emotional needs</li> </ul>	

Participants also identified characteristics of an unsuccessful support person, or someone whose focus during the session is self-focused. As shown in Table 4, these findings indicate support persons who present with a personal agenda and/or are highly invested in the results of the session may be limited in their ability to provide patient-centered support. The present findings indicate an unsuccessful support person often presents with good intentions for the patient, but frequently fails to recognize differing agendas exist between the two parties. Examples include mothers who are seeking genetic counseling for their children without their children's assent, spouses who pressure their partner to undergo testing, and support persons who are anxious or apprehensive about the results of testing. These findings are consistent with previous literature demonstrating anxious genetic counseling support persons were less able to provide effective support to patients at risk for Huntington's Disease (Williams et al., 2000).



Additionally, these findings are supported by research that outlines the negative impact of conflicted marital relationships on health outcomes (Kiecolt-Glaser & Newton, 2001).

The present results strongly suggest an ineffective support person is likely to be one who likely has a good-intentioned agenda for the patient, but for various reasons, their agenda does not match the needs and wishes of the patient. Additionally, consistent with the social undermining research conducted by Rock (1984), patients whose relationship with the support person is negative (e.g., coercive, tense, domineering) may have more severe reactions, proportionately, than their reactions to those support persons who are successful. Therefore, the relationship between the support person and patient may be a significant contributor to psychological well-being of the patient or the outcome of the appointment.

Results indicate the genetic counselors manage unsuccessful support persons in several ways. Mostly commonly, they seek to re-focus the session away from the support-person's needs and back to those of the patient. Many genetic counselors said they avoid directly intervening when a support persons' actions seem unhelpful because: they do not want to disrupt the dyad's relationship dynamic, they do not feel qualified to intervene, and/or they believe if the patient chose that particular support person, they did so for a reason. Finally, one genetic counselor reported welcoming conflict in the session because it expedites and deepens the counseling process; this counselor reported addressing the conflict directly.

The present sample of genetic counselors endorsed the value of a support person in the appointment. Additionally, they affirmed that unsuccessful support persons can be

damaging to the patient and can lead to unmet patient needs. However, when asked about their perceived role with regard to guiding patient choice of a support person, responses varied. While a minority of participants claimed to have this conversation as part of their typical practice, most said they either had not thought about it or they did not view it as their role to do so. These results stand at odds with the expressed value and importance the support person plays in patient outcomes, particularly with regard to patients who are at risk or present with complicated cases. Thus, the actual and the ideal support persons do not match. Genetic counselors might be able to increase the likelihood of patients bringing a support person who provides successful support by discussing the importance of fit and perceived support needs with their patients.

### **The Role of the Genetic Counselor in Facilitating Psychosocial Support within the Genetic Counseling Process**

This research question sought to elicit participants' perceptions about their role in facilitating patient psychosocial support within the counseling session. The findings indicate most participants feel that it is the role of a genetic counselor to talk with patients about choosing an appropriate support person. Some shared that a discussion about this topic is important, while others noted this topic should be covered in a brochure, intake paperwork, or over the phone while scheduling a cancer genetic counseling appointment. Though the participants endorsed this discussion as important and worthwhile, as previously discussed, most indicated they do not routinely talk with their patients about bringing a support person. Their explanations for why this is the case, included the practicality of having this discussion prior to the first appointment, feeling unqualified to

have this discussion, and/or believing the patient may not think this is an important discussion to have.

The genetic counselors were also asked if they consider it their role to provide guidance to the support person about their supportive role. Their responses were mixed; some stated this is an essential component of genetic counseling practice whereas others expressed surprise about this question, noting it is not their role. Interestingly, a possible cohort effect was observed in participants' responses. Participants who had more genetic counseling experience were more likely to affirm this practice as within the scope of their role, while counselors who had less experience commented that providing this type of guidance would be "stepping on boundaries," "not very culturally competent," or they had never thought to do this.

This possible generational difference may be a function of differences in genetic counselor training, perhaps graduates from the 1980's and 1990's were exposed to more psychosocial training than graduates within the last decade. This hypothesis was affirmed by two participants who stated that psychosocial training and Rogerian training is not as embedded in certain training programs as it was 15-20 years ago. Additionally, several participants noted that due to the advancement of science and technology in the field, there is less time for psychosocial conversations that emphasize considered decisions.

Counselors were also asked if they believe it falls within the scope of their practice to provide guidance to the support person as they prepare to continue their supportive role after the appointment. Findings indicate most participants were confident

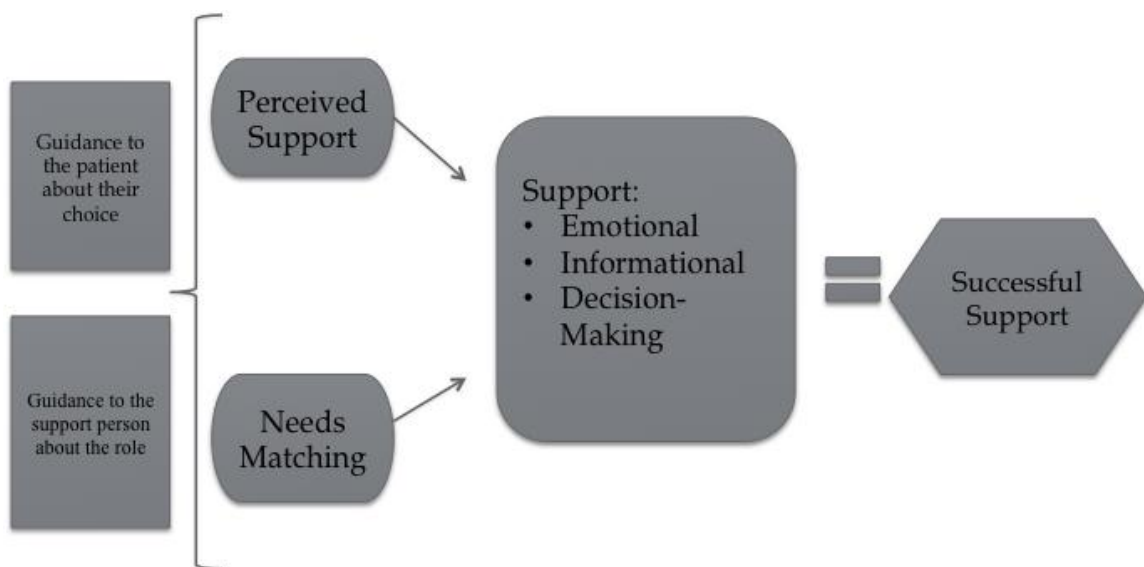
that it is their role to provide this type of guidance. Several others expressed enthusiasm for this question, stating that they had not thought to do this before, but would find it helpful. The participants recommended that genetic counselors can best prepare the support person for their continued role by encouraging the support person to provide emotional support, by encouraging the support person to help the patient to utilize their support networks, and by talking to support persons about self-care for care-givers. The majority of participants further noted this practice is particularly relevant to patients who present with 50/50 risk or have a complex condition. A handful of individuals said they either had never thought to do this, or they feel ambivalent about including the support person in this manner.

### **Core Theory: Goodness of Fit and Perceived Support**

The data were analyzed according to grounded theory methods proposed by Glaser (1978) and Strauss & Corbin (1990); these methods emphasize the generation of a core category that primarily motivates the data. This investigator established the core category, or theory, through data saturation, consultation between data analysts, and through relevance of the data to the research questions. The results of this data analysis are consistent with the main tenets of Relational Regulation Theory (Lakey & Orehek, 2011), specifically, social support appears to buffer against negative patient reactions, and, the specific mechanism through which that buffering occurs is perceived support. From the present findings it can be concluded that the support person achieves the most success when the following core conditions are met: 1) perceived as supportive, 2) matches the patient's needs, and 3) is emotion-based, information-based, focused on

decision-making, or a combination of the three (Figure 2). This theory argues that support persons function best when there exists a goodness of fit among the three core conditions. This core theory furthers that genetic counselors facilitate this process by: 1) providing guidance to the patient about their choice early in the genetic counseling process (i.e., prior to the first appointment or during the first appointment) and 2) providing guidance to the support person about their supportive role throughout the genetic counseling process.

Figure 2. Core Theory



### Study Strengths and Limitations

The results of the present study were strengthened by the quality of the recruited sample. The inclusion criteria for this study (Appendix B) stated that qualified genetic counselors must have amassed at least five years of professional practice within the field of genetic counseling. All of the participants met this criterion, where the least experienced genetic counselor had been in the field for seven years and the most

experienced genetic counselor had been in the field for 40 years. Half of the sample had at least 16 years of experience in the field of cancer genetics. Combined, the data collected in this study represent 232 years of experience in cancer genetic counseling practice and research. The participants' accumulated professional experience contributes to the validity of the qualitative results.

The current study is limited by a small sample size and qualitative nature (i.e. qualitative data are not intended to be generalized to the population of interest). As discussed in Chapter 3, the use of "shadowed data" suggests a larger sample size, perhaps between 20-30 participants. Because the data were shadowed, it is unclear whether data saturation occurred or if additional themes may have emerged with the addition of more interviewees. Additionally, this sample is not representative of culturally diverse populations as the interviewees were primarily Caucasian women. Despite the fact that the sample proportionately mirrors the demographics of the genetic counselor population, the inclusion of diverse genders and racial/ethnic identities may have led to richer, more complex themes. Participants for this study were volunteers, and thus it is unknown whether they differ in salient ways from cancer genetic counselors who did not volunteer.

Another limitation is that the study did not ask participants about the way culture mediates the relationship between the support person/patient dyad and the genetic counselor/counseling process. Also, the interview questionnaire did not collect data about which sessions patients tend to bring support persons to. However, the genetic counselors referenced all contact with patients, including the first session, pre-session phone calls, follow-up sessions, and results sessions (both in person and on the phone) in their

responses. Future studies would benefit from specifically making this distinction.

Finally, the study was limited to the use of support persons in cancer genetic counseling.

It is unclear whether the findings would be similar for other types of genetic counseling specialties.

### **Implications for Practice**

The third research question in the present study concerns ways in which cancer genetic counselors can help patients construct the best psychosocial support within the context of the genetic counseling appointment and following termination of the genetic counseling relationship. Data from this study suggest that genetic counselors can most effectively encourage a successful support person outcome by walking the patient through three considerations. First, they can provide psychoeducation about the role of a support person (i.e., emotional support, informational support, and decision-making support). Next, genetic counselors can discuss characteristics of support persons that can lead to helpful and unhelpful outcomes (Table 3). Finally, genetic counselors can emphasize the importance of matched agendas and needs. These recommendations are consistent with a recently proposed model of genetic counseling practice, the Reciprocal Engagement Model (REM; McCarthy Veach, Bartels & Leroy, 2007). The REM emphasizes a practice strongly rooted in a biopsychosocial patient perspective. Overall, the cancer genetic counselor can facilitate a good Patient X Support person fit by addressing these three considerations.

Results indicate that many patients have not fully considered the implications of choosing one support person instead of another, or of choosing no support person at all.

The participants agreed that a part of the role of a genetic counselor is to “see further” than the patient with regard to the contributions a support person can make to the session. Because patients may not be able to anticipate their needs with regard to support, it is recommended that genetic counselors routinely encourage patients to invite a support person to the appointment. As the present results indicate a support person has the potential to contribute substantially throughout the counseling process (and beyond), counselors might suggest the support person attend both an initial appointment as well as follow-up appointments. Several participants identified their schedulers as possible sources of support with regard to this type of invitation; therefore, it is recommended that an initial suggestion to bring a support person be included in intake paperwork, over the phone with a scheduler, and/or on the clinic website. Genetic counselors would be ideally situated to provide training to scheduler in how best to provide this invitation.

Participants in this study also discussed their experiences with negative or unsuccessful support persons. Results indicate that these experiences are rare, but they severely impact a patient’s experience when they do occur. The majority of counselors stated they intervene when they perceive that a support person is negatively impacting a session. First and foremost, counselors should be aware the best way to prevent this type of experience is by educating patients about their decision to include a support person. A handful of counselors in this study articulated that education both empowers the patient and allows the counselor to provide the highest quality of care possible. Additional interventions include dismissing the support person from the session by asking for time alone with the patient, re-directing the support person back to the patient’s needs, and



talking with the patient about their option to choose a different support person (e.g., for future appointments). One participant recommended Angel Care (Angel Care Foundation) for cancer patients who may not have reliable supports in their lives. Overall, the majority of genetic counselors expressed the belief that managing negative dynamics within the session falls squarely within the role of a genetic counselor.

### **Research Recommendations**

The present study, despite its limitations, provides initial empirical evidence of a clear link between support person behavior and the quality and outcome of the session, based on cancer genetic counselors' perceptions. Future researchers should conduct quantitative studies with patient samples to examine the interaction between social support and patient psychological well-being. The results of such research would provide important information regarding the impact of a support person on a patient's decision-making process and their overall psychological well-being. If psychological well-being impacts decision-making abilities, then this would be an important and relevant component of a genetic counseling session.

The present participants varied with respect to routinely engaging patients in conversations about bringing a support person to appointments. Research could be done to assess the effects of the presence or absence of such conversations on genetic counseling processes and outcomes (e.g., differences in the number of patients who bring a support person, patient satisfaction, decision outcomes, etc.). The counselors identified a number of strategies for managing negative or unsuccessful support person behaviors. Studies of actual genetic counseling sessions would help to validate these suggestions.

Additionally, several participants expressed concern about their ability to involve a support person when, increasingly, many test disclosures occur via telephone (Bradbury et al., 2010). Investigations comparing the impact of telephone disclosures on the psychological well-being of the patient and the patient's family system versus in-person disclosures, with and without the presence of a support person, are warranted.

Multiple participants addressed the role of culture as a variable that moderates the relationship between the support person/patient dyad and the genetic counselor.

Participants identified a number of cultural factors that may impact a patient, a support person, and/or or a session, including: support persons from communities with strict gender roles, (e.g., Hutterites), racial/ethnic communities that are more collectivistic and will receive and disclose information with larger numbers of people, and communities that de-emphasize the expression of affect (e.g., Scandinavian families). Additional research is needed to highlight the way culture contributes to the role of the support person in the genetic counseling session and process. Finally, studies should be done to compare and contrast the role of the support person in different genetic counseling specialties. This research should assess the perspectives of the patient and the support person as well as the genetic counselor.

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## Appendix A: IRB Approval Letter

### UNIVERSITY OF MINNESOTA

*Twin Cities Campus*

*Human Research Protection Program  
Office of the Vice President for Research*

*D528 Mayo Memorial Building  
420 Delaware Street S.E.  
MMC 820  
Minneapolis, MN 55455  
Office: 612-626-5654  
Fax: 612-626-6061  
E-mail: [irb@umn.edu](mailto:irb@umn.edu) or [ibc@umn.edu](mailto:ibc@umn.edu)  
Website: <http://research.umn.edu/subjects/>*

07/09/2013

Ruth M Swartwood Univ Counseling/Consultin Room 130 CofH 1420 Eckles Ave St Paul, MN 55108

RE: "Who should I bring? A qualitative exploration of the choice to bring a support person to the genetic counseling appointment" IRB Code Number: **1306P37041**

Dear Dr. Swartwood:

The referenced study was reviewed by expedited review procedures and approved on July 8, 2013. If you have applied for a grant, this date is required for certification purposes as well as the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA 00004003). Approval for the study will expire one year from that date. A report form will be sent out two months before the expiration date.

Institutional Review Board (IRB) approval of this study includes the consent letter received June 25, 2013.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 20 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

The code 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.

As the Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received. Unanticipated problems and adverse events should be reported to the IRB as they occur. Research projects are subject to continuing review and renewal. If you have any questions, call the

IRB office at 612-626-5654.

On behalf of the IRB, I wish you success with your research. Sincerely,

Christina Dobrovolny, CIP Research Compliance Supervisor CD/ks

CC: Mary Ahrens, Bonnie LeRoy, Melissa Truelson, Patricia Veach

A handwritten signature in black ink, appearing to read 'CD/ks', located below the typed name.

## Appendix B: Study Invitation

**University of Minnesota**  
Twin Cities Campus  
203-4317

*Ruth Swartwood, MA, ABD*  
*Study phone: 612-*

Dear Genetic Counselor:

My name is Ruth Swartwood and I am a doctoral candidate in Counseling and Student Personnel Psychology (CSPP) in the Department of Educational Psychology at the University of Minnesota, Twin Cities Campus. I am requesting your participation in this study because you have developed an expertise in the area of genetic counseling for cancer patients, have worked 5 or more years in this specialty, are currently working directly with cancer patients (at least part-time), and are not employed in a commercial setting. The purpose of the study is to explore the nature of the support person chosen by the genetic counseling patient from the perspective of the genetic counselor. In particular, this study aims to develop insight into the extent to which you value the presence of a support person, the cases for which you value the presence of a support person, and the variables that you believe are responsible for making that a positive or negative experience for the patient. In this interview, I will ask you to share examples from your years of practice.

This research is the basis of my doctoral dissertation. This study will be directly supervised by Patricia McCarthy Veach, PhD, Licensed Psychologist, Professor in the Department of Educational Psychology at the University of Minnesota, and Affiliated Faculty for the Genetic Counseling graduate program at the University of Minnesota.

### **Background Information**

Receiving information about genetic risk can be an emotional experience. Genetic counselors sometimes encourage patients to bring a support person with them to their appointments, but the role that person plays in the counseling session is unclear. Additionally, the extent to which the support person actually helps a patient is unclear. The purpose of this study is to gain insight into the process of involving a support person in genetic counseling, and then document that information for the benefit of the broader genetic counseling community.

### **Procedures**

Participation in this study will involve one 20-30-minute phone interview that will be scheduled at your convenience via email. These interviews will take place during the summer and fall of 2013.

*You qualify for this interview if:*

1. You have received an email invitation directly from [stens094@umn.edu](mailto:stens094@umn.edu) addressed to you.
2. You have at least five years of experience working in this specialty
3. You specialize in cancer genetics and are currently seeing clients, at least part-time
4. You do not work in a commercial setting.

### **Risks and Benefits of the Study**

If you choose to enroll in this study, the risks to you are minimal. Some participants may feel discomfort when sharing emotions, experiences, or concerns about their professional practice. Though there are no direct benefits to you, some participants may value this as an opportunity for reflection on professional issues, your case history, or other professional topics.

### **Confidentiality**

The information you provide for this study, including your personal information, patient information and contact information, is confidential. Any information you share about patients will be de-identified. The results of this study may be published in a professional journal. All information linking your identity to your responses will be destroyed rendering your responses completely anonymous. Research data will be stored on an encrypted USB drive that will be used only on password-protected computers updated with the most recent security software. All irrelevant information that is not used for the study will be deleted.

### **Voluntary Nature of the Study**

Your participation in this study is entirely voluntary. If at any time you choose to withdraw from this study, you are free to do so without and questions asked.

### **Contacts and Questions**

If you have questions or concerns of any nature, you are encouraged to contact me, Ruth Swartwood, the primary investigator, (612-203-4317 or [stens094@umn.edu](mailto:stens094@umn.edu)) or Patricia McCarthy Veach, my faculty advisor and supervisor of this project (612-624-3580 or [veach001@umn.edu](mailto:veach001@umn.edu)). If you feel that you need to address a question or concern with a University representative outside of our research team, you are encouraged to contact the Research Subjects' Advocate Line at 612-625-1650. The mailing address for the Advocate Line is D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota, 55455.

Thank you for your time and consideration. We look forward to the opportunity to talk with you.

Best regards,



Ruth Swartwood, M.A., ABD  
Counseling and Student Personnel Psychology (CSPP)  
University of Minnesota, Twin Cities

## **Appendix C: Interview Protocol**

### **Interview with Genetic Counselors: Protocol**

#### **Approach to Talking with Patients about Support**

1. Do your patients tend to bring support persons to their genetic counseling appointment? (Prompt: About what percentage of your patients bring a support person?) Do they bring them to the first session? The test results session?
2. Why do you think patients bring a support person?
3. Do you talk with patients about bringing a support person to their appointment (their initial appointment, results appointment, or both). Can you say more about why you do/do not talk about it?
4. If you do discuss this, tell me about how you typically approach your patients about bringing a support person (Prompt: What do you say?).
5. Are there cases where you would encourage the use of a support person more so than others (if so, describe)? Are there cases where you would discourage the use of a support person....?

#### **Impressions about Patients' Decision-Making Process**

6. From your experience, how do patients choose whom they will bring to the appointment? (Prompts: Relationship to patient such as a relative? Characteristics of the person? Pragmatic reasons such as they are the only one available?, Extent to which the person is knowledgeable about the patient's appointment and/or the nature of genetic counseling)

#### **Examples from practice: Positive**

7. In what ways does bringing a support person benefit patients? (Prompt: What are the advantages, if any, of bringing a support person...)
8. Can you provide an example(s) of a case where the inclusion of a support person seemed beneficial to the patient?

#### **Examples from practice: Negative**

9. In what ways does bringing a support person adversely affect patients? (Prompt: What are the disadvantages, if any, of bringing a support person...)

10. Can you provide an example(s) of a case where the inclusion of a support person seemed detrimental to the patient?

### **Looking Forward**

11. How would you describe an “ideal” support person? (Prompts: relationship to patient, characteristics, pragmatic factors, knowledgeable about the patient’s appointment and/or the nature of genetic counseling)

12. How might genetic counselors provide guidance to patients about making their choice of a support person?

13. How might genetic counselors provide guidance to the support person about their supportive role during the genetic counseling appointment?

14. How might genetic counselors help the support person prepare to continue their supportive role after the patient’s appointment?

### **Conclusion**

15. Is there anything else that you would like to share?

### Appendix D: Email to Genetic Counselors

Greetings from the University of Minnesota:

You have been purposefully selected for a research study based on the following criteria:

- Your current work with cancer genetic counseling patients
- Your longevity and expertise in cancer genetic counseling
- Your employment in practice and/or research, not in a commercial setting

The purpose of this study is to use qualitative methods to investigate the role and obligations of the genetic counselor to the support person brought to session with the patient, to better understand the variables that GCs believe contribute to successful and unsuccessful involvement of a support person, and to determine if the GC can influence positive outcomes with regard to involving a support person in the appointment. A summary of the study can be found in the attached study invitation.

Participation in the study would entail a one-time, 1/2 hour interview with the primary investigator over the phone. Interview questions will be sent to you prior to the phone call.

I appreciate your time and look forward to incorporating your thoughts and feedback into this study.

Please see attached study invitation for further information. If you are able to participate in this study, please respond to this email address and we can work together to find a time that is convenient for you (weekdays, evening and weekends are all viable options).

With appreciation,

-Ruth Swartwood