Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors

By

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ABSTRACT

Background: A positive BRCA1/2 carrier status impacts an individual on various levels with implications to an entire family due to shared family genes. A gap exists in the research literature in the area of parental disclosure and non-disclosure of genetic test results to younger offspring. Additional studies in the area of parental disclosure and non-disclosure will help clinicians to better support parents and children during this process.

Purpose: The purpose of this qualitative hermeneutic phenomenological research study was to attain an understanding of the lived experience of parents' perceptions regarding the disclosure and non-disclosure of a positive BRCA1/2 test result to minors.

Results: The essence of the lived experience of the 15 study participants was a parental desire for healthcare professionals to take the BRCA1/2 conversation a step further which was uncovered in the seven research themes.

Discussion: For the study participants interviewed, stories reflected an identified need for axillary support that specifically pertained to the disclosure and non-disclosure decision-making process. Findings suggest ways in which parental support may be coordinated though intra and interdisciplinary team approaches to patient care.

Implications: The findings from this study support the need for mixed methods studies of parental disclosure and non-disclosure of BRCA1/2 test results to minors. Specifically, studies assessing positive BRCA1/2 males and individuals from our gay community, members from our lower socioeconomic and diverse ethnic community, and fathers and children's perceptions regarding the disclosure of parental BRCA1/2 test results to minors are warranted.

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This thesis is dedicated to my grandparents (Winnifred A. Ramsay, Bridgelal Singh-Osman, Agnes Marion Jordon-Boodhoo Seenandan, and Manus Seenandan), and to my parents (Ingrid M. Seenandan and Henry F. Langford). Additionally, it is dedicated to my husband (Tulsie Sookdeo), children (Kyra A. M. Dookheran, Salina A. M. Dookheran, Alyssa Sookdeo, and Nathan Sookdeo), brother (Keiron A. V. Seenandan), and sister-in-law (Suzanne S. Seenandan). Furthermore, this thesis is dedicated to our first grandchild, our grandson (Kale H. W. Tindall).

Chapter I

Introduction

In Canada approximately 23, 800 breast cancers are diagnosed each year while ovarian cancer affects about 2, 600 individuals (Canadian Cancer Society, 2013). The 2011 Manitoba statistics estimates 820 breast cancer diagnoses and 100 ovarian cancers (Canadian Cancer Society, 2013). Nearly 5-10% of these two groups are regarded as high risk for a hereditary breast-ovarian (HBO) cancer (Carroll et al., 2008). Consequently, Winnipeg Regional Health Authority (WRHA) offers genetic services to high risk Manitobans since BRCA1/2 mutations place people at an increased risk for breast, ovarian, and other cancers (Bellosillo et al, 2006, p.230; de Carvdho, et al., 2003, p.426; Seenandan-Sookdeo & Sawatzky, 2010, p.109). A positive BRCA1/2 carrier status impacts an individual physically, psychologically, and socially with implications to an entire family due to shared family genes. The person who initiates genetic testing is further tasked with the responsibility to share the test result with core and extended family members. This places an extra burden on these individuals during a time when other personal health decisions are paramount. To assist this patient population oncology nurses must be knowledgeable regarding the biology of genetics, educated about oncology history assessments, and informed about the impact of genetic testing on individuals and families. A solid foundation in these aspects of genetics provides a clinician with a holistic perspective in her or his care delivery.

Statement of the Problem

A review of the HBO literature revealed numerous quantitative studies that assessed the psychological impact and barriers of genetic testing with female participants

(Braithwaite, Emery, Walter, Prevost, & Sutton, 2006; Croster & Boehmke, 2009; Hamilton, Lobel, & Moyer, 2009; Meiser & Halliday, 2002; Pasacreta, 2003; Schlich-Bakker, ten Kroode, & Ausems, 2006). Furthermore, communication of test results to sisters has been extensively researched (Green, Richards, Murton, Statham, & Hallowell, 1997; Howard, Balneaves, & Bottorff, 2009; Hughes, Lerman, Schwartx, Peshkin, Wenzel, et al. 2002; McGivern, Everett, Yager, Baumiller, Hafertepen et al., 2004; McInerney-Leo, Biesecker, Hadley, Kase, Giambarresi, et al., 2005). However, a gap exists in the exploration of the needs of male HBO mutation carriers (Finlay, Stopfer, Burlingame, Evans, Nathanson, et al., 2007; Hallowell, Arden-Joanes, Eeles, Foster, Lucassen, et al., 2006; Lodder, Frets, Trijsburg, Tibben, Meijers-Heijboer, et al., 2001) along with the need for auxiliary studies in the area of parental disclosure and non-disclosure of genetic test results to younger offspring (Clarke, Butler, & Esplen, 2008; Peshkin, DeMarco, Tercyak, 2010). Additional studies in the area of parental disclosure and non-disclosure will help clinicians to better support parents and children during this process. Therefore, a hermeneutic phenomenological theoretical perspective that applies semi-structured interviews was used to capture parental perceptions for this qualitative research project. Women and men who are BRCA1/2 mutation carriers were asked to explore their communication or non-communication of test results to their offspring, information and support seeking needs, decision-making strategies, and personal experiences involving their interactions. The study involved the recollection of HBO communications and support needs after receiving positive BRCA1/2 test result between the years of 2008 and 2012.

Purpose of the Study

The main purpose of the research project was to explore BRCA1/2 carriers' parental perceptions regarding the disclosure, or non-disclosure process of test results to minors.

Goal of the Study

The specific goal of the study was to provide a rich understanding of BRCA1/2 carriers' perceptions regarding the parent-child communications about BRCA1/2 test results to minors, parental information and support seeking needs, decision-making, and personal experiences regarding parent-child interactions. Furthermore, a second goal of the study was to ignite interest and future BRCA1/2 research studies in the province of Manitoba for the purpose of implementation of clinical practice changes based on study recommendations. Future qualitative, mixed methods, and quantitative methodology studies may evolve; in addition, to studies that directly assess children's perceptions regarding the disclosure of parental BRCA1/2 test results.

Research Questions

The primary research question framing the study is, "What are Manitobans' parental perceptions regarding the disclosure and non-disclosure of a positive BRCA1/2 carrier status to offspring who (at the time of disclosure) are between the ages of 6 and l9?" The following questions helped to answer the overarching research question:

1. What parental decisions are involved in the process of disclosure and non-disclosure?
2. Why do parents disclose, or choose not to disclose BRCA1/2 test results to minors?
3. What do parents disclose to younger offspring?
4. How do the children react and respond to the disclosure?

5. How do parents feel after disclosing (or not disclosing) a BRCA1/2 test result to minors?

6. What supports were provided to prepare parents for disclosure or non-disclosure and / or what was required to better prepare and support parents during this process?

7. What recommendations do parents have for healthcare providers regarding BRCA1/2 parent-child communication process?

8. What recommendations do parents have for other BRCA1/2 parents regarding the decision-making process?

Chapter Summary

Chapter one provided a brief introduction to HBO cancer along with the rationale for the purpose of this thesis based research project. There is very little published on the parental disclosure and non-disclosure process of HBO test results to younger offspring. An extensive comprehension of parents' choice to disclose or not disclose will benefit nurses and other healthcare clinicians. An understanding of this process will help clinicians to prepare, support, and assist parents, as required, with their decisions to share or to not share genetic test results to minors.

Chapter II

Literature Review

Hereditary Breast and Ovarian Cancer

The understanding of hereditary breast and ovarian cancer (HBOC) dates back to 19th century monk and science teacher, Gregor J. Mendel (1822 to 1884). Chapman (2007) reported that to advance human genetics, Mendel developed a framework that describes how characteristics from a parent organism are passed onto an offspring. These discoveries were based on his research with pea plants, which lead to Mendel's Principles of Hereditary (MPH) that eventually assisted other researchers in the identification of ribose and deoxyribose nucleic acids (RNA and DNA respectively). In 1953, Francis Crick and James Watson proposed the double helix structure and base pairing of DNA (Chapman, 2007). In 1980, Botstein and colleagues used the MPH and the knowledge of DNA structure and function to create a map of the human genome. Chapman (2007) highlights that in the 20th century, the Human Genome Project was launched as an international collaborative initiative, sponsored by the Department of Energy and National Institutes of Health and managed by the National Center for Human Genetics, within the National Institutes of Health with a primary goal of identifying the 30,000 to 40,000 coding genes in the human genome (International Human Genome Sequencing Consortium - IHGAC, 2001).

In 1990 and 1994 respectively, basic research scientist Mary-Clair King discovered the BRCA1 gene, and Michael Stratton and his colleagues discovered the BRCA2 gene which were both cloned by Myriad Genetics (Haites & Gregory, 2002; Narod, & Foulkes, 2004). For oncology nurses, the discovery of these two genes opened

Pandora's box since they are challenged to be knowledgeable in the area of genetics in order to assist individuals and families regarding complex needs arising from the impact of genetic and genomic information. The Human Response to Illness (HRTI) model was used as a framework in this literature review in order to provide a comprehensive understanding of HBOC. Oncology nurses can translate the knowledge acquired from this evidence based review to clinical practice as it provides holistic care to individuals and families facing an actual or potential risk for HBOC. The use of the HRTI Model provided a detailed exploration of HBOC as it revealed future nursing research initiatives.

Incidence and Prevalence

Globally, cancer rates are increasing, and as a nation, Canada is experiencing a similar trend. The Canadian Cancer Society estimated that 187,600 new cancer cases (excluding non-melanoma skin cancers) would be diagnosed in 2013 resulting in 75,500 deaths. Approximately 40% of Canadian females and 45% Canadian males will develop a cancer during their lifetime. Specifically, Canadian breast cancer incidence rates are projected to be 23, 800 which accounts for approximately 23,600 females and about 200 males. The total death rate related to breast cancer is expected to be 5,000 females and 60 males. Furthermore, 2,600 ovarian cancer cases are predicted which accounts for 1,700 female deaths (Canadian Cancer Society, 2013).

The majority of breast and ovarian cancers (70%) are sporadic (de Carvalho, Jenkins, Nehrebeky, & Lahl, L., 2003; Zawacki & Phillips, 2002) with approximately 15-20% categorized as familial, and linked to low penetrance genes such as p53, RAD51 and CHEK2 (Bellosillo & Tusquetes, 2005; Zawacki et al., 2002). The remaining 5 to 10% of

cancers are attributed to a hereditary predisposition to high penetrance BRCA1/2 genes (Carter, 2011; Haites et al., 2002; Narod et al., 2004; Whtiesell, 2006). A mutation in either of these genes places both female and male offspring at an increased risk for breast, ovarian / prostate and other cancers. Thus, genetic testing for HBOC is a family affair as it holds implications for future generations.

Approximately 3-7% of high-risk individuals will have a positive BRCA1/2 gene mutation (Bellosillo & Tusquetes, 2006). According to Chen and Parmigiani's (2007) meta-analysis, a mean cumulative female cancer risk to the age of 70 for breast cancer is 57% (95% confidence interval, 47%-66%) for BRCA1, and 49% (95% confidence interval, 40%-57%) for BRCA2. An ovarian cancer risk is correlated to 40% (95% confidence interval, 35%-46%) for BRCA1 and 18% (95% CI, 13-23%) for BRCA2. In men, the risk for a breast cancer to the age of 70 for a BRCA1 carrier is 1%, BRCA2 carrier is 6%, and for prostate cancer is 6 to 14% (Hallowell, et al., 2006). Moreover, a deleterious BRCA1/2 mutation status confers an increased risk for a number of other cancers for both genders (Bellosillo et al, 2006; de Carvdho, et al., 2003; Seenandan-Sookdeo et al., 2010). As a result of the autosomal dominant patterns of inheritance of BRCA1/2 genes, offspring of carriers may be at a risk for similar parental cancers. Therefore, the decision to proceed or decline genetic testing needs to be understood from a holistic perspective as it impacts on the health care needs of future generations.

Conceptual Framework: Human Response to Illness

The Human Response to Illness (HTRI) Model developed by Mitchell, Gallucci, and Fought (1991) is the conceptual framework used to organize an evidence-based literature review in the area of HBOC and to guide this thesis project. The model framed

the literature review as it illustrates how physiologic, pathophysiologic, behavioral, and experiential perspectives affect human responses to health, and to a potential or actual compromise in human health status. The experiential perspective of the HRTI model guided the research study was the research question was formulated from this perspective. Additionally, the holistic nature of the model was taken into consideration during all phases of the research project. Humans' response to health and illness, whether potential or actual are influenced by relationships between ones' internal and external environments. Hence, in order to truly understand an individual's lived experience, one needs to appreciate concepts from all four perspectives of the model. The philosophical underpinning of the study, hermeneutics phenomenology also supports the concept that an individuals' lived experience is influenced by internal and external factors such as social and cultural influences which is in keeping with the HRTI model.

The HRTI model was used to guide the literature review as it takes a holistic approach to health and illness by considering the biomedical, biopsychosocial, and environmental aspects in the human response to an actual or potential illness. An examination of these perspectives provides a holistic insight into disease processes, and how they may affect individuals and families. This framework is ideal for the examination of a potential disease entity that impacts generations of families since it can provide an extensive examination of the potential for HBOC. This literature review is used to discuss current HBOC issues in the areas of nursing practice, education, and research. The information gleaned from the literature review is a comprehensive knowledge base for oncology nurses to use in professional and patient education, genetic history assessments, identification, referrals, and supportive care of individuals and

families.

Physiologic Perspective

Mitchell et al. (1991) stated that an understanding of the physiologic perspective begins with knowledge of the normative biological functions of the human system. The body's response to cancer is grounded in a basic fact that cancer is a genetic disease. Therefore, knowledge in HBOC commences with an understanding of chromosomes, deoxyribose nucleic acid (DNA), and genes. It also includes the fundamental principles in the stages of a cell cycle, and the role of the BRCA1/2 genes in the cell cycle.

Chromosomes. In the nucleus of most cells, chromosomes are threadlike structures that contain genes which are coiled units of DNA, and histone protein (Beery, 2008; McCance & Huether, 2006; Winkelmen, 2004). Histones are responsible for nucleic activity (McCance, 2006; Winkelmen, 2004). Loescher et al. (2006) and McCance et al. (2006) acknowledge the human genome usually consists of 46 chromosomes which is contained in 22 paired chromosome and a pair of sex chromosomes (XX for females and XY for males). The germ cells (ova or sperm) contain only half the number of chromosomes, and some liver cells contain four times the normal chromosome number (Winkelman, 2004). One chromosome of each pair is contributed from the maternal and paternal lineage; hence, an offspring inherits half of his or her chromosomes from the mother and half from the father. Scientific evidence supported the DNA genotype of siblings is 50% shared whereas grandparent and grandchildren share about 25% (Beery, 2008). Each somatic (body) cell carries an entire copy of the human genome with the exception of sex chromosomes and some cells in the liver (Winkelman, 2004).

Chromosomes are held together by a centromere which divides chromosomes into two arms; a short arm denoted as p and a long arm denoted as q. The ends of the chromosomes, known as telomeres are involved in replication and structural stability (McCance & Huether, 2006). Distinct banding patterns identify specific regions on each chromosome. For example, regions are documented on the BRCA1/2 genes recognized to be involved in HBOC susceptibility. BRCA1 is linked to chromosome 17q21, or band 21 on the long arm of chromosome 17; whereas, BRCA2 is located on chromosome 13q12.3 (King, Rowell, Love, 1975; Yoshida & Miki, 2004; Zawacki et al., 2002). This knowledge contributed to our basic science understanding of the familial aspects of HBOC and the importance of genetic testing for the identification of potential risk factors.

DNA: Collins and McKusick (2001) stated from a genetic viewpoint that humans are 99.9% identical based on a DNA blueprint and 0.1% DNA variation holds the answers to genetic diseases. Within the nucleus (and mitochondria) of each cell are chromosomes where DNA is found and directs protein synthesis in the body (Winkelman, 2006; McCance et al., 2006). Chromosomes contain compact functional units of inheritance known as genes, these are composed of sequences of DNA which are molecular structures formed from two stands composed of sugar, deoxyribose, and phosphate molecules twisted together with base pair combinations of nitrogen bonds between the double helix strands (Loescher et al., 2003; McCance et al., 2006). Four nitrogen bases are linked together by weak nitrogen bonds, where cytosine bonds with guanine and adenine with thymine (denoted as C, G, A, T) (McCance et al., 2006; Evans, Skrzynia, Susswein & Harlan, 2006). Winkelman (2004) and Berry (2008) noted more

than three billon nitrogen base pairs make up the human genome. Consequently, opportunities for errors in protein synthesis exist, supporting the potential for genetic risk associated with many disease entities.

Genes. The IHGSC (2001) identified about 30,000 to 40,000 protein coding genes in the human genome. Lister Hill National Centre for Biomedical Communications, U.S. National Library of Medicine, National Institutes of Health, Department of Health and Human Services (LUND, 2011) summarized the steps involved in the process of genes making proteins which involve phases known as transcription and translation. Genes made of DNA are the working segments of inherited information that controls growth, development, and function of cellular activity. DNA stores genetic information that directs the synthesis of proteins which are made up of sequences of long chains of amino acids. During transcription, DNA accurately replicates itself using several different types of proteins, such as enzymes, messenger, and transport proteins. Weak hydrogen bonds between nitrogen base pairs are broken as ribonucleic acid (RNA) polymerases moves along the single strand DNA adding the correct complementary nitrogen base pairs (Beery, 2008; Loescher et al., 2003; McCance et al., 2006). The RNA polymerase also participates in point checks, and repairs any mistakes (LUND, 2011; McCance et al., 2006).

According to McCance et al. (2006) and LUND (2011) the DNA code is copied into a messenger RNA (mRNA) which moves from the nucleus to the cytoplasm where protein synthesis occurs which involves translation. Translation begins when ribosome attaches to the beginning of the mRNA molecule; consequently, transfer RNA brings the amino acid which corresponds to the triple code in the mRNA. Once the protein is

translated the protein can then perform its designated function (Loescher et al., 2003, LUND, 201, McCane et al., 2006).

Stages of the Cell Cycle: The preservation of the human genome is dependent on the normal function of the cell cycle. Somatic cells (body cells) are involved in a cell division process known as mitosis. The complex stages in the cell cycle consist of the resting phase (G1), DNA synthesis (S), pre-mitotic phase (G2), and mitosis (M) (Schafer, 1998). McCance et al. (2006) acknowledge that at the end of the normal cell cycle, cells duplicate genetic material and form two new cells. G1 mechanisms are activated to ensure readiness for DNA synthesis which is completed in the S phase of the cell cycle. Cell growth is preceded in G2 by protein production checkpoints ensuring the accuracy of DNA replication. All cell growth ceases in mitosis where the cells energy is directed towards the chromosome alignment which is followed by a sequence of cell division events that produces two identical daughter cells. Checkpoints are innate in the phase of mitosis ensuring the cell is prepared for complete cellular division (McCance et al., 2006).

A review of the literature verified meiosis is a type of cell division that occurs in reproductive cells called gametes (sperm and ova cells). Gametes consist of haploid cells as they contain one member of each human chromosome pair. In meiosis, the sharing of genetic information called crossing over occurs with an end product of four gametes, each containing twenty-three chromosomes. After fertilization, a new cell with 46 chromosomes is produced which contains shared genetic information from maternal and paternal lineages. HBOC follows a Mendelian autosomal dominant pattern of inheritance with incomplete penetrance, whereas offspring (female and male) have a 50% chance of

inheriting a mutated gene (King et al., 1975; McCance, 2006; Chapman, 2007; Kelly, 2007; Narod et al., 2004; Yoshida & Miki, 2004). In summary, the basic concepts of chromosomes, DNA, genes, and the stages of mitosis and meiosis are critical for clinical nurses to understand in order to facilitate individual – family centred health education related to inheritance.

Role of BRCA1/2 genes. Two categories of genes that play pivotal roles in cellular control include proto-oncogenes and tumour suppressor genes. Proto-oncogenes are involved in cell cycle pathways that promote cell proliferation (Loescher, et al., 2003). In contrast, tumour suppressor genes regulate cellular activity by sending out 'stop' signals to enable damaged cells to be repaired; in addition, they control signals for cell apoptosis 'cell death' (Zawacki &Phillips, 2002). The BRCA1/2 genes are examples of tumour suppressor genes. The BRCA1/2 genes are linked to a variety of cellular functions; consequently, the context of this discussion will examine the role of BRCA1/2 genes in the cell cycle.

BRCA1/2 genes support the physiology of a number of cellular processes including, but not limited to, homologous recombination, non-homologous end joining, ubiquitination, chromatin remodeling, cell cycle checkpoints, and transcription. Furthermore, these genes are involved in apoptosis, DNA replication, and the maintenance of genomic integrity (Powell & Kachinc, 2006).

The functional domains of the BRCA1/2 genes interact with other regulatory proteins to preserve cellular stability. Deng (2006), Gudmundsdottir, Witt, and Ashworth (2006), Powell and Kachnic (2003), Narod et al., (2004), and Yoshida and Miki (2004), confer that BRCA1 is found on chromosome 17q21 which is made up of 1863 amino

acids, and is composed of a N-terminal Ring Finger and two C-terminal BRCT domains. The Ring Finger segment is associated with protein ubiquitination whereas the BRCT domains are primarily involved in DNA pathways. The role of BRCA1 in the cell cycle is multifaceted. During G1/S phase of the cell cycle, BRCA1 undergoes biochemical interactions with other proteins such as ATM, BARD1, p53, RB, RAD51 to facilitate cell cycle progression. The essential role in the S phase is cell cycle checkpoints to enable DNA repair or promote cell cycle arrest. In G2/M phase, BRCA1/2 genes continue to interact with proteins at checkpoints to activate mitosis. Specifically, during cell cycle progression, the BRCA1 gene is involved in DNA replication, transcription, chromatin remodeling, and repair of double-strand DNA by homologous or non-homologous pathways (Deng, 2006; Gudmundsdottir et al., 2006; Hartman & Ford, 2003; Nardo et al., 2004; Powell et al. 2003; Yoshida et al., 2004).

In comparison, BRCA2 is located on chromosome 13 and is composed of 3418 amino acids which makes it the larger of the two genes. The BRCA2 gene consists of eight BRC repeats and one C-terminal domain (Yoshida et al., 2004; Gudmundsdottir et al., 2006; Narod et al., 2004). Ashworth (2002), Pellegrini et al. (2002), Murphy and Moynahan (2010), and Powell (2003) acknowledge that the role of BRCA2 in cellular stability is specific to DNA repair via facilitation of homologous recombination. BRCA2 directly binds with RAD51 on the BRC repeats and the C-terminus domains during the S-phase of mitotic cell division, and in meiosis. The co-localization of these proteins forms complexes required for double strand DNA repair that supports cellular integrity and chromosome structure. The role of BRCA2 in transcriptional regulation and cell cycle checkpoints is unclear where research studies support no role in ubiquitination (Pellegrini

et al., 2002; Powell et al., 2003; Yoshida et al., 2004). As documented in the literature, BRCA1 versus BRCA2 has a broader role in cellular stability which has implications for the cancer risk profile of a BRCA1 and BRCA2 mutation carrier. Thus, genetic testing for the identification of the BRCA1/2 gene implicated in high-risk BRCA1/2 individuals' health and illness assessment is important from a health preventative perspective.

The understanding of the cell cycle and the roles of BRCA1/2 genes is a direct result of basic science research which informs the current knowledge of tumourigenesis. Basic science research in the long term positively influences clinical treatment options; thus, continued funding of basic science research is imperative. Furthermore, understanding the physiologic role of BRCA1/2 genes in HBOC will assist oncology nurses educational competencies in genetics and genomics, and helps nurses to provide informative health education (Beery, 2008).

Pathophysiologic Perspective

According to Mitchell et al. (1991), the pathophysiologic perspective is the biological response to a state of bodily disorder that is measurable and observable with the use of scientific instruments. The pathogenesis of inheriting a deleterious BRCA1/2 gene mutation is complex as it has the potential for personal and familial ill health. To gain an understanding of HBOC pathophysiology, the discussion begins with Knudson's two hit theory, BRCA1/2 genes and tumourigenesis, and common types of mutations and ethnic specific mutations.

Knudson Two Hit Theory. The two hit theory by Alfred Knudson is based on the widely accepted fact that cancer stems from an escalation of mutations in the cells' DNA. Knudson's two hit model was built on theories put forth by Carl Nordling, James

Null, Phillip Burch, and others (Merte, 2006), which is the principle that is applied to autosomal dominance in HBOC. According to Knudson (1971), the two hit theory arose from experimental, clinical, and epidemiological observations of retinoblastoma cases. In autosomal dominant inheritance, a germinal mutation is inherited and the second is due to DNA damage in a somatic cell (Knudson, 1971, Narod et al., 2004) that arise from factors such as irradiation, chemical agents, environmental, and/or life style choices (Bellosillo et al., 2006; Seenandan-Sookdeo & Sawatzky, 2010). Hence, the loss of function in the matched pair of the mutant BRCA1/2 gene is required to support tumourigenesis. Furthermore, an offspring of a BRCA1/2 carrier has a 50% chance of inheriting a mutated gene which increases their risk for a potential cancer, if a somatic cell mutation occurs.

BRCA1/2 genes and tumourigenesis. BRCA1/2 genes are large proteins with numerous functions that support genomic stability. The literature clearly verified that deficiencies in the BRCA1/2 genes can lead to the initiation and progression of carcinoma as DNA repair pathways are compromised (Evans et al., 2006; Ewald et al., 2009; Honrado et al., 2006; Murphy et al., 2010; Narod et al, 2004; Powell et al., 2003; Tutt & Ashworth, 2002; Yoshida et al., 2004). Cell cycle repair pathways are regulated by BRCA1/2 genes interactions with other proteins. Consequently, a deleterious mutation in a BRCA1/2 gene hinders cellular repair mechanisms. Specific to BRCA1 is deficiencies in signaling pathways responsible for the repair of damaged double strand breaks in DNA by homologous recombination, cell cycle checkpoint controls (between G1 – S, in S phase, and G2 – M), ubiquitination, nucleotide repair, and chromatin remodeling. BRCA2 mutation primarily threatens genomic stability due to a loss of

control of RAD51 which is involved in the recognition of damaged DNA (Muggia, Safra, & Dubeau, 2011; Tutt & Ashworth, 2002. In the presence of defective BRCA1/2 genes, damaged DNA is deferred to an error prone cellular repair pathway known as non-homologous end joining. This pathway leads to a high probability of chromosomal instability that increases the risk of HBOC (Evans et al., 2006; Ewald et al., 2009; Honrado et al., 2006; Murphy et al., 2010; Narod et al, 2004; Powell et al., 2003; Tutt & Ashworth, 2002; Yoshida et al., 2004).

Common types of BRCA1/2 mutations and ethnic specific mutations. The literature broadly supports that majority of genetic diseases result from variations in nuclear DNA. If mistakes fail to be corrected, an inherited alteration may occur such as frame shift mutation (insertion and deletion), missense mutations, (Bellosillo et al., 2006) duplication, inversion, and translocation (Evans et al., 2006; Loescher et al., 2003).

According to Bellosilo et al. (2006) and Narod et al. (2004), the Breast Cancer Information Core database (http://research.nhgri.nih.gov/bic/) identified a large number of mutations associated with BRCA1/2 genes. At the same time, a number of mutations are categorized as not clinically significant while others are linked to an increase in cancer risk. This database also catalogued various founder mutations allied with specific ethnic groups. For example, Stadler et al. (2010) acknowledged that Ashkenazi Jewish individuals of Eastern European decent have a 1 in 40 chance of carrying one of the three BRCA1/2 founder gene mutations in either BRCA1 (185delAG and 5382incC) or BRCA2 (6174delT). Moreover, on full gene sequencing, 2 to 4% of Ashkenazi families are positive for a non-founder BRCA1/2 mutation (Stadler et a., 2010, p.581). Other ethnic specific founder mutations that are routinely tested in Manitoba include Icelandic,

Polish, and Ojibway Cree. Thus, part of the role of a nurse working with the HBO population involves basic genetic education regarding Knudson Two Hit Theory, the role of the BRCA1/2 genes, tumourigenesis, and a comprehensive history assessment that includes questions pertaining to ancestry.

Behavioral Perspective

The third component of the HRTI model takes into consideration objective and observable behaviors which include non-modifiable (i.e. genetic make-up) and modifiable (lifestyle) risk factors that may be indicative of a potential or actual underlining disease entity (Michelle et al., 1991; Shaver, 1982). An oncology history assessment is an excellent tool for healthcare providers to initially use when evaluating cancer risk. Nurses are in a lead position to conduct this assessment followed by appropriate referrals to genetic clinics for a pedigree analysis. In collaboration with a detailed family pedigree, family medical records, and with the use of predictive models, genetic counselors can estimate the risk of a mutant BRCA1/2 for the purpose of offering genetic testing (Chapman, 2007; Nelson, Huffman, Fu, & Harris, 2005).

Oncology history assessments. A HBOC risk assessment begins with a meticulous family and individual oncology history that preferably includes a pedigree. The American Society for Human Genetics has educational information on patterns of inheritance to assist nurses in enhancing genetics knowledge and in the use of a pedigree as part of an assessment and patient teaching tool. The oncology history assessment includes details pertaining to the family and individual medical history.

Family History Assessment: The autosomal dominant patterns of inheritance for HBOC take into consideration maternal and paternal lineage. Patterns of inheritance are

separately assessed for each side of the family. Each offspring (male and female) has a 50:50 chance of inheriting a deleterious BRCA1/2 gene from either side of the family (Chapman, 2007). When evaluating a family history, a clinician keeps in mind plausible errors based on inaccuracies in the knowledge of ones' family health information, the age of diagnosis of each cancer, and the overall size of family (i.e. number of members) as part of the risk evaluation process. Questions should facilitate information on chronic illness and genetic disorders as well as birth defect and learning disabilities in the family (Chapman, 2007). Risk assessment guidelines are specific to each country and to each province or state; consequently, the following are general family characteristics that are indicative of a HBOC predisposition and consequently a referral to a HBOC clinic (Berliner & Fay, 2007; National Cancer Institute, 2012; Nelson et al., 2005; Petrucellli, Daly, Culver, Feldman, 2007; Pruthi, Gostout, & Lindor, 2010; S. Marles, personal communication, November 29, 2013):

- Multiple breast cancers cases at young age of onset (< 50 years of age)
- Ovarian cancer of certain pathologic types such as papillary serous
- Breast and ovarian cancers in the same individual
- Bilateral breast cancer in the same individual
- A male breast cancer
- Breast – ovarian cancer in two or more first – or second degree relatives
- Family pedigree with multiple breast cancer and / or ovarian cancers (of specific
- pathological types) across generations
- Family pedigree reflective of fallopian tube, prostate, pancreatic (individuals of Ashkenazi Jewish descent) and melanoma cancers

- Ethnicity: Ashkenazi Jewish, Eastern European, Icelandic, Ojibway Cree
- Relative with a known BRCA1/2 mutation

Individual History Assessment: A detailed individual assessment for HBOC takes into account non-modifiable and modifiable risk factors which differ slightly for breast and ovarian cancers; furthermore, evidence based recommendations vary for the general population verses the HBOC population. The following discussion is specific to risk factors for individuals who are genetically susceptible for a BRCA1/2 positive test result. The National Cancer Institute (NCI, 2012) identified the non-modifiable risk factors of age, reproductive and menstrual history, history of benign breast masses and mammographic density, surgical history, and radiation exposure. Modifiable risk factors include use of oral contraception (OC), hormone replacement therapy (HRT), alcohol consumption, dietary fat, cigarette smoking, and physical activity (National Cancer Institute, 2012; Pruthi et al., 2010).

An individual history assessment in conjunction with a family history provides many clues regarding risk for HBOC. In conducting an assessment, a clinician will keep in mind the following information in order to facilitate education and referrals accordingly. Younger age of a breast cancer diagnosis (<50 years old) and ovarian cancer (of specific pathological types) at any age increases the likelihood of a BRCA1/2 mutation (U.S. Preventive Services Task Force, 2005). Pruthi et al., (2010) confered an increase risk for BRCA1/2 mutation with breast cancer, but not ovarian cancer with the early onset of menarche (<11 years old). No associated risk is reported with a females' first birth after the age of 30 for ovarian cancer of specific pathological types; although, the breast cancer risk for BRCA1/2 carriers is decreased with BRCA1 and increased with

BRCA2 (Pruthi et al., 2010). According to NCI (2012), benign breast disease (i.e. fibroadenoma) and increased breast density are likely to be seen in women with a genetic susceptibility. In contrast, Pruthi et al. (2010) suggested no increased risk for a BRCA1/2 carrier as it pertains to increased breast density. Additionally, increased sensitivity to radiation may be associated with BRCA1/2 carriers, but mammographic studies are conflicting (NCI, 2012). Research supported an overall reduction in ovarian cancers with bilateral tubal ligation and hysterectomy. Furthermore, a 90% reduction in ovarian cancer and a 50% reduction in breast cancer are associated with a prophylactic salpingo-oophhrectomy in BRCA1/2 mutation carriers (NCI, 2012). It has been long accepted in the research literature that OC decreases the risk of ovarian cancers for BRCA1/2 carriers; however, caution is recommended in the use of OC for females 35 years and older with a familial risk for breast cancer (Horsman, 2007). HRT use in the BRCA1/2 population is controversial as studies are inconsistent, but the overall endorsement is the use of HRT on a short-term basis only (NIC, 2012). Inconclusive evidence exists for alcohol intake, dietary fat, and cigarette smoking with BRCA1/2 carriers as it relates to both breast and ovarian cancers whereas physical activity reduces the risk of breast cancer in BRCA1/2 carriers (NCI, 2012; Pruthi et al., 2010).

Genetic Testing: Technology has made it possible to examine human DNA for the purpose of diagnosing an actual or potential genetic disorder. For BRCA1/2 testing it is best to initiate this process with a cancer survivor person who has had a diagnosis of a breast or ovarian cancer of certain pathologic types. The information gained is used for treatment decision-making for a current health issue, or to offset future health consequences. A comprehensive history assessment in conjunction with risk

assessment models and laboratory gene sequencing unlocks Pandora's box of familial consequences for oneself, offspring, and extended family members.

Many risk assessment tools exist with advantages and liabilities. Based on a history assessment, a geneticist and / or a genetic counselor will choose the most applicable model to generate a risk assessment score. The BRCA PRO is an example of a computerized tool that takes into consideration the variety of HBOC risk factors for both first and second degree relatives to determine the probability of carrying a deleterious BRCA1/2 gene (Berliner et al., 2007; Nelson et al., 2005). The genetic counselor takes the estimated score into consideration along with a confirmed family history to inform collaborative decision making with an individual regarding DNA sequencing (Chapman, 2007; Evans, Skrzynia, & Harlan, 2006; Pruthi et al., 2010). If sequencing is deemed justifiable and consent is obtained, a small blood sample is taken for analysis.

The HBOC DNA analysis process involves examining the entire length of the BRCA1 and BRCA2 gene, or a target examination of an ethnic or founder specific mutation (Bellosillo et al., 2006). For example, the molecular analysis for an Ashkenazi Jewish person first involves examination of BRCA1 the deletion of adenine and guanine at position 185 (185delAG) and 5382 insertion of cytosine (5382insC). Additionally, BRCA2 is examined for 6174-thymine deletion (6174delT) (Bellosillo et al., 2006). If no mutation were identified, then a full sequencing of the BRCA1/2 genes would ensue. As previously noted many other ethnic specific mutations have been identified such as ten ethnic specific mutations in the Norwegian population (Moller, Hagen, Apold, Maehle, Clark, et al., 2007) Thus, gene analysis starts with an examination of the BRCA1/2 genes for an ethnic or founder specific mutation before full gene sequencing. As the genetic

testing process unfolds, decisions along the journey are required which impacts an entire family.

Confirmation of genetic tests results may occur as quickly as within one month or as long as three years. The variations in wait times depend on whether full sequencing or targeted sequencing is indicated, as well as the county, province, or state where the individual resides. Test results are positive, negative, indeterminate, or inconclusive. Vadaparampil et al. (2004) acknowledged a positive genetic test result means a deleterious gene mutation was inherited and the person tested is at an increased risk for a breast, ovarian, and other cancers. A negative test result equates to no alteration in the BRCA1/2 genes is noted; subsequently, the individual remains at a population risk for cancers. An indeterminate result is not informative as it means either the present technology is unable to detect any changes in the genes, or another gene may be responsible for familial risk predisposition patterns. In contrast, an inconclusive test result means a defect in the BRCA1/2 gene is found; however, it is uncertain if this defect is responsible for familial patterns or if it is simply a harmless gene variation (Vadaparampil et al, 2004). Consequently, the finalization of predisposition test outcomes brings with it a list of questions along with personal and familial uncertainties related to social, emotional, and possible economical burdens. The pursuit of genetic testing may be a personal decision, but it bring with it implications to an entire family; thus an informed decision is required regarding the benefits, risks, and limitations to self and family.

Experiential Perspective

Mitchell et al. (1991) described this segment of the HRTI model as the subjective

perspectives of individuals' self-reports of their lived experiences. A self-report is the conscious reflection on ones' inner thoughts, desires, and feelings that are shaped by personal and family norms which are influenced by social and cultural norms (Shaver, 1985). The decision to seek genetic counseling and testing has direct implications on health decisions for a proband (the first individual in a family to initiate genetic counseling and testing) with connotations to an entire family. A positive BRCA1/2 gene mutation confers with 50% susceptibility of passing a germline mutation to each child, and a 50% that other first-degree relatives are affected (parents and siblings), and a 25% change to second-degree relatives (nieces, nephews, cousins, aunts, uncles) (Daly, Barsevik, Miller, Buckman, Croster, et al., 2009; Peshkin, et al., 2010; Pasacreta, 2003). Hence, a comprehensive understanding of the HBO genetic counseling process will assist an intra-disciplinary team of healthcare providers to appropriately support a proband, thus an entire family, during the disclosure process. The HBO genetic counseling process is subdivided into consultation stages lead by a medical geneticist, or a genetic counselor that has a Masters degree in the healthcare profession and in Canada is certified by the Canadian Association of Genetic Counselors (Canadian Association of Genetic Counselors, 2012).

In general, the genetic process as described by Green et al. (2007) remains true in our current healthcare structure. Genetic counseling begins with a referral to a genetic clinic which commences with a confirmation of a consultation with a written request to complete a detailed family pedigree. This pedigree generally involves connecting with close and distant family relatives to discuss the families' health history. The genetic team will confirm the high-risk status of potential testers before booking an initial genetic

counseling session. The first session involves a review of the family pedigree, education about inheritance and testing, and discussions related to potential management. At this appointment, an individual may proceed, delay, or decline to be tested. If genetic testing is sought, a follow-up consult is booked to discuss test results, implications, and healthcare options. The proband is provided with a report of genetic findings along with a letter for family members to assist in explaining test results, and if appropriate, an invitation for family members to seek genetic counseling (Green et al., 1997). Therefore, genetic risk communication with close and distant relatives begins pre-counseling with the potential responsibility to the proband to communicate complex health information to other family members.

A review of the research literature by Croster et al. (2009), Hamilton et al. (2009), Howard et al. (2009), Meiser et al. (2002), Pasacreta (2003), and Schlich-Bakker, ten Kroode and Ausems (2006) discussed findings related to the psychosocial well-being of molecular testing of proband, and issues associated with disclosure of test results. The above-mentioned review articles is dominated by the United States of America, Australia, Europe, and the United Kingdom with a small amount of published studies from Canada. The following summary relates to the research and clinical literature specific to the lived experience of the proband and the affects of disclosing test results to offspring.

Proband. Predictive testing for BRCA1/2 may benefit individuals and families, but equally it also holds unfavorable consequences. Familiar cancer counseling clinics have an established process that commences with risk assessment, molecular testing if requested, and surveillance and prevention education (Meiser et al., 2002). The decision to proceed with genetic testing opens Pandora's decisional box, and future decisions

depend on test results that are either positive, true negative, indeterminate, or inconclusive (Vadaparampil, Wey, & Kinney, 2004). Depending on test results, ones' gender decisions may include 1) prophylactic surgery, 2) medications, 3) surveillance, 4) lifestyle changes, 5) reproduction, insurance, and discrimination issues, 6) participation in research studies such as bio-banking and clinical trials, and 7) disclosure of test results (Crotser et al., 2009; Howard et al., 2009; Liede, Metcalfe, Hanna, Hoodfar, Snyder et al., 2000; Vadaparampil et al., 2004). These complex decisions ideally should be achieved in a manner that is informed and with the assistance of a multi-disciplinary healthcare team.

A systematic review by Crofter et al. (2009) assessed aspects of psychosocial functioning, with distress, depression, and anxiety representing the most frequently measured psychological variables in the quantitative studies. Prevention and surveillance, in addition to disclosure decisions are complex issues with potential psychosocial and emotional effects on the proband and family members.

Distress: Women and men who received positive test results voice concerns about a future cancer; however, the majority of studies show no significant increase in distress (Crotser, 2009; Hamilton, 2009; Finlay, Stopfer, Burlingame, Evans, et al., 2007; Pasacreta, 2003; Schlich-Bakker et al., 2006). Although Crotser et al. (2009), acknowledged advanced levels of distress after the confirmation of BRCA1/2 mutation status in a sub-group of individuals who demonstrated higher levels of uncertainty and distress prior to genetic testing. An increased level of distress is evident in parents of children under the age of 15, and in individuals who experienced a death in the family due to breast cancer. Pasacreta's (2003) integrative review extended the list to included women younger than 40 years with a strong family history of HBOC, introverted

personalities, an admittance of stressors with a positive test result, and individuals contemplating a prophylactic mastectomy. A systematic review by Howard et al. (2009) concluded that decision-making of testers is distorted by an individuals' psychological state and decreased levels of distress could be attributed to psychological counseling (Meiser et al. (2002). Thus, a sub-group of HBO carriers that exhibit the aforementioned characteristics may benefit from additional supports.

Hamilton, Lobel, and Moyer (2009) conducted a meta-analysis of 20 quantitative, prospectively designed studies regarding the emotional consequences of genetic testing. This meta-analysis consisted of Australian, European, and American studies with populations that were primarily Caucasian females. Distress levels were assessed at pre and posttest with post assessments completed 1 to 52 weeks after genetic test disclosure to the proband. Hamilton et al.'s (2009) meta-analysis supports Crotser et al. (2009) findings of no significant increase in distress, and also note levels of distress returned to baseline for proband with positive, true negative, and inconclusive test results. Higher distress levels in a subgroup of individuals as discussed in Crotser et al. (2009) review is considered by Hamilton et al. (2009) as a potential to influence a proband' cognitive and behavioral traits such as guilt and anger. The impact of distress levels on cognition and behavioral traits may influence a sub-group of BRCA1/2 carriers' decision-making processes with an array of familial consequences (Crotser et al., 2009; Hagoel, Neter, Dishon, Barnett, Rennert, 2003; Hamilton et al., 2009; Howard et al., 2009; Hutson, 2003; Pasacreta, 2004; Schlich-Bakker, et al., 2006). However, the quantitative literature consistently states that the overall psychological impact of genetic testing on carriers and non-carriers is comparable to general population levels of the impact of

psychological distress (Crotser et al., 2009; Hagoel et al., 2003; Hamilton et al. 2009; Pasacreta, 2003). Nonetheless, quantitative studies fail to capture the richness of the proband' lived experiences. The qualitative studies report female and male BRCA1/2 carriers acknowledged many stressors with recommendations for supports during specific times such as disclosing test results to children (Croster & Dickerson, 2010; Liede et al, 2000; Ratnayake, Wakefield, Meiser, Suthers Price et al., 2011). More research that seeks to gain an understanding of the lived experiences of both male and female proband are warranted. Clinical nurses play a vital role in the assessment of women and men who may be vulnerable to psychological issues; thus, they may benefit from additional education and supportive psychosocial counseling.

Cancer Specific Distress: In Crotser et al.'s (2009) review of the literature, 18 studies assessed the impact of genetic test disclosure on cancer specific distress for carries and non-carriers. More than 80 percent reported no significant increase in cancer specific distress as assessed seven days after the disclosure of test results when using a reliable psychometric tool known as the Impact of Events Scale that measures intrusion and avoidance related to cancer feelings. Nevertheless, Hamilton et al. (2009) meta-analysis found significant differences in carriers and non-carriers based on the time period between test results disclosure and the assessment of cancer specific distress. Using the Cancer Worry Scale, analysis also found significant differences between carries, non-carriers, and individuals who received inconclusive test results. Based on pre-testing assessments, carriers were found to have an increase in cancer specific distress whereas non-carriers and persons with inconclusive test results both experienced a small decrease in cancer specific distress. In time, carriers, non-carriers, and recipients

of inconclusive results all return to a pretesting emotional state with genetic counseling possibly influencing these outcomes (Croster et al., 2009; Hamilton et al., 2009). Interestingly, in the United States study, participants experienced a larger decrease in distress versus Australian and European counties (Hamilton, 2009). These reviews identified slightly different outcomes in cancer specific distress that may be due to the choice of psychometric tools, the time period the psychological assessments were completed, and differences in international cultural and social norms (Howard et al., 2009; Schlich-Bakker et al., 2006; Vadaparampil et al., 2004). The psychological implications for cancer specific distress are multi-dimensional and there exists a lack of Canadian specific studies to draw strong conclusions that may be specific to Canadian cultural and social norms.

Depression: The hereditary literature describes research concerning the implications of genetic testing and depression studies generally use self-reports (Aver, Haegermark, Platten, Lindblom, & Brandberg, 2004; Hutson, 2003; Valaparampil et al., 2007). An integrative review of the evidence collaborated no significant association noted in depression based on carrier status and decliners of genetic testing compared to the general population norms (Pasacreta, 2003). Crotser et al. (2009) reached a similar conclusion in a review of 12 studies; although, study variations were discussed as it pertained to depression and genetic testing when comparing carriers and non-carriers. This review highlighted a 2002 Australian study (n=90 women mixed carrier and non-carrier status) that reported a decrease in depression using the Beck Depression Scale one year after the genetic test disclosures which contrasted a 2003 European study (n=89 women mixed carrier and non-carrier status) that conveyed an increase in depression 7 to

10 days post results disclosure. In the Australian study, at 7 to 10 days positive carrier status participants maintained depression scores similar to their baseline scores, whereas non-carriers showed a decrease in depression post results disclosure (Meiser, Butow, Fridlander, Barratt, Schnieden et al., 2002). Consequently, despite the overarching conclusion of no significant depression in women seeking BRCA1/2 testing, these studies highlight the importance for more studies (short and long term) relating to depression and genetic testing (Crotser, 2009; Pasareta, 2003). These comparisons also support the notion of possible national differences between countries.

Anxiety: The third psychological response associated with genetic testing that is commonly assessed in the research literature is anxiety (Hamilton, 2009; Howard, 2009; Mesier, 2002; Pasacreta, 2003; Schlich-Bakker, 2006). Anxiety levels while waiting for genetic test results are comparable to general population norms (Pasacreta, 2003). Hamilton et al. (2009) acknowledged that anxiety levels for non-carriers and individuals with an inconclusive test results either declined, or were similar to baseline test scores. However, a small increase in anxiety post molecular disclosure was confirmed for carriers especially for those who are parents, and those who contemplated, or elected to have risk reduction surgeries as part of a treatment plan (Howard et al., 2009). Thus, positive carriers experience an increase in stressors as additional decision-making unfolds. General distress, cancer specific distress, depression, and anxiety psychologically impacts on a sub-group of individuals who may benefit from supplemental health services. An example of one group is parents who choose to disclose or not disclose test results to offspring who are minors.

The process of how parents communicate the disclosure of BRCA1/2 positive

status to minors is not very well understood, with minimum publications on the topic (Clarke et al., 2008; Hamilton et al, 2009, Ratnayake, et al., 2001; van Oostrom et al., 2007) even though disclosure to minors is taking place (Tercyak et al., 2001). The following discussion highlights our current understanding of the parental disclosure of BRCA1/2 test results to their children with a focus on children under the age of 19 years.

Disclosure and non-disclosure of genetic test results to offspring: As a result of Canadian Federal Protection Laws under *the Personal Health Information Protection Act (FIPA)* the proband is responsible for the disclosure of genetic test results to family members which is accomplished by communication between the proband and family members. In Canada, a proband has an obligation of a duty to follow-up with *adult* family members post-counseling regarding test outcomes (Personal communication, Dr. S Males, November 29, 2013) which may be an added stress to a proband who has a positive BRAC1/2 test result because it a deleterious BRCA1/2 test result also brings with it a web of complex health information and decision-making. Interestingly, some parents choose to extend the obligation to disclose to offspring who are under 19 years of age which adds to stressors (Tercyak et al., 2002). These stressors are related to decision to disclosure because the act of disclosure requires information as to how, what, and when to disclose. Moreover, decisions involving disclosure and non-disclosure may require follow-up related to consequences of parental decision-making.

Predictive testing is a family affair that holds implications for the proband, offspring, and other family members (Crotser et al., 2009; Howard et al., 2009; Vadaparampil et al., 2004). A positive BRCA1/2 test result brings with it self-acceptance, adjustments to one's own risk factors, individual health choices along with the

responsibility to disseminate complex information to family members (Clarke et al., 2008). The literature indicated that one incentive for genetic testing is the determination of an offspring' future cancer risk (Tercyak, Peshkin, Steisand, & Lerman, 2001; Bradbury, Dignam, Ibe, Auh, Hlubocky et al., 2007, p.3710). The following discussion conveyed findings related to parental reasons for disclosure of genetic testing to offspring, and psychological consequences of the disclosure.

Reasons for parental disclosure and impact of disclosure: For parents, the confirmation of a BRCA1/2 positive result first brings to the forefront the plethora of issues directly related to testing, then the consequences of living with choices made as a result of testing, and implications on the next generation (Hamilton, Williams, Skirton, & Bowers, 2009). The decision to disclose or to not disclose is complex. Julian-Reynier, Eisinger, Chabal, Lasset, Nogues, et al. (2000) conducted a multi-centre (n=5) cross sectional survey in France's genetic clinics to assess women's attitudes (n=383) about familial genetic test results disclosure. Findings supported other research that indicate disclosure is highest amongst first degree relatives verses second degree relatives in the order of siblings (83%), mother (71%), offspring (70%), and father (65%) (Finlay, et al., 2008, p.81; Green et al., 1997; McGivern et al., 2004). Of importance is the fact that disclosure varied depending on the proband psychological state (Julian-Reynier et al., 2000) which has implications on the proband interpretation and delivery of complex and sensitive health information which may or may not be shared with offspring.

The communication of parental BRCA1/2 test results to offspring is an important clinical issue, but to date research in the area is limited (Bloom, Stewart, D'Onofrio, Luce, & Banks, 2008; Bradbury et al., 2007; Clarke et al., 2008; Crotser et al., 2010;

Peshkin et al., 2010). Minors are not eligible for BRCA1/2 testing as current surveillance and preventative risk-management strategies are contradicted for numerous reasons (Bradbury, et al. 2007; Tercyak, Hughes, Main, Snyder, Lynch, et al., 2001). Despite this fact, most parents disclose test results to children irrespective of a positive, negative, indeterminate, or inconclusive result (Bradbury, et al., 2007; Liede et al., 2000; McGivern, et al. 2004) with approximately 50% of parents disclosing test results to children under the age of 19 years (Bradbury et al., 2007; Miesfeldt, Cohn, Jones, Ropka, & Weinstein, 2003; Peshkin et al., 2010; Tercyak, et al., 2001; Tercyak, Peshkin, DeMarco, Brogan, Lerman, 2002). This disclosure may, or may not have undesirable consequences on the parent, on the child, and on family dynamics.

A number of studies provided insight into the consequences of parental disclosure of molecular test results to offspring. Bradbury et al. (2007) interviewed forty-two mixed gendered (females n=37, males n=5) BRCA1/2 carriers regarding the experience of disclosing test results to children who were under the age of 25 years old. Equal amounts of parents choose to disclose versus not to disclose with 17.95 representing the mean age of children at the time of disclosure. The primary reasons why parents communicated test results to their offspring was to provide health information, increase awareness of familial cancer history, and to discuss the opportunity of genetic testing. Additional reasons included a means to explain current parental medical treatment, feeling that children were age appropriate, and the disclosure was unexpected. Moreover, a large number of young HBOC survivors advocate for personal risk information sharing for children ages 13 to 18 years (McGivern et al., 2004). Research studies specific to men support the primary motive for genetic testing is for their children and family members

(Liede et al., 2000; Lodder, et al., 2001). The rationale for parental disclosure may be a way of parents supporting open family communication in order to slowly transition children into an adult world of HBOC. In contrast, Bradbury et al. (2007) also acknowledged that parents who chose not to disclose felt that children were too young, and parents feared the information would cause anxiety and worry in children. This notion may hold some truth, but children are equally being informed of BRCA1/2 familial risk status by members of the extended family (Hallowell, Ardern-Jones, Eeles, Foster, Lucassen et al., 2005) which holds potential negative consequences for young children and family cohesion. Therefore, the process of disclosure should ideally be an informed decision made early in the genetic trajectory in consultation with appropriate healthcare providers.

The communication of genetic test results to offspring is likely shared in the absence of healthcare professionals, and occurs in advance of surveillance and preventative risk-management options being available to younger children which may have implications on parent-child relations. The literature noted that the majority of parents do not rely on a health professional to discuss parental test results, and felt the process of disclosure did not have adverse affects on children or on parent-child relationships (Bradbury et al., 2007). Although parents felt that children do not fully understand the conversations, and some children initially experienced ill effect to parental disclosure (Bradbury et al., 2007). Other studies indicated no increase in child cancer worries and anxiety after parental disclosure (Perhkin, et al., 2010; Tercyak, Pershkin, Streisand, & Lerman, 2001). In contrast, Tercyak et al. (2001) stated that children reported an increase in future cancer worries and anxiety for those who presented with

psychological issues at baseline. Additionally, increased parental psychological issues pre-counseling was also described as an indicator for the likelihood of results disclosure to offspring prior to one month of parents receiving this information (Tercyak et al. 2001). Furthermore, sharing test results does not alleviate parental distress, but holds the probability of increasing parental self-distress as well as causing distress in children. Thus, the process of parent – child risk communication will be affected by the state of parental uncertainties and distress at the time of disclosure.

A study by Tercyak et al. (2002) was conducted with forty-two female carriers and non-carriers regarding parental disclosure of test results to their children ages 8 to 17 years (mean age 13.4 years). Parents acknowledged the reasons for communicating information included the child's right to know and the parent's responsibility to share this information; the results were negative, and include promoting open communication. Whereas non-disclosers stated young age, and parental concern for childhood fear and anxiety as explanations for not sharing test results. Parents in the above study had a strong sense of children's right to know and parental responsibility to share medical information. These parents described an opened parent-child communication style versus parents who elected not to disclose test results. The contrast in the Tercyak et al. (2002) and Bradbury et al. (2007) studies regarding parental reasons for disclosure versus non-disclosure was probably influenced by the domination of carrier verses non-carrier status, and the offspring age ranges in the respective studies.

A prospective research study (n=271 participants) also supported improvements in parental-child relationships for non-carriers, and families with open-communication and extensive support systems (van Oostrom, Meijers-Heijboer, Duivenvoorden,

Brocker-Vriends, van Asperen et al., 2007). Furthermore, van Oostrom (2007) reported that carriers experienced feelings of guilt regarding the probability of an offspring inheriting a mutated BRCA1/2 gene. Consequently, individual family dynamics, communication styles, and parental carrier or non-carrier status could influence study outcomes, and the individual and parent-child dyad well-being.

Early research on family communication regarding the disclosure of predictive testing continues to be endorsed by current findings that female proband are most likely to seek out genetic testing and communicate conclusive findings with first degree females relatives on the maternal side (mother, daughters, and sisters), and to children younger than 18 years (Green et al., 1997; Hughes et al. 2002; Lerman, Peshkin, Hughes, Isaacs, Lombardi Cancer Centre, et al., 1998; Ratnayake, et al., 2011). In contrast, some reports indicate disclosure to progenies of both genders (Segal, Esplen, Toner, Baedorf, Narod et al., 2004; Tercyak et al., 2002; Tercyak et al, 2001). Collectively, these findings may imply a lack of clarity among some proband regarding BRCA1/2 patterns of inheritance and risks, the implications of inconclusive or indeterminate test results, and full comprehension of risk management and surveillance strategies. This in return may impede accurate information shared between parent and child.

The how in the disclosure process of if, when, what, and how to communicate genetic risk information to minor children is important to understand, as this information will impact on the present and future health of young children. Daly et al., (2001) encouraged familial risk communication using a six-step strategy which includes 1) getting started (identification of who, format information will be shared, and in what setting), 2) how much to disclose, 3) how much does the individual what to know, 4)

actual sharing of information, 5) Support of feelings / reactions, 6) planning for the future with additional resources. Healthcare providers may assist parents to build skills and provide information tools to parents who choose to disclose or not disclose genetic test information. Additionally, professionals may assist parents who choose to disclose to facilitate communication of genetic risk information in a manner that is age appropriate and supportive. But first a broader Canadian perspective of the parental – child disclosure and non-disclosure process is needed.

Chapter Summary

The HRTI model facilitated a broad understanding of HBOC in the area of physiology, pathophysiology, behavioral, and experiential perspectives. Additionally, the model helped to highlight gaps in HBO Canadian research with one example being parental communications of positive BRCA1/2 test result to younger children (Clarke et al., 2008; Crotser et al., 2009; Hamilton et al., 2009; Hamilton et al., 2005; Lodder et al, 2001, Liede et al., 2000; McGivern et al., 2004; Peshkin, et al., 2010; Ratnayake et al., 2010). The literature also identified a sub-group of HBOC individuals who express uncertainty and distress as most likely to benefit from additional supports. These individuals are likely to be young females parents with minor children whose family pedigree indicates a strong HBOC history, a recent oncology related death in the family, individuals contemplating prophylactic surgery, those who have introverted personalities, and at the time of a positive BRCA1/2 carrier diagnosis presents verbal, or non-verbal cues of distress (Crotser et al., 2009; Pasacreta, 2003). Van Oostrom (2007) noted characteristics of this sub-group of individuals also include those in a non-cohesive nuclear family, those who lack support systems, those who have a partner that is not

involved, and family interactions lacking open communication. Parents have identified the need of additional supports to aid in the communication of BRCA1/2 test results with minors. Nurses are perfectly situated to identify individuals at increased risk for distress. Furthermore, nurses have the skill set to assist and / or prepare parents to share BRCA1/2 risk information with younger children. However, the disclosure process between parents and minors needs to be better understood.

Chapter III

Methodology and Methods

This chapter describes the methodology and methods undertaken in this nursing research study. The methodological section discusses the philosophical underpinnings of the study, and the rationale for selecting the methodological approach that will guide the study's research methods. The methods section examines the research design, sample recruitment and access, data collection methods; in addition, research setting, data analysis, and methodological rigor will be considered. In closing, ethical considerations are discussed.

Methodology

This author views nursing as a science and an art because, nursing is grounded in natural science (physiology and biology) and social science (human behaviors and social patterns) since nursing is concerned with actual and potential human health issues. Thus, nursing inquiry is best served by employing both empirical and interpretative sciences in order to study human beings. The methodology chosen to investigate a research question was directly related to the question under investigation; therefore, a qualitative methodology directed the exploration of parental perceptions regarding the disclosure of HBO test results to minor offspring.

A phenomenological study is one approach to qualitative research. Dowling (2007) acknowledged various phenomenological paradigms exist which include the positivist (Husserl), post-positivist (Merleau-Ponty), interpretivist (Heidegger), and constructivist (Gadamer) to list a few. The work of philosophers Martin Heidegger, Han-Georg Gadamer, and Paul Ricoeur guided hermeneutics as an interpretive approach

(Streubert et al., 2011). Hermeneutic phenomenology was elected for this research study because it considers human beliefs, culture, relationships, and context to answer research questions that address the social experience and meaning of human life (Lopez & Willis, 2004). Additionally, hermeneutic phenomenology was chosen because the philosophical underpinnings are concerned with the existence and nature of reality (Lopez et al., 2004). This section introduces the philosophical underpinnings of hermeneutic phenomenology, and justifies the selection of hermeneutic phenomenology for this study.

Philosophical Underpinnings of Hermeneutic Phenomenology

Philosophy dates back to ancient Greece, to philosophers such as Plato, Alexander the Great, and Aristotle. Hare (1986), was a 20th century philosopher who viewed philosophy as the study of human beliefs as a whole to capture a general depiction of the human experiences. The word phenomenology has Greek roots from the word phaenesthai meaning "to appear" (Dowling, 2007; Sembera, 2007), and logos to study or reason (Sembera, 2007; Walters, 1995). Phenomenology is considered the study of the lived human experience, or the life-world which in the 21st century is classified as a philosophy, research approach, and a research method (Koch, 1995; Laverty, 2003; Mackey, 2005; Omery, 1983).

Two popular phenomenological traditions evident in nursing research studies included descriptive (positivist) phenomenology and interpretative phenomenology; descriptive is primarily associated with Edmund Husserl, and interpretative hermeneutics is allied with Martin Heidegger and others (Lopez et al., 2004; Mackey, 2005). The understanding of both Husserl's and Heidegger's philosophy is subject to the reinterpretations of various translators which have influenced the ways these philosophies

are comprehended, and used by researchers seeking to understand behavioral science in humans (Dowling, 2007; Koch, 1995; Lawler, 1998; Mackey, 2005).

Edmund Husserl (1859-1938). According to an online peer-reviewed academic source known as the Internet Encyclopedia of Philosophy (IEP) (2012), Husserl was born April 8, 1859 in the small town of Prossnitz, Moravia (then Austria-Hungary, now Czech-Republic) whose population majority was Slavic. The town's middle-class was compromised of individuals of Jewish and German descents. While Husserl's father was a non-orthodox Jewish clothing merchant, Husserl in his adult years was baptized as a Christian which was his religious faith for the remainder of his life. As a young man, Husserl studied astronomy, mathematics, and physics at the University of Leipzig, and then pursued an education in philosophy under the philosopher Thomas Masaryk (1850-1937) who was a former student of German-Italian philosopher Franz Brentano (1838-1917) (IEP, 2012; Laverty, 2003, Stanford Encyclopedia of Philosophy, 2012).

Husserl is recognized as the founder of phenomenology who introduced the concept of 'life world' or 'lived experience' based on an epistemological perspective that views knowledge as a transcended human experience or as evolving from pure conscious experiences of constructed thoughts (Annells, 1996; Mackey, 2005; Walters, 1995). Two principle assumptions of Husserl's phenomenology are that human conscious experiences strengthen scientific inquiry and that all lived experiences of similar situations share mutual themes (Lopez, 2004). Husserl's main philosophies are categorized as intentionality, essences, and phenomenological reduction (Koch, 1995).

Husserl believed that the knowledge of reality begins with intentionality which views all internal states (i.e. thoughts, desires, beliefs) as acts of pure consciousness that

are absolute, and without external prejudice. A Husserlian phenomenologist gains an understanding of humans lived experiences by capturing internal states of consciousness that are not self-reflected on, or externally influenced by factors such as culture, society, or politics (Dowing, 2007; Koch, 1995; Lopez, 2004). It is believed that humans who share a similar lived experience have a mutual story to their collective lived experience (Koch, 1995; Lopez, 2004). Therefore, Husserlians also seek to understand the shared essence of lived experiences which offers generalized descriptions of the phenomenon, and scientific rigor to this paradigm (Lopez, 2004). Scientific rigor is furthered enhanced by Husserl's concept of phenomenological reduction or bracketing. Bracketing is the process by which a person suspends all their bias in order to truly perceive the reality of a phenomenon (Laverty, 2003). However, not all phenomenologist embraced all views held by Husserl, one example is his assistant Martin Heidegger.

Martin Heidegger (1889-1976). IEP (2012) stated Martin Heidegger was born September 26, 1889 in Messkirach, Germany to a Catholic family. As a young man, Heidegger initially pursued theology, but Franz Brentano and Aristotle ignited his interests in philosophy from readings. At Freiburg University, Heidegger abandoned theology studies for philosophy, mathematics, and natural science. In 1913, Heidegger graduated with his doctorate in philosophy with a dissertation on the Doctrine of Judgment in Psychologism under the advisement of Heinrich Rickert, a neo-Kantian philosopher. After graduation, Heidegger was drafted to serve in World War I, but within two months was discharged due to health concerns. In 1916, Heidegger worked as a junior colleague of Edmund Husserl. However, in 1918 he was again drafted by the military where he served ten months. Thereafter, Heidegger worked as Husserl's

assistant, and in 1923 was appointed assistant professor at Marbury University. In 1927, Heidegger dedicated his published work of Being and Time to Edmund Husserl. Being and Time earned Heidegger full professorship at Marbury University; subsequently, in 1928 Heidegger succeeded Husserl as chair of philosophy at Freiburg University upon Husserl's retirement.

IEP (2012) and Mackey (2005) highlight Heidegger's non-affiliation with politics until 1933 when he joined the Nazi Party headed by Adolf Hilter. Heidegger resigned from office a year later, but Heidegger's association, and resignation from the Nazi party directly impacted his academic and personal life during the 1930's to mid 1940's. Heidegger was dismissed from Freiburg University with an eyeful watch from the Gestapo, and at one point Heidegger was sent to dig trenches. Years later, Heidegger was reinstated at Freiburg University (IEP, 2012; Mackey, 2005).

This author acknowledges her belief that Heidegger has been rightly criticized in the literature for his immoral association with Nazism, and despicable public support of the Holocaust (Mackey, 2005; Holmes, 1996). Discrepancies exist as to possible influences of Heidegger's philosophical insights and politics on his contributions to philosophy. Despite Heidegger's history with the Nazi party, hermeneutic phenomenology guided this research project because 1) Heidegger's philosophy associated with the Being and Time was used, versus his philosophies acknowledged as 'the turn' which came after his association with the Nazi party, 2) the time line of events of the publication of the Being and Time (1927) commenced before Heidegger's association with the Nazi Party (1933), 3) the literature is non-conclusive regarding any relations between Heidegger's philosophy and politics (Darbyshrie, Diekelmann, &

Diekelmann, 1998; Holmes, 1996; Mackey, 2005), and 4) the concepts in the Being and Time best fit the methods for the purpose of this study as it seeks to understand the lived experience of a phenomena. Two concepts of Being and Time which will be discussed include 'being-in-the-world,' and fore-structures.

Being-in-the-world: Koch (1995), Laverty, (2003), Mackey (2005), and Dowling (2007) recognize Heidegger's hermeneutic phenomenology was based on an ontological (relating to existence) understanding of 'being-in-the-world.' Heidegger claims our 'being' (existence) in the world is framed by the notion of background, pre-understanding, and co-constitution. Humans are born with a set of biological traits (background-history) that influence the ways human beings exist, act, interpret, and relate to the world. From pre-birth onward 'being-in-the-world' is grounded in a culture (i.e. language, beliefs, practices, values) that situates pre-understandings of future lived experiences. Heidegger referred to *dasein* as a state of caring, a state of self-interpreting and self-defining which makes one self-aware of one's 'being' (existence) (Annells, 1996, Koch, 1995; Laverty, 2003; Mackey, 2005). Lived experiences are understood because human beings reference reality based on pre-understandings which comes from a state of dasein. As a result, human beings are co-constituted as humans are shaped by the world, and simultaneously humans construct the world based on one's background, history, and experiences (Dowling, 2007, Koch, 1995, Lavery, 2003; Mackey, 2005).

Fore-structures: Koch, 1995, Lavery (2003), and Marckey (2005) stated, Heidegger believed that all understanding comes from a set of fore-structures which first needs to be acknowledged as these structures influence one's interpretations. Fore-structures come from one's prior awareness of background, history, culture, and / or lived

experiences. As previously stated, 'being-in-the-world' is an interactive process between human beings and the world. Heidegger called this reciprocal interaction the *hermeneutic circle* which facilitates an interpretive process for understanding phenomena. The circular process begins with the disclosure of fore-structures followed by a back and forth examination of the parts and the whole in order to gain a new understanding of the phenomena. Therefore, in hermeneutic phenomenology fore-structures such as background, history, culture, and knowledge are not bracketed and put aside, but they are made explicit for the purpose of incorporation into the process of understanding (Koch, 1995; Lavery 2003; and Marckey, 2005).

Historically, nursing is known as a caring profession rooted in holistic nursing practices involving individuals, families, communities, and populations (Seenandan-Sookdeo, 2011). Thus, a phenomenological inquiry guided this research project because the approach requires a holistic perspective to unveil the richness of people's life experiences. Specifically, hermeneutic phenomenology was selected as the methodology because the study was designed to explore why, and how parents disclose, or choose not to disclose a BRCA1/2 test result to minors. This interpretative approach facilitated an investigation into the realities of the phenomena which are centered on the lived experiences of individuals. Furthermore, hermeneutic phenomenology is endorsed because the purpose of the study was to reveal the meaning of the phenomena that is not recognized, and necessitated an interpretive effort that involves a researcher not to bracket preconceptions, but instead engages in the *hermeneutic circle* during analysis (Streubert & Carpenter, 2011). The engagement in the hermeneutic circle occured with data analysis as the researcher acquired an understanding of parts of the text by reflecting

on the whole, and in turn understood the whole by taking individual parts into consideration. The hermeneutic circle involved a continuous movement between the parts and the whole for the purpose of capturing the essence of the lived experience (Streubert et al., 2011).

Methods

This section examines the research design which takes into account sample recruitment and access, data collection methods, data analysis, and methodological trustworthiness. Additionally, ethical considerations when conducting research with human participants are discussed.

Research Design

A qualitative inquiry was selected to explore the experiences of research participants regarding the disclosure and non-disclosure of BRCA1/2 test results to children because a qualitative approach captures a rich understanding of everyday life experiences by generating in-depth meaning of the phenomenon under investigation. The literature review identified the paucity of research in the area of parental-children communication of BRCA1/2 test results. Therefore, the current study is designed with a qualitative phenomenological approach to supplement clarity to this area of inquiry which is specific to the shared meaning of the lived experiences of a small group of individuals. Additionally, a qualitative design conveyed the personal experiences by sharing the collective voices of BRCA1/2 carriers.

Hermeneutic phenomenology restricts the use of a fixed set of techniques, procedures, and concepts to guide a research study (van Manen, 1990). Despite the non-methods approach of hermeneutic phenomenology, van Manen (1990) proposed six

activities to guide the methods aspect of a research project which has been accepted by many healthcare professionals from various disciplines (Maggs-Rapport, 2001). For example, nursing scholars such as Thomlinson (2002), and Whitehead (2002) reference Max van Manen's methodical processes in the analysis of hermeneutic phenomenological research. Furthermore, van Manen's six-step approach was effectively used in a range of research studies from assessing women living with ovarian cancer, health patterns of women with fibromyalgia, to the value of parenting (Maggs-Rapport, 2001). Therefore, van Manen's six-step approach was applied to this research project because it fits the philosophical underpinnings of the study, and researchers have confirmed the analytic strength of the six-step approach. The six-steps included: 1) identifying a phenomenon of interest that best fits hermeneutic phenomenology, 2) investigating the phenomenon, 3) reflecting on the essential themes, 4) describing the phenomenon in text, 5) maintaining a nursing relation to the phenomenon, 6) interpreting the parts and the whole, and disseminating research findings (van Manen, 1990). The process takes a holistic approach as van Manen advocates for flexibility in implementing other activities as based on life interactions.

Sample Recruitment

This section discusses the research design as it pertained to the criteria for sample selection, sample size, access to participants, sample recruitment, and remuneration.

Criteria for sample selection. According to Streuber et al. (2011) purposeful sampling is generally used in phenomenological studies, and sample selection is derived from the underpinnings of the research question. The goal of qualitative research is not to generalize findings to a broad population, but to explore the meaning of lived

experiences. Therefore, a purposeful sample selection was employed due to the likelihood of generating comprehensive descriptions regarding parental perceptions about the disclosure and non-disclosure of BRCA1/2 test results to minors. Additionally, a small sample pool of BRCA1/2 positive individuals exists; therefore, snowballing was administered as a sampling strategy, but resulted in no participant referrals.

The selection of participants was based on the following criteria: 1) able to speak and read in English, 2) males and females who are 18 years of age and older, 3) received a BRCA1/2 positive diagnosis from Health Science Centre Hereditary Breast and Ovarian Clinic, 4) parents with at least one child who (at the time of disclosure) are between the ages of 6 and 18 years old, at the time of the initial research conversation the child(ren) was (were) younger than 19 years of age, within one year of receiving a positive test result have disclosed or choose not to disclose a BRCA1/2 test result to a minor, and parental BRCA1/2 test result was received between 2008 and 2012.

Sample size. The sample size for a qualitative study is generally smaller when compared to quantitative studies. The anticipated sample size for this study was a small sample size with since qualitative recruitment is based on the notion that each participant will generate a substantial amount of rich information. Consequently, data saturation, or until the researcher understood the structures of the participant's experience was the researcher's guide to sample size (van Manen, 1990). Thus, the aim was to obtain information-rich cases for an in-depth analysis.

Access to participants. Permission for access to potential participants was submitted to Winnipeg Regional Health Authority (WRHA) Research Resource Impact Committee (RRIC) for recruitment from Health Science Centre Hereditary Breast and

Ovarian Clinic. Additionally, a RRIC letter was submitted to CancerCare Manitoba (CCMB) RRIC for recruitment from Breast Cancer Centre of Hope. Please refer to Appendix A and B for a copy of WRHA and CCMB Request to Assist with Participant Recruitment letters. Furthermore, a letter of permission was submitted to the University of Manitoba Faculty of Nursing (FON) for use of an interviewing room (see Appendix C for FON Request for an Interview Room).

Sample recruitment. Participants were all recruited from WRHA Hereditary Breast and Ovarian Clinic in which healthcare professionals actively assisted with sample recruitment. A genetic counselor at WRHA Hereditary Breast and Ovarian Cancer Clinic offered recruitment packages to potential participants. The participants were asked to contact the student researcher directly by telephone, if interested in participating (see Appendix D, E, F, G, I, J, and L for a copy of the study package invitation letter, informed consent form, telephone script, reminder letter, the demographic form, request to forward summery of the lived experience, and a request for research summary findings).

Remuneration. In appreciation of participants' time and invaluable information, participants were provided with a $10.00 coffee gift certificate to a local vending franchise at the time of the interviews. Parking fees were paid for participants who choose to be interviewed at the University of Manitoba, Faculty of Nursing.

Data Collection Methods

This section reviews the data collection methods for the impending study which included demographic forms, semi-structured conversations, and a reflective log.

Demographic Form

To assist in understanding participants' context, a demographic form was included in the HBO study information packages (see Appendix I for the Demographic Form). The student researcher developed the demographic form which was specific to the study. The anticipated time to complete the demographic form was ten minutes.

Semi-structured Conversations

Interviews are a common method of data collection associated with qualitative research. van Manen (1990) conveyed that hermeneutic phenomenological human science conversations (interviews) are a means of gathering rich stories for the purpose of understanding and interpreting life events, as the understanding occurs in the interpreting. Questioning is part of the interpretive process and for the hermeneutic phenomenologist, a conversationalist approach was promoted. Semi-structured interviews were seen as conversations with open-ended questions that orient the participant to the phenomenon. The use of open-ended questions facilitated an interactive research-participant dialogue in the exploration of parents' views, decision-making, experiences, and perceptions regarding the sharing, or not share of BRCA1/2 test results with children (see Appendix M for the Interview Guide). Semi-structured conversations guided by open-ended questions permit participants to steer the description of their lived experience and enabled the researcher to be objective and subjective to the shared experience (Streubert, 2011, van Manen, 1990). The student researcher gently facilitated conversations that help to explore the parts, and the whole of personal stories. Additionally, patience, silence, the use of respectful voice tones and body expressions, repeating a last thought or sentence, paraphrasing, and *close observations* (captured in the reflective log) was applied as part

of the engagement process (van Manen, 1990).

In hermeneutic phenomenology, the engagement of participant involvement is important (van Manen, 1990). Subsequently, in order to facilitate involvement from across the province of Manitoba, participants chose to have conversations on the telephone and / or in-person. The potential participant by way of a telephone contact initiated the preliminary communication. During this initial telephone contact the student researcher described the study, confirm eligibility criteria, ascertain willingness to participate, reviewed the consent form, and answered preliminary questions pertaining to the study. At the time of the telephone contact, two follow-up conversations (telephone or in-person) were scheduled for individuals who were eligible and interested in participating. These two conversations were scheduled in order to capture the essence of the lived experience. The collaborative practice of a back and forthness between participants and the author which embraced the process of the hermeneutic circle (Koch, 1995; Lavery 2003; Marckey, 2005; van Manen, 1990).

During the initial telephone contact (initiated by the potential participant), the student researcher encouraged participants to forward the signed consent form and the completed demographic information to the student researcher's office. A pre-addressed stamped envelope was provided in the HBO study packages for this purpose or the student researcher retrieved the completed forms (informed consent and demographic forms) at the beginning of the scheduled interview. The approximate time of the initial telephone contact (initiated by the potential participant) was 20 to 30 minutes.

Telephone Conversations. If a telephone conversation was requested the *first telephone conversation* was for the purpose of participants to share their lived experience

in order to allow for a deep understanding of the phenomenon (see Appendix M for the Interview Guide). After each conversation, the student researcher postal mailed, or emailed a conversation summary of the participants lived experience to the address of the choice of the participant (see Appendix J for the letter of permission to postal mail, or email Lived Experience Summary). The *second conversation* was offered to participants in order to allow them an opportunity to reflect on the text (summary of the first conversation) for the purpose the participants to offer the student researcher further insights and or clarifications of the described phenomenon as outlined in the conversation summary (see Appendix K for the Second Conversation Script, and Appendix H for a Participant Involvement Chart).

In-person Conversations. If an initial in-person dialogue was chosen, the participant choose the location of the venue, either at the participant's home or office, or the University of Manitoba, Faculty of Nursing interview room. The *first conversation* allowed for a deep understanding of the phenomenon (see Appendix M for the Interview Guide). The second dialogue (telephone or in-person) offered the participant an opportunity to reflect on the text (summary of the first conversation) to offer further insights and clarification of the described phenomenon (see Appendix K for the Second Conversation Script, and Appendix H for a Participant Involvement Chart).

To preserve the essence of the conversations (telephone and in-person), all *conversations* were recorded using a digital voice recorder. For participants who choose the telephone conversation mode a digital recorder adapter was used to ensure conversations were directly captured into the digital recorder. Telephone conversations were offered as a mode for participation in order to allow the opportunity of residents

from rural Manitoba to contribute to this research project. The initial conversations were about 60 minutes with the majority (about 93%) of second communication falling into the category of a simply confirming that the conversation summary was accurate. One participant's follow-up communication was for the purpose of offering additional information that she forgot to share in the initial conversation. To ensure accurate and timely transcriptions, a professional transcriptionist transcribed all conversations verbatim, and the author reviewed each transcription for accuracy (see Appendix N for Transcriptionist Confidentiality Agreement). To safeguard participants' confidentiality individual names, place of employment, and any personal identifiers were eliminated from all transcriptions. Moreover, each audiotape recording with the corresponding transcription and demographic form were assigned the same code. To further preserve the spirit in which stories are shared, all communications as it related to this thesis (text and oral) did not disclose the identity of participants or the participants' family.

A master list of participants names, codes, and contact information was kept in a file under lock and key, and accessible only to the student researcher. Additionally, correspondence from participants which contained participants names and contact information were kept in a file under lock and key, and accessible only to the student researcher. Furthermore, all signed informed consent forms were kept in a separate file under lock and key, and accessible only to the student researcher.

Reflective Log

Nurse theorist and researcher, Patricia Benner long encouraged nurses to engage in reflective practice which Benner extended to research grounded in hermeneutic phenomenology (Mackey, 2005). A reflective log was the third source of data collection

method used to capture the authenticity of participants' lived lives. van Manen (1990) advocated for reflective logs after each conversation; thus, the student researcher logged *close observations* such as insights gained, perceived patterns, and reflect on past logged reflections. The process of reflection involved appreciating the participant's lived experience by attaining a curiosity that searched out narrative anecdotes that has a point for interpretation (van Manen, 1990). The purpose of reflections is not to bracket, as supported by Husserlians, but to bring observations (internal and external) to the forefront of one's conscious level to gain a deeper meaning and interpretation of the phenomenon (Annells, 1996, Koch, 1995; Laverty, 2003). Communications along the research process between the author and thesis advisor supported a deeper understanding of conversations and the text.

Data Analysis

The purpose of hermeneutic phenomenology is to understand through interpretation, the meaning of the lived life. In qualitative research, data analysis occurs concurrently with data collection (Streubert, 2011). Therefore, from the onset of data collection, the author immersed in a hands-on process that corresponds to van Manen's (1990) selective approach of describing parents' lived experiences of disclosing, or not disclosing BRCA1/2 test results to minors. van Manen (1990) views phenomenological description and interpretation as an insightful construction of the desire to uncover and interpret the structures of experience (themes) which make up the experience. This discovery process is not rule bound; thus, it could embraced other methods that the researcher feels is required to grasp an understanding of the phenomenon (van Manen, 1990).

The demographic form, reflective log, and transcribed conversations were used for the data analysis. Descriptive statistical measures were applied to describe data collected on the demographic forms (Whittemore, Grey, Kirton, & Sing, 2006). van Manen (1990) described an approach to data analysis that involved a thematic analysis to uncover essential themes. Consequently, the reflective log and transcribed conversations were analyzed using van Manen's selective approach since the approach reflects the philosophical underpinnings of hermeneutic phenomenology. The selective approach is summarized below in four main steps (van Manen, 1990):

1) First, the author read each text as a whole (transcriptions and corresponding reflective log) to gain a deep understanding of the lived experience in order to begin to conceptualize interpretations of the text for analysis. Multiple readings of a text were necessary to truly appreciate the richness of the data.
2) Next, the author isolated phrases, sentences, and examples that best described insightful parental perceptions of BRCA1/2 communications or non-communications with offspring. During this step preliminary structures of experiences (themes, an sub-themes) began to unfold.
    a. According to van Manen (1990) this step reduced the data in order to uncover *essential* themes (a unique characteristic(s) of the phenomenon and without it the phenomenon could not be what it is), and *incidental* themes (qualities that are incidentally related to the phenomenon). The question that one ask oneself to distinguish essential from incidental themes is, "does the phenomenon without this theme lose its fundamental meaning?" (van Manen, 1990, p.107).

   b. Once structures of experiences (themes and subthemes) were identified, a second conversation with the corresponding participant was ensued to support collaborative interpretations of the preliminary themes based on the participant's lived experience. This allowed the participant an opportunity to assess that stories were accurately captured and it also provided an opportunity for the participant to offer further insight to misinterpretations.

3) The third step involved bringing the parts of the whole together. This was accomplished by identifying meaningful patterns between participants' text conversations, and then all text conversations as a whole. This step involved interpretative readings of the text which may involve re-thinking, re-flecting, re-cognizing, re-organizing, and re-writing which van Manen (1990) referred to as *linguistic transformation* which was reflective of the concepts grounded in the hermeneutic circle.
   a. In addition to prior communications with the author's thesis advisor, at this stage a meeting with the thesis advisor was pre-scheduled to discuss the text and linguistic transformations.
4) The final step is the interpretation of the whole consisted of reflecting on transcribed conversations and the reflective log to ensure a holistic reflection of the lived experiences of the participants was captured (van Manen, 1990).

Methodological Trustworthiness

Guba and Lincoln's (1994) four standards of trustworthiness are traditionally applied to qualitative research projects to establish methodological rigor. The four

standards include: credibility, dependability, confirmability, and transferability.

Credibility

Guba and Lincoln (1994) acknowledged that a study's credibility is measured against the activities taken to increase the probability that findings accurately reflect the participants' lived experiences. A number of strategies to increase the credibility of the research findings was supported such as prolonged engagement, member checks, and peer review and debriefing (Guba & Lincoln, 1994). Prolonged engagement with the subject matter was evident in the study's design to have two conversations with each participant. The first conversation was for participants to share their lived experiences with the author, and the second dialogue was to collaborate and confirm the truthfulness of the findings (member checking). Additionally, at the time of conversations, the author actively listen to stories while utilizing skills such as paraphrasing and summarizing with the purpose of assessing the author's accuracy of the shared story (member checking). These steps allowed participants an opportunity to immediately correct, clarify, or question interpretations. Moreover, periodic peer reviews and debriefing between the student researcher and thesis advisor allowed for insights from an expert psychosocial clinician and the researcher.

Dependability

The standard for dependability was attained once the study demonstrated credibility in the findings (Streubert, 2011) which was implemented for this study. Dependability was also assessed by the researcher against the study's audit trail that detailed a record of the study activities over time (Streubert, 2011) which lead to the third aspect of trustworthiness which is confirmability.

Confirmability

The standard of confirmability allows other researchers to understand the decision making that lead to the study findings which may be assessed by the study's audit trail (Guba & Lincoln, 1994). The planned audit trail included transcriptions of conversations, demographic forms, a detailed reflective log after each conversation, the researchers workbook, and the preservation of all text which relates to the analysis process. All audit trail items do not contain information that would reveal the identity of the participants.

Transferability

According to Guba and Lincoln (1994), transferability is judged based on the notion that the findings of the research study have meaning to others in a similar situation, and that valuations are made by the users of research. Transferability of research findings is outlined in chapter five of this thesis.

Ethical Considerations

Approval of the author's thesis committee was obtained from the University of Manitoba, Faculty of Nursing Graduate Studies Committee. The author obtained certification in Queen's University online Course in Human Research Participant Protection (CHRPP), and completed the Pledge of Confidentiality - Personal Health Information (see Appendix O and P**)**. Submission to the University of Manitoba, Education / Nursing Research Ethics Board (ENREB), Winnipeg Regional Health Authority RRIC, and CancerCare Manitoba RRIC were all granted.

The Tri-Council Policy Statement (TCPS, 2010) for the ethical conduct for research involving humans was taken into consideration during all stages of this research project. The following discussion directly pertains to the study's ethical

considerations which are grounded in TCPS (2010) core ethical principles of respect for persons, concern for welfare, and justice.

Respect for Persons

According to the TCPS (2010), respect for person takes into consideration the principle of autonomy as a person's right to self-governance, and the basic value of human beings. A written informed consent will be obtained from each participant prior to conversations about parental lived experiences. Participants were informed (and reminded) that study involvement was voluntary, and withdrawal was possible at any time. The research study was executed in a manner that was respectful, free of personal judgments, and appropriate safeguards were implemented, as required during all phases of the research process.

Concern for Welfare

Concern for welfare of a person takes into regard a holistic view of a person's life experiences such as the individual's (and his or her family's) physical, psychosocial, economic, and spiritual health (TCPS, 2010). Throughout the study, the author remained cognizant of participants' needs and used appropriate voice tones to convey a safe environment. The concern for participants' welfare was also sustained through conversational skills that are intuitive to the needs of the participants. As required, appropriate referrals were offered. In summary, all interactions and communications upheld the principles of autonomy and beneficence.

Justice

The principles of justice were endorsed during all stages of the research study. TCPS (2010) defines justice as the application of treatment of individuals in a fair and

equitable manner, whereas fair means treatment with equal respect and concern. Equity is concerned with the fact that benefits and risk associated with a research study are equally distributed in the population, while knowledge gained from the research is accessible to all (TCPS, 2010). In addition to maintaining these principles during the study, special consideration was also being afforded to segments of our population that are considered vulnerable or marginalized (TCPS, 2010).

Confidentiality and the right to privacy was maintained, and safeguards were implemented to assure all information gathered was kept in a manner that does not disclose the identify of participants. For the purpose of follow-up communications (i.e. the second interview and distribution of research findings), a master list of participants' names and contact information linked to a coded number was kept under lock and key with only the author having access. All information gathered during the data collection and data analysis phase was kept in a separate location under lock and key which will be confidentially destroyed seven years after the author's successful defense of her thesis.

Chapter Summary

A hermeneutic phenomenological study was designed to explore parental perceptions regarding the disclosure, or non-disclosure of HBOC test results to minors. Data collection methods included semi-structured conversations, demographic forms, and a reflective log. Data analysis was guided by van Manen's (1990) selective approach to uncovering and interpreting the structures of experiences (themes) which make up lived experiences. Guba and Lincoln's (1994) standards of credibility, dependability, confirmability, and transferability are used to assess methodological trustworthiness. Furthermore, TCPS (2010) core principles of respect for persons, concern for welfare,

and justices are discussed in relation to the research study process.

Chapter IV

Findings

This chapter details the findings of this hermeneutic phenomenological study which was driven by the research question what are Manitobans' parental perceptions regarding the disclosure and non-disclosure of a positive BRCA1/2 test results to minors? A summary of the characteristics of the sample population is outlined, followed by the study's main finding, and emerging themes. The main finding of the study is parents requested healthcare professionals to take the topic of disclosure and non-disclosure a step further. The themes that materialized from the interviews included 1) influential factors, 2) testing is a family affair, 3) decision-making and family communication, 4) the inner circle, 5) knowledge deficit, 6) and supportive resources. The chapter concludes with a summary of parental recommendations specific to healthcare professionals and BRCA1/2 positive parents.

Description of the Sample Population

Seventeen eligible participants responded with an interest to participate in the research study from a total of *47 mailed invitations. This accounts for a 36%* response rate. One eligible participant was not interviewed due to life circumstances, and the second participant's interview was not recorded because, the digital recorder failed to record the interview. This participant was unable to reschedule the interview due to family issues.

The final sample consisted of 15 female participants who received a positive BRCA1/2 test result from the Winnipeg Regional Health Authority's Hereditary Breast and Ovarian Clinic. All participants were residents of the province of Manitoba at

the time they received their test result. Nine resided in the city of Winnipeg, and 6 were residents of rural Manitoba. The ratio of urban versus rural participation was 66% urban to 34% rural. A greater percentage of rural versus urban participants requested telephone conversations. See Table 1.0 for a comparison between type of residency and type of interview.

Table 1.0: ***Participants Demographics – Residency and Type of Interview***

	Type of Interviews	
	In-Person Interview	Telephone Interview
Urban	6	3
Rural	2	4
Total	8	7

The 15 parents who participated in the study had a mean age of 40 years and an age range of 28 to 54 years. All parents received a positive BRCA1/2 test result between 2008 and 2012. The participants either chose to disclose to a minor offspring within 36 months of receiving the test result, or choose not to disclose by the time of the first study conversation. The total number of children of the 15 participants was 26. At the time of consent 22 out of 26 children were between the ages of 6 and 18 years at the time of the initial study conversation. The event age (age of child[ren] at the time of disclosure or time parent given BRCA1/2 test result) range of the eligible children was 7 to 16 years. The mean age of the children who were eligible for the topic of discussion was 12.4 years. Of the 15 participants 8 parents disclosed, 6 did not disclose, and 1 disclosed to

one child, but not to two others.

The study population consisted of 11 married / common law, and 4 divorced / separated individuals. A significant percentage of parents who disclosed were in a married / common law relationship (53%). See Table 1.1 for a comparison between marital status and disclosing and non-disclosing decision-making.

Table 1.1: Comparison Between Marital Status and the Decision-Making

Marital Status	**Decision to Disclosed % (n = 9)**	**Decision to Not Disclosed % (n = 7)**
Married / Common Law	53% (8/15)	27% (4/15)
Divorced / Separated	7% (1/15)	20% (3/15)

*The parent who disclosed to one child, but not the others was included in both columns. Total number of parents = 15.

All disclosing parents had some secondary education with university education (33%) as the greater percentage. The majority of non-disclosing parents were also university educated (20%) with equal percentages (13%) having community / technical college and high school education (13%). See Table 1.2 for a comparison between highest level of educational achieved and decision-making.

Table 1.2: Comparison Between Level of Education and Decision-Making

Educational Facilities	**Decision to Disclosed % (n=15)**	**Decision to Not Disclosed % (n=15)**
High School	0	13% (2/15)
Community / Technical College	27% (4/15)	13% (2/15)
University	33% (5/15)	20% (3/15)

*The parent who disclosed to one child, but not the others was included in both columns. Total number parents = 15.

Initial interviews were conducted between October 25, 2012 and June 4, 2013. See Table 1.3 for the number of interviews per month and Table 1.4 for a detailed demographic review of the sample population.

Table 1.3: ***Number of Interviews Per Month*** **(n = 15)**

October	November	February	April	May	June
1	4	2	3	3	2

Table 1.4: ***Detailed Demographic Information (n = 15)***

Participant's Age (years)

Frequency

Age Range (years old)	Frequency
25-30	1
36-40	4
41-45	6
46-50	2
51-55	2

Mean	40
Median	44
Range	28-54

Marital Status

Married / Common Law	11
Divorced / Separated	4

Highest Level of Education

High School	2
Community / Technical College	5
University	8
- *Self identified as post graduate*	2

Employment Status

Employed	14
Unemployed	1
Full-time	8
- Self identified on medical leave	1
Part-time	5

Ethnic Background		
Caucasian		9
Ashkenazi Jewish		3
Ukrainian		1
Icelandic		1
BRCA1/2 Status		
BRCA 1		6
BRCA 2		9
Cancer Status		
Affected		8
Breast	6	
Ovarian	2	
Unaffected		7
Prophylactic surgeries	5	
Surveillance	2	
Age of Children (years)		
Mean age at time disclosing parents received a positive BRCA1/2 test result		12.4 (SD = 2.65)
Range		7-16
Mean age at time of disclosure		12.4 (SD = 2.65)
Range		7-16
Mean age of disclosing parents' children at time of the initial research conversation		14.4 (SD = 2.33)
Range		10-18
Mean age of non-disclosing parents' children at the time parents given BRCA1/2 test result		6.9 (SD = 4.03)
Range		1-13
Mean age of non-disclosers' children at the time of the initial research conversation		10.8 (SD = 4.56)
Range		6-17

Main Finding

The study's research question was, "What are Manitobans' parental perceptions regarding the disclosure and non-disclosure of a positive BRCA1/2 test result to an offspring who at the time of the initial research conversation are between the ages of 6 and 18, and who are less than 19 at the time of the initial research conversation?" This section concentrates on answering the research question by describing the essence of the participants lived experience.

The essence of the lived experience of parental perceptions regarding the disclosure and non-disclosure of a positive BRCA1/2 test result to minors was an overarching parental desire for healthcare professionals to take the decision-making process a step further. Approximately 89% (8 out of 9) of disclosing parents and 57% (4 out of 7) of non-disclosing parents communicated the need to 'take it a step further.' Forty-seven percent of the study's sample population (disclosure and non-disclosure) admitted to being armed and ready to share or not to share BRCA1/2 test results. Although, the majority (72%) of the 47% also supported the concept of 'taking it a step further' in order to better meet specific needs of parents and children regarding the disclosure and non-disclosure process. Despite the fact that 47% of parents admitted to feeling prepared to engage in the decision-making process they still preferred to have had healthcare professionals to *'take it a step further.'*

Take it a Step Further

Parents described the various healthcare disciplines they encountered along the genetic testing journey as supportive and informative in explanations related to BRCA1/2 test results, pathology reports, and available surgical and surveillance options. However,

the majority of parents requested supplementary professional support specific to the topic of disclosure and non-disclosure of BRCA1/2 test results to minors. In other words, parents expressed a need for healthcare professionals to take the discussion 'a step further.'

> "I mean any healthcare provider or doctor in explaining to somebody that they have this genetic result should take it a step further. If you want to share the information with them (children) but you're not sure how to do it, you know, maybe there could be some assistance in that regard." [Parent who has a positive BRCA2 [2011], unaffected cancer status, and 2 children [ages at time of disclosure were 11 and 14]).

Other disclosing parents supported the sentiment that care providers needed to 'take it a step further' which is illustrated in the following quotes.

Parent 1 explained:

> "Um. You know I think there probably is a gap there. There is (pause). It is sort of weird one because you're not telling your child that you have cancer. You're telling them that you have the possibility of having cancer or a heightened possibility. So I think it probably should be acknowledged that that's a tough decision." (Parent who has a positive BRCA2, [2011], unaffected cancer status, 1 child, [age at time of disclosure was 14]).

Parent 2 added:

> "Um. (thinking). Well I think like after they told me and when we're discussing things I guess it should have been brought up at that time. But they kind of went. Because like, um, kind of a little bit of in a shock. So like after you discuss it for a while, I guess it should have been brought up about our children, yea. I know this is a lot of information for you. I don't know if you've given thought about the children as to whether or not you will be sharing your test result with them. Have you? We have supports to help in this decision process. That's what I think before you even go home because by the time I got home I already decided to tell them." (Parent who has a positive BRCA1 [2009], unaffected cancer status, and 2 children [ages at time of disclosure were 14, 18]).

Parent 3 shared:

> "When we first met with [name of member of genetic team] and [s/he] shared the information with us about being positive with the BRCA 2 gene probably a follow-up appointment would have been helpful. It was a lot of information to

process. I was completely surprised. Both my husband and I were completely convinced that this was just a formality and that the result would be negative, and we would move on with our lives. …[Name of member of genetic team] might have suggested that we think about how we want to proceed with the information. Um. I was, at that time, feeling very, I don't want to say pressured but I really felt that need to get the information out to the rest of my family as in my cousins because I have many female cousins that are the same age of me. And so I did feel the need to share the news with my aunts and uncles and cousins fairly quickly just so they could be aware of their risk and get whatever testing need to be done to help them out. But whether or not to share it with my children, it really wasn't talked about. And so probably would have been helpful to have a second interview just to have sort of put more thought into that decision." (Parent who has a positive BRCA2 [2012], positive ovarian cancer diagnosis, 2 children, [ages at time of disclosure were 11, 13]).

Parent 4 stated:

"I think the conversation should be opened. Honestly, I don't remember if someone had said, you know, obviously this affects your children. Um. And maybe even, like an appointment around that because I guess at least from a the female perspective there's a lot, I don't know, hurry but it seemed to me like there was a lot of decisions to make and it was kind of quick. It's sort of a lot around me and figuring out which surgeons and everything. But not really supports around. I guess maybe we could have had a conversation with somebody about, okay, so what are the things to think about. And not that I would have then wanted to be told, but it is one kind of medical diagnosis where it does affect others because it's genetic, right. Um. And it sort of seemed to be well someday they'd have to think about getting tested. But as far as disclosing it to them, there was no discussion or support or help. So I think it's worthwhile. They care for me and prophylaxis but, there's also the whole, this is now a part of my family." (Parent who has a BRCA1 [2011], unaffected cancer status, 3 children, [ages at time of disclosure were 13, 15, 15])

The following was from a non-disclosing parent who also advocated for the notion of 'taking it a step further:'

"I think that even though it may be a difficult topic for some individuals, I think it's an important one for health care professionals to raise. Not to push information on people but I think just a topic that has to sort of be out there. And then hopefully there'll be some resources that you can refer them to or make an offer to meet again to discuss this at whatever point in time." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15]).

Armed and Ready to Go. The following excerpts are two examples of parents'

readiness to disclose and not to disclose test results to minors which also illustrates parental self-preparation as instrumental in the decision-making process.

> Interviewer: I hear you saying that yourself and your husband made the decision to disclose your BRCA test result to your children. Were any supports provided to help you prepare for the discussions with your children?
> Participant: I don't think that we necessarily need it. Um. Just because I think we just made it part of the big conversation. (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [age at time of disclosure 9, 6 [not disclosed], 18 months [not eligible]).

A second disclosing parent described her readiness to share based on a self-assessment that the information was "not earth shattering" because she was mentally prepared for a positive result. Whilst a third disclosing parent continually described a strong moral and ethical conviction to honesty; consequently, disclosing was not "an issue in my mind."

Parent 4 noted:

> "I don't think it was a topic as far as I can remember. And I'm sure there are things that [name of member of genetic team] discussed with me that I don't remember. I do not remember it as being part of the discussion. What we talked about is when is the proper date for [child's name] to do genetic testing which is a completely different question I think."

This participant went on to say:

> " … It's my privilege to work in this field so I have people around me who I can bounce off my thoughts as a way. I can go directly and say, how? Other people will not have that." (Parent who has a positive BRCA1 [2012], breast cancer diagnosis, 1child [age when parent given BRCA result was 6]).

Both categories of parents endorsed the need for assistance in the area of parental disclosure and non-disclosure to minors. In other words, care providers needed to 'take it a step further.' A detailed account of parents' recommendations to healthcare professionals and BRCA1/2 parents follows the review section titled themes and sub-themes.

Themes and Sub-Themes

The essence of an overarching parental desire for healthcare professionals to take the decision-making process 'a step further' is reflected in the following themes: 1) influential factors, 2) testing is a family affair, 3) decision making and family communication, 4) the inner circle, 5) knowledge deficit, 6) supportive resources, and 7) parental recommendations. This section describes the themes and sub-themes that materialized from conversations with study participants.

Influential Factors Regarding Disclosure and Non-Disclosure

Disclosing and non-disclosing parents described similar *influential factors* in their decision to reveal or not reveal genetic information to younger children. This section discusses aspects cited by both groups of parents (disclosers and non-disclosers) regarding their decision-making which included children's characteristics and awareness, and parental insights. The issue of family dynamics stands alone as a consideration for disclosing parents. See Table 1.5 for a summary related to theme and sub-themes for 'Influential Factors Regarding Disclosure and Non-Disclosure.'

Children's Characteristics & Awareness. Collectively parents described the sub-theme children's characteristics and awareness as a factor taken into consideration when faced with the decision to disclose or not to disclose. The features of the sub-theme included children's cognation, age and maturity, emotional health, and gender. Another element of the sub-theme was disclosing parents' decisions were also influenced by previous awareness of family cancers.

Cognition, Age, and Maturity. Despite parents perceived need for healthcare professionals to take the genetic conversation 'a step further' disclosing parents

Table 1.5: ***Summary of Influential Factors Regarding Disclosure and Non-Disclosure***

1. **Influential Factors Regarding Disclosure:**
    a. *Children's Characteristics & Awareness*
        i. Age, cognition, and maturity
        ii. Emotional health
        iii. Gender
        iv. Previous awareness of family cancer(s)
    b. *Parental Insights*
        i. Preparation for the future
    c. *Family Dynamics*
        i. Honesty
        ii. Parental responsibility
        iii. Importance of family history
        iv. Family response and secrets
        v. Participant's parent decision not to share family history
        vi. "Part and parcel"
        vii. Group prayer
2. **Influential Factors Regarding Non-Disclosure:**
    a. *Children's Characteristics & Awareness*
        i. Age, cognition, and maturity
        ii. Emotional health
        iii. Gender
    b. *Parental Insights*
        i. Preparation for the future
    c. Factors Influencing a future disclosure

communicated results with minors within one to two months of receiving a BRCA1/2 result. The decision to disclose was based on parental knowledge of individual children's chronological age, cognitive development, and maturity. Parent identified the initial conversations was a building block for continued discussions.

The average age of children at the time of disclosure was 12.4 years which also accounts for children's age when parents received BRCA1/2 test results. Children's age range at the time of disclosure was 7 to 16 years. Parents of older children self-identified that if their children were younger they would have either delayed the conversation due to perceived concerns related to developmental readiness, or proceeded to disclose, but selectively share information based on developmental needs. Overall disclosing parents

felt their children were “old enough” and “mature to handle it.” The following examples illustrate the above commentary.

Parent 1 specified:

> “So he does not fully understand the ramifications of being tested positive. I don’t think he will be able to really comprehend that. Probably there’s a reason why that kids are not adults until they’re 18 because their brains are not developed enough. So, yes, I’ve told him. Does he even understand what it means? I would beg to differ.

This parent later added:

> “…Obviously our conversations will be changed over the years to match his comprehension of what’s actually happening or what it means.” (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7]).

Parent 2 divulged:

> “… They’re old enough to understand this stuff now. I mean if they were younger, perhaps I may have waited. … If they were 8, that might for me just be a bit too young to share some complicated information with them. Um. So their age and their ability to process the information I think was a relevant factors in choosing to share. You know, when you’re in middle school, when you’re in high school you start to develop that abstract level of thinking. You’re not as concrete a thinker, oh my gosh, she’s got this. This is what’s going to happen. You can process more information in there. They have better problem solving skills. They better comprehension skills. Both my kids thankfully are doing very well academically so they have that level of ability to understand some complicated information. Yea. I believe they have the ability to understand that just because I have this diagnosis does not mean I’m going to get breast cancer. All it does mean is we know my risk is increased from the general population.” (Parent who has a positive BRCA2 [2011], unaffected cancer status, and 2 children [ages at time of disclosure were 11 and 14]).

Parent 3 noted:

> “You know if my child was 5 years old when I had this test, I never would have told her anything. I wouldn’t have. … I think (pause) it really depends on the individual child. I would think that if my daughter were younger, she would not be able to even really understand the information of what genetics are and how it works. That would be really foreign to her. Then you wouldn’t even have kind of a place to begin and not, you know. So I think that there could be a lot of misunderstandings and things could become very. I think it would be real easy for

> a younger child to think that a BRCA2 positive means that their mom's going to get cancer. Or that their mom has cancer. … I would just have told her a very limited amount." (Parent who has a positive BRCA2 [2011], unaffected cancer status, one child [age at time of disclosure was 14]).

Parent 4 stated:

> "I told my children because they were old enough to understand. … I feel I did the right thing. I feel it was good. I just know that I couldn't have kept things from them being the age that they were. They were old enough to understand what was happening because of what was going on. I probably would have done the same thing if I had to do it over. Maybe if my kids were younger when this happened, I think it would have been a different story. They were mature enough to handle it."

This parent later went on to say:

> "If my kids were younger, like say if they were 10 or when they were 11 and like younger than that I wouldn't have probably had told them. Because that's too young to process something like that. But being both teenagers and like she knows all about, I mean she has her period, like she's mature." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14 and 18]).

Non-disclosing parents also cited age, cognition, and maturity as their rational for deferring initial genetic conversations with children. All non-disclosing parents shared they fully intend to "have this conversation" with their children in the future. The approximate years that elapsed since non-disclosing parents received a positive BRCA1/2 test result and the initial study conversation were 2.5 years.

Collectively non-disclosing and disclosing parents accounted for similar decisional influential factors. The mean age of children at the time that non-disclosing parent's received a positive BRCA1/2 test result was 6.9. The average age of children of disclosing families at the time that parents received test results was 12.4. Subsequently, children from non-disclosing families were 5.5 years younger than children from disclosing families. The younger ages of the children at the time of parental confirmation

of a positive BRCA1/2 test result contributed to the decision to delay communications. Disclosing parents felt that children were "old enough" to understand the information while non-disclosing parents held the belief the children were "too young" to "understand it fully." Moreover, disclosing parents admitted if their children were chronologically younger an alternate path would have been chosen. Hence, children's age and cognition were part of the parents' deliberation process along with parental assessment of children's individual characteristics. Like disclosing parents, non-disclosing parents supported the views that with age comes maturity, the ability to think abstractly, and children's problem solving skills are advanced. Non-disclosing parents made the decision to postpone the conversation versus the initiation of a tailored age appropriate discussion. See below for supporting passages.

Parent 1 explained:

> "Like she's six years old. She doesn't understand. She knows I've been through surgeries. She knows, she doesn't understand. It's too complex for a 6-year-old's brain. But when the time comes when she's old enough I will explain to her that there are test available if you want to pursue it, but I don't think I'll let her know that her mom is BRCA2." (Parents who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age when parent given BRCA result was 5]).

Parent 2 expressed:

> "I think one major factor is her age. She is a very mature 7-year-old and I don't think there is a sudden age where I would say I would have told her if she was 12 or 14 or 15. With everything that we've been through with her knowing that I'm sick, she knows I have breast cancer. She never said I had chemo. She is too young to understand all the implications of what it means. I do believe I will have this conversation with her later on. …I want her to be able to have some abstract thinking to be able to conceptualize that a gene does not mean that you will get the disease. That genes are expressed in different ways, and some people will have it at 18 and some people will have it at 48 and there is no way we can know. So it's not her age, it's her level of maturity and abstract thinking. She's not ready yet. She doesn't have abstract thinking to understand what genetics means. I don't think she needs or she wants to know yet." (Parent who has a positive BRCA1 [2012], positive breast cancer diagnosis, 1 child [age at time parent given BRCA

result was 6]).

Parent 3 articulated her reason for non-disclosure was related to age because she did not want to:

> "…Burden him with information that really we're not going to be able to take any steps beyond that given that he's a minor. I didn't feel that there was really any benefit in telling him. So that's one of the reasons why I haven't given that information to him at this time. I know they don't do genetic testing on minors."

This parent later added:

> "Like right now he's 17 so he's got a lot of thoughts. Just the way he communicates right now, um, in my eyes he's just not mature. He's not mature in the way he thinks of responsibility, he's very egotistical right now. He's kinda not really interested in anybody else but himself and his friends. I just don't think he'd be interested in it or, again, would understand. I could be wrong but right now that's what I'm thinking." (Parent who has a positive BRCA1, positive breast cancer, 1 child [age at time parent given BRCA result was 15]).

Emotional Health. A second distinct element in the sub-theme children's characteristics and awareness was parental concerns regarding children's emotional health as parents desired not to negatively impact an offspring's psychological state. Some parents realized there own emotional stability at the time of disclosure would play a role in children's response. Therefore, parents were cognizant of the importance of being emotionally prepared to disclose predictive testing information to kinship.

Both categories of parents (disclosing and non-disclosing) assessed the impact of genetic information on children's anxiety levels as part of the decision-making process. Parents primary concern was not to increase children's level of anxiety or cause them unnecessary worry. Part of the deliberation took into consideration current and past family stressors, children's personal health requirements, and how or if genetic information would benefit children. The following passages support disclosing and non-disclosing parents concerns regarding children's emotional health.

Parents 1 explained:

"I kinda don't want to put that on her. I don't want her to think about that. I don't want her to sort of feel like I did because I don't want her to think there's something wrong with her. She can't lead a normal life because of this. I know it's not as bad as being told you're paralyzed or I mean actual cancer but it's pretty detrimental to your mental health, your emotional state." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5]).

Parent 2 uttered:

"I have a daughter who has some anxiety. Didn't want to instill unnecessary anxiety in them. I don't know right now if it's worthwhile them knowing that because science is going to change so much by the time they're at that point. And I want them to make decision about having children, not having children, you know, even if they're little, but based on that. I didn't want to have a cloud on them. Um. Anxiety for them." (Parent who has a positive BRCA2 [2012], unaffected cancer status, 2 children [ages at time parent given BRCA result were 9, 11]).

Parent 3:

"He had just gone through a lot of cancer. I went through cancer, a lot of treatments. I've had two primaries. Since he's been two he's been through me have cancer pretty much most of his life. When he was 3 my mother also passed away from cancer. His grandfather died from cancer probably around that time as well. So there's been a lot of cancer. I don't really know how this has affected him as far as his fears, whether he's even thought about whether it would happen to him. He hasn't shared that with me. So I just felt it would have been inappropriate and may have just scared him."

This parent later when on to share:

"…I didn't know how he would process it, the fear or worry that he would get. They got a lot going on as teenagers. …I don't really see the point when they're young. I don't think they understand it and they might take it the wrong way and it could affect something psychological that you don't know about and they carry through for the next 10 years. And maybe at that time it wasn't handled right or they didn't process it right." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age at the time parent given BRCA result was 13]).

Parent 4:

"…And I mean it wasn't going away. By not telling her I think that would have caused more anxiety than telling her. I probably would have maybe waited a

> little bit. Um. Unfortunately she was having some health difficulties as well, and the treatment that was indicated for her problem was to go on birth control pills at the age of 14 and I had misgivings about her doing that without her doctors having all the information that she had a 50% chance of being, uh, BRCA 2 positive. And, so I told her at the same time. …There were things going on and I knew that she was observant, she's a smart girl, I knew that she would recognize that things were different and that would cause anxiety for her. She would know if somebody was lying to her or keeping things from her because she's very sensitive that way." (Parents who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Parent 5 noted:

> "I think my ultimate intent is to share. But it's not straightforward. I have a son with special needs. He has a significant anxiety disorder. …His anxiety disorder has been severely impacted by my situation the past two years. First having had the prophylactic hysterectomy and more recently the mastectomies. So it's something that at some point I think will be important for him to know but I'm not quite sure when, at what time frame that will be."

Later this parent added:

> "In addition to the anxiety disorder my son has other challenges and that's really my big concern is not causing him to worsen or struggle even more than he has to day-to-day now. … My approach is to first do no harm. And there was no benefit to telling him at this point in time. Basically the only thing that I thought that it would do would just increase his anxiety overall the other sort of challenges that he's had this year. The changes in our routine and things like that have been hard on him. So it would just be giving him information that he would be doing nothing with. It didn't change anything at all in terms of what I had done or his experience of what I had done. So there was really no benefit to telling him at this point. Except in a negative way. I mean because it's going to cause him worry." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15]).

Parent 6 simply added:

> "Like emotionally, cognitively. She's got a good head on her shoulders. And very aware of her surrounding and what's going on and stuff like that. And I just felt it would be very beneficial to her." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [age at time of disclosure was 16, 20 – not eligible]).

Parents acknowledged that stressors related to receiving a BRCA positive test result went well beyond the disclosure of test results to children. Despite the multitude of

stressors 60% of study participants consciously choose to communicate BRCA1/2 test results to minors because, it was part of "three dozen" issues impacting the family. This was illustrated in the following disclosing parents story.

> "It wasn't a heavy sadness just because we had three dozen things to be sad about. Because for me, I found out that day before I went for my double mastectomy. So in our household the genetic testing part was inclusive in the big gigantic circle of surgery and chemo and cancer diagnosis and all that. So the role it played wasn't that huge of a role." (Parent who has a positive BRCA 2, breast cancer diagnosis, 3 children [ages at time of disclosure were 9, 6 – not disclosure, 18 months - not eligible]).

In contrast, 43% of non-disclosing parents self assessed a personal need for emotional stability prior to the disclosure conversation. The first parents admitted that they carried a sense of guilt and anxiety because they felt distraught about the possibility of passing on a deleterious mutant BRCA1/2 gene to an offspring. A second affirmed emotional fragility at the time of receiving a positive BRCA1/2 result while the third parent was conscious that her emotional reactions may be mirrored by her child. Consequently, these parents acknowledge time was needed for them to emotionally heal before the commencement of a disclosure conversation.

Parent 1 shared:

> My "anxiety and a little bit of guilt for me probably too. You sort of feel like you've passed on this shitty gene. …Uh, I just wasn't sure if I was in a space where I was emotionally ready to share with them." (Parent who has a positive BRCA2 [2012], unaffected cancer status, 2 children [ages at time parent given BRCA result were 9, 11]).

Parent 2 added:

> "If you're going to tell your child about something and you're going to look sacred or be sad, then that's how they're going to respond. I want to make sure when the time comes I'm emotionally in a space where it not going to trigger something that I'm going to start crying." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age at the time parent given BRCA result was 13]).

Parent 3 shared:

> "When this was all occurring, I lost my baby, I lost my husband, I lost my job. There was a lot of stuff going on. So that's one more thing. It's like, whatever, you know, what's next. … I think it's going to be very emotional (future disclosure conversation). Um. I mean I've been through it so I'm still emotional about it because it's very fresh. But by then (future conversation) it won't be that big of a deal for me. What will be painful for me is to know that my daughter has to go through what I went through. The possibility is there." (Parent who has a BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5]).

Gender. Twenty percent of the study participants acknowledged that children's gender played a role in their decision-making process. These parents acknowledged an understanding that the associated risk for cancer related to a mutant BRCA1/2 gene was higher for females compared to males. Two disclosing parents and one non-disclosing parent accounted gender as a factor that was contemplated.

Parent 1:

> "Well I felt that especially since they're boys and the way it was explained to me was that BRCA2 has fairly high risk for women, but not necessarily high risk for men or boys. They could proceed through their lives just being well monitored and being aware of what information means to them, but that it wasn't necessarily something that they need to worry about or be scared about. Their risk, if they have those defective genes wasn't something that they needed to necessarily be too overly worried about."

The above parent later went onto to say:

> "…They were male. The risk to them are not as high as they would be to females so I felt that it wasn't information that they needed to be scared of. I felt that they would then be well equipped to deal with the information and take the necessary precautions through their lives in being aware that this is a potential risk in their life but it's not a high risk" (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [age at time of disclosure were 11 and 13]).

Parent 2 added:

> "…They're boys. I think it was I guess less, that part was less worrying in terms of what it. Not that they will be totally unaffected but just, um, it might be less to them, or less problematic for them." (Parent who has a positive BRCA1[2011],

> unaffected cancer status, 3 children [ages at the time of disclosure were 13, 15, 15]).
>
> Parent 3:
>
> "…I think the fact that he's a male and it's BRCA1 and really with BRCA1, what I've been told is that the risk for prostate and pancreatic cancers are relatively, are not that significantly elevated as they are with BRCA2. You know the fact that he's doesn't have, or I mean there is the elevated risk of breast cancer given, for men. But I sort of feel like there's not the same urgency similarly as a girl." (Parents who has a positive BRCA1 (2009), breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15]).

Previous Awareness of Family Cancers. Twenty-two percent of disclosing parents admitted children's prior knowledge of family cancers play a role in the decision to communicate BRCA1/2 results. As a result of "cancer being a household word" some parents felt their children would be better prepared for a disclosure conversation than children who were not exposed to a world of cancer. However, not all parents who admitted to a family environment infiltrated by cancer shared that known cancers in the family impacted the decision to disclose.

Parent 1 shared:

> "…There's a lot of cancer in my family. My parents both died of cancer and my kids have seen a lot so I chose to disclose to them. … My daughter was helping to look after my mom who had breast cancer. I was left with them at home so my children were always here. Like they died at home and I looked after them. And my two nieces passed away so they knew all of this was happening. I know my son definitely was of age, and my daughter she's very close to me and it's just something that she had to know because eventually down the road she's going to have to know anyways. …My kids have been around people with cancer since they were like 5. Like when my parents were sick my daughter would have been maybe 6 and my son 10. When my mom passed away 7 years after she was diagnosed, my daughter was 10 and my son 13. So they've kind of been around people all the time. And like I told you, I looked after them at home. And they were here with me. They saw a lot. Not many kids would see that. They did. So my children are more aware of that kind of stuff than others would be." (Parent who has a positive BRCA1 [2011], unaffected cancer status, of 2 children [ages at time of disclosure were 14 and 18]).

Parent 2 conveyed:

> "I would say the main reason why I decided to tell my children was for the fact that I had to live through my mom dying of cancer. And my father had cancer and my nieces. And it's just, I want them to know what it's like to have to deal with somebody who's going though cancer. And now they both have been around people who have had cancer. So they have a sense of knowing what it's all about and what the outcomes can be. …Yea. Like we've always been open with what my mom had gone through. What I went through with my mom and my girlfriend dying at a young age from breast cancer too. That cancer's like a regular word in this house. …So I think if they're brought up in the environment where people are talking about cancer all the time who've lived thought it, have had family member with it, I think the processing is a lot easier that somebody who's never ever had to deal with somebody with cancer. I just told them because it was, like I say, it's a household word in our family. And just them knowing that their chances now being affected by it personally that they could have it as well. Or it could happen to them down the road." (Parent who has a positive BRCA2, unaffected cancer status, 2 children [age at the time of disclosure 16, 20 – not eligible]).

Parental Insights. This section looks at the sub-theme parental insights which takes into consideration the wisdom of parenthood that naturally influenced decisions to reveal, or not to reveal BRCA1/2 test results to minors. Differences were assessed regarding the rational between disclosing and non-disclosing parents' decision-making process. An overwhelming percentage of all parents (93%) noted preparing children for the future as the reason for communicating test results. Disclosing parents (53% of the 93%) cited sharing family history, body awareness, and the promotion of children's self-advocacy as the primary reasons for parental communication. In contrast, non-disclosing parents reasons for not communicating test results included the desire to implement life and critical illness insurance, the avoidance of children making rash choices, and advancements in future technology.

Preparation for the Future. Eighty-seven percent of disclosing parents' comments supported a parental desire to enhance children's awareness of their families' genetic history. Most parents shared the belief that family health information would

promote healthy behaviors and prepare children for self-health advocacy. Parents believed it was vital for minors to be knowledgeable of genetic information because, "…it's a disease they could possibly have…" and "…in the long term it could potentially affect them …" Parents viewed sharing genetic information was positive because it would empower children to be "proactive." The decision to disclose was summed up by one parent who professed, "This is not a crisis it's just a glitch in the genetics" and "it was a no brainer for me to disclose."

This parent went on to say:

> "There's things that we can do and I think it's okay for them to know this. It's not a huge secret to me. It's just what would be the difference if you had diabetes in your family. Are you going to keep that all a secret? A positive test result to me wasn't a crisis." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at the time of disclosure were 11, 14]).

Parent 2 shared:

> "I just feel very strongly that it's a positive thing in our lives that we're able to have these tests to help us make decisions in our lives about our health care. I didn't see or view it was a negative thing but rather a positive thing where we could then be proactive and proceed with health care decisions." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, children 2 [ages at time of disclosure were 11, 13]).

Parent 3 added:

> "It's a disease he could possibly have so why would you hide it from somebody? Reminding him of proper lifestyle and choices you do have that in your back pocket that you can enforce it a bit better the reasoning behind eating, having a healthy lifestyle and eating right, and taking care of himself." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at the time of disclosure was 7]).

Parent 4 noted:

> "…She's getting to an age where she is making more decisions about her own health care. And even if she had not had that specific health condition she's getting older, um, she's making decisions about her diet and whether or not to

consume alcohol or to smoke. If you are BRCA2 positive, you shouldn't smoke. I guess I wanted her to make the most informed decisions about herself." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

The subsequent four disclosing parents reinforced the similar opinions:

Parent 1:

"I know they are getting closer to being 18. Although we would support them whatever their choice is, we would feel quite strong that they should be tested themselves and be very mindful of that part of their family history, especially with their doctors and just being monitored. I try to continually educate them as things come out that are new or if things that are found out stay the same. Um, just to encourage them to be tested and remind them that just the positive test doesn't mean that they're getting cancer but it's just something to be mindful of. Just to pay close attention." (Parent who has a positive BRCA 2 [2009], left breast cancer, 3 children [ages at time of disclosure were 9, 6 – not disclosed, 18 months - not eligible]).

Parent 2:

"I think it's important for them to know because for their history when they get older, when they have to start going to the doctor more often, they need to do a family history. That's why they need to be aware of what they need to look for if they have any issues. …I think they should know for their future health and for their generation. And for their children. Just so you're aware. That if you do have any problems or something does crop up in your medical history, you know this could be part of this or could this be happening because of this. You should know your family history. …I think it is important to tell the kids because they need to be proactive with their own health when they are older. Being proactive is important because it is your life. You need to know as much information, within reason, so you can make clear decisions, choices in life." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages at time of disclosure were 9, 12]).

Parent 3:

"I was aware that it is part of their heritage as well. So it's part of their genetic make-up, potentially. I think in some ways it's part of our family story, because there's been so much deaths of women on my dad's side of the family before I was born. It's certainly something that I was always aware of." (Parent who has a positive BRCA 1 [2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

Parent 4:

> "Made the decision to tell them due to my family history because there's such a huge history of cancer that I thought it was only fair to let them know what their chances are and possibilities of them when they, developing cancer and a possibility of myself developing cancer….And the potential consequences of what that may mean to them in regards to their lifestyle. Just so that you know that if there's anything that doesn't seem right that you don't just leave it. You have it checked because you can get cancer at any age. It has no barrier around your age." My daughter is, "more in tune with her body and possibly checking herself more often. Just being aware that there could be changes going on and what it could mean, what the outcome could be. And that if she has any issues that she seeks medical attention right away." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [age at time of disclosure were 16, 20 – not eligible]).

In contrast to disclosing parents, non-disclosing parents forethoughts regarding children's preparation for the future concentrated on ensuring life and critical illness insurance policies were first implemented, the delay in disclosure would avoid children from making impulsive life altering decisions, and the belief that changes in technology would inevitably lead to advancements in surveillance, prophylactic, and chemoprevention choices. Consequently, a deferral in disclosure allows for parental planning and the natural sequence of life events to unfold. The next two examples support the above claims. The first example speaks to a parent's concern for the provisions of insurance and the second relates to the avoidance of rash decisions.

Parent 1:

> "One of the biggest things for non-disclosure right now is life insurance. That's a huge thing because if he tested and receives a positive result he won't get life insurance. I mean, no that he won't but it will really make it difficult for him to get life insurance and critical illness insurance. That's the main reason. …So as far as that goes like that's why I think, I wish insurance companies and people would get their head around that because this knowledge can actually prevent a lot of deaths. …We (the parents) talked about it recently, like in the last 6 months about life insurance and this gene and getting that in place before disclosure." (Parent who has a positive BRCA 2 [2008], breast cancer diagnosis, 1 child [age at time BRCA result given was 13]).

Parent 2:

> "I think it's important to not hold it from her, but I don't want her to feel like she has choices to make immediately. It's the rush right. I don't what her to feel like she has to do this now. Whether it be the surgery or whether it be to have a child. I'm going to lose my ovaries and then that's it, you know. So I don't want her to feel obligated to move forward quickly, but I think she has the right to know." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of BRCA result was 5]).

Twenty-nine percent of non-disclosing parents communicated advancements in technology as playing a role in the decision-making process. The following quotes briefly underscore the aforementioned point.

Parent 1:

> "I don't know right now if it's worthwhile them knowing that because science is going to change so much by the time they're at that point. Just don't know that it's pertinent for them at this moment. Like it will be later. But at this moment in time it's not pertinent to them." (Parent who has a positive BRCA2 [2012], unaffected cancer status, 2 children [ages at time BRCA result given were 9, 11]).

Parent 2 collaborated with the above as she indicated:

> "Um. Mind you technology will be so far advanced by then it may be a lot easier for her. She has to make a decision and I know how hard that decision was to make. So my empathy will be with her for sure." (Parents who has a positive BRCA 2 [2011], unaffected cancer status, 1 child [age at time of BRCA result was 5]).

Family Dynamics. This section addresses the sub-theme family dynamics which was unique to disclosing parents as factors impacting decision-making. Family dynamics reflects daily family expectations, conduct, and interrelationships. A hundred percent of disclosing parents' stories revealed some aspect of honesty, established relationships, and / or part and parcel of everything as influential decision-making factors.

Honesty. Fifty-six percent of disclosing parents shared that the principle of honesty guided the decision to communicate BRCA1/2 test results to children.

Parent 1:

> "We decided along with the cancer diagnosis and the positive genetics to not hide anything from our children. Not to scare them but just to make sure they were mindful of what was going on. …We felt it was important to let him know. Um. I guess we didn't feel that it was something that we needed to keep from him."

This parent went on to express her irritation with her parents' because they refuse to be open about their genetic testing information. She briefly added that their family secrets coupled with her commitment to honesty had influenced her decision to disclose.

> "I have expressed frustration to both my parents. My father just has not been tested. He has no desire to be tested. My mother has been exceedingly secretive of whether she has been tested or has not been tested. Whether they are or not tested won't affect me any more than I've been affected. …This medical information affected me and my health. And so that definitely pushed my husband and I to chose to make sure that we did tell our children …" (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [ages at time of disclosure were 9, 6 – not disclosed, 18 month – not eligible]).

> Parent 2:

> "It was never even thought of as being an option of whether I would or not. I didn't even question it. It was not an option that I would not tell my child. It's the truth. I wouldn't lie to somebody or mislead them. I wouldn't lie or mislead a child, or my own child. …I don't like to lie and I could never uphold a lie for that long. I could not carry on that lie for 6, 8 years, or however old until he was an adult." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 children [age at time of disclosure was 10]).

> Parent 3:

> "Well I think I want to be honest with my daughter. I think that's really important. I didn't want her hearing information and wondering why I never told that to her. I wanted to have a very honest relationship with my daughter. That's one of the reasons that I told her. I wanted to show respect to my daughter and that's why I wanted to tell her." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

> Parent 4:

> "Um. Probably we're a very close family and we discuss everything. So if I kept it to myself they would have noticed that something was wrong. They would have been able to tell that something was bothering me so I find it easier to talk about things that are going on than to keep them inside. (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure

was 14, 18]).

Parent 5:

> "They had been such an active part of the cancer journey. Um. And so I felt that it was important to be very honest and up front with them about what we were dealing with." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11, 13]).

Established Relationships. Parents' testimonials illustrated a sense of responsibility to communicate BRCA1/2 test results to minors because of established relationships and family norms with children, extended family members, and the larger community. At least 33% of parents' thinking process was prompted as a direct result of personal interactions with individuals which is captured the following three passages. The third example addresses how established relationships, and family routines at home and in the community influenced a parent's decision-making.

Parent 1:

> "Um. Because both my parents chose to not disclose to me. But obviously one of them carries. And it's not a blame thing but it's frustrating from a grown-up child's perspective not to be told. Even though I understand that they're individuals and they have the right to their own medical information, their own privacy and whatever. But this medical information affects me, and my health. And so that definitely pushed my husband and I to choose to make sure that we did tell our children and to be up front with our children about it." (Parent who has a positive BRCA2 [2009], left breast cancer diagnosis, 3 children [age at time of disclosure was 9, 6 - not disclosed, 18 months – not eligible]).

Parent 2:

> "…I was on the phone with the doctors and like I know that she would have been listening. I knew it would have increased her angst and left her wondering what, is something wrong with mom because something was wrong with auntie, something was wrong with grandma? I had to have that discussion to let them know that nothing's wrong. This is what it is. I think rather that them sitting and wondering and worrying, it was more important that I just laid the cards on the table for them." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure was 11, 14]).

Parent 3:

> "Um. Well they were teenagers, right. So they are kind of stressful. And so I said, you know I can't handle all of your stuff as well as I might want to because I have this going on in my mind as well." Part of the decision-making was also influenced by the fact that "we pray as part of our regular family routine. I guess so then we would pray about items like that. ...You know I should probably add that's one of the reasons that we would have told them is because other people were knowing. Again because of our faith community."

Later the above participant shared how her brother's reaction to the information impacted her decision-making:

> Interviewer: Did you seek out the advice from your own family members as to whether you should, or should not disclose?
> Participant: Um. No, not I would say advice. But I mean certainly I think more listening to how they reached to knowing about the gene in our family. I'm the oldest so I'm used to being the one to lead the way, and give the advice. When my brother reacted actually quite strongly finding out that he was also positive. I sort of took that into consideration about, okay, that's the only man I know of. He's got it. He wanted to know. He was very keen to get tested." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 3 children [ages at the time of disclosure were 13, 15, 15]).

"Part and Parcel" of Everything. The confirmation of a mutant BRCA1/2 test result entered participants' lives with an assortment of decision-making. Additionally, a positive BRCA1/2 result is sometimes accompanied by a positive cancer diagnosis, which compounds a complex decision-making process. Parents expressed reasons for disclosure was based on the following: 1) a double dose of stress, 2) life had notably turned upside down, and 3) the children's involvement in the process from the beginning. The following quotes account for 56% of the study's sample population which supported the decision to disclose based on the notion of "part and parcel" of everything.

Parent 1:

> "I think it just was kind of part and parcel of getting him kind of the rundown of what things were going on. But in between that time and when I was diagnosed there were probably about 3 or 4 other diagnosis of breast cancer in our family. So

it made it more I guess more real. Well I mean honestly I think that probably if I would have had the diagnosis or had the genetics before a cancer diagnosis, I don't know that we would have necessarily discussed it with our children. Not to keep it from them but just it didn't really pertain to their lives. Um. I think that we would have probably had the discussion with our children once they reached 12 or 13 instead. Not to be hiding anything but just it doesn't affect their lives or it didn't. I think if it was a genetic decision without a cancer diagnosis then for us we wouldn't have discussed it with them until they were teenagers. …It fit into the conversation at the time in that it was pertaining to cancer and to health and to our family. So it kind of came all together." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [ages at time of disclosure were 9, 6 – not disclosed, 18 months – not eligible]).

Parent 2:

"Well basically they already knew my cancer diagnosis. And then it was now explaining a little bit more why I kinda got it. Kind of give them a quick biology lesson that they'll learn more in grade 12 about genetic and all that other stuff. Well it's just that with those surgeries going to happen this is kind of like the segue into it. These are the reasons why. I go for the surgery in February because this is what was suggested. These are the steps I have to do." (Parent who is BRCA1, breast cancer diagnosis, 2 children [age at time of disclosure 9, 12]).

Parent 3:

"Knowing that surgeries would come up. I'm not going to be able to sort of hide the fact that I'm in the hospital." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure 14]).

Parent 4:

Interviewer: What would be your top three reasons as to why you chose to disclose your test result to your children?
Participant: Um. One, it would affect them as well. Both in the long term and the short term like because of the surgery I was going to be having and I would be off work and how that would change their daily life in the short term. Why did we tell them, because I was having surgery but for them to know that I wasn't sick. Actually when your have a prophylactic surgery, it's kind of different because you're well and then you putting yourself through a surgery." (Parent who has a positive BRCA1, unaffected cancer status, 3 children [ages at time of disclosure 13, 15, 15]).

Parent 5:

"I was advised at the beginning of the test a BRCA1/2 positive was fairly low and

> so I was really actually quite surprised with the test results. I had openly shared everything with them sort of assuming everything was probably wasn't going to amount to anything. So was quite surprised when I found out that it actually I was positive for BRCA2. But all things considered my husband and I just felt that our children were mature enough to understand the context of the information. I think it was a fairly quick decision. Our children were involved. They knew that I had gone through the genetic counseling and was waiting the test result." [Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 boys [ages at time of disclosure was 11, 13]).
>
> Parent 6:
>
> "Like they didn't seem really surprised about it. I guess because we talked so much about it and I figured that there's a good chance I was positive. It's like something we talked about many times. Like they knew that I was going for genetic testing. They know why I was going for genetic testing. And knew of the outcomes from my cousins and my other cousins and their kinds and others that had been tested." (Parent who has a positive BRCA2, unaffected cancer status, 2 children [ages at time of disclosure was 16, 20 – not eligible]).

Factors Influencing a Future Disclosure. The subsequent section discusses non-disclosing parents views regarding factors influencing the future disclosure of BRCA1/2 test results to minors. The sub-themes mirror that of disclosing parents which included children's characteristics and awareness, parental insights, and family dynamics. See Table 1.6 for a summary related to theme and sub-themes for influential factors regarding non-disclosing parents future disclosure conversation.

Table 1.6: ***Summary Related to Factors Influencing a Future Disclosure***

1. **Factors Influencing a Future Disclosure:**
    - *a. Children's Characteristics & Awareness*
        - i. Cognition, age, and maturity
    - *b. Parental Insights*
        - i. Preparation for the future
    - *c. Family Dynamics*
        - i. Opportunity presents itself
        - ii. Parental responsibility
        - iii. Healthcare professionals
        - iv. Honesty

Children's Characteristics & Awareness. The theme children's characteristics

and awareness resonance with the decision-making of non-disclosing and disclosing parents. The mean age of the children when non-disclosing parents received a positive BRCA1/2 test result was 6.9 years with an age range of 1 to 13 years. The mean age of these children at the time of the initial research study conversation was 10.8 years with an age range of 6 to 17 years . All non-disclosing parents acknowledged their intent is to share BRCA1/2 test results with minors in the future. The disclosure conversation is dependent on children's self interest in their health and other personal matters. Similar to disclosing parents, non-disclosing parents remarked that children's needs and characteristics such as children's age, cognition, and maturity will guide the initiation of the disclosure conversation. Collectively, non-disclosing parents felt the appropriate time for the conversation to commence was between the ages of 18 to 30 years. The majority of parents intend to disclose during early adulthood. Parental guidelines to assess children's information readiness included eligible age for genetic testing and children's maturity level. Maturity level was equated to a specific age, cognitive abilities, health and body awareness, and / or children's interest in pursuing a serious lifelong relationship. The following quotes support the above.

> Parent 1:
>
> Interviewer: You said you are planning on telling your son in the future about your BRCA test result. Is there anything in particular that you are looking for that will make you feel it is the right time for you to tell him?
> Participant: Yeap. Maturity.
> Interviewer: Anything else?
> Participant: Whether or not he asks for more information about it. There might be something that might happen, or he might hear about. If he's asking more information about cancer, my experience, or his own health.
> Interviewer: Okay.
> Participant: Um, you know, those might be triggers. Um. Age.
> Interviewer: So what's that magical age?
> Participant: Um. Probably 23, 25. …So again, it's based on timing, when you feel

it's right and how much they would understand. Just their maturity level about the whole thing. …I also think when you're young there's just no way you think about your mortality like you do when you're older." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 13]).

Parent 2 explained:

"So when she becomes of age, or when she's 18 or 19, I may sit down and explain to her that there's a possibility. She'll definitely be an adult. I will not tell her before she's 18. That's not something I want to stress a teenager out with."

Later this parent added:

"Anywhere between 20 and 30. That's when people get into new lives with relationships and marriage and they want to have children. And I think it's pertinent for them to know before they have children that they may carry this gene because that was a huge factor for me, um, concerning whether I should have another child or not. …You have to find the right age and every kid's different. So you can't say, well when they're 18, when they're 19. It could be when they're 28. I'm still 27, that was still too young for me. In addition to my life changes and what was occurring. But you have to find the right time and the right moment and they may never be a moment. There may be a child who may be 40 before you tell them, before the moment's right. But I think it's important for them to know. " (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5])

Parent 3:

Interviewer: What things will you be looking for that will make you think this might be a good time to start opening up initial discussions on the topic?
Participant: Well, I mean it'll just depend on how mature they are I suppose.
Interviewer: Mature is a broad term. When you say mature, is there anything that you're specifically looking for?
Participant: Yea. I don't know if I can pinpoint anything in particular. I just kind of have it in my head that when but the time they turn 18, I would hope to have told them. But I don't know why, why that age is in my head. Maybe that's the age when they said that they would test them.
Interviewer: So one thing you have in the back of your mind is age as a factor.
Participant: Uh, huh.
Interviewer: And along with that maturity.
Participant: Yea.

The above parent later noted:

"I wouldn't lie about it. But I known that they don't have any understanding of

genetics and things like that. That's not entering into their brain at this point. But should they come to me before I formally want to address the issue I'm more than prepared to discuss it with them." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages when parent given BRCA result was 1, 4]).

The last three parents explained:

Parent 1:

"…By then my daughter will be 13, almost 14. They reach a different level of awareness of the body at that point. The breasts. And she'll be getting breasts, and things like that. (Parent who has a positive BRCA2, unaffected cancer status, 2 children [ages at time of parents BRCA result were 9, 11]).

Parent 2:

"I do think when she is doing biology and genetics and when she comes with questions. Um. I will be open about the fact that she has 50-50 chance of carrying the same gene. Um. I will wait for her to come with that question. Um. And her willingness to take in the information. I want to see that she needs the information. I don't want it to be for my own self-serving purposes. I want to know that she needs to know it for her own reasons. …I'm aware of the fact that it is not a permanent decision."

Further on in the conversation the interviewer asked the above parent:

Interviewer: You mentioned you would likely disclose prior to the age of 18. Why 18?
Participant: Why 18? Well when I had this discussion about having the gene test with [name of genetic department professional]. Um. [S/he] said that they would recommend for my daughter to have the genetic testing done anywhere between the ages of 18 and 25. So 18 is the legal age where she could decide to go for it and find out. And I do believe that 18 is too young to make that decision. That might be my overprotective motherness, but when we're having this conversation I would probably recommend for her to push it closer to 25. I do think we'll have this conversation somewhere when they're talking about genetics that she's going through in school. So it would be before the age of 18. (Parent who has a BRCA1 [2012], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 6]).

Parent 3 expressed:

"So that's one of the reasons why I haven't given that information to him at this time. I know they don't do genetic testing on minors. I think his anxiety disorder

> has been severely impacted by my situation the past two years. First having the prophylactic hysterectomy and more recently the mastectomies. So at some point I think it will be important for him to know but I'm not quite sure when, at what time frame that will be." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15]).

Parental Insight. The sub-theme parental insight was gleamed from the study transcriptions of non-disclosing parents as an assessment for the commencement of a future disclosure conversation. Parental insight takes into consideration the wisdom of parenthood that will naturally influence the decision to reveal BRCA1/2 test results to minors. All non-disclosing parents supported the notion that a parent should "absolutely disclose at some point" as they communicated the intent to share BRCA1/2 test results with children. However, forty-three percent of the non-disclosing parents verbally voiced the need for certain preparations to be established before the BRCA1/2 dialogue ensues. For these parents preparation was important prior to disclosure. Collectively, parents wished to ensure the implementation of insurance policies, a healthy parent and child emotional state, and pre-established supportive care for the children. Parents indicated:

> Parent 1:
>
> Interviewer: I hear you saying you are waiting for him to bring up the conversation.
> Participant: Yea. To lead… And I want to talk to his father about having some insurance in place for him before that.
> Interviewer: So insurance is something you are looking at implementing prior to any discussions with him?
> Participant: Absolutely. Like that has to be purchased. …Getting that in place before it's disclosed and before his doctor starts officially screening him for that.
>
> The above parent went on to share:
>
> "…I need to be in a space where it's not going to trigger something that I'm going to start crying. I want to talk to him like this is really valuable information as opposed to this is really horrible that this has happened to us. …Highlight awareness. Um, yeah, because awareness is key. …He really doesn't need to be worried about it right now. I mean the only thing again is the sun, sun protection,

healthy eating. And I think that just comes into general teaching as a parent anyways." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 13])

She further inserted:
"I just feel there's a huge thing going on with him right now. So this just isn't the time to have another serious discussion. Like I don't know how he'll respond and if he's going to be psychologically affected. And if he is, what is he going to do with this? …I need to be ready to share it too again so that I don't share it in a fearful way, or start crying and trigger a bunch of things."

Along the lines of parent readiness two other parents explained:

Parent 1:

"Um. Well to take my own anxiety out of it. To make it about her and not about myself. So it needs to work to sort of take me, um to be aware of my own emotional tolerances and anxiety and fear and sadness and loss." (Parent who has a positive BRCA1 [2012], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 6]).

Parent 2 added:

"I would feel compelled to discuss it with his father before sharing it with my son. …Probably prior to. And regardless I would still share it with my son even if his father doesn't feel I should, unless he came up with some really good reasons not to. But, um, yea. I would let him know as well. …I envision this will create more anxiety for my son, and so to then have some ongoing support available would be ideal." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15])

Family Dynamics. An overwhelming 86% of non-disclosing parents were of the opinion that relationships between parent and child, and among family members could impact the timing of a future disclosure. The interplay working within and between family members was similar to disclosing parents. Parents described established relationships, a moral parental obligation to honesty, respectfulness to children's inquiries and circumstantial situations as influencing the future disclosure conversation.

Parent 1:

"I don't know that if I didn't tell my child that I could live with that forever. I

> would feel guilty I think if I didn't tell her at a certain age or ever. I would feel incredibly guilty that I was withholding that from her and not giving her an opportunity to help herself.' (Parent who has a BRCA2 [2011], unaffected cancer status, 1 child [age when parent given BRCA result was 5]).

This parent went on to share:

> "I wouldn't do it anywhere between now and 18 unless she came to me. That would be a right time because she's obviously heard somewhere or she's understanding a little bit about it and she wants to know more. Then maybe that's the right time to sit down and say this is what it is."

Three other parents similarly declared:

Parent 1:

> "I wouldn't lie about it. …Should they come to me before I formally want to address the issue I'm more that prepared to discuss it with them." (Parent who has a BRCA1 [2009], breast cancer diagnosis, 2 children [ages when parent given BRCA result was 1, 4]).

Parent 2:

> "I will wait for her to come with that question" (Parent who has a positive BRCA1 [2012], breast cancer diagnosis, 1 child [age when parent given BRCA result was 6]).

The third parent admitted that her father was aware she chose not to disclosure her BRCA1/2 result to her children. However, this father chose to disrespect this mother's decision because he proceeded to share with his grandchildren that there mother's hysterectomy "was cancer prevention." This mother shared she had "never even mentioned cancer to them" regarding her surgery. Consequently, she was faced with a pending disclosure conversation, but "I haven't really thought about it that much. It's sort of if the opportunity presented itself then I would, but I haven't really been strategizing on a disclosure process at all." (Parent who has a BRCA2 [2012], unaffected cancer status, 2 children [ages when parent given BRCA result were 9, 11]).

The next two parents exemplified how extended family interactions might

influence a disclosure conversation.

Parent 1:

"I think that the reason that we haven't discussed it with the other two is more that it hasn't come up in conversation. I guess it wouldn't be something that would be a big deal to them. But definitely with middle one and the older one we will have more of a discussion with them when my sister has her surgery. I have a sister who was just given a positive BRCA from genetics. She will be going for surgery and so we will talk with our oldest two about how, just because you don't have cancer, there's still prophylactic surgeries and discuss why she would choose to that. We would probably discuss that with her and some without her. (Parent who has a positive BRCA2 [2009], left breast cancer, 3 children [age at time of disclosure were 9, 6 – not disclosed, 18 months -not eligible]).

Parent 2:

"I mean I have one sister who I'm going to talk too. We've talked about when are you going to tell them. I sort of want to stay close to her with that because my son has cousins and I don't want her child to know and then talk to my son about it. So I want to stay close with her about when and what she's talking about because that could happen between the two cousins. (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 13]).

Further on in the conversation the interviewer asked:

Interviewer: Have you thought about what you would do if she disclosed and you were not ready to disclose to your son?
Participant: That's an interesting question. Um. I might think about moving up the discussion.
Interviewer: And why is that?
Participant: Because I'd worry that he'd find out through his cousin and then not be fully informed, or wouldn't be told the proper way. So yours and my discussion is probably triggering that I need to talk about this with them more as our kids are getting older.
Interviewer: You need to talk with your sister?
Participant: With my sister. Yeah.

Testing is a Family Affair

The second theme, *testing is a family affair* speaks to disclosing and non-disclosing parents insights as to what BRCA1/2 testing means. Although, BRCA1/2 testing leads to major life altering decisions both categories of parents agree it provides

individuals with the opportunity to engage in personalized healthcare. Overall, parents viewed the results from BRCA1/2 testing as information that belongs to an entire family. One parent shared, even though "it was my diagnosis in some ways it's not just my diagnosis." Another parent added, "… He has a right for me to tell him. … I think it would be wrong to not eventually let them know that because, it could protect them down the road." A third parent compared BRCA1/2 testing to testing for a chronic illness, "It's like getting your blood tested and you've got diabetes or something. I wouldn't hesitate not to tell my child until he was 18 that I was a diabetic, and that it might run in the family. The actual environment with the environment being his age would have a factor of me bringing it up with him." Consequently, disclosing and non-disclosing parents perceived BRCA1/2 testing in a positive light, despite the decision-making process and accompanied consequences. Both groups of parents' thoughts are categorized under the sub-theme testing is a family affair. See Table 1.7 for a summary related to the theme and sub-themes for testing is a family affair.

Decisions All in the Family. The decision to proceed with BRCA1/2 testing is complex and for some the complexity never ended. However, parents learned to live with choices despite echoes of regret and guilt. Disclosing and non-disclosing parents claimed positive aspects of BRCA1/2 testing in the midst of all the complexity. Eighty-nine percent of disclosing parents and 86% of non-disclosing parents viewed BRCA1/2 testing as an act that can protect individuals because, it facilitates participation in individualized healthcare planning. Even though parents declared BRCA1/2 testing revealed valuable information they also equated testing with big decisions. Parents' decisions went beyond whether to disclose, or not to disclose. The decisions were layered by consequences that

Table 1.7: ***Summary Related to Testing is a Family Affair***

1. **Testing is a Family Affair:**
    a. *Decisions All in the Family*
        i. A Gift that Protects a Family
        ii. Equates to Big Issues

impacted not only one's self, but an entire family. Ultimately, parents perceived BRCA1/2 testing as a gift that protects a family.

A Gift that Protects a Family. A review of the transcripts supported parents deemed BRCA1/2 testing and a positive test result as a "gift." Forty-seven percent (56% of disclosing and 29% of non-disclosing) of parents' professed BRCA1/2 testing as a protective healthcare option that offered families' an opportunity to be proactive regarding early detection because, a positive test opens the doors to surveillance options. It also offers BRCA1/2 carriers the opportunity to decrease their risk factors through prophylactic options such as surgery and chemoprevention. Parents declared, "It's the greatest thing because it just gives you the insight on what your possibilities are." A second parent added, "I think it's really a great thing to have because, it just makes you more in tune with what's going on in your body." A third parent contributed, "I think it's important health information for children to have. It protects them." This parent went on to shared:

> "For my own health it's better to have the knowledge so that I could get more closely monitored. I can be more closely screened. If I didn't know I had that gene they wouldn't be watching me. And then something could happen that I wouldn't find out until it was needing much more significant treatment. …I think it's better that they (the children) know so they can also be protected …" (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

Another disclosing parent regarded a known positive BRCA1/2 result as potentially lowering her cancer risk due to the availability of prophylactic options.

> "I was glad that I had the information. I thought it was important information to have. People who are BRCA 2 positive don't necessarily get cancer. Most people who get breast cancer in particular breast and ovarian cancer, or any type of cancer, there is no genetic reason for it. I'm lucky in some ways, you know, by being really proactive, by having the two surgeries. I will have a much lower incidence of cancer than just the regular person. And so that it could be positive." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

The next parent viewed 1/2 testing as worthy regardless of the distress that may accompany a positive result because the advancements in technology offered hope.

> "It's pretty upsetting to get a diagnosis like I did, but then you have to think of other people. I just think so much of my friend that is sick right now and if she had the opportunity to have that genetic testing done maybe something could have been done for her. It's being proactive. Like if you, well 10 years ago people would not have even had the choices that I have now. Like knowing that I have the gene I can do something about it. So things are moving in the right direction." (Parent who has a positive BRCA1 [2011], cancer status, 2 children [ages at time of disclosure were 14, 18 – not eligible])

An optimistic light shines in this parent's view of BRCA1/2 testing as an optional healthcare tool because it offered control at time when an individual may feel immobilized. Furthermore, she felt testing offered a person preventative choices.

> "I didn't see or view it was a negative thing but rather a positive thing where we could then be proactive and we proceed with our healthcare decisions. …We're very much of the opinion that knowledge is power and that we can do something with this knowledge so isn't that nice that we have the ability to take a little bit of control in a situation where you can feel a little powerless at times." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11, 13]).

The following non-disclosing parent also acknowledged similar sentiments.

> "I think when you first hear this right away you think, oh, you just feel responsible for your kids that if they get sick because of you. But I don't know, I kinda look at it like it's a gift that we know. Because I think of people carry different things. But we're kind of fortunate to have this testing because then you can put the proper screening in place. A lot of, especially with breast cancer, a lot of cancers if they're caught early you can survive them." … We're kind of lucky that we have this information. It's kind of better to know it an then you can choose… I mean it is scary receiving it but at the same time I was actually

> relieved because I thought, okay, it probably wasn't from that extra wine I had or that, you know, that. You know I didn't do anything wrong to get cancer. I was predisposed. I was probably going to get it. So for me it was kind of like a relief that I felt I didn't do anything wrong. Because I think sometimes you feel, when you get cancer, you feel guilty that you've maybe done something or exposed yourself to something or ate something or just did something as a teenager or something. Maybe that's why I look at this as although it's hard information its positive information to know about your own genetic make-up. I mean I think it would be great for everybody to know that." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age when parent given BRCA result was 13]).

Equates to Big Issues. Disclosing and non-disclosing parents identified positive attributes of BRCA1/2 testing and the provisions of a positive test result, but a dark side also shadowed it. Sixty-seven percent of study parents shared that there were complexities involved in BRCA1/2 testing because, it went beyond the decision to disclose or not to disclose. Complexities ranged from surgical to surveillance options, insurance perplexities, to how your choices will affect yourself and family. BRCA1/2 testing and a positive test result presented dramatic life-altering decisions that impacted everyone. As one parent stated, "So there is kind of a lot to be finding out with information and you have to think a lot about what you're going to do for yourself." But as stories developed it became evident it was not just about self, but self and family. It was about you and them. It was about now and the future. It was about consequences that are short and long term. It was a web of decisions!

The following illustrated that disclosing parents' decisions varied from sharing genetic information with minors to extended family, insurance considerations, surgical decisions, and facing decisions once ignored.

Parent 1:

> "Not only sharing information with your children, but sharing information with your other family members. Because the onus really when we left the office the

onus was really put on my husband and I to then contact our family members and proceed with genetic testing for them. That's proven to be quite a difficult and challenging task. We have family members all over North America. … You're trying to deal with your own information and now you have to then take that one step further. So that might be something the healthcare system might want to consider." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11, 13]).

Parent 2:

"The only thing that I really worried about in getting my test done which delayed me a bit was if it's a known factor that I have this, would that affect my life insurance. Is that going to affect my mortgage insurance? Like that was my bigger worry over anything else was, is this. And that's what I think about for my kids. I think they should delay getting testing done until they're older, until after they have mortgage insurance, until after they have life insurance. Because I really worry about what insurers would say about a positive result?" (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

Parent 3:

"I'm in a good place. I've had my hysterectomy. I go and have every six months check-ups. Actually I just had one. I had an MRI and it came back good. Now I'm just kind of waiting to have my surgery and I kind of have mixed feelings about that because you don't know if you're doing the right thing. I do have mixed feels about that." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18 – not eligible]).

Parent 4:

"Anyway I got scheduled for a hysterectomy the following December. So a year later in 2010. And that was all fine. I thought I was home free after that. And was scheduled for a prophylactic mastectomy. It as February 2011 that I had the mastectomy and it was that summer that I went though with the chemo and with that. Started back to work December 2011. It really was only like a year and a couple of months. Really it may seem like a long time, but a year and a half for all that is a lot at one time and your dealing with children and life and everything else. So lots of decisions being made." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages when parent given BRCA result were 14, 18 – not eligible]).

Parent 5:

"Many of my aunts and uncles had gone in for testing so that would have been

> 2001ish, 2000, 2001ish. I was interested in finding out the information then, but what I found out to me felt like too drastic of a change because at 25 I wasn't ready to accept that idea of prophylactic mastectomy, hysterectomy, possibly pills for the rest of my life. I was not interested in those being the end result of a positive test. Because it wasn't my mother it was a few of my sister so I stepped back and make it just like some families have heart attacks and our family has breast cancer, and kinda ignored it. But in between that time and my diagnosis there was probably 3 or 4 other diagnosis of breast cancer in our family. So it made it more, um, I guess more real." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [ages at time of disclosure were 9, 6 – not disclosed, 18 months – not eligible]).

Non-disclosing parents also faced the same web of decision-making. One non-disclosing parent confessed:

> "Genetic testing is something that involves an ethical dilemma. It's not easy thing to deal with because you don't know what comes out of it. So if it's a no, great. If it is a yes, then there are a lot of difficult decisions that you need to make. And it's personal choices and it's very emotional." (Parent who has a positive BRCA1, breast cancer diagnosis, 1 child [age when parent given BRCA result was 6]).

The belief parents are faced with a web of decisions that impacts others is further articulated in the words to the following non-disclosing parent.

> "…I mean even getting out of surgery and I have no other adults living in this household. I was told I couldn't have any kind of home care of anything. You know, you come home with four drains and binders and actually I didn't come home. I moved in with my 81 year-old mom. My son couldn't be with me for a month." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 1 child [age when parent given BRCA result was 15]).

Parents also experienced decisional conflict between a parental obligation to protect and nurture and or a parental belief in children's right to familial risk information which is reflected in the following three quotes.

Parent 1:

> "So again, it's something that at some point I think will be important for him to know, but I'm not quite sure when, at what time frame, you know, that will be. …But for me it was do no harm was anything going to change by him having this information at this point in time, other than causing him more worry. That was really my main issue. …No I don't think I feel guilty. I mean it is what it is. I

> have this gene and there's noth… But I just, as a parent, I feel badly. I mean I do feel for my son. …I feel badly that it's something that he's going to have to potentially deal with and potentially add some complications to his life. (Parent who has a BRCA1 [2011], breast cancer diagnosis, 1 child [age when parent given BRCA result was 15]).

Parent 2:

> "…I have a right to disclose it, I mean he has a right for me to tell him that." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age when parent given BRCA result was 13]).

Parent 3:

> "I still think it's really important to tell kids the truth no matter how old they are. Because no matter how small or how minor those treatments are or whatever, you don't know what the results are going to be. I just think it's really unfair for kids to all of a sudden be without a parent and not understand why or have the chance. (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages when parent given BRCA test result were 1, 4]).

The next non-disclosing parent explained the varied decisions involved with BRCA1/2 testing as she tried to maneuver through a complex maze of decisions during a heart wrenching period of time in her life. This young parent's genetic story commenced with the birth of a child who was born with a genetic abnormality that lead to genetic testing. As she grieved the loss of her stillborn baby she was faced with multiple decisions. Decisions involved BRCA1/2 testing, surveillance, and surgical options. Furthermore, she was confronted with a marriage breakdown and life as a single parent. Decisions made upfront had long-term consequences that included grief and loss of one's fertility, surgical complications, menopause, body image issues, and the contemplation of future family planning as a result of a new relationship. Her story unfolds with her acknowledgment that she felt it was now or never.

> "I don't know what mentality I was in but I' thinking I'm going to get this. I need to get rid of this now and do it now or I'm not going to do it at all. And the

> trouble with that was I believed in faith wholeheartedly and I mean it just happened for a reason. I don't know what yet but eventually I'll find out. Um. Of course I want to have a child. I mean that's why my husband and I left each other. That's our foster daughter. It just kind of crumbled. I wanted another chance. I wanted to have another baby but I can't now. But I mean I think it happened for a reason I'm not quite sure yet. I'll figure it out eventually. But, um, I just felt I had to do it now or I'm not going to do it at all."

Today this parent realizes she was in no condition to be making life-altering decisions.

> "I was depressed. I lost a child. So, and not in a nice way. I mean it was all really a bad experience, and to be told that (a positive BRCA test) within the same year. It's just like, okay, you know, just do it, I don't care. It was just kid of that mentality like get it out of here. Also mentality-wise I felt like I was diseased. I felt like I was going to die. I just felt really gross, this silly gene's inside of me. It was really complex and everything. I was, I don't have to worry about breast cancer. I don't have to worry about ovarian cancer or any more cervical issues. So that's very positive. I see the positives."

Moreover, body image issues were intensified by the actions of an innocence child.

> "She won't come near my chest any more. She won't touch me. If I have my shirt on, she'll give me a hug, she'll do this. She thinks it's gross which makes me feel terrible but I mean she's 6 she doesn't understand."

A heart-wrenching lesson learnt by this young mother was decisions made today have lasting lifelong consequences.

> "So there are day I say that oh I should have just waited. I would have preferred chemo to what I deal with. Some days. I know it's terrible to say but there's some days you're like I should have waited. It is what it is now. … So like I said everything happens for a reason. I'm very strong. But there are days when I'm weak and I feel like I should have waited. I'm in a relationship now. My boyfriend's 23. He makes me feel a lot better. Tells me all the time we could adopt and I actually have websites saved so we've been looking into different options. … I'm going through menopause and the hot flashing every 15, 20 minutes and being up all night. I'm working 5 jobs and I'm a single mom. I drop [name of daughter] off in the dark, I pick her up it's dark. It's supper, shower, it's bed. It's me, I'm so wiped but then I can't sleep because I got the night sweats. I still have disks in my breast to expand my skin. That was in May and they're still in there. They hurt like hell. I can't sleep on my sides. My muscles are contorted.

> There's a lot of issues and they hurt, they physically hurt. …Everything's changing. My weight's changing. My shape's changing. It's all estrogen related I'm sure. There's a lot of issues happening so there's days I'm just like, oh, you know, I could have just waited. And there are options. There's estrogen I can wear and I've tried them. It's a funny thing with the whole thing is let's help you out and get rid of all this. The thing is they don't help you when you're done. So now I have to buy patches that are 50, 48, 50 dollars. I have 8 patches. I change them every three days, every 72 hours. I don't have health coverage. So I'm paying for those. I can't afford them so I don't get them. I've tried the pills which are cheaper. Still out of my pocket 40 bucks or whatever but they don't work. They don't do anything. So why put a pill in your body that's not going to help me. So there's a lot of underlying issues. …Disappointed I did get a hysterectomy for sure because I would have liked another baby."
>
> Consequently, she lives with regret and gratitude.
>
> "I regret that every second day but I can't undo anything. Like when I have see little babies or my menopause symptoms or my pain like I'm having right now in my right chest bones, the scar on my back is hideous. You know things like that. I regret my choice. But in the long run, I mean I just have to snap out of that and realize the positive attributes which is that I'm alive and I don't have to worry so much about it. There are still things I have to worry about. Pancreas and pelvic and, um, you know. In the interim things are okay. So I can't say I totally regret my decision, there's days where I'm why didn't I just wait. I would have done it anyway. But ultimately it's just right now I thought maybe I should have waited just a little while. But I'm not 21 anymore. I mean I'm not completely old and I' not completely young. I'm in the realm where ovarian cancer is an issue. I have to think about that." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age when parent given BRCA result was 5]).

Decision-Making and Family Communication

The third theme uncovered in participants' stories was *decision-making and family communication*. This theme assessed family decision-making and communication patterns. Forty-four percent (4/9) of disclosing parents acknowledged dialog existed between parents regarding the decision to disclose, 22% (2/9) made an independent decision, and 33% (3/9) offered no comment. For non-disclosing parents 14% (1/7) admitted to parental dialog, 43% (3/7) made an independent decision, and 43% (3/7) made no comment. Hence, based on parents who offered an opinion regarding decision-

making, greater dialog occurred between disclosing parents (44%) versus non-disclosing parents (14%) and a greater percentage of non-disclosing parents engaged in independent decision-making.

See Table 1.8 for a comparison between disclosing and non-disclosing parents specific to family communication styles and decision-making. Based on the parents who responded it may be assessed that family style of communication may have influence the decision to disclose. However, a sizeable percentage of parents made no comment. Therefore, no relation between family communication patterns and parental decision-making can be truly assessed.

Table 1.8: Comparison between Family Communication and Decision-Making

Family Communication	**% Disclosing Parents (n=9)**	**% Non-Disclosing Parents (n=7)**
Open	67% (6/9)	43% (3/7)
Style Not Expressed	33% (3/9)	57% (4/7)

The following represents disclosing and non-disclosing parents' statements regarding decision-making patterns and family communication which supports the above observations.

Parent 1:

> "I don't think we actually had a discussion. I think that when we talked about going for testing it was kind of agreed between the two of us that it was something that the children would know the results of. …I mean if for some reason they heard something on the news or read something and had a question we would not have any problem discussing anything with them. We try to be open. I think we are definitely more open now that we were 4 years ago. I think that just in the last couple of years that the kids have seen that if they have a problem or if they have a question about something that we are very open to answering it." (Parent who has a positive BRCA2 [2009], breast cancer

diagnosis, 3 children [ages at time of disclosure were 9] [6 – not disclosed, 18 – not eligible]).

Parent 2 responded to the question:

Interviewer: How would you describe your family communication style?
Participant: It's pretty open. It's very open amongst the adults.
Interviewer: How about with you and your children?
Participant: Very open. I mean there is some things I wouldn't talk to my kids about and I'm sure at their ages of being teens that there are some things that they don't tell me. But it's very open.
Interviewer: Did the fact that you had a style of open communication established come into play in your decision to speak with your children?
Participant: Oh for sure. Well yeah. I mean if you're kind of disengaged from your kids it's pretty hard to have an open discussion with them about any serious topic, right. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

Parent 3 shared:

"I think we have a very open relationship. We do talk about a lot of things. My daughter is very intelligent and she things about things a lot. I'm a very private person. I'm from along line of really private people. We are kind of a little bit different that way. But I think that my daughter and I have a very honest relationship. I think that we can talk about things, important things."
(Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Parent 4 explained:

"The same day we found out when I came home I sat down with my children and my husband and I told them about the results. …I think it depends on your family dynamics because we're a very close family. I just don't mean like me and my husband and the two children I have two brothers and a sister and we're very close. They all know what's going on. They were tested as well. Like we were all tested and I was the only one that was positive. So they all know." (Parents who has a positive BRCA1, unaffected cancer status, 2 children [ages at time of disclosure were 14, 18 – not eligible]).

Parent 5 shared:

"It's something that is discussed quite a bit in our family. I just felt that this is information that I got about me. I felt it was my decision whether I wanted to share it with my kids right away or not." [Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 17, 20 – not eligible]).

Non-disclosing parents communicated similar stories regarding close parent child relationships; however, these parents chose to delay disclosure related to other factors:

Parent 1:

> "We've always had a very good relationship. I have made time with him to sit down and talk and I try to listen. I've always been the one that would sit and talk to him. I think he feels comfortable sharing things with me. He has shared some pretty personal things as a teenager with me. …I absolutely think you should disclose at some point. But it depends on their maturity, and what they're going to do with that information." (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age when parent given BRCA result was 13]).

Parent 2:

> "I think we're fairly open about most things. So I think that's important for him to know. I think had I known I had cancer in advance I would have shared that information with him." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age when parent given BRCA result was 15]).

Supportive Resources

The theme *supportive resources* addresses disclosing and non-disclosing parents' assessment about the resources utilized. Parents spoke to services at Winnipeg Regional Health Authority's (WRHA) Hereditary Breast and Ovarian Clinic (HBOC) and other community services.

WRHA's Hereditary Breast and Ovarian (HBO) Clinic. Disclosing parents and non-disclosing parents shared their perceptions regarding consultation appointments with the WRHA's HBO Clinic as it specifically pertained to BRCA1/2 decision-making to minors. Collectively, parents admitted useful information was acquired and the team provided support; however, it was assessed the services could have been taken 'a step further.'

Disclosing Parents. Eighty-nine percent of disclosing parents explained members of the WRHA's HBO Clinic did not specifically discuss disclosure verses non-disclosure

issues. However, 44% of disclosing parents communicated supportive services was not required because of parental confidence in the decision to disclose. The following exemplifies parents' thoughts related to services at WRHA's HBO Clinic.

The first four testimonials endorse disclosure was not initiated by members of the genetic department with parents; however, the following parents believed it was not essential.

Parent 1:

> Interviewer: Was there any support provided to you at the time to help you both prepare to have the discussion with your child?
> Participant: Right. I don't think they necessarily did. Just because I think we just made it part of the big conversation, or a series of conversations.
> Interviewer: Will you seek any kind of assistance from anyone to prepare you for your next conversations?
> Participant: Well I will probably look into seeing if there are more specific genetic type of books available for children that are simplified down. But other than that, I don't think so. (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [age at time of disclosure were 9, 6 – not disclosed, 18 month – not eligible]).

Parent 2 shared:

> "No. Nobody ever asked me if I was going to have any discussions with the kids. The only thing that ever came up about my children was me saying, you know what I'm a single mom and I have two kids. So if I don't have to do a mastectomy now and end up sick and not able to get them to school, not able to do this. Then I'm just going to go for my monitoring. Nothing about if I would share the information with them or not. That never was mentioned.
> Interviewer: Do you think it was something that should have been brought up?
> Participant: I don't know. Either way, I'm not sure. Um. For me, it wouldn't have mattered whether, obviously it didn't matter whether they brought it up or not, I chose to share it with my kids. … So I don't think that I really needed any support in my own handling of the result. And I didn't really think that I was going to need support in explaining to my kids because I felt that if I explained it to them calmly, they will take it calmly." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

The parent below agreed with the above two parents.

> Interviewer: What kind of support was involved in preparing you for disclosing

test results to your children?
Participants: You know what the geneticist may have mentioned something. I didn't need it because when I even did my cancer treatment I rarely, well I only did one session." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [ages at time of disclosure was 7]).

The next parent acknowledged information was provided regarding testing eligibility, but the discussion did not include the disclosure and non-disclosure topic which was not an issue for the following parent.

"I don't recall. The only person that would have said that was the [lady/ man] that actually gave me the test result and I don't recall that conversation ever taking place. I could be wrong. But it wasn't an issue for whether I was going to tell him or not or whether I was going to read a book to say, hummmm, am I going to. I didn't even question it. I guess that's a better thing. I didn't question my thought process on what I was doing."
Interviewer: When you received your test result from the Genetic Department did they offer you support around disclosure or non-disclosure to minors? Did anyone say we noticed that you have a young daughter, are you thinking whether or not you will be disclosing this information to her?
Participant: No. When they took the original information they were interest in whether or not I had a daughter or a child and how old my child was. And that's when I got the information that she would not be eligible for testing until she was in her 20's."
Interviewer: So the specifics around are you thinking to disclose or not disclose was not brought to your attention either through the Genetics Department or by the surgical team?
Participant: No. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

The next four examples testify to the fact that good information and support was provided by members of the genetic team. However, these parents acknowledged that the topic of disclosure and non-disclosure should be discussed.

Parent 1:

"Um. Actually, the most support we got when we went though for the testing was there was a [name of member of genetic team]. So I could have asked any questions that I wanted. They were very informative. …The support was good. They have a lot of information for me and they were good to me. They gave me a number to phone and asked if I need counseling or anything. But I didn't need any of that. When I came home I went to see my family doctor and we're very

close. He's been my doctor since I was a child. So I really trust him and we had a long talk and he was a big support to me."
Interviewer: Did anyone ever say, I notice you have two children have you thought whether or not you will share or not share your BRCA1/2 information with your children, and is there anything that we can do for you to assist you with your decision-making process?
Participant: No, actually nobody ever said that to me. Nobody ever. Come to think of it, I don't think anybody really asked me that if I was going to share that with my children or not.
Interviewer: Do you think it would have been appropriate for a healthcare provider to bring up the topic?
Participant: Um. You know they might have, yes. Maybe I would have gotten some different ideas. I don't know. I probably would have done the same things. Um. Maybe. Hard to say. …I think it would have been helpful. (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18]).

Parent 2 agreed:

"Well I was referred to [name of allied health professional] if I had or anybody in our family had any need or desire for further counseling. And then [name of member of the genetic team] who shared the information with my husband and [s / he] made [her/ himself] available. Um. Though email or though telephone, any kind of conversation. I guess that was it. Those two supports were offered to us.
Interviewer: At any point in time did the conversation specific to decision-making about disclosing or not disclosing test result to the children come up?
Participant: Uh. I don't recall that it did when we discussed things with [name of member of genetic team] initially. I don't believe that [s/he] addressed share it with the children. …That being said [s/he] made [her/ himself] very available if we had any future questions, and [s/he] has been very accessible. I have emailed [her/him] and [s/he] has been very prompt with getting back to us.
So a lot of assistance and help in the processing. Discussing whether or not to share it with our children, I don't believe was even really discussed. And it wasn't something that I thought a lot about at the time. …And so probably would have been helpful to have had a second interview just to have sort of put more thought into that decision." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11, 13]).

Parent 3 added:

"I think the only thing I remember in respect to my children was some day they might have to make a decision about whether they would be tested and that would be down the road. I don't remember anything else. We didn't talk about whether it was a good idea or if there was a certain way to do it or not. …We asked do they need to know now because they would be test now or is it something that when they're adults themselves they have to decide. And trying to think through what

> would be the implications for them and then how we can make that easier. …I don't remember there being something about a specific conversation about disclosure. I think when I received your information, like the study information it might have been the first time somebody formally put it that way of actually disclosing. So it makes me think that okay this at a real thing and yet nobody really sort of said it. We sort of had to bring it up.
> Interviewer: Should someone have brought up the topic?
> Participant: Um. I think so. (Parent who has a positive BRCA1 [2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

Parent 4 collaborated:

> "I just basically took it upon myself and decided this was information that I felt was valuable for them to know. So I told them about it. Outside of the home I had no information on how to go about telling them something like this. Like I don't know if I had got other information on how to approach my kids on this subject and stuff like that if I would have done it any differently. But I wasn't offered the chance to talk to anybody about it really and discuss it with anybody before I talked to them. …I just think [name of member of genetic team] did the best [s/he] could answering my questions. [Name of member of genetic team] told me what about my changes of breast cancer. What about my chances of ovarian cancer and the other cancers and stuff. [S/he] told me that. [S/he] told me what my choices were. I can have a hysterectomy. I could wait. This or that. I can have my breast removed. Like so I did have some information. But whether or not, if we had me with my kids, if they would have had different questions, I don't know what kind of questions they would have come up with and whether or not she would have had the answers for them. So I think the best thing is to have somebody who's there that can answer pretty much any of the questions that you might have for them. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [age at time of disclosure were 16, 20 – not eligible]).

Non-Disclosing Parents. Similarly, 86% of non-disclosing parents commented that healthcare professionals did not raise the topic of disclosure versus non-disclosure. However, a number of parents' self-confessed recall maybe an issue. Some participants noted testing eligibility was discussed, but parents voiced that the discussion should be taken 'a step further.' Although, 43% of non-disclosing parents also agreed that support in the decision-making process was not necessary. The proceeding quotes characterize parents' thoughts pertaining to services at WRHA's HBO Clinic.

Parent 1:

"Support was always there through [name member of genetic team], my family doctor, and my sisters. I mean I had that. I just had made up my mind and didn't think it was a big deal at the time.
Interviewer: You mentioned a little while ago that no healthcare provider approached you regarding the topic of disclosure / non-disclosure.
Participant: No. I've never heard anybody ask about this.
Interviewer: Do you think they should have? Would it have been helpful?
Participant: Um. It could be, yeah. I think they could bring it up. Like have you thought about whether or not you'll talk to your children at some point about this? (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 13]).

Parent 2:

Interviewer: When I asked you what kind of recommendations you have for healthcare professionals you mentioned for them to tell you that it's okay not to tell your child your test results right now. Did anyone ever bring up the topic with you?
Participant: No I don't think so. I just think like it would be frowned upon. To know something this vulnerable that you can change the direction of one's health and not tell someone about it. You know what I mean? I think it would be frowned upon. That's my perspective of it.
Interviewer: Why do you feel that way?
Participant: …You know I'm from the perspective of a physician that what they're there for is health. But in the perspective of a parent my job is to keep my daughter safe and happy and not weigh down with decisions like that. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5]).

Parent 3:

Interviewer: What kind of support was provided to you specifically around the decision-making process as to whether to share or not share genetic test results with your children?
Participant: I can't say that there was any discussion about it at all. There was lots of offers to speak to a counselor, come to this, do this, talk to them. There was almost too much to the point where I was almost getting annoyed by it.
Interviewer: Was it to come and speak to counselors specific to your genetic test result and sharing or not share this information with children?
Participant: No. More specifically to the cancer diagnosis. Through CancerCare. Like a lot of offers of support though CancerCare. Test results was through [name of member of genetic team] in the office and I mean [name of member of genetic team] was great. I always felt comfortable with [her / him]. I always felt like I could call [her/him] if I needed to.
Interviewer: Okay
Participant: I don't recall any discussion about sharing it with the kids, or not with

> [her / him] or anybody in [her/ his] office. That's not to say it didn't come up. I never heard it. I don't remember it. But also in all fairness, I was never one to feel like I need all of that support or that I was going to take advantage of those offers. So if it had been brought up to me, I might have just brushed it off.
> Interviewer: Do you think it would have been appropriate for someone to say to you, I see that you have two children who are 5 and 8. Have you thought whether you'd be sharing or not sharing this information with them? Is there anything we can assist you with in the decision-making process?
> Participant: Yes, I think it's appropriate. It might have been kind of obvious through my discussions with [name of member of genetic team] or somebody in her office that I wasn't open to that." [Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages at time parent given BRCA result was 1, 4]).

A non-disclosing parent's response to the question what kind of support was provided during the decision-making process as to disclose or not to disclose test results to your children simply replied:

> "None actually." (Parent who has a positive BRCA 2 [2012], unaffected cancer status, 2 children [age at time parent given BRCA result were 9, 11]).
> Parent 5 added:

> "I don't actually think anything. I really don't feel I received any support around that issue." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15]).

> Parent 6 declared:

> "I don't think it was a topic as far as I can remember. I'm sure there are things that [name of member of genetic team] discussed with me that I don't remember. I do not remember it as being part of the discussion. What we talked about is when is the proper date for her to do genetic testing, which is a completely different question. … It is my privilege to work in this field so I have people around me whom I can bounce off my thoughts as a way. I can go directly and say, how. Other people will not have people around them who have worked with kids for 30 years and know mental health issues. (Parents who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5]).

Other Valued Resources. Other valued resources identified by parents as helpful during the decision-making process included a variety of individuals, specific tools, programs, and services. Eighty-nine percent of disclosing and 29% of non-disclosing

parents noted at least one valued source of support, outside of WRHA's Genetics Department. Although, one parent shared that time to access supportive resources was viewed as a luxury, and another shared it was not helpful. The following passages emphasize parents' views.

The first example refers to a program offered by CancerCare Manitoba Kids Can Cope which is accessible to children of parents diagnosed with cancer. This example showed that value of the skills learnt at the program were transferable for dealing with other emotional life events. This child found benefit in using the program's workbook as he coped with the BRCA1/2 disclosure information. Additionally, other tools identified as beneficial were books and movies borrowed from the library at Breast Cancer Center of Hope, although they were not specific to BRCA1/2 disclosure. The books and videos were generalized to disclosure of a cancer diagnosis to child.

> "Our kids did Kids Can Cope through CancerCare. And they really learnt a lot through them, even if the same things was said by us, just that with someone else saying it then they listened. …We had watched and read a couple of books and movies and things on this. Just how to tell your kids about a cancer diagnosis. As so that's the method that we took. We looked for things specific for our age group of children. I guess mainly from Breast Cancer Center of Hope. Um. I was sent to Breast Cancer Center of Hope at one of my doctor visits to see the nurse practitioner there after my biopsy. Just so we go the ladies there to give us a hand with finding movies on how to tell anyone. … Thinking about it I should probably give Breast Cancer Centre of Hope a call maybe and find out if they have any material specific to genetics, um, just more if the kids have trickier questions. I mean beyond the basic of how come it's our family? We mostly gave our kids reading books that were geared towards children themselves. Some of them were written by children for children. …I think Kids Can Cope was their big thing because it gave them tools to deal with things once the course was over. Talking about your feelings or talking about how it's okay to be angry or it's okay to be scared, or what to do when you're in a certain situation. It was good for them to discuss it with other kids who are going through very similar things and adults that aren't involved with their parents. So it would be okay to be angry in that situation and you're not hurting your parents or your parent's not going to be upset because you're acting out. Yea, I think probably those Kids Can Cope

> books they got back to quite often. And initially, for our kids, then some of the books we would read to them. And then of course our oldest was old enough to read to himself." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [age at time of disclosure were 9, 6 – not disclosed, 18 months – not eligible]).

The subsequent seven parents described support as coming from family and friends, professional colleagues, family doctors, mental health professionals, surgical oncology physicians, and the faith community. Additionally, parents noted their own information seeking behaviors on the Internet and self-coping abilities as beneficial.

> Parent 1:
>
> "My boyfriend came to some appointments with me. Actually he was a good guy. Um. I actually had some information that [name of genetic department healthcare professional] gave me from genetics and I shared the basics of that with my children. I guess if you have enough natural supports I think you might not need externals. Let's face it, not everyone has natural supports." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).
>
> Parent 2:
>
> "I don't know if I looked for any support. My only support system would have been my husband." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages at time of disclosure were 9, 12]).
>
> Parent 3:
>
> "We're a very close family. Like I just don't just mean like me and my husband and the two children. I have two brothers and a sister and we're all very close. My sister, she's like a mother to my children. So she's always there for them too. … The most useful I found was my family doctor. I think that's just because we have a close relationship. I could talk to him about anything and plus he lives outside of the city. The others are in the city. So if there was ever anything I need to talk about I would go to him. I found just talking with my family and I have actual friends that have this gene, just talking about it with them basically works the best for me. I try not to dwell on it after like a month or so. I decided I'd just have to kind of put it in the back of my head and go for my appointments and just keep going. …I'll also say Dr. [name], [s/he] was my breast doctor, [s/he] was a support for me so I found it was awesome." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18]).

Parent 4:

"Our faith community was "sort of being supportive even if they weren't specifically are you going to tell the boys or how or whatever?" (Parent who has a positive BRCA1 [2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

Parent 5:

Interviewer: What kind of support was provided to you during your decision-making process?
Participant: When I was first diagnosed with breast cancer the psychosocial team at CancerCare was offered to me as an option. I chose to go another route and I had my own therapist by then. I think sort of in the time frame around finding out I did talk to my therapist and to a couple of people who I know have expertise in working with children. I also talked with my most senior colleagues. …What I do remember very fondly, like with lots of warmth was this gyne-onc surgeon who did my oophorectomy, prophylactic oophorectomy who asked me how is your daughter doing? …[S/he] then said, sometimes kids do not show how much they understand. And that was very personal. I really appreciated the way that she addressed my fears. She was thoughtful enough to put it in a very kind and sort of gentle way. (Parent who has a positive BRCA1 [2012], breast cancer diagnosis, 1 child [age when parent given BRCA result was 6]).

Parent 6:

"I'm doing all my own research already. Not that there wasn't people to talk to, I just didn't feel comfortable talking to some stranger. Probably going to the Internet which is not always reliable but because I've been through it, I know ins and outs of it. … I would call my mom (tears) … sorry. Yea. It was nice to talk to her about it. …I really didn't have professional support. My close friends some I told what I was going through. Actually I posted my journey online. I posted some pictures. Just my incisions and my healing. So everyone knows around me and are extremely supportive. I went back to work quite early. They were all cheering me on and happy for me. My partner, he's been there the whole way now. He's been there for me." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age when parent given BRCA result was 5]).

Parent 7:

"I don't have the luxury to going out to talk to somebody because it would help me." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7]).

Parent 8:

> "Well I was referred to [name of allied health professional] if anyone in our family had any need or desire for further counseling. …The only person that addressed it with me was, I can't remember [her/his] name, um, a doctor at Breast Health Clinic. [S/he] asked if we had shared the information with our children. Then asked how they handled the information. Then addressed whether or not we should consider future testing for them once they turned 18. And [s/he] had some fairly strong thoughts on that. [S/he] agreed definitely that the information should be shared and that they should be aware of the risks that are involved to them. [S/he] agreed that the risks to them is minimal. [S/he] also reminded me which is something I sort of forgot about, in that it has huge implications for them with future opportunities to have insurance, um, health insurance and mortgage insurance, those kind of issues….So that was good to be reminded that, although information is a powerful tool, it sometimes can have a bit of a negative side effect so we have to weigh those carefully when the boys are of legal age." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11,13]).

> Parent 9:
>
> Interviewer: What kind of support, if any, was provided to you to prepare you for disclosing the information to your daughter?
> Participant: I want to say none. But it's very hard for me to because when I received my initial diagnosis I think I went into a little bit of shock and I don't really have very many memories of what I was told. …I didn't want a pamphlet that talked about what the death rates for breast cancer are. I did not think that was helpful for me. I remember at the time (pause) I think that there was like a card I was given that they had a social worker or a psychologist that you could approach but I don't think that was ever given in terms of helping you to tell your child. I don't know if they even brought up my child at all. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

The Inner Circle

The fourth research theme is the *inner circle*. The first part of this section speaks to disclosing parents' perceptions about the conversation. This is followed by parents' views regarding the children's reactions to the disclosure conversation. Thereafter, parents reflect on their decision to disclose, or not to disclose. The chapter ends with non-disclosing parents' vision regarding a future disclosure conversation. See Table 1.9 for a summary related to theme and sub-themes for the inner circle.

The Conversation. This segment summarizes parents' examination of the disclosure conversation which includes the content of the conversation, how it materialized, and general impressions. See Table 2.0 for an overview of disclosing parents' examination of the disclosure conversation.

Table 1.9: ***Summary Related to The Inner Circle***

1. **The Inner Circle:**
    a. The Conversation
    b. *Mixed Ball of Reactions - Children*
    c. *Mixed Ball of Reactions - Parents*
        i. Disclosing Parents
        ii. Non-disclosing Parents
    d. A Future Conversation

Table 2.0 Disclosing Parents Examination of the Conversation

Type of Conversation: - Unplanned - Not structured - Causal - Series of conversations - Shared at level of understanding - Positive manner - Provided reassurance
Where and Who Present? - Home on the couch / dinner table - Car - Mother and child - Nuclear family - Nuclear and extended family
What Shared? - BRCA1/2 result - What the BRCA1/2 genes are and inheritance - Risk - Implications to parent and child - Preventative options - Available testing and when - Life style and body awareness
What would you change, if anything? - Nothing - Husband present - Planned and thoughtful

Similarities exist among the conversations. For example, the parent who is the BRCA1/2 carrier presented as the lead conversationalist. Additionally, all of the conversations were not planned, not structured, and occurred in a familiar casual environment. Most parents described conversations as a series of discussions with the intension of building on the information content by taking a developmental approach. The majority of parents acknowledged the information shared was basic, factual, and presented in a positive manner. Collectively, parents spoke to children regarding what are BRCA1/2 genes, associated risks, implications to children, surveillance and prophylactic options, healthy lifestyles and body awareness, and testing availability. The following is a collection of examples of parental quotes that provide insight into the disclosure conversations.

Parent 1 shared:

> "I would not have changed anything. We just made it part of the big conversation. Or I guess a series of conversations. And it was done very casually no in a, okay, we're sitting down and discussing this. But more in a hanging out on the couch and mommy went for this test and it was more of that kind of conversation than a formal sit down deep conversation." (Parent how has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [age at time of disclosure were 9, 6 – not disclosed, 18 month – not eligible]).

Parent 2 explained:

> "They already knew my cancer diagnosis. And then it was now explaining a little bit more why I kinda got it. Kind of gave them a quick biology lesson that they'll learn more in grade 12 about genetics and all that other stuff. Basically I just explained to them that mom's got one of those funky genes that has a bit of a mind of its own depending one how it wants to react and something reacted with it and this is what happened. Kind of like a predisposition. But trying to explain that to them at their level. …There were certain surgeries that were suggested. …I'm just making sure you are aware that you need to make sure when you go see your doctor he needs to know or she needs to be aware. These are the tests you need to have done. And make sure you have them done on a regular basis. … It was kind of like a casual sit down and explain it and then asked them if they had any questions. …They know I'm going in for surgery in February but

we'll discuss that closer to February because they'll forget between now and then because Christmas is coming. …. You know when they hit that magical age of 18 they have that option of having genetic testing. I think that's how it went with the geneticist. They had like a certain age where they could initiate that to see if they actually carry that gene. It may be about then, you know, here's your options. You may want to explore it. You may not want to explore it because you know what, at 18 you're an adult. You can make that decision. That'll be a decision you'd have to make. Here's all your options. You may. You may not." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages at time of disclosure were 9, 12]).

Parent 3:

"We just sat down and explained to them what the results or the findings were and the risk wise what that meant for me personally and then risk wise what that meant for them being male. How I was going to proceed with this information and what a positive, really positive bit of news it is in that we have the ability then to take that information and be proactive about it. So we very much viewed this information as a positive in our lives." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [age at time disclosure were 11, 13]).

Parent 4 noted:

"It was not a planned discussion. It was a very natural flow. This is what this is about. I didn't actually sit down and have some kind of serious conversation with them about it. I just said that was the doctor and this is what it was for and this is why and this is what it means. …I have this gene which puts me in a bit of an increased risk for breast cancer. And that the majority of breast cancers that are diagnosed they don't even have the gene. It minimally increases my risk, um, that it's important that they monitor me just to screen me carefully in case something shows up. Usually it's very slow growing. The earlier it caught the better it can be treated. So it's better to know than not to know. …She didn't specifically ask if I was going to have a mastectomy. It was just what could you do? Well I could do this or this or this. But I'm not going to have a mastectomy now and I'm kind of debating on the oophorectomy. I haven't decided on that one yet. And I just said, we'll just monitor me closely and if something comes up, then I'll deal with it." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

Parent 5:

"I think it took place over numerous discussions. It wasn't just one. But it wasn't like I'm going to sit down and tell him. Over casual dinner conversations it was probably was more talked about when he was involved, when I was talking with other people. He was the second part in the conversation."
Interviewer: I hear you saying you had a number of discussions with your son.

Overall what specific information was shared with him in all the discussions?
Participant: Everything that happened. What the test results were. What it means. What it means right now? What it means in the future, and what it mean to our family. Because he is aware that it has affected other family members on my side of the family. So he understands that he might have it because my cousin has it, because my aunt, my uncle has it. I think he grasps that."

Additionally, this parent later added:

Interviewer: You mentioned due to your son's age you feel he does not comprehend the information fully. Are you planning on sitting down and reopening the discussions in order to build his understanding, and if so what do you envision that discussion will be like?
Participant: Whenever the topic comes up that I would feel it would be necessary for him to know more. You know, during a doctor's appointment maybe. I would never come out and say in a threatening way you've got to be scared because you've got this gene, you've got live your life in a bubble. I would never do something like that. I would just have normal conversations. But I'm not waiting for his like 16th birthday or something like that. Like I'm not going to go I've got to tell his on his 16th As I mentioned before, I'm open and honest and I'm not going to withhold information from my child. Obviously our conversations will be changed over the years to match his comprehension of what's actually happening or what it means?" (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7]).

Parent 6 expressed:

"Well it's two years ago. We were speaking in the context of her own health issue and her own worries about what was going on with her body. We were taking about going on long-term birth control, or short-term birth control actually at the beginning. Then that's when I told her about the diagnosis. I told her we had cancer in our family. …I just talked about all the things that we care about like eating healthy and not smoking and not drinking, um, they an contribute. That's something that she can do now to limit her changes of having cancer. But also limit her heart disease, it limits diabetes. They're all good things to do anyways. I just said I didn't want her to worry about it. That there was no reason to worry about it. She didn't have to make any decisions. She didn't have to decide that she was going to have the testing. She didn't have to decide, oh I should have my family early so that I can have the same surgeries that my mom is having. Those decisions could wait. Like we had several conversations over a couple of weeks. It was in the car where all our deep conversations took place. …I mean I think it was a positive conversation. I mean I was proud of myself because I held it together during the conversation and I was able to sort of take my own emotions out of it and really be there for my daughter. I think I was okay. I think I was kind of relieved afterwards because I don't know how you'd have that kind of conversation with someone. It's not I don't know how you plan

it or make it so. I think it went as well as it could have actually. I feel good that I shared that information with her. I don't want to feel like I'm lying to my child. And I'm glad that I don't."
Interviewer: Reflecting back on your discussion with your daughter is there anything you would have done differently, or changed, or are you good with how it unfolded?
Participant: I don't know. Maybe if my husband had been there it would have been better. I might change that. He's really sensitive and supportive. Maybe it just would have been another support for her, for her dad to be there. They're very close. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Parent 7 explained:

"Well we didn't have like a sort of big sit down family conversation that was specific like we didn't have a plan. It was at the dinner table. … Just let them know that I would be having surgery. I was having surgery but for them to know that I wasn't sick. That when you have prophylactic surgery it's kind of different because you're well and then you're putting yourself though a surgery. …We would have been specific so it was a oophorectomy and hysterectomy. I was having my ovaries removed because that prevent or helps to prevent breast cancer and ovarian cancer.
Interviewer: I hear you saying that you shared that you were going for preventative surgery and it was to decrease risk factors for cancer. Did you link that to the family?
Participant: We said that was related to the fact that I had a gene from my family.
Interviewer: Reflecting back on the disclosure conversation, would you have done anything differently?
Participant: I don't know. I guess to make it more planned and thoughtful. We hadn't necessarily planned we're going to talk about this or whatever. (Parent who has a positive BRCA 1[2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

Parent 8:

"Interviewer: When you shared the BRCA information with your children, can you tell me how that was done, what was shared, and who was present?
Participant: It wasn't preplanned. It just happened. They all knew what I was going for. Well, me and my sister went together to get our results. The same day we found out when I came home, I sat down with my children and my husband and I told them about the results. I explained to them that I just have an increase with getting breast cancer, and what I was going to do about it because I had already pretty much decided. I'm very knowledgeable about it. I just sat down with my children and I just told them what it was. It didn't mean I have cancer. Means I was just at an increased risk. And that when they're of age. Like I would never want my children to be tested now because I think it's too much for them.

> Like I was 42 when I found out but I'd already had my children and everything. When you're of age it's your decision if you want to be tested or not. We talked about all that. And then just had a discussion. They were okay with it. …We had a family discussion about what to do about certain things and it was okay. It was a little emotional but I think it was just like I go to the doctor every 6 months. I have a mammogram and an MRI and they know when I go and they're keeping a close eye on me so that's all we can do. (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18 – not eligible]).

Parent 9 added:

> "I kind of figured I was going to be positive. Both of my kids knew I was being tested and why. When I got the results I basically just sat down with my kids and told them that you know what this is what I've been dealt with from my mom. That there's a good chance because I am positive that my chances of ovarian cancer and breast cancer goes up significantly. I told [daughter's name] especially that if you feel you want to be tested to see if you have the gene as well, I'm totally behind you on that. I feel that you're mature enough to handle something like that. …Like we discussed you're at a higher chance of also these other cancers and stuff like that. That be aware and look for changes in your body and stuff like that. Unfortunately there's no test for pancreatic and gastro or whatever. But they're aware that they have a high risk for those types of things too. …I basically told them that I was positive and stuff like that. That what it did to my chances by this much and this much. I'm going to have a hysterectomy and what not. I told [daughter's name] if you choose to be tested they don't like to do it before you're what is it, 22 or whatever. But depending on maturity and stuff like that they will do it younger. So she said that when went to be tested and so she was tested a while later. (Parent who has a positive BRCA 2 [2011], unaffected cancer status, 2 children [age at time of disclosure were 16] [20 – not eligible].

Mixed Ball of Reactions – Children. Disclosing parents' perceptions about the children and parental reactions were collapsed into a sub-category labeled a mixed bag of reactions. The first section addresses the children's reaction to the disclosure information followed by parental self-reflections about their own reactions.

Children were described as understanding the disclosure information appropriate to their individual developmental ages. Parents made this assessment irrespective of whether children asked questions or exhibited behavioral changes following the disclosure. Parents declared children handled the information well. Although, other

parents admitted uncertainty existed as to the impact of the disclosure information on the children. Parents' assessment of the children's reactions is reflective of developmental stages of childhood and adolescent, and individual personality characteristics. For one parent the disclosure revealed family secrets; consequently, it opened Pandora's box. See Table 2.1 for a summary of parents' perceptions of children's reactions to the disclosure conversation.

Table 2.1 Parents' Perceptions Regarding Children's Reaction to the Disclosure Information

Reported Details	Number of Children (n=14)	%
Parents description of understanding:		
- Comprehended based on age and child's point of reference	2	14%
- Asked questions		
- No	1	7%
- Yes	13	93%
o Him/her related to how it applies to them and testing options	7	50%
o Parent's well-being	3	21%
o General clarifying questions	4	29%
Overall personality changes:		
- No	13	93%
- Yes	1	7%
o Now internalizes things, stays indoors, keeps close to parent		
Initial reactions:		
- Not upset, not worried, no panic; matter of fact	9	64%
- Upset, crying	2	14%
- Withdrawn	1	7%
Affected parent-child relationship:		
- No	2	14%
- Yes	-	-

The following excerpts illustrated parental perceptions of children's reactions that was symbolic of a mixed bag of reactions. The first example is a parent who shared her decision to disclose to one child but not the younger two was jointly made by both parents who took into consideration individual children's developmental readiness and personality characteristics. The parent's commentary was suggestive that to some extent her son (then nine years of age) understood changes were going on with his mother; subsequently, she needed extra care. His reaction to the information was to keep "an eye me" and stay in close proximity to his mother. This mother described her son as a "boy who played outside" and now "insists on staying inside." The change in the child's behavior was viewed as act of concern towards his mother, the need to protect, care, and to be reassured of his mother's well-being. The passages below acknowledged the understanding of the innate developmental differences between children versus adult cognitive understanding of complex information. This parent shared:

> "The oldest one has gone from being a boy who played outside 10 hours a day to being someone who insists on staying inside and escaping into books, and hanging out with me. I guess kind of keep an eye on me, or whatever. I think that they are a lot of things that he internalizes more. If there were things that he was worried about, or if a surgery or an illness concerned him he would internalized it more whereas my daughter is much more vocal. … I really think his desire to hang out and keep an eye on things definitely changed. Changed his personality a bit."

The parent later added:

> "I don't even know that now at 12 he would necessarily comprehend it. I mean he would comprehend it to a point, but as far as how it applies to his life and things like that he just didn't grasp it as something that applied to him. …I don't know that really the genetics part really affects them until they are older. …I guess probably at least half of it is not having a full understanding of things. I don't know even now at 9 and 12 that they should have a full understanding of
>
> things. Kids don't have the same points of reference as an adult would. You would tell an adult the exact same information and perhaps in the same way. But

> kids don't have those points of reference. They don't necessarily know that people die of that, or that one thing leads to another or like they just don't apply. I guess we were surprised at how not a big deal it was because as adults we were very heavy hearted having these discussions and very serious and they were that's interesting, for them next." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [age at time of disclosure were 9, 6 – not disclosed, 18 months – not eligible]).

Similar to other parents, the following parent assessed cognition and individual personality characteristics influenced information uptake.

> Interviewer: When you shared the information with him what was his response to the information?
> Participant: As I said before, he was a 7 year-old child, he did not comprehend the severity of being tested or having that gene in their family. He cannot understand the actual big picture. To him a mosquito bite is just probably as bad as having cancer. Like he knows it's worse but he doesn't have past experiences to relate, like a judgment on it.
> Interviewer: Did he ask any questions or can you recall any facial expressions?
> Participants: No. (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7])

The next excerpts also illustrate appropriate reactions based on children's developmental stages. A younger child's coping style was characterized as an outwardly responsive reaction. In contrast, older children's coping and level of understanding were reflected in their level of questioning. Some parents' comment exemplified the adolescent stage of being egotistical.

> Parent 1:
>
> Interviewer: Have you seen any changes in their personalities since your disclosure conversation?
> Participant: No, no. They're going through puberty so there are major personality changes. But nothing that I can pinpoint as related to the disclosure. No. They kinda had that look on their face, like oh, does that mean I have it. Mm. You probably do but we don't know. But I'm just making you aware that you need to make sure when you go see your doctor he needs to know or she needs to be aware. These are the tests you need to have done.
> Interviewer: Have you seen any changes in the relationship between yourself and them since disclosure?
> Participant: No

Interviewer: Did they have any other questions?
Participant: No, not really. They're typical boys. (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages at time of disclosure were 9, 12]).

Parent 2 noted:

"It really was a matter of fact very frank conversation, very calm. I mean they weren't alarmed. They weren't worried. They had some questions about what exactly what that meant. Does that mean you have cancer. No. …They weren't upset. They was no big panic. There was no tears. There was no just, it was just kind of like okay. Right. …Here and there might be a question and then it, okay, well this is, that might mean or this is what I'm going to do because they know now that, uh, they had questions for me following that because they know that I was going for the consult about whether or not I was going to have an oophorectomy. They knew all of those things. They weren't worried too much about it. It was just a matter of fact and we dealt with it very matter of factly actually. …I think my daughter asked me like what can you do. What can you do about this." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

Parent 3 explained:

"They've been great. They're aware that I'm also making medical decisions based on the information. They are handling it all in a very positive way. …We kept them involved in all those discussions and decision-making processes as we proceed. But as far as it affects them personally, um, every now and then, they just ask for clarity on when they might be tested and again we just discuss a little more about how it will affect them. It's just an open dialogue between them and they have not been upset by the news, um, emotionally affected. To my knowledge they've been very good about everything. …They asked about whether or not they would be tested for the defective gene now. I explained to them that they would wait until they were 18 and we would cross that bridge when we got to it and that they didn't have anything to worry about at this point for themselves personally. They have been absolutely fine with everything. They rarely talk about it now. They just move forward understanding that this is a positive bit of information that we'll deal with later when they're older." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11, 13]).

Parent 4 shared:

"It was her right off the hop saying that I want to be tested now which didn't really surprise me. Like I figured she would probably want to know for herself. The only question I got from my daughter was when could she be tested." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children

[ages at time of disclosure were 17, 20 – not eligible].

Parent five's story demonstrated the notion that the daily life of children naturally moves forward.

> "I'd say that they didn't really ask questions about it too much. Just kind of took it matter of fact. We would have responded to any questions, but they sort of left it at where it was. No. Just I guess kind of matter of fact, okay, yea, then that's good. Didn't question anything about or show concerns.
> Interviewer: Has there been any changes in the children that you've assessed?
> Participant: Not that I'm aware of." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

The proceeding commentary shows how children's reactions were consistent with their developmental age. Additionally, it illustrates how one child coped by keeping informed about her mother's health needs. Presented also is how parents comforted distressed children by the acknowledgment of the positive and by keeping children informed.

> "They were okay with it. …At first my son tried to be stronger than girls, but my daughter cried because it's another thing for her to take in. But after we explained everything to her and told her that this is actually an opportunity for them to do something for me than not. She understood. She's actually old for her years. She is good, but initially she was upset. My son well you know boys, he cried for a bit and then he's on to his next thing. Often we'll talk about things and she's like, well mom, you're actually kind of lucky because they're going to be able to help you. Whereas my friend, she didn't even know. Like, she understands that this is an opportunity for me to do something before. …Since I've had my hysterectomy things have been pretty normal. Like we don't talk about it unless I'm going for a mammogram or something. We're just trying to be the same as normal which I have to because I have to go on with life so you just keep going. … At first she just wanted to make sure that I was okay and stuff. But now she's involved. When I had my hysterectomy and stuff I explained why I was having that. If I made an appointment or something she wants to make sure that I'm going. She's aware that I'm looking after myself." (Parent who has a positive BRCA 1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18 – not eligible]).

The aforementioned example demonstrates a parent's attempt to be honest while meeting individual children's developmental stages. The passage also highlights the need

for continued dialogue building as children age. The following example revealed how the disclosure conversation could open Pandora's box and a child's reaction to family secrets.

> Interviewer: Did you notice any changes in behaviors or personality traits or anything after you disclosed the information to your child?
> Participant: No, I didn't.
>
> The above parent went of to share:
>
> Participant: What I sort of tried to tell her was that we had cancer in our family. That was just the part of it that went the worst because she didn't know that my mom had cancer twice. That my mom had breast cancer because she was much younger when that happened. My mom asked me not to tell her. And because my mom lived in a different province, I was able to comply with that. So my daughter didn't know at all. She was very upset that I hadn't told her that her nana had cancer."
>
> Later the interviewer restated a prior question:
>
> Interviewer: So how did your child react or respond to the disclosure information?
> Participant: I think she was worried because she was asking a lot of follow-up questions. She started a little to cry. So I think she was sort of trying to put it together in her mind. She'd known I was going for these doctor appointments in the city and she knew that her dad was taking time off work to take me into them. I think she knew maybe something was up. I don't know. I reassured her. I think later on when she had follow-up questions and I think she wanted to know would she have testing right now. Could she go for testing and I said, no, they wouldn't do it.
> Interviewer: Did she have any other follow-up questions?
> Participant: What she wanted to know was I going to be all right. I could reassure her that I was. I told her that I was planning on having two surgeries. One of them would come up fairly shortly and the other one probably not for a couple of years. She wanted to sort of know about those. I said that when I had more information I would share it with her. And so I did." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Mixed Ball of Reactions – Parents. Collectively, the self-assessment of disclosing parents' personal reactions to the communication of BRCA1/2 test results to their children ranged from not feeling anxious, to a sense of sadness, uncertainty, and feeling comfortable. See Table 2.2 for a summary of disclosing parents' reactions after

Table 2.2 Parents' Self-Perception of Their Reactions to Disclosure

Reported Details	% (n = 9)
Confidence without bewilderment	33% (3/9)
Neutral	22% (2/9)
Sadness, guilt, anxious, remorse, wonderment	44% (4/9)

the disclosure conversation. Thirty-three percent (3 out of 9) of disclosing parents' expressed confidence without any bewilderment after the disclosure conversation. Another 22% (2 out of 9) of parents' expressed neutrality after disclosure. The remaining 44% (4 out of 9) verbalized feelings of sadness, remorse, or wonderment. However, all disclosing parents at some point voiced an overall sense of contentment with the decision to disclose. Twenty nine-percent of non-disclosing parents shared a mixed bag of emotions regarding the decision not to disclose which accounted for feeling comfortable with postponing disclosure to being neutral to feelings of wonderment. Similar to disclosing parents; non-disclosing parents also voiced a sense of comfort with their decision-making. The following are examples of disclosing and non-disclosing parents' views that illustrate a mixed bag of parental emotions.

Disclosing Parents. The following parent confessed feeling comfortable with sharing the information; however, she experienced sadness, a sense of relief, and wonderment, as how events would unfold if circumstances were slightly different.

> "I was good I guess. I wasn't anxious about disclosing. I was relieved to know that answer as far as receiving my own, um, like finding that out for myself. …I guess I was saddened but just in that knowing that if I carry then out of three children, very likely at least one of them will carry. But it wasn't a heavy sadness just because we had three-dozen things to be sad about. …Everything happened at once. So I'm kind of curious in a what if kind of way if I would have tested positive two years before diagnosis, or 8 years ago, you know if I would have

> done the test when I first went in, would that have changed how we told our children and how our children reacted. Would it have changed how they reacted to a cancer diagnosis as well? In that, if they already knew that I carried the gene, then would it have been not so much a surprise to them? Not so much a shock." (Parent who has a positive BRCA 2, breast cancer diagnosis, 3 children [ages at the time of disclosure were 9, 6 – not disclosed, 18month – not eligible]).

Similar to the above parent, the parent below endured feelings of sadness and relief. She also acknowledged her sadness was rooted in feeling remorse from the knowledge of possibly passing a mutated BRCA1/2 gene onto an offspring. Relief came after telling her story to her children for the purpose of reassuring the children.

> "You know there was a part of me that felt a little sad about it because of that mother guilt. Oh God did I pass on this gene to my kids. I mean we have no control over that, but there was apart of me that felt a little sad that I wouldn't have wanted them to have to worry about it. … I think there was also a lot of relief in explaining it to reassure them that this wasn't a horrible thing to have this positive result. But a little element of just feeling a little sad because something that they might have to worry about later. But I don't know." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).

Parent three also confessed to feelings of sadness. Additionally, she acknowledged concerns about placing heaviness on her child and the impact of the information on her well-being.

> "I don't' really know. I mean I was sort of sad to put a burden on my daughter. And those are the same thoughts I had when I was having that conversation which was I kind of babbling and just giving her information overload. Or am I leaving gaps that she's going to be filling in and she's going to fill them in with something kind of awful." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Parent four conveyed a sense of wonderment as to if she did right by her children.

> "I wouldn't say I was relieved. I would say I think I questioned maybe my motivations after might be a weird thing. Although, they were fine with it I did still question myself about whether I had done what was in their best interest. Because I guess I feel like I don't know if it was right or not. …I guess that because as a parent I'm use to thinking about them and not me. And this was a weird situation to have to give them information that was potentially uncomfortable and it was around me. And wondering if, yea, if they needed to

know and whether we'd said it in the right way. Even though there was no indication that's not the case."
The interviewer further inquired:

Interviewer: Do you feel any regret?
Participant: No.
Interviewer: Would you have done anything differently?
Participant: Uh. I don't know. I guess not unless maybe to make it more planned and thoughtful. Like it happened in a natural way for our family but I guess it sort of second guess at the way other people would do it. (Parent who has a positive BRCA1 [2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

Some parents were expressive in their opinions while others were brief regarding their feelings of neutrality as noted in the next two quotes:

Parent 1:

"Interviewer: How did you feel after disclosing the information to your children?
Participant: Feel fine.
Interviewer: Anything else?
Participant: No. (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages at time of disclosure were 9, 12]).

Parent 2:
"I didn't feel any different because I know that he probably wouldn't understand or when he was involved in conversations that was brought up when I wasn't directly speaking to him about it that yea, he just can't comprehend it." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7]).

The last three disclosing parents expressed confidence in their decision to disclose:

Parent 1:

"I feel I did the right thing. I feel it was good. I just know that I couldn't keep things from them being the age that they were. They were old enough to understand what was happening because what was going on. I feel good about it. I probably would have done the same thing if I had to do it over." (Parent who has a positive BRCA1 [2011], cancer status, 2 children [ages at time of disclosure were 14, 18]).

Parent 2:

"I felt the chances of having a positive result for BRCA 2 was so low, I involved them in the discussion right from the beginning. But had I known, certainly thinking back on it, if, um, now that I realize that it is a positive result, I would have been more careful on how I shared the information for sure. The conversation went well. And just based on how the boys have handled the information I would definitely share again and use the same terminology. I would definitely do it over again." (Parent who has a positive BRCA2 [2012], cancer diagnosis, 2 children [ages at time of disclosure was 11, 13]).

Parent 3:

"I felt good. I felt it was important for them to know. I don't resent telling them any of it. I think it was all-beneficial. And if I had to do it again I would do it again." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 17, 20 – not eligible]).

Non-Disclosing Parents. Only a few of non-disclosing parents commented on their feelings regarding non-disclosure; however, all voiced a sensation of contentment with the decision.

Parent 1:

Interviewer: How do you feel abut your decision not to disclose your test results to your children?
Participant: Pretty good. Pretty good. (Parent who has a positive BRCA2 [2012], unaffected cancer status, 2 child [ages when parent given BRCA result were 9, 11])

Parent 2:

"Confident!" (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages when parents given BRCA results were 1, 4]).

Parent 3:

"I feel comfortable" (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age when parents given BRCA results was 5]).

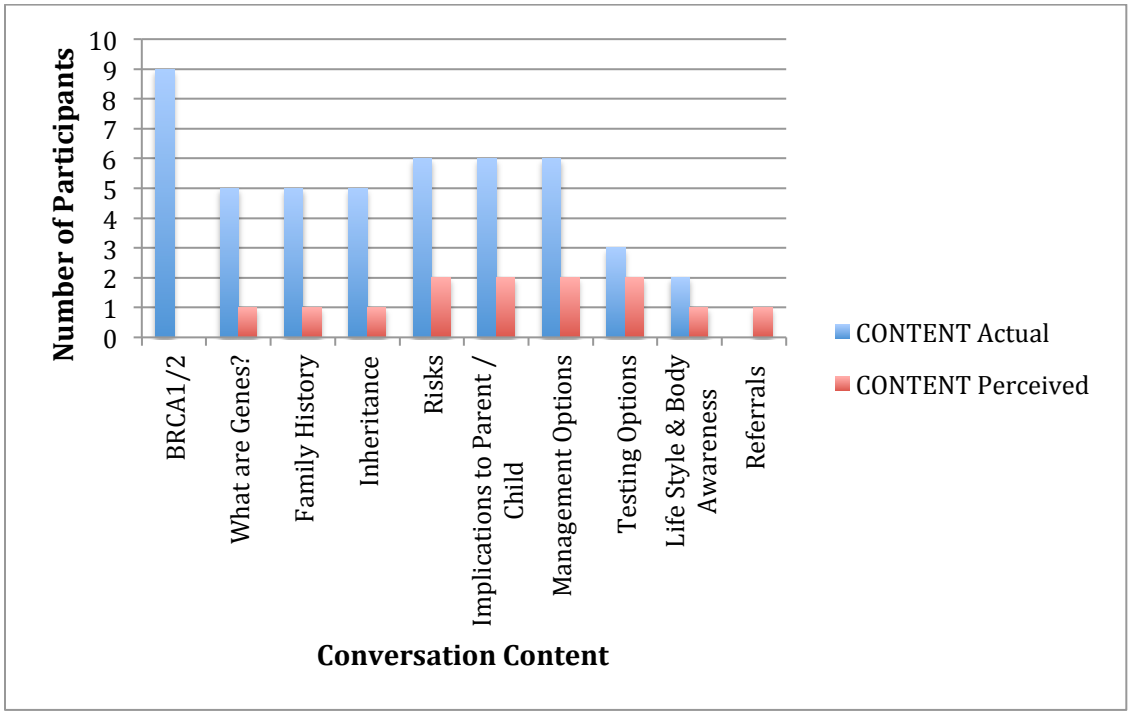
Parent 4 explained:

"I think had I known that I had cancer in advance I would have shared that

> information with him. Because it sort of came about after the prophylactic mastectomies and because I didn't need any other treatment. …I'm not at all conflicted about my decision not to disclose. I mean I feel like that's the right way of approaching it right now. I don't feel there's an urgency to doing this. Like it's not something that I'm not losing sleep over, but it is something that I know ultimately that it's important information for him to have. … Um. I mean there is the piece as a parent, like I think you feel responsible for your child and like this is just that guilt piece which we haven't really touched on. I don't know that I feel guilty. It's just is what it is.." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age when parent given BRCA result was 15]).

A Future Conversation. Non-disclosing parents acknowledged the intent to communicate BRCA1/2 test results to children. This section provides an insight into parents' vision regarding the future conversation. It also summarizes disclosing parents actual disclosure content and non-disclosing parents perceived content for a future disclosure conversation. See Table 2.3 for a comparison between disclosing and non-disclosing parents actual and perceived conversation content. Furthermore, parents described their action plan pertaining to preparation, the disclosure information content, individuals who would be present, and how the conversation would unfold. The majority of parents considered themselves to be information seekers; consequently, resources would be accessed as part of the preparation process. The list of intended resources included staff members at Hereditary Breast and Ovarian Clinic, Breast Cancer Centre of Hope, Breast Health Centre, Breast Cancer Centre of Hope, Breast Health Centre, family doctors, psychiatrists, services providers at CancerCare Manitoba Patient and Family Support Library, and the Internet. The information content planned includes family history, inheritance of genes, screening, management and testing options, and body awareness and lifestyle choices. Most parents commented that they intend to present information in a positive manner. Parents envisioned the conversation as unplanned and casual, or plan and structured. The proceeding examples illustrate non-disclosing parents'

Table 2.3 Actual and Perceived Disclosure Content



vision about the future disclosure conversation.

The following parent previously disclosed a BRCA1/2 test result to the eldest, but not the two younger children. Her plan is to share genetic information with all the children; however, discussions will be tailored to individual children's cognition. Breast Cancer Centre of Hope, Breast Health Centre, Hereditary Breast and Ovarian Clinic, and the Patient Family Support Resource Library at CancerCare Manitoba were identified as valuable resources that will assist with preparatory needs. This mother explained as a result of a family member's pending surgery she intends on disclosing in the near future. The conversation would begin by sharing that:

> "We went for genetic testing and this is how it went. We'll probably discuss it in that way. I think we'll really have to remind her (daughter) that it's not just women who get breast cancer. Just so that she doesn't just jump to the conclusion that okay, I'm the girl in this family and so that means this is going to be happening to me. I don't know that we would discuss the genetics part of it at all with our youngest because we wouldn't even necessarily be discussing the

> surgeries with him. ….I probably would have a talk with Breast Cancer Centre of Hope, and very likely with whoever my nurse was at Breast Health Centre. …I would also refer back to emails I have from the Hereditary Breast and Ovarian Clinic (HBOCC). And so I may just shoot a quick email off to HBOCC to see if there's any new books. Or I would very likely just refer to CancerCare to see if they had things in their library. I think those probably would be our main sources of information." (Parent who has a BRCA 2 [2009], breast cancer diagnosis, 3 children [ages when parent give BRCA result were 9, 6 – not disclosed, 18 months – not eligible]).

Parent 2:

This parent described a future conversation involving her and her husband sharing BRCA1/2 factual information with their children. The content was seen as including family history, changes of inheritance within families, risks, and available options. This parent explained the purpose of disclosure would be to highlight awareness and the promotion of self-advocacy for personalized healthcare. Prior to disclosure parents intend to pre-organize counseling support for the children and reconnect with healthcare professionals with whom they had established relations. This included professionals from Breast Health Centre, Hereditary Breast and Ovarian Clinic, and their family doctor.

> "Well I'll share the fact of our family history. Obviously. The reality of their likelihood of being positive for that gene as well. And choices, they might be faced with. I would expect my husband to be part of that conversation. And I just expect we'll sit at home and have that conversation one night. …I don't plan on having any counselors involved or anything like that, but I would make sure to have those resources available to my kids if they wanted to talk to somebody after so I would make sure that was lined up. …I won't tell my kids for the purpose of them going and seeking out genetic testing. So I would tell them so they were a little more aware that they need to take those symptoms seriously. …I'll keep it factual. Have been pretty factual with them all along. Like though my diagnosis and through my illness. They always know that I had cancer and never really showed any sort of reaction to that. I was very straight forward about the medicines and things like that. And the side effects of those medicines. I never showed them physically what it meant. Like I never showed them my scars and things like that because I don't think they were ready for that. But they seemed to tolerate the facts pretty well. …Let them know the percentage of their risk. And what the common procedures are at that time. I mean that's 10, 15 years down the road. …Well I would check my facts, that's for sure because it's been a while and

> I don't remember. I think when you go through it you hear a lot of that stuff and then you tend to suppress a lot of it too. I would probably go to Breast Health Centre. I would also talk to [name of professional at HBOCC] maybe or somebody like that that I've talked to before and just get [her/him] to give me what recommendations are being made and that kind of stuff. And I'd probably talk to my family doctor." (Parent who has a BRCA1 [2009], breast cancer diagnosis, 2 children [ages when parent give BRCA result were 1, 4]).

Parent 3:

The next parent expressed confidence in her abilities to have a future disclosure conversation with her child which she envisioned as a structured, factual, and at a predetermined time. However, this mother admitted she is opened to dialog at any time if it was self-initiated by her daughter. The conversation would include information as to what a gene is, and the availability and testing process.

> "I don't think there's any one person I would seek advice from because I've lived it. I mean who better to give advice that someone who's been through it. Resource wise, I would definitely do the same thing I did when I found out about the genes. Doing research and getting all my facts together to show her. I wouldn't set it aside, guess what, I've got this gene, you may or may not have it. You can go get tested. It's going to be structured and it's going to not overwhelm her because I know it was very overwhelming for me when I was seeking information. I'm doing all my research already. Not that there isn't people to talk to, I just didn't feel comfortable talking to some stranger. I just want to give her all the facts. As far as resources, probably going on the Internet which is not always reliable, but because I've been though it I know the ins and outs of it. Just kind of put it out there and show her what it is and the odds, all that stuff. And whether she wants to get tested. Giving her the right information, the right people to interact with in order to get those things accomplished. …If I do decide to tell her earlier, I mean it's just going to happen on its own if it's meant to happen. She'll come to me with it. I'll give her the facts, explain what the gene is, what it does, and how you can get tested. That's your choice." (Parent who has a BRCA2 [2011], unaffected cancer status, 1 child [age when parent give BRCA result was 5]).

Parent 4:

This parent envisioned a scheduled conversation with both parents present. The information shared would be simple and use of medical terminology eliminated.

> "I haven't planned it out in my mind. But I think it would be a good idea to think it through and to sort of to prepare for it. It probably would be a good idea to have her father at the table when we're having this conversation. It should be sort of a time we can sit down and have some quiet and peace and sort of no distractions and address it in a way that there will be still time left. Sort of not in a hurry to go to the next soccer game or something like that. Both my husband and I have some medical understanding of biology. I do not want us to be providing her medical information. I don't want her to see us as teaching her about biology. I do think this is her biology teacher's task to do that because I want her to know that we're her parents. So a piece of it would be not to go into medical terms. Not to use our knowledge to bombard her with likelihoods and statistics and epidemiology." (Parent who has a BRCA 1 [2012], breast cancer diagnosis, 1 children [age when parent give BRCA result was 6]).

Parent 5:

This parent simply described the future conversation as seizing the moment, but being prepared for the seized moment. Part of the preparation included communications with her daughter's psychotherapist for advice and guidance.

> "The resources [name], my daughter has a psychiatrist that she does psychotherapy with her. Really great woman. I'd probably talk to her a bit. Um. How would I do it? I wouldn't just tell them. Sit down, have a talk. Or in passing. Probably seize the moment. The moment when it comes up. Well I would talk to them both, but at separate times." (Parent who has a BRCA2 [2012], unaffected cancer status, 2 children [ages when parent give BRCA result were 9, 11]).

Parent 6:

This parent noted her intentions to share test results with her son; however, she is uncertain exactly how the discussion would unfold. She did stress the importance of information sharing in a positive manner and herself as the primary communicator of the information. The conversation would emphasize the importance of a lifelong commitment to age appropriate screening and healthy lifestyle choices.

> "Highlight the awareness. And just really take note when the government or ads are trying to teach you about prevention in those certain cancers to really take that seriously, especially with our family. Don't think well that won't happen to me because it actually could with the gene we carry. So to really pay attention and follow those instructions and guidelines and make it a part of your lifestyle

> because awareness is key. You know a lot of people are caught up with having suntans and the sunburns and sun tanning booths and things like that. So I think hopefully he will take it seriously and do what he can to prevent. I'm not a doctor or a nurse so I'll only go as far as I know but I think I understand more than the average person will. …I know my son best. How to say it to him and what to say and to listen and to make sure he is informed properly. I don't want it to come from a cousin or somebody else saying did you hear we might have this scary thing and we're all going to die. I just want to make sure gain the style I've chosen to tell him that it's presented that way. It's the way you tell him. I mean if you sit and cry and you have this scary look then they're going to treat it as being scary. If you treat it as matter of fact you probably are aware that there's cancer in our family so it's something you want to be careful of. And I actually carry the, you know, I sort of haven't thought about how I will say it. …We're kind of lucky that we have this information because I have it so it's better to know it and then you can choose to highlight awareness. …I want to really be careful of how I present it to him because you want to make it serious but you don't want to make it like this is a death sentence and again you don't want to make him fearful. You just don't want to make him fearful. You just want to make him aware. And again, how you treat it. If you treat it like it's serious, but it's not something you want to worry about the rest of your life, then that's how he'll respond. So I guess I have to feel really ready in that way as well." (Parent who has a BRCA2 [2008], breast cancer diagnosis, 1 child [age when parent give BRCA result was 13]).

Parent 7:

Not unlike the other non-disclosing parents, this parent is uncertain how a future disclosure conversation would materialize. Planned preparations included resource services such as mental health and the genetic department.

> "I'm not sure how I'm going to go about it. But I wouldn't just sort of send him to an office like without sort of him having some kind of understanding as to why I did the surgery that I did and that this may mean that there are some other medical sort of screens that he has to have over the years. I mean obviously I feel I need to speak to genetics again to make sure that I have the facts because the facts from different sources have varied. So I want to make sure that I know that I'm accurate in what I'm thinking. I'm not really sure to be honest. You know he has some support though [name of a specific program]. So if there is a sort of mental health professional involved that would be a resource. But beyond that I don't know, and the genetics department ultimately as well." (Parent who has a BRCA1[2011], breast cancer diagnosis, 1 child [age when parent give BRCA result was 15]).

Knowledge Deficit

An assessment of the 15 study participants' transcriptions revealed that some parents lacked knowledge regarding specific BRCA1/2 information. Thirty-three percent of all study participants (5 out of 15) self-identified the need for further information on a specific topic or they were unconscious of the existence of a knowledge deficit. Of this 33%, 40% disclosing parents (2 out of 5) and 60% non-disclosing parents (3 out of 5) were classified as having a knowledge deficit. Knowledge deficit was identified in the following areas: BRCA1/2 risk factors, chances of inheritance, the impact of a defective BRCA1/2 gene on males, screening recommendations for males, considerations for life and mortgage insurance, and testing eligibility. The following study participants' quotes are representative of parental knowledge deficit:

1. "I was saddened a bit just in that knowing that if I carry then out of three children very likely at least one of them will carry." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 children [age at time of disclosure were 9, 6 – not disclosed, 18 months – not eligible]).
2. "Quite frankly, I'm really not that clear on how much it affects males, having a BRCA positive result.
    a. "Having more information about life and mortgage insurance would alleviate a lot of people's fears in maybe getting testing done or choosing to get the testing done in the future." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 11, 14]).
3. "I may sit her down and explain to her that there's a possibility. Because I did have two children, and it's 50-50. So lets hope that if anything great came out of [name of child]'s loss, it was the fact that she has the gene.
    a. "I know I have the choice to get her tested right now if I wanted to find out." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5]).
4. "I was always very paranoid because of my family history. No, no, no, you're way too young. Of course, hearing this I'm like, uh, that's kind of why I knew I was positive because with the issues of my cervix and my family history, and just different things that were happening during sexual intercourse. Different things like the pain I was having, and no one could touch my breast, ever. I felt like there were lumps in my nipples all the time…" (Parent who

has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time parent given BRCA result was 5]).

5. "Where as with guys, you can't really, I don't know if you can really do your monthly breast exam. I don't know if guys can really do a monthly prostate exam." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2
6. child [age at time of disclosure were 1, 15]).
7. "Again with males when does it become more critical that they have this information, and what about screening?"
    a. "It does become sort of less clear to me with a male. I mean obviously a son, if they marry and have children and they have the potential to have daughters. I'm not sure at what point it sort of becomes more important for him to have this information because how would it change what medical follow-up he has at this point." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age at time parent given BRCA result was 15]).

Parental Recommendations

The last theme is *parental recommendations*. The lived experience involved in the decision to disclose or not to disclose offered study participants' a unique insight that has enabled them to propose recommendations to healthcare providers and words of advice to other BRCA1/2 positive parents. Overall both groups of parents felt they had received quality service from healthcare providers. However, parents felt they needed more information specific to the topic of disclosure and non-disclosure. Parents believed disclosure should occur, but they differed on when this should happen because, it is individual to the needs of the child and family. See Table 2.4 for a summary of disclosing and non-disclosing parents recommendations to healthcare professionals.

Disclosing Parents Recommendations to Healthcare Providers. 'Take it a step further' was the key message from disclosing parents. The responsibility for introducing the topic of communication and non-communication of BRCA1/2 test results to minors was delegated to healthcare practitioners. Suggested topics for conversation included risk factors, inheritance information, and specifics regarding the if, when, what, and how to

Table 2.4 Parental Recommendations to Healthcare Professionals

Resources: - Books, pamphlets, videos, internet sessions, in-person group sessions, face-to-face private appointments regarding the basics of BRCA1/2 information; pros and cons of disclosure; if, when, how to disclose, dealing with non-disclosure - Above resources available in kid friendly language for various age groups - List of community resources - List of credible websites - Referrals to allied healthcare practitioners for parents and children's needs - Kids-Help Phone - Peer Support - Follow-up appointments 1, 2, 3, or 4 weeks post BRCA1/2 results appointment
Mode of Delivery: - Group Sessions - Private face-to-face one-on-one - Interactive online sessions - Telephone
Facilitator: - Clinician knowledgeable in genetics, management options, family needs, supportive care (i.e. member of genetics team, genetic case manager, nurse, oncologist, social worker)

disclose. Parents also felt referrals should be provided to allied healthcare professionals for educational and supportive care. Furthermore, parents desired printed information on the topic of BRCA1/2, a supplementary resource list with a contact telephone numbers, and a list of reliable Internet sites. Other suggestions included resources that targeted children's cognitive and emotional needs such as educational sessions, information packages, and a kids-helpline. The following passages endorse the above summary.

Parent 1:

> "I think any healthcare provider or doctor in explaining to somebody that they have this genetic result should take it a step further. I don't know if they have those numbers though. If there's a 50% change, a 30% change or whatever chance your children may also have this. If they had that information, then they could say okay this much of a chance. You may choose to tell your children and these are the reasons why you might choose to tell them. If they did choose to tell their children, their children didn't react well, they should have some kind of service or support in place to help those kids who didn't react well. Even if there was a list of resources, a separate sheet that's given in a package that says some people

> choose to share this information with their children and if you should choose to do that or need support around that, if you need tips or guidelines, or this is how you could discuss it with your kids. Or these are the resources your kids could use if they need it. If you want to share the information with them but you're not sure how to do it, maybe there could be some assistance in that regard. …I think it would be really good for the parents who choose to share it with a minor, if they have some kind of education forum or something like a group workshop. Maybe that would be in order for some kids. Having it in kid friendly language with kid friendly graphics, charts, whatever. Even an information package for kids saying this is what it means. …Even a kids-help phone. If you need to talk about this or if there was someone at CancerCare that they could call if they had questions that they didn't want to ask their parent. That might be a really good support for some kids I could see." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [age at time of disclosure were 11, 14]).

Another parent supported the above with these comments.

Parent 2:

> "The only thing that maybe, depending on how old the kids were, was how to explain it to them? Some type of information after you saw [name of genetic team member]. Is there some type of place you could go to help you choose your words for them to understand at their level. Or some type of visual, Internet where you can go for a visual presentation for them to understand at their level." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 2 children [ages at time of disclosure were 9, 12]).

The next three parents concurred with the need for decision-making guidance that included printed material with factual information and the ABC's of the if, when, what, and how of disclosure versus non-disclosure. A two to three week follow-up contact was suggested either by telephone communication, in-person dialogue, peer-to-peer support, and or an interactive Internet session. Furthermore, it was proposed that practitioners could plant a seed at the initial genetic appointment about the fact that part of the decision-making process of testing for the BRCA1/2 gene might involve the decision to communicate, or not communicate a positive test result to minors. It was acknowledged this information should be provided in advance of parents' consent to BRCA1/2 testing because, "the news was shocking" and the process "stressful."

Parent 1 simply stated:

"Giving the ramifications of disclosing that information whether it be printed literature, website, YouTube. Um. Peer to peer counselor." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7]).

Parent 2 added:

Participant: I think there probably is a gap there. I think at the very least probably some literature or guide me towards some literature how you would speak to your child about that. I think it probably should be acknowledged that it's a tough decision.
Interviewer: When along the process do you think it would be an appropriate time for a healthcare provider to acknowledge that to a parent?
Participants: I don't think when they give the original results. I would say probably a week to two weeks later. I would say then is a good time after somebody's had an opportunity to process that information, and then bring it up. Let them know if there is any services to help them with that decision, or let them know that if they haven't made a decision yet services are there to help. I think probably telephone is best way."

This parent later shared what information she would like to have received:

"What I would like to see is things you may want to bring up with your child. Even getting more factual information. I think a pamphlet could help. I think an Internet tutorial might be a good way to go. Presentations with an opportunity to ask questions by email or by chat. I don't know how it all works. But I think something like that might work. I think going to session could lead to emotional thoughts and there's a full room of people who've had the same information that you've had and everybody is trying to process it in their own way. I think that can really be a stressful time. I don't know if I would go to something like that. I think probably telephone is best. If you have a face-to-face you have to go into CancerCare and nobody want to go to CancerCare. And it's so easy to misinterpret emails or to not be able to convey any kind of caring or compassion over an email. That's very difficult to do with electronic media. So I think a phone call is probably best. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Parent 3 further communicated that:

"A second interview after we heard the initial news, [s/he] might have suggested we think about how we want to proceed with the information. I did feel I needed to share the news with my aunts and uncles and cousins fairly quickly. So it would have been helpful to have a second interview just to put more thought into that decision. Maybe even planting the thought up front would be an appropriate

> time as well. It was just through my experience I was some what surprised by the information. Our visit was an hour and a half. The information was overwhelming, discussing and processing my personal risks, found to be a BRCA 2 positive. The news was quite surprising and shocking. I felt this sort of added pressure of processing for myself and processing for my family, my nieces, and my cousins. So probably a follow-up in two weeks time would have been helpful just to have gone thought where we go from here? How do we let the family know? Probably would have been a good thing for them to have just said, bring a family member with you because it was a shocking bit of news to have received and I was so glad I wasn't alone when I received the news. A follow-up visit reminding us about the risks that would be involved to our children so we could be presenting the information as accurately as possible. And then whether or not we should be sharing that information. That would be helpful. When the result are shared with the parents then maybe the option could be given to them if you would like a follow-up visit to discuss how and when and why you might want to share this information with your children and how this should be done. … I think in person is a very helpful way to have that information shared. Private-one-on-one with printed material highlighting the risks associated with the diagnosis would have been helpful." (Parent who has a positive BRCA 2 [2012], ovarian cancer diagnosis, 2 children [age at time of disclosure were 11, 13]).

Similar to the above recommendation another suggestion was for clinicians to introduce the topic of disclosure and non-disclosure to parents at the BRCA1/2 test result consult because, children's awareness of genetic testing may be initiated early in the process. Parents desired to have speaking points and felt they needed to be emotionally ready before they engaged in conversations with their children.

> "I think after they told me the when we were discussing things it should have been brought up at that time. But, um, kind of a little bit in a shock. So after you discuss it for a while it should have been brought up about our children. That's what I think before you even go home because, by the time I got home I already decided to tell them. You need a lot of information before you can tell them something like that because, they're going to ask you questions about it. And you just have to be prepared emotionally."
> Interviewer: What kind of information is need for a parent to help a child?
> Participant: What your options are, what it actually means to have this gene. The percentages and stuff like that written in words that a child could understand. I think if you had young children, or if my children hadn't been, I would have taken them to counseling or something. We never did any of that. But I think that should be offered." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [age at time of disclosure were 14, 18]).

The request for added support in the decision-making process was again echoed in the comments of the following two disclosing parents. Items on parents' wish list included academic information such as the how-to-of disclosure, potential reactions from the children, and how a parent can support the broad-spectrum of responses from children. Parents requested academic information to be supplemented with other BRCA1/2 positive parents' views regarding the benefits and contradictions to disclosure. A contact name and telephone number of psychosocial clinicians for children who are not coping well were regarded as a valuable service; in addition, a contact telephone number for parental inquires. Other suggestions included printed literature, creditable online sites, and face-to-face conversations with a knowledgeable professional. It was also suggested that an invitation should be extended to core family members to attend the results discussion or a follow-up core family consult appointment scheduled.

Parent 1 stated:

> "There's a lot of information so maybe have a brochure and say something like you don't have to stress out about telling your family or make a big issue. You can call this number and get some ideas about how to do it if you, or when you get around to thinking that's what you want to do. Something about when you're disclosing. What other people's experiences have been because, you don't know how your kids will react? Is it common that they would be really upset or is it common that they'll just kind of go okay. What if there are really upset, what would you do then. Is there any kind of support for them. The pros and cons of disclosing. Talk about how it's inherited. Um. Sort of considerations. Things to consider before deciding. Things that you might want to think about and be prepared to answer or how children at different ages might react. Information online I would look that up if its was given from a healthcare provider or the genetic department." (Parent who has a positive BRCA1 [2011], unaffected cancer status cancer, 3 children [age at time of disclosure were 13, 15, 15]).

Parent 2:

Interviewer: What would have been helpful to you?

> Participant: I would have like to have heard what other people would have had to say about telling like how to go about telling your kids than just bluntly saying, I'm BRCA2 positive. I would have like to have had some help to find out if it would have been a good thing to tell her or how should I have gone about telling her. It would have been good to have some kind of insight on how to approach them, or just exactly how much to tell them. Like if somebody said, we have a sit down type of meeting that helps you to explain to your kids information like this, would you be part of it? I would have. Because there is something else that I could have told them or maybe there's something I shouldn't have told them that I did.
> Interviewer: Who would you have liked to have spoken with you about the disclosure process and when should it be done?
> Participant: I think maybe [name of member of genetic team] and I had sat down and talked, like I felt comfortable talking with [her/ him]. [S/he] could have sat down with me and said this is what we recommend to do to inform your children. Or maybe a psychologist, a social worker or … somebody who knows more about the whole ovarian, breast cancer and stuff like that. …So if there were questions that the kids had that they would be able to answer them. …It might be helpful to have somebody sit down with everyone in our core family. I think a face-to-face discussion would be best. I know they don't have time because, they're very busy. But like even the interns that train with them, it could be part of their job even to meet with a family. Because they do know the ins and outs of it. That's what they're training for. So like even somebody like that could be beneficial.

The above parent added the following comment regarding the results appointment:

> Participant: I think that would have been a good time to suggest that we can meet together as a group with your children and sort of back you up with whatever information you need to give them. Yea. And discussing with you when you get your results do you want to have the family with you? See like it wouldn't bother me to have my husband and my two kids with me when they told me that I was positive. It would have left my kids open to ask somebody who knows much more than I do about what does this all mean for my mom, for me. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 2 children [age at time of disclosure were 16, 20 – not eligible]).

Non-Disclosing Parents Recommendations to Healthcare Providers. Non-disclosing parents reinforced the views of disclosing parents in that fact they perceived healthcare professionals have a responsibility to engage parents in the decision-making process. Assistance in the process meant providing educational information for parents

and children to learn about the potential inheritance and consequences of BRCA1/2, the how to disclose to minors, and how children may react. Additionally, offer group sessions, supportive care, and reassurance for parents who choose not to disclose. It was also suggested to provide resources that identified creditable websites, fact sheet, and connecting parents with parents. These actions were viewed as efforts that will assist parents to make informed decisions. The following two non-disclosing parents noted the aforementioned recommendations.

> "They're informed about or thought about why, think about their plans, the future, about whether or not they choose to. They're informed of all the reasons that it could benefit or not for them personally. They could bring it up by saying have you though about whether or not you'll talk to your children at some point about this?" (Parent who has a positive BRCA2 [2008], breast cancer diagnosis, 1 child [age when BRCA result given was 13]).

Parent 2 added:

> "I think encouraging parents to make the decision that they think is best for their child. Nobody knows your child but you. And letting them know its okay not to feel bad about not doing that. Telling them as much information as they can. …I think they should have something where parents and family can attend and learn more about the gene and how it affect everybody, things you can do about it or how you can. I think that would be awesome. …Just give straight up facts what is BRCA 1, BRCA 2. Have more resources where parents or people can go on different links of different websites and find out more information about it. I found the best stuff on the Internet.
> Interviewer: On the note about telling children, what would you like to see there?
> Participants: Just the best way to go about it, maybe even just phone the parents that have done it, or that have different ideals and putting a few on there. Just different ways to approach it. … I think you should get some kind of session going. There's books on how to tell your children about the birds and the bees. There's books on how to tell you children about drugs and alcohol. There should be a book on this because it's so vast now. Extremely important to have some kind of reference guide or fact sheet or something that you could provide to your child when you're ready to tell them. …Have a group session with parents that went through it. I think it'd be helpful just the same way when I was going through my surgery having that group counselor or that peer counselor was extremely helpful. I think it would be the same sense as parents going through the decision to tell to their children or not. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age when BRCA result given was 5]).

Disclosing and non-disclosing parents voiced the need for a member of the genetic department to discuss sharing and not sharing BRCA1/2 results with minors. However, contrary to some parents the following parent suggested the topic should be acknowledged prior to individuals consenting to BRCA1/2 testing because, a positive test result involved multiple layers of decision-making. A discussion before the commencement of testing would allow parents to truly make informed decisions as it pertained to genetic testing. Furthermore, the need was identified to invite parents back to consult with practitioners. The process of how to reconnect with the genetics department or another supportive resource should to be clarified "upfront."

> Interviewer: Would it have been appropriate for a healthcare professional to bring up the topic? And when would be the appropriate time to do so?
> Participant: Before the test results around just the BRCA1/2 testing process? Something in there. I met with [name of team member from genetic department] at the beginning before I had my test. Before I actually had the test. [S/he] was explaining to me what the impact of the results could mean either way for me. At that time I think would have been the right time to talk about services or the options for support for the family. Before the results are actually provided because it's not a lot of work that goes into it. Like I know you don't want to put a lot of work if it's something that you don't know it's going to be positive or negative. But there's not a lot of effort to say that these services are available or maybe there's something you'll want to think about should these results come back positive. Because once they do come back positive there's a lot of things to think about. I'll have to get back in touch with those people to get my facts straight. You know, having that option available, if I called [name of team member from genetic department] in 10 years is [s/he] going to be willing to talk with me? Cause it seemed like you go through CancerCare and then once you're done you're kinda done. You're sort of pushed out of the system a little bit. Like I should be able to come back into your system if I need to without having to go through hoops. They should let you know that if down the road you have questions about the disclosure and non-disclosure of genetic test result to your children you can come back. You can call or this is the process that will have to be followed. This is what you actually have to do. Whether it be to go back to the family doctor. (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [age when BRCA result given were 1, 4]).

The following two parents agreed there is a need for an additional genetic

appointment, following the results consultation. The first parent supported the notion of a follow-up four-week appointment to discuss issues of disclosure versus non-disclosure. A follow-up discussion appointment with an allied health professional (versus an upfront discussion) was deemed as beneficial because, parental denial was seen as a helpful coping strategy during stressful time periods. Additionally, a once-a-year 15-minute update appointment was deemed valuable. The second parent also identified the need for an allied health professional to take on the role of a genetic case manager. The responsibility of genetic case manager was seen as connecting with BRCA1/2 carriers to assist in decision-making and other follow-up needs. This endorsement came from a parent who counsels suicidal individuals. She compared the suicidal journey with the genetic journey and identified the decision-making process involved stages of change. Consequently, one role for the genetic case manager was seen as guiding individuals along the decision-making continuum. Counseling was also mentioned as a good resource.

Parent 1 suggested:

> "I had a one time meeting with [name of member of genetic team] when the papers came back. I do believe they should offer you to come back if you have any questions, call us again. I'm a professional. I know everything myself. Um. I wonder if scheduling a second meeting and address things like that would have been helpful. Maybe. I don't know. It's hard to tell. I do believe that sometimes denial is helpful. There are certain situations where being in denial does help you to get through. And for some parents this might be one of those areas. Where the children are still small, do you really want someone to walk you though letting them know that whatever almost killing you right now will kill them eventually as well. Um. Probably not. I could see a second appointment with an allied health professional as being helpful. Perhaps offer genetic counseling or the CancerCare team saying we've noticed that you have young kids. There are some other points you may encounter at one point in life, do you want to talk about it. I do think that having a second appointment, there was a shell shock of this information even if you are expecting it, and I was expecting it. The other thing is to meet maybe in four weeks. Um. Other families have found it helpful to look at how do we talk to

children. Is there something that you're thinking about and would you like some help in preparing yourself for that disclosure at some point? Face-to-face. Again, people will be different around that. I would say scheduling a once a year follow-up would make sense with [name of member of genetic team] or with an allied. The team just say, these are new developments. This is what we know now, what we didn't know a year ago. Or where are you at with this knowledge. Do you have any more questions about it? Is there anything? That might be just for 15 minutes. But to sort of go along those lines, have you talked to your kids or how are your kids taking it." (Parent who has a positive BRCA1 [2012], breast cancer diagnosis, 1 child [age when BRCA result given was 6]).

Parent 2 further noted:

Interviewer: I hear you saying that you would find it helpful for someone to discuss with you the pros and cons of disclosing and not disclosing?
Participant: Yea. Like it would be specific to the family. At first just with me face-to-face. … I can imagine like as a genetic counselor what [her/his] caseload must be. But I think that if you have a genetic counselor that would be your family genetic counselor to provide that counseling to your family. I think there should be like a genetic counselor case manager kind of thing for the family. I would say face-to-face. Like maybe there should be a support group to get together and talk. I think right now everybody is quick to refer to a website or blog. I would say there should be some counseling offered.
Interviewer: When do you think would be the best time for that intervention to happen?
Participant: A week after you get your result because you're kind of shocked right away. I think it would be more about them saying what's up? How are things going?

This parent admitted she did a lot of suicide prevention and compared the two:

"It's like the river of suicide where it's very specific path that most people who are suicidal take. Kind of weird comparing the two, but there's also probably a very specific path around disclosure. Like they could say, where are you on this path? Like there's stages of change. Just to help people identify the path towards change and looking at are you here? Are you here? How are you? Where do you want to be next? How can we help get you there? Are you comfortable there? It's sort of quantifying it a bit into a continuum for non-disclosure to disclosure. …Come see me in a week and we'll start figuring out where you are on this path and if you want to be there or if you want to move forward how do we help you." (Parent who has a positive BRCA2 [2012], unaffected cancer status, 2 children [age when BRCA result given were 9, 11]).

The following parent concurred with all study participants regarding a need to "take it a step further." This parent thought information sessions lead by a knowledgeable

healthcare professional was needed for the purpose of discussing a broad spectrum of information directed towards the needs of disclosure and non-disclosure. In order to meet a variety of individuals learning styles, the delivery format suggestions ranged from online, in-person, private, and group sessions.

> "I think it would be really helpful if there was some kind of information session provided to families in general just to discuss that issue, when you have children if there are any recommended approaches or whatever. I'm a reader I'll look up things online. I've looked at like the Force website. …I think it would have been right to say that this does have implications for your family. And when you kind of get through this or when you're ready we can meet with you again to discuss how you might approach that subject with your family. I think it would be helpful if they gave you that option. …It would be nice, I mean I know in Ontario there's like Willow which is like a support. It would be nice if there was something like that locally where you could talk to other families and what their experience has been. You could learn things from other families. …Additionally, what would be ideal is that there was somebody, counselors available in a short expedited way to provide support while a person's making that decision. Um. So to know that you can call up genetics department and say, okay I'm now ready for this information. So just to know that that's available to you. That you don't necessarily have to go through a whole kind of referral process again or whatever which is time consuming. Lengthy waits and things like that"

She later added:

> "You know this is something that's inherited potentially, at some point you may want to discuss further. And these are the resources that would be available to you at that time. I personally prefer it to be in-person because, then you can individualize it because everyone's unique and there's going to be unique situations. Frankly, I think there's probably some worth to having both private session and a group session. If someone doesn't or they just want to attend one or the other then they can do that. But probably someone like me would attend both. You know it could be an oncologist. It could be a genetic counselor, or just the geneticist. I'm not stuck on who it is as long as the information is current and accurate and consistent … and something that is produced by Manitoba that's accurate. I'm a hands on person so I like physical paper. Even thought it may be a difficult topic for some individuals, I think it's an important one for healthcare professionals to raise."

Specifically this parent wished to know more about:

> "The pros and the cons of disclosure. Aside from the insurance pieces are there other kinds of cons to knowing this information. What are other people concerned about? What are people's experiences have been when they sort of give this

> information to their family? What about males, what sort of impact does it have? Are there certain tests and things that they should be having? I'm not sure about that because, again the information I've gotten has been a little bit inconsistent." (Parent who has a positive BRCA1 [2011], breast cancer diagnosis, 1 child [age when BRCA result given was 15]).

Disclosing Parents Words of Advice to Other BRCA1/2 Parents. All disclosing parents offered advice to other BRCA1/2 parents. Collectively, the parents counseled others to take children's individual characteristics and life situations into consideration prior to disclosure. They also encouraged parents to be honest and prepared.

Tailored Conversations. The advice from the following three disclosing parents was to tailor conversations to individual children characteristics. The commencement of the initial disclosure conversation needs take into consideration life circumstances surrounding child's world. Moreover, ongoing conversations must meet the needs of the children based on individual cognitive and psychosocial development.

Parent 1 shared:

> "I think parents should definitely look at the age and temperament of their child. Because some kids get overloaded with information and just can't handle it. And to look at the situation too, are they tell their child at the same time as they're telling about a cancer diagnosis? Or are they telling the child when that is kind of the only big news? …Sharing information on an ongoing basis that's age appropriate as well as emotionally appropriate for different children." (Parent who has a positive BRCA2 [2009], breast cancer diagnosis, 3 child [age at time of disclosure was 9, 6 – not disclosed, 18 month – not eligible]).

Parent 2 contributed that parent's need to:

> "Keep in mind what age your children are? You can't explain genetics to a 5-year old. They're just going to look at you and say can I go. A 15-year old may actually listen depending on how it's presented. You know every child is different. You know your child so you need to gauge how you're going to present that." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 child [ages at time of disclosure were 9, 12]).

Parent 3 admitted:

> "There's so many variables. You know if my child was 5 years old when I had this test, I never would have told her anything. I wouldn't have. I think it's really important to tell parents that there's no right answer or a wrong answer. Is what I would say to parent's. If you want to tell your child, I don't think there's really a wrong way to do it short of saying, guess what you have a death sentence on you or something which nobody would ever do." (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age at time of disclosure was 14]).

Parent 4 stated:

> "Well I just always believed in being open and honest with my kids about anything. So to say what somebody else should do, I can't really say that because, that's my own opinion. I just feel the more information you get the better you are. So the more informed, the better decisions you're going to make. Every situation is going to be different because, it all depends on what your kids are like. What their mentality is, or how they can handle information like that. So it's very individual with how people or whether or not they should be telling their kids this information. Depends on the needs of your family and the maturity and where your kids are at. If you feel that this is something that your children can handle that I would say 100% go ahead and tell them because it only makes them more informed." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18]).

Truth Be Told. Parents encouraged other parents to be honest as nothing is gained from being dishonest.

Parent 1 shared:

> "As long as there's no ramification, I would not hold it back. I just don't understand why you wouldn't tell your child. Like maybe there might be certain circumstances where they child is going through a heart transplant or whatever. You're not going to tell the child that he can get cancer now, You're really prone to getting cancer. Like there'd be certain excruciating circumstances that you wouldn't divulge that information, but for the majority of us who have a fairly stable life or the life of that child is fairly stable, I wouldn't see why not. Just be honest. Be honest with your child. You have nothing to gain if you don't disclosure the truth. You're only going to be doing harm when it comes to somebody's health and their ability to seek treatment and their ability to maybe change their lifestyle." (Parent who has a positive BRCA2 [2010], ovarian cancer diagnosis, 1 child [age at time of disclosure was 7]).

Parent 2 simply noted:

> "Well the best thing you can do is to be honest because there is no point in

> covering it up or sugar coating it because, it's going to happen. It's there. You have to deal with it. Just sit them down and tell them exactly what's going on. Reassure them. Like keep stressing that. You have to be honest." (Parent who has a positive BRCA 1 [2011], unaffected cancer status, 2 children [ages at time of disclosure were 14, 18]).

Be Prepared. Parents advised other parents to be prepared emotionally and knowledgeable on the subject matter. Prior to disclosure parents should seek professional assistance or simply engage in self-preparatory activities.

Parent 1 shared:

> "Children are all so different. The decision to share with our children was a positive decision, I feel. That being said, children are different ages and different levels of maturity, so it's hard to make a blanket statement based on other people's decision. It such a personal decision that I wouldn't feel comfortable advising a parent one way or another on whether or not to disclose. I would recommend them dealing with a counselor or a genetic counselor of some kind for that type of information." (Parent who has a positive BRCA2 [2012], ovarian cancer diagnosis, 2 children [ages at time of disclosure were 11, 13]).

Parent 2 noted:

> "I would say go at your own pace. And before you jump in be mindful of what you're doing." (Parent who has a positive BRCA2 [2012], unaffected cancer status, 2 children [ages at time of disclosure were 9, 11]).

Parent 3 explained:

> "I would say it wasn't that big a deal in the way it happened for us. Kind of seemed to have happened naturally. I was prepared although I said it was stressful thinking among all the things I had to do. In my mind I wasn't surprised. Like I didn't take it as a big shock that I was positive so I was in okay state to be able to giving the information. Like I was kind of being able to be matter of fact about it. I wasn't emotional about it. That might be difficult if I had been." (Parent who has a positive BRCA1 [2011], unaffected cancer status, 3 children [ages at time of disclosure were 13, 15, 15]).

Non-Disclosing Parents Words of Advice to Other BRCA1/2 Parents. Non-disclosing parents' advice paralleled that of disclosing parents because they also promoted the act of disclosure which parents noted should commence based on parental

assessment of individual and family needs.

Disclose. Non-disclosing parents advised other parents to disclose, but to be cognizant that the time to disclose is based on the needs of children and families. Parents were guided to trust their own judgment regarding timing of the initial disclosure conversation.

Parent 1 noted:

> "You can't go wrong. It's ultimately your decision to make. It's your child and nobody knows your child better than yourself and how they're going to react. I would encourage them to wait because, I was 27 when I found out, it was extremely hard to grasp with reality. I'm waiting till 18. I think waiting is the most important thing to do if you're going to tell them. Children do deserve the right to know. (Parent who has a positive BRCA2 [2011], unaffected cancer status, 1 child [age when BRCA result given was 5])]).

Parent 2 explained:

> "Each parent has to decide for themselves when the kids are ready to hear it. I don't think it's right to withhold it forever like my mother sort of did. I think it's kind of mean not to tell them about that. It doesn't have to be that big of a deal. It doesn't have to be a death sentence or anything like that." (Parent who has a positive BRCA1 [2009], breast cancer diagnosis, 2 children [ages when BRCA result given were 1, 4]).

Tailored Conversations. This non-disclosing parent advice to other parents was a reminder that disclosure conversations are personal in regards to if, when, what, and how to disclose. The conversations should be personalized to children's needs.

> "Whatever you do is the right thing for you to do. It's not right or wrong. It's not a one-time conversation. Kids usually process it in little bits and pieces. So they will come back two weeks later or two months later with a little follow-up question. You have to be prepared that the conversation is not over. You've opened the conversation. If you present it in a way the kids feel safe to approach this topic, it will be an ongoing conversation." (Parent who has a positive BRCA 1 [2012], breast cancer diagnosis, 1 child [ages when BRCA result given was 6])]).

Summary of Study Findings

The purpose of the hermeneutic phenomenological research study was to

understand the lived experience of BRCA1/2 parents' perceptions regarding the disclosure and non-disclosure of a positive BRCA1/2 test result to minors. The study consisted of 15 research participants with whom eight disclosed, six did not disclose, and one disclosed to the eldest, but not to the younger children. All participants were given a positive BRCA1/2 test result between 2008 and 2012. Both men and women were invited to participate; however, all participants were women. No men made an inquiry regarding the study. Among the 15 female participants, the average age was 40 years with an age range of 28 to 54 years. Sixty percent of the research population were Caucasian, 20% Ashkenazi Jewish, 10% Ukrainian, and 10% Icelandic. The majority of participants resided in the city of Winnipeg (60%), were married or in a common law relationship (80%), or divorced or separated (27%) with the average number of children per family equaling 1.7. Fifty-three percent of study participants had a university education of which 13% self identified as post-graduates, 40% had community or technical college, and 13% were high school graduates. Fifty-three percent (8 out of 15) received a cancer diagnosis with 40% (6 out of 15) diagnosed with a breast cancer and 13% (2 out of15) ovarian cancer.

The essence of the lived experience of the study participants was a parental desire for healthcare professionals to take the BRCA1/2 conversation 'a step further.' Seven themes were explored in the body of chapter four. The following presents a concise summary of the seven themes. Chapter five compares and contrasts the study's findings with other published academic research.

Influential Factors. Disclosing and non-disclosing parents accounted children's cognition, age and maturity as factors that influence the decision-making process. The

emotional stability of the child's psychosocial well-being, children's prior awareness of cancers in the family, and children's gender contributed to parental judgment. Moreover, parents professed a need to prepare children for the future. Disclosing and non-disclosing parents differed regarding the rational behind preparing children for the future. Disclosing parents wanted to prepare children for the future for the purpose of education regarding their family history. Parents believed this would foster children's active engagement in their own health decisions. Non-disclosing parents preparation for the children's future equated to the implementation of life, critical, and mortgage insurance prior to a disclosure conversation. These parents also chose to delay the conversation in order to avert child from having to make impulsive decisions early in life. Parents felt future developments in technology will change the BRCA1/2 landscape. Thus, there was no need to place added stress on young children.

Exclusive to disclosing parents' decision-making was a parental moral commitment to honesty and the norm of established relationships with child, other family members, and the community. Disclosing parents also noted the decision to share BRCA1/2 results with minors were prejudiced by the stress of a cancer diagnosis, demanding life altering decisions that came along with a positive BRCA1/2 test result, and children's awareness of parental BRCA1/2 testing from the onset.

All non-disclosing parents' declared intentions to communicate their BRCA1/2 test results to children. However, the initiation disclosure conversations were anticipated to be when the children were 18 to 30 years of age. In contrast, the age range of child with whom parents disclosed was 7 to 16 years. The majority of non-disclosing parents anticipate the conversation would take place during early adulthood. Similar to disclosing

parents non-disclosing parents acknowledged children's cognition, age, and maturity as cues to disclosure readiness.

Testing is a Family Affair. Collectively, parents viewed BRCA1/2 testing as a family affair because the outcomes went beyond impacting an individual to impacting an entire family. Consequently, all parents believed test results should be shared with children. Both groups of parents agreed a positive BRCA1/2 test result was accompanied by major decisions; however, parents also concurred testing was a powerful health prevention tool.

Decision-Making and Family Communication. Disclosing and non-disclosing parents acknowledged an open style of family communication. Thirty-three percent of disclosing (3 out of 9) and 57% of non-disclosing parents (4 out of 7) did not comment on family communication styles. Based on parents who commented, 44% of disclosing compared to 14% of non-disclosing parents admitted to consulting with the co-parent regarding the decision-making process. Twenty percent of disclosing versus 43% of non-disclosing parents made an independent decision to disclose or not to disclose.

Children and Parents' Reactions. Theme four examined disclosing parents' reflections about children's reaction to the disclosure information, parental decision to disclose and their reactions to the disclosure conversation, and evaluation of the conversation. Additionally, the theme explores non-disclosing parents' feelings regarding non-disclosure, and their vision for the future disclosure conversation.

Children's reactions to the disclosure dialogue varied. A number of parents were unable to judge how or if, the information shared affected the children. While other parents evaluated that the children handled the information in a satisfactory manner. A satisfactory outcome was attributed to a child understanding the content of the disclosed

material appropriate to developmental stages of childhood or adolescence, and to their individual personalities. Overall younger children responded by physical acts of closeness and or with age appropriate questions. Adolescences abstract level of thinking was evident by inquisitive questions such as how does this information impact me, can I be tested, and what options are available to you and me?

Disclosing and non-disclosing parents both expressed a range of personal feelings pertaining to the decision-making process. Collectively, parents' spirits ranged from feelings of being comfortable to neutrality to wonderment. All disclosing parents described their feelings about the conversation as either comfortable with wonderment and or sadness, feelings of impartiality, or comfortable and confident. Non-disclosing parents shared the decision not to disclose was temporary because a future disclosure discussion was anticipated. These parents expressed feeling comfortable with their decisions.

Disclosing parents all described the conversations as unplanned, non-structured, casual, and delivered in a positive manner. The information shared was kept basic and factual. The topics included what are BRCA1/2 genes, risks, implications, surveillance, prophylactic options, healthy life style choices, and testing availability. The majority of parents noted the objective was to build on the information content as children matured.

Non-disclosing parents envision having a positive conversation which is either unplanned and casual, or planned and structured. They portrayed themselves as information seekers; consequently, the anticipated preparatory plans included seeking out guidance with familiar healthcare providers and community services. Additionally, the Internet was noted as a source of information. Predicted topics for a future discussion

included the families' oncology history, inheritance of genes, screening and testing, and lifestyle choices. Although, one non-disclosing parent felt confident in her knowledge of BRCA1/2 risk information, consequently she felt no need to engage in preparatory plans.

Knowledge Deficit. A detailed review of the transcripts revealed parental knowledge deficit in the areas of BRCA1/2 risk factors, gene inheritance, impact of a defective gene on males, screening recommendations for males, life, critical, and mortgage insurance issues, and testing eligibility.

Resources. Disclosing and non-disclosing parents agreed that valuable information was provided by members of the WRHA's Genetic Department that pertained to a positive BRCA1/2 test result. Although, parents concurred that the discussions related to the decision-making process to disclosure or not to disclose to minors was not examined. Parents believed that disclosure and non-disclosure discussions should be facilitated by healthcare providers; consequently, they proposed that the BRCA1/2 discussions should be 'taken a step further.' Parents acknowledged other supportive sources were various individuals within their personal circle of contacts, specific program tools, programs, and services.

Recommendations. The study uncovered that despite that parents' expressed feeling comfortable in their decision to disclose or not to disclose, the majority of parents still requested a preference for clinicians to offer information specific to the topic of disclosure and non-disclosure of a BRCA1/2 test result to minors. A short list of parents suggestions included a follow-up appointment to discuss if, when, what, and how of disclosure to minors, referrals to allied healthcare professionals, a list of reliable Internet sites, and a kids helpline. Parents also requested printed information that was specific to

the topic and written for parents and child.

Chapter Summary

Chapter four presented the findings of the study that commenced with a description of the sample population. The proceeding section discussed the essence of the lived experience that parents' perceived that clinicians needed to take the BRCA1/2 results conversation 'a step further.' Themes included 1) influential factors, 2) testing is a family affair, 3) decision-making and family communication, 4) supportive resources, 5) the inner circle, 6) knowledge deficit, and 7) parental recommendations. Theme one, influential factors, described factors influencing parents' decision-making regarding the disclosure and non-disclosure of BRCA1/2 test results to minors. Theme two, testing is a family affair, presented parents' perceptions about BRCA1/2 testing. Theme three, decision-making and family communication, assessed parental insights about family decision-making and established communication patterns. Theme four, supportive resources, described services that parents acknowledged as being helpful. Theme five discussed parents' views on how children and parents reacted to the disclosure information. Theme six, knowledge deficit, reflected parents BRCA1/2 information needs. Theme seven, parental recommendations, is a collection of parents' suggestions to healthcare providers regarding supports for parents and families. Additionally, advice from BRCA1/2 parents to other BRCA1/2 parents was addressed. The chapter ended with a summary of the study findings.

Chapter V

Discussion of Findings

Chapter five presents a discussion of the study findings. The purpose of this hermeneutic phenomenological project was to attain an understanding of the lived experience of parents' perceptions regarding the disclosure and non-disclosure of positive BRCA1/2 test results to minors. As a reminder, the study consisted of 15 female participants; age range was 28 to 54 years with a combined total of 26 children. According to the study's eligibility criteria parents were aware conversations specific to children who were in the age groups of 6 to 18 years based on the children's event age, and were less than 19 years of age at the time of the initial research conversation. Consequently, the total number of eligible children for parental discussions was 22 out of the 26 children. For disclosers, the event age range was 7 to 16 years with a mean age of 12.4 years. For non-disclosers, the event age range was 1 to 13 years with a mean age of 6.9 years. In chapter four, the essence of the lived experience of parental perceptions, the themes and sub-themes, and recommendations to healthcare professionals and other BRCA1/2 parents were discussed.

This chapter discusses the study's findings with the integration of other published academic research. Findings are grounded in the essence of participants' perceptions of the lived experience for healthcare professionals to 'take it a step further.' Presented is an examination of methodological limitations and strengths of the study. The chapter concludes with a review of the study's implications to nursing practice, education, and research.

Research Findings

This section discusses the essence of the study participants' lived experience regarding the disclosure and non-disclosure of a BRCA1/2 test result to minors by examining the studies themes alongside other published research studies.

Themes

Clarke, Butler, and Esplen (2008) described three phases of parental disclosure of BRCA1/2 genetic information to an offspring which includes the pre-disclosure phase, the disclosure phase, and the impact of the disclosure phase. The proceeding provides some insight into these three phases.

The framework that guided this research project was the Human Response to Illness (HRTI) Model. The experiential section of the HRTI model focuses on the subjective experiences of individuals' self-reports of their lived experiences (Mitchell et al., 1991). 'Take it a step further' was the essence of study participants' self-reports which were captured in the seven study themes discussed in chapter four. In addition, a concise summary of the findings was outlined. The seven themes included: 1) influential factors, 2) testing is a family affair, 3) decision-making and family communication, 4) supportive resources, 5) the inner circle, 6) knowledge deficit, and 7) parental recommendations. Consequently, the proceeding concentrates on participants' self-reports of their lived experiences in relation to the study themes assessed alongside other research findings.

Influential Factors Regarding Disclosure and Non-Disclosure

The first theme, *influential factors* regarding disclosure and non-disclosure, assessed parents decision-making process which is specific to BRCA1/2 risk information

to minor offspring. The two sub-themes that supported parents' decisions were children's characteristics and awareness and parental insights. The sub-theme family dynamics was exclusive to disclosing parent while factors influencing a future disclosure pertained to non-disclosing parents. According to Clarke, Butler, and Esplen (2008) the above three subthemes are characteristic of the pre-disclosure phase. See Table 1.5 (page 72) for a summary related to influential factors regarding disclosure and non-disclosure.

Children's Characteristics and Awareness. In this research project factors that influenced parents' disclosure and non-disclosure decisions included: 1) age, cognition, and maturity, 2) emotion health, 3) gender, and 4) preparation for the future. Disclosing parents were also influenced by children's previous awareness of family cancers and family dynamics.

Age, Cognition, and Maturity. Similar to other studies, parents' reported that age, cognition, and maturity were influential aspects of the decision-making process (Bradbury et al., 2007; Segal et al., 2004; Tercyak et al., 2002). To date there are no medical concerns for minors pertaining to a deleterious mutant BRCA1/2 gene; however, the disclosure of test results to young children is high (Burdbury et al., 20007). Consistent with other study findings, the majority of parents (60%) disclosed a positive BRCA1/2 test result and discussed predictive testing issues with at least one or more offspring (Bradbury et al., 2007; Miesfeldt, Cohn, Jones, Ropka, & Weinstein, 2003; Peshkin et al., 2010; Tercyak et al., 2001; Tercyak, Peshkin, DeMarco, Brogan, Lerman, 2002). The findings from the current study showed that children who received disclosure risk information were between the ages of 7 to 16 years with the mean age of 12.4 years. The average age of children of non-disclosure parents was 6.9 years. Tercyak et al.

(2001) and McGivern et al. (2004), reported lower disclosure rates at 41 to 53% by BRCA1/2 carriers to offspring < 18 years of age. Consistent with previous research, disclosure rates were associated with the age of an offspring in that older children were more likely to be informed than younger children (Bradbury et al., 2007; Clarke, Butler, & Esplen, 2008; Segal et al., 2004; Tercyak, Peshkin DeMarco, Brogan, & Lerman, 2002; Tercyak et al., 2001). Interestingly, Clarke, Butler, and Esplen (2008) literature review reported adolescent children received BRCA1/2 risk information at the same rate as adult offspring.

Emotional Health. In this study, 20% of the parents assessed children's emotional health as part of the decision-making process, in addition they expressed concerns towards parental emotional readiness to disclose. Parents worried that the disclosure knowledge would have a negative impact on children's lives. Furthermore, parents took into consideration the their families' present and past stressors, children's current health status, and the advantages associated with children knowing genetic information. Parents' primary concern was that the disclosure process would negatively impact young impressionable children. Bradbury et al. (2007), Clark et al. (2008), and Tercyak et al. (2002) also reported parental deliberations regarding disclosure information on children's psychological health. Similar to Segal et al. (2004) and Bradbury et al. (2007) in this study 43% of non-disclosing parents delayed genetic conversations because they were cognizant that children's emotional stability was an important part of genetic information sharing.

Tercyak et al. (2001) findings supported no significant association between cancer status and mutation status with parental disclosure decisions. In this study, 44% of

disclosing parents were personally affected by cancer while 56% were personally unaffected by cancer. However, 71% of non-disclosing BRCA1/2 carriers had a cancer diagnosis while 29% were unaffected. Findings in this study supported no significant association between mutation status and disclosure. However, the findings showed a greater percentage of non-disclosing parents (71%) had a cancer diagnosed as compared to 44% of disclosing parents, which may have influenced non-disclosure rates. Tercyak et al. (2001) study illustrated increased levels of parental baseline pre-counseling general distress and not cancer-specific distress may be associated with high disclosure rates (Tercyak et al., 2001) which may influence the quality and content of information shared with minors. Distress levels were not measured in this study, but the examination of parental coping styles along the BRCA1/2 genetic journey would assist clinicians to identify parents who may require counseling before the commencement of a disclosure conversation. Research examining the role of parental distress (general and cancer-specific) is warranted.

Gender. Findings in the research literature fluctuated regarding the association of children's gender and parental decision-making. According to Tercyak et al. (2002) no significant association was reported. Although, Segal et al. (2004) study supported 25.8% (8) parents considered gender differences as part of the deliberation process while 22.6% (7) parents noted gender did not impact the decision-making process. In this study, 20% (3) of the parents indicated gender issues factored into the decision-making process. Parents acknowledged they were counseled that a male offspring was at a decreased risk in comparison to a female offspring. These three parents had sons (total equaled 6 males), and two of the three carried a BRCA2 mutation status. One parent acknowledged that she

understood the risk for cancer was higher for a positive BRCA1 verses BRCA2 male. Factually, a male BRCA1/2 carrier status is associated with an increase risk for prostate and pancreatic cancers with a higher risk for breast cancer in BRCA2 carriers (Personal communication, Dr. S Males, November 29, 2013). In this study, parents' understood cancer risks were associated with BRCA1/2 male carriers; although, discrepancies existed between a mutant BRCA1/2 gene and male risk factors. Regardless, parents verbalized that sharing genetic information would not increase male offspring stress levels, because gender differences and concerns associated with males were adult onset cancers. Furthermore, surveillance options could be implemented. Findings from this study suggest there is a need for clear and concise gender specific BRCA1/2 positive gene guidelines.

Clarke, Butler, and Esplen (2008) documented that mothers' voiced concerns related to BRCA1/2 disclosure information specific to their daughters' vulnerabilities such as negative implications regarding screening, preventative options, and relationship issues. In this study, no parents of daughters mentioned gender as affecting disclosure considerations. However, differences in these two studies are likely associated with the variations in the ages of the children whereas adult offspring were included in parental discussions in the Clarke, Butler, and Esplen (2008) study.

Previous Awareness of Family Cancers. Bradbury et al. (2007) reported, that intra-familial oncology experiences acted as a disclosure barrier for some BRCA1/2 carriers. Findings in this project supported children's familial experiences with cancer (22%, 2 out 9) factored into parental decisions to disclose. Consequently, past intra-familiar cancer communications may have served as a decision-making factor. Further

studies regarding core family oncology communications will assist in gaining a comprehensive understanding of parental decisions to disclose.

Parental Insights. An overwhelming 93% (14 out of 15) of study participants verbalized the need to prepare children for the future as part of the decision-making process.

Preparation for the Future. Fifty-three percent of disclosing parents' believed genetic discussions with minors regarding their families' genetic history would facilitate children's preparation for adult self-health advocacy roles, and promote body awareness and healthy life style choices. Bradbury et al. (2007) found family history was factored into parental decisions to disclose, but no connection was made between children's early knowledge about a families' genetic history with healthy life style choices, and body and health advocacy awareness (Bradbury et al., 2007).

Thirty-three percent of non-disclosing parents equally believed in the future preparation of children; however, they viewed this as safeguarding children's critical and life insurance coverage. Parents expressed the desire for additional information that detailed insurance issues. Clarke, Butler, and Esplen (2008), Lynch et al. (2006) and Segal et al. (2004) also reported parental non-disclosure was linked to concerns about insurance discrimination.

Family Dynamics. The context of family dynamics played a critical role in the decision to disclose for all disclosing parents. Components of the family dynamics that influenced decision-making was the moral commitment to parental honesty, established norms within various relationships, and part and parcel of everything along the BRCA1/2 genetic journey which was inclusive of a cancer diagnosis, prophylactic surgery, and children's awareness of parental BRCA1/2 testing.

Honesty. The notion of honesty was factored into decision-making because it played a strong role in established parent-child relationships. Consistent with Tercyak et al. (2002) findings, this study also supported parental moral obligation to honesty as a factor impacting disclosure decisions. Similar to Tercyak et al. (2002) the current study findings supported that 56% of parents shared the notion of honesty was factored into their decision-making. Clarke, Butler, and Esplen (2008) also documented disclosing parents pledge to honesty, although the findings reinforced parents' admission of being torn between a parental moral obligation to honesty, and a parental instinct to protect and nurture children. The instinct to protect and nurture lead some parents to misrepresent family genetics information when children suddenly approached the topic with parents. In this study, no findings of parental misrepresentations were uncovered.

Established Relationships. Comparable to other study findings, family context influenced this study's population of parents' decision to communicate BRCA1/2 test results to minors (Clarke, Butler, & Esplen, 2008). Thirty-three percent of the disclosing parents chose to disclose genetic information because of established patterns of relationships with children, extended family members, and the community. Parents particularly mentioned, a close mother-child bond, and a family coping style of 'laying the card on the table' as influential factors. Another parent self-confessed, that parental bonds with her parents were not well established which in turn shaped her relations with her children, subsequently this lead to her decision to disclose. A third mother commented, that the close relationship with her brother and his reaction to her positive BRCA1/2 test result had influenced disclosure decisions. This family church attendance and prayer routines at home also contributed to their decision to disclosure. In summary,

parents' decision-making was not only influenced by relationships within a core and extended family unit, but also incorporated established relationships within the larger community. In order to gain a better understand of BRCA1/2 carriers' disclosure deliberations additional studies in the area of family communications, in the context of the core and extended family units, and the larger communities are suggested.

Part and Parcel of Everything. The majority (56%, 5 out of 9) of disclosing parents attested to a life tuned upside down, accompanying stressors, and children's involvement in the decision to proceed with genetic testing as impacting the decision to disclose. In agreement with Bradbury et al. (2007) parents' decision to disclose to children was related to pending parental surgical procedures. Bradbury et al. (2007) reported 9% association between parental surgical procedures and motivations to disclose versus a 44% association in this study's findings. Possible explanations for the broad percentage range may be differences in study eligibility criteria, core family dynamics, support systems, and perceived parental distress. Clarke, Bulter, and Esplen (2008) and Tercyak et al. (2001) findings supported that increased parental distress was likely related to disclosure. This study did not assess parents perceived levels of distress, but general stressors are a plausible explanation because, parents' stories supported increased stress levels were directly related to a plethora of decisions in relation to the confirmation of a BRCA1/2 carrier status. More studies are recommended that evaluate parents' stress levels along the entire BRCA1/2 decision-making continuum.

Influential Factors Regarding a Future Disclosure.

This section is consistent with Clarke, Butler, and Esplen (2008) pre-disclosure phase. Similar to another study, the current study offered insight into non-disclosing

parents' views regarding a future disclosure conversation. The sub-themes influencing a future disclosure mirrored disclosing parents decision-making factors, which was categorized under the sub-themes of children's characteristics and awareness, parental insights, and family dynamics.

Children's Characteristics and Awareness. Non-disclosing parents shared that their personal assessment of children's readiness for family genetic information included children's age and maturity level, emotional health, an interest in personal healthcare needs, and children's interest in pursuing a serious relationship. Similarly, Clarke, Butler, and Esplen (2008) reported a delay in parental disclosure was related to a parental assessment of children's lack of readiness. However, what characteristics constituted children's readiness was not clear. Bradbury et al. (2007) indicated age was a factor that influenced a future disclosure; however, parents' adjustment to the genetic information versus specific characteristics of children's readiness was factored into parents' thought processes. The difference in responses may be related to the age differences of the parent's children in each respected study. In Bradbury et al. (2007) the children's age range was 5 to 24 years. Clarke, Butler, and Esplen (2008) the age range was 2 to 30 years and in this study the age range was 6 to 18 years. Research that specifically focus on the assessment of minors and parental communication of BRCA1/2 risk information is needed.

In this study, non-disclosing parents believed an appropriate disclosure age range was between 18 to 30 years of age. These findings were comparable to Segal et al.'s (2004) findings where 35.5% of parents supported disclosure between the age groups of 19 to 25 years. In Segal et al. (2004) a small percentage of parents (3.2%) indicated a

positive BRCA1/2 test result should never be shared with children. However, in this study all non-disclosing participants acknowledged the intent to disclose.

Parental Insights. Similar to Segal et al. (2004) this study showed that before proceeding with a BRCA1/2 disclosure conversation, non-disclosing parents expressed a strong desire to ensure insurance coverage was implemented. Segal et al. (2004) study supported a 13.3% of non-disclosing parents acknowledgement of insurance issues versus 43% (3 out of 7) findings in this study. Consistent with other studies, findings supported parents' wanted to be self-assured of their own emotional readiness to offer genetic information and children's psychological readiness to receive the information (Clarke, Butler, and Esplen, 2008; Segal et al. (2004). Various studies also reported parental request for supportive strategies such as counseling and education that concentrated on techniques that would facilitate the communication of genetic risk information to minors (Peshkin, DeMarco, & Tercyak, 2009; Hallowell et al., 2005; Segal et al., 2004; and Ratnayake et al., 2001).

Family Dynamics. In agreement with another study, the majority of non-disclosing parents (86%, 6 out of 7) confided that the following will influence a future disclosure conversation: 1) concerns regarding family members sharing information with children, 2) a parental sense of guilt and an obligation to honesty, and 3) respecting children's verbal requests of readiness (Clarke, Butler, and Esplen, 2008). Non-disclosing parents' worries were attributed to the potential 'spilling-out' of genetic information by other family members before parental readiness to disclosure (Clarke, Butler, and Esplen, 2008). Similarly, in this study, 29% (2 out of 7) of non-disclosing parents expressed a fear that a family member would disclose BRCA1/2 risk information to their child.

According to Clarke, Butler, and Esplen (2008), life events such as 'spilling-out' of the 'gate-keepers' knowledge could cause parental decisional conflict that potentially contributed to parents' feelings of regret and seconding guessing decisions (Clarke, Butler, and Esplen, 2008). Similarly, in this study parental decisional conflict was evident in some non-disclosing parents stories.

Testing is a Family Affair

The second theme, *testing is a family affair*, captures study participants' views regarding BRCA1/2 testing. This was collectively seen as information that belonged "to an entire family." Amongst the plethora of issues (e.g. to disclose or not to disclose to offspring, ethical dilemmas, insurance issues for parent and offspring, an obligation to share BRCA1/2 test result with extended family members, and risk management options) parents held strong to the notion that BRCA1/2 testing was equivalent to hope. The sub-theme, decisions all in the family is reflected in Clarke, Butler, and Esplen's (2008) pre-disclosure phase. See Table 1.7 (page 100) for a summary related to testing is a family affair.

Decisions All in the Family. Together the parents involved in this study believed that they served as an instrument that unlocked a door to the past that ultimately belonged to an entire family. Disclosing and non-disclosing parents summarized their views of BRCA1/2 testing into the following two categories: 1) a gift that protects my family, and 2) equates to big issues.

A Gift that Protects my Family. Findings from this study, supported 89% (8 out of 9) of disclosing parents and 86% (6 out of 7) of non-disclosing parents felt that BRCA1/2 testing functioned to protect themselves and family members. The majority of

parents viewed BRCA1/2 testing in a positive light because it offered an "insight into what's going on in your body, options for preventative and surveillance choices." In addition, technological advancement offered hope for a brighter future. Segal et al.'s (2004) study participants also viewed BRCA1/2 testing in a positive light because of the possible advancements in science such as imaging techniques and early detection. However, participants also expressed remorse due to the lack of foresight about all plausible implications of the genetic information on children and themselves. Similarly, in this study, about 13% (2 out of 15) of the parents specifically expressed a sense of remorse or guilt towards BRCA1/2 testing. Oostrom et al.'s (2007) findings reinforced, participants' positive views about the availability of genetic testing which was seen as improving family communications, understanding, support, and general appreciation for each other. However, not all participants (17%) perceived genetic testing as positive due to a negative impact on family relationships (Oostrom et al., 2007).

This study showed, no variation in participants' views about BRCA1/2 testing based on a cancer status. Although, Julian-Reynier et al. (2000) noted individuals who had a high-risk cancer profile and a positive cancer diagnosis pursued BRCA1/2 testing because of the benefits to family members. However, those with a high-risk profile and an unaffected cancer status proceeded with testing for their own personal needs (Julian-Reynier et al., 2000). Studies are needed which directly assess BRCA1/2 carriers' and offspring views regarding the impact of disclosure and non-disclosure.

Equates to Big Issues. In agreement with other reports, despite parental gratitude towards the availability of BRCA1/2 testing, in this study participants (67%, 10 out of 15)) admitted that a positive BRCA1/2 test comes with a web of issues that are life

altering for an entire family (Bradbury et al., 2007; Clarke, Butler, & Esplen, 2008; Lynch et al., 2006; McGiverns et al., 2004; van Oostrom et al., 2007; Ratnayake et al., 2011). Parents in this study, shared stories about the complexities involving decisions pertaining to sharing test results with children and extended family members, ethical dilemmas, insurance discrimination issues for the parent and offspring, and risk management options regarding surveillance, prophylactic surgeries and chemo-prevention. Similarly, Clarke, Butler, and Esplen's (2008) findings reinforced parental concerns caused by discrimination issues related to their children securing insurance and a lifetime partner. Parents in this study also experienced decisional conflict between obligations to protect and nurture versus their belief in children's right to know (Clarke, Butler, and Esplen, 2008). In this study, an example of parental decisional conflict is reflected in the follow quote, "So again, it's something that at some point I think will be important for him to know, but I'm not quite sure when, at what time frame, you know, that will be. …But for me it was do no harm was anything going to change by him having this information at this point in time, other than causing him more worry. That was really my main issue. …No I don't think I feel guilty. I mean it is what it is. I have this gene and there's noth… But I just, as a parent, I feel badly. I mean I do feel for my son. …I feel badly that it's something that he's going to have to potentially deal with and potentially add some complications to his life." Additionally, parents experienced mixed feelings regarding decisions which ranged from guilt to regret to gratitude. Bradbury et al. (2007), McGiverns et al. (2004), and Ratnayake et al. (2011) study findings supported parents stressors related to pressures associated with disclosure to children and extended family members. Consequently, there appears to be a need for comprehensive support

from healthcare professionals in the area of communication of test results to minors.

Decision-Making and Family Communication

The third theme, *decision-making and family communication*, documents parents' assessment of their families' communication and decision-making patterns. See Table 1.8 (page 108) for a comparison between family communication and decision-making.

Nycum, Avard, and Knoppers (2009) review article specified that intra-familial communication of family members either facilitated or hindered genetic information. In this study, a large percentage (67%, 6 out of 9) of disclosing parents characterized open patterns of family communication, and 33% (3 out of 9) offered no comment. In comparison, 43% (3 out of 7) of non-disclosing parents described family patterns of communication as open, and 57% (4 out of 7) did not declare a pattern. Consequently, no comparisons between the two groups can be truly drawn due to the sizeable percentage of no responses from parents. However, based on responders; a review of the entire research sample showed that 60% (9/15) of the responders classified their general family communication as open. Segal et al.'s (2004) findings showed about 68% of BRCA1/2 carriers believed their family communication style was very open. However, Segal et al. (2004) concluded no difference was noted between disclosures and non-disclosers perceived openness of family communication. Although, Tercyak et al. (2002) reported disclosing parents' perceived a more open style of communication than non-disclosing parents. van Oostrom et al. (2007) study also correlated open patterns of family communication with positive nuclear family adjustments to risk information sharing and the opposite was gleamed to be true. Moreover, families described as having very loose

family structures experienced problems coping with genetic information (van Oostrom et al., 2007). Studies specifically investigating parent-child communication styles are warranted because the research literature supports numerous factors of family context impacts coping abilities (Nycum, Avard, Knoppers, 2009; Segal, Butler, & Esplen, 2008; van Oostrom et al., 2007).

Regarding the decision to disclose BRCA1/2 test results, 44% (4 out of 9) of disclosing parents noted discussions between parents occurred, 22% (2 out of 9) made independent decisions, and 33% (3 out of 9) offered no comment. In contrast, 14% (1 out of 7) of non-disclosing parents noted discussions between parents occurred, 43% (3 out of 7) made independent decisions, and 43% (3 out of 7) offered no comment. Therefore, 58% of study parents conversed with a co-parent, and 65% made decisions independently. Segal et al. (2004) documented, the lack of a male partner's involvement in the decision-making process. Therefore, in this study the high percentage of independent decision makers was not surprising because, all of the participants were female. In this study, female single parent households may have factored into the high rates of independent decision-making because, non-disclosures divorce rates were 43% (3/7) versus 11% (1/9) for disclosing parents. Consequently, the presence of a supporting partner may have influenced the decision to disclose. Segal et al. (2004) reported four parents (22.2%) had collaboratively disclosed BRCA1/2 risk information to children. In this study, findings supported the presence the co-parent (100% or 9 couples) at the time of BRCA1/2 conversations.

Supportive Resources

The fourth study theme, *supportive resources,* speaks to study participants'

information and support seeking behaviors which were specific to the decision-making process.

WRHA's Hereditary Breast and Ovarian Clinic & Other Valued Resources. Disclosing and non-disclosing parents acknowledged, that members at the Winnipeg Regional Health Authorities' Hereditary Breast and Ovarian Clinic offered very good education and support, and provided appropriate referrals.

As suggested by prior research, healthcare practitioners involvement with BRCA1/2 carriers' decision-making is limited (Bradbury et al., 2007; Norris, Spelic, Snyder, & Tinley, 2009). When questioned whether clinician with the WRHA's HBO Clinic initiated the topic of disclosure and non-disclosure of BRCA1/2 risk information to minors, the majority of disclosing (89%, 8 out of 9) and non-disclosing (86%, 6 out of 7) parents' response was negative. For many reasons the topic of disclosure and non-disclosure to minors may not be part of the mandate for the WRHA HBO Clinic. However, a substantial percentage of disclosing and non-disclosing BRCA1/2 carriers' feel the conversation needs to be taken 'a step further.' Other studies have supported that limited involvement of clinicians in parental decision-making have had negative consequences on minors inaccurate understanding of BRCA1/2 risk information which has contributed toward initial negative responses to the information by a subgroup of children (Bradbury et al., 2007; Daly et a., 2001). Consequently, further studies are required to assess children's understanding of the BRCA1/2 risk information and the impact of disclosure on their overall well-being.

When parents were asked if they had any other forms of support, 89% (8 out of 9) of disclosing parents and 29% (2 out of 7) of non-disclosing parents acknowledged at

least one valued source of support, outside of WRHA HBOC. Other sources of support included family, friends, professional colleagues, family doctors, mental health practitioners, and the faith community. Additionally, one parent shared time to access support was a luxury while another stated that support was in the form of the Internet and self-coping abilities. Interestingly, a greater percentage of disclosing parents versus non-disclosing parents identified a source of support. This may or may not have contributed to parental decision-making. This is an important assessment as other studies have shown family and community support is associated with healthy adjustments to life altering events (McInerney-Leo et al., 2005; Nycum, Advard & Knoppers, 2009). Clinicians are ideally positioned to assess various aspects of family context which impacts an individual and families coping abilities (Gallo, Angst, Hadley, 2005).

The Inner Circle

The fifth theme, the *inner circle* is a comprehensive insight into participants' disclosure conversations, children's reactions to the BRCA1/2 risk information, and disclosing and non-disclosing parents' reflections on their decisions. This section ends with non-disclosing parents' views about a future conversation. According to Segal, Butler, and Esplen (2008) the theme, inner circle is consistent with the disclosure and impact of disclosure phases the decision-making process.

The Conversation. This section provides an insight into the content of the disclosure conversation. See Table 2.0 (page 121) for disclosing parents examination of the conversation.

The published research that directly addresses the content of BRCA1/2 disclosure discussions is limited. Consistent with other studies, disclosing parents shared BRCA1/2

test results with a minor child within one to two months of a confirmed carrier status (Tercyak et al., 2002). As previously suggested, BRCA1/2 carriers functioned as the principal conversationalist during the disclosure conversation (Segal et al., 2004) which in this study primarily occurred in the company of core family members. Although, two exceptions consisted of a mother-daughter dyad during a car ride, and the other during a family dinner with extended family members. Most parents described conversations that were commonly unplanned and causal, which lends itself to the possibility of parents being unprepared to engage in conversation (Clarke, Butler, and Esplen, 2008). Clarke, Butler, and Esplen (2008) findings suggested the risk of parents to mislead children in situations where disclosure is unplanned. However, in this study parents' stories attested to parents' abilities to respond truthfully. Despite that a small number of disclosing parents admitted feeling decisional conflict, all disclosing parents in this study remained true to parental honesty. Additionally, parents generally presented BRCA1/2 risk information in a series of positive, relaxed, and reassuring conversations that mirrored a developmental approach to information sharing. This approach was similar to that taken by other study parents who faced sharing genetic risk information with minors (Gallo, Angst, Knafl, Hadley, & Smith, 2005).

The disclosure conversations clustered around the following areas: 1) parental results of positive BRCA1/2, 2) what are genes, inheritance, and family history, 3) risk factors, 4) implications to the parent and the child, 5) management options, and 6) parental course of action. Other topics that were discussed, but to a lesser degree included: 1) testing availability during adulthood, and 2) the importance of lifestyle and body awareness. Segal et al. (2004) reported on the content of disclosure conversations

compared to the anticipated content of disclosure by non-disclosing parents. Notable differences between Segal et al. (2004) parent's content of disclosure and this study's parents content of disclosure were assessed. In Segal et al. (2004) parents stated they discussed children's and carrier's feelings, health and illness concerns, and future technology, which were not included in this study's parents, content list. In this study and Segal et al.'s (2004) study, parents tended to concentrate less on diet and exercise (life style and body awareness). Moreover, in Segal et al.'s (2004) study, parents focused more on testing issues as compared to this study's parents. An explanation for the difference may be related to the age range of children in the aforementioned studies, and a broader availability of provincial supportive and educational services that are specific to the BRCA1/2 carrier population.

Mixed Ball of Reactions – Children. This segment addresses parents' perceptions of children's reactions to the disclosure conversation. See Table 2.1 (page 127) for parents' perceptions regarding children's reactions to the disclosure information.

Collectively, the current study consisted of nine disclosing parents who had a total of 14 children with an event age range of 7 to 15 years. Of the 14 children, 10 were males and 4 were females. Similar to other studies, a variety of children's responses were assessed as it pertained to children learning about their parents' positive BRCA1/2 test result and familial risk information (Bradbury et al., 2007). See Table 2.1 (page 127) for parents' perceptions regarding children's reaction to the disclosure information.

In this study, parents perceived a small percentage (22%, 3 out of 14) of children responded negatively to the disclosure information, which may or may not be associated with parental perceptions of the reactions of a largely male offspring population. Herman

and Appelbaum (2010) conceived that parents generally underestimate adverse reactions of health related information on children's psychological well-being. This was supported by Bradbury et al.'s (2007) findings where higher rates (48%) of parents assessed negative emotional responses (anxiety, crying, and fear) in children related to the disclosure information. Tercyak et al.'s (2001) findings highlighted children self-reported worries related to their own future cancer, and 50% worried about cancer inflicting other family members. These findings are reflective of Bradbury et al.'s (2007) study findings regarding parents' perceptions of their children's emotional response to disclosure. However, the literature suggested that even Bradbury findings might be limited related to the size of the study population (Herman and Appelbaum, 2010). Limited studies exist in the area of parental communication of genetic information to minors. Additional, studies that assess minors' perceptions are essential in order to truly understand the impact of parental disclosure of BRCA1/2 risk information on minors.

In this study, parents noted (93% or 13 out of 14 children) children asked questions (except one, the youngest child). Children's questions pertained to themselves (i.e. how does this apply to me [1], when can I get tested [6]), questions specific to parent's well being [3], and /or general clarifying questions [4]. Segal et al. (2004) reported a lower percentage (67%) of offspring asked questions; however, the questions were similar (i.e. specific to testing options for minors and parents health). Furthermore, in this study 14% of parents (2 – children aged 7 and 9) specifically noted comprehension was appropriate to children's developmental cognitive stage. Furthermore, the majority of parent's (88% or 8 out of 9 parents) indicated that their children understood the disclosure information which was evaluated based on the content of children's questions

and age appropriate developmental reactions. However, Bradbury et al. (2007) reported, that parents perceived that only 50% of the children appeared to have understood the BRCA1/2 risk information. Discrepancies in the research findings may be associated with differences in the demographic sample population.

Consistent with previous research, parents' overall perceptions of children's responses were categorized as developmentally age appropriate, and congruent with individual personalities (Segal et al., 2004). Parents in this study denied any changes in children's general personalities with the exception of one. This mother described her 9-year old son as an active outdoors child who "play outside 10 hours a day" and since the disclosure conversation he "insists on staying inside and escaping into books, and hanging out with me." He was also the only child who was described as "internalizes more" and now "worries." Two older children [both female and 14 years of age] were described as initially crying. Consequently, 21% (3 out of 14) of the children showed a more reactive response to the initial disclosure information. Of interest, today, the two older 'crying' children's view BRCA1/2 risk information as positive. Parents believe the children's changed views are attributed to continual parental reassurance and information sharing. No children of disclosing parents were described as having any psychological health concerns. Similarly, Segal et al. (2004) and Peshkin, DeMarco, and Tercyck (2010) reported the majority of parents assessed no changes in children's reactions; however, a small percentage (one child from each study) of children were described as expressing signs of worry, anger, and distress. Clarke, Butler, & Esplen (2008). acknowledged children who at baseline presented with signs of psychological distress were more inclined to be susceptible to illness and increased cancer worries.

Not all parents commented on whether the disclosure conversation strengthen or negatively impacted the parent-child relationship. Only one parent (mother of two) of the nine disclosing parents made an acknowledgement that the disclosure conversation did not adversely effect the parent-child relationship, which is similar to other study findings (Tercyak et al., 2002). Other study findings supported the parent-child bond was either not impacted or it was strengthened as a result of the disclosure (Segal et al., 2004; Bradbury et al., 2007).

Mixed Ball of Reactions – Parents. This section of the chapter addresses disclosing parents' reflections on the act of disclosing BRCA1/2 risk information to minors, and non-disclosing parents' feelings regarding the decision to delay disclosure.

Disclosing Parents: Similar to other studies, parents described their feelings after disclosure as anxious, sad, uncertain, and comfortable (Lynch et al., 2006; Meiser et al., 2002; Clarke, Butler, & Esplen, 2008). See Table 2.2 (page 133) for parent's self-perceptions of their reactions to disclosure.

Consistent with previous research, parents' sense of sadness, guilt, anxiety, remorse, and wonderment were linked to the uncertainty about if they "did the right thing," and a guilty realization regarding the possibility of "passing a mutant gene" to an offspring (Lynch et al., 2006; Meiser et al., 2002; Clarke, Butler, & Esplen, 2008; Tercyak et al. 2001). Lodder et al.'s (2002) findings maintained one to three weeks after disclosure parents' anxiety levels were slightly elevated when compared to baseline anxiety levels. These findings indicate that a subset of BRCA1/2 carriers may benefit from supportive counseling immediately after disclosing. Future parental self-assessment studies are needed that specifically assesses parental feelings after the disclosure

conversation. These studies would assist clinicians, such as nurses to better meet the needs of parents.

Non-Disclosing Parents: Similar to other research, parents who choose not to disclose took into consideration individual children's age, readiness, interest, and psychological health (Gallo, Angst, Knafl, Hadley, & Smith, 2005; Segal et al., 2004). Fifty-seven percent (4 of 7 non-disclosing parents) of non-disclosing parents collectively remarked that they felt contentment as it related to their decision. All admitted they intend to disclose in the future and acknowledged it would occur during the adult phase of the children's lives. Specifically, the three of the four (75%) responding parents stated they felt confident, comfortable, pretty good, and one (25%) noted she was conflicted. In accordance with Clarke, Butler, and Esplen (2008) parents who expressed conflict likely experienced decisional conflict between parental moral responsibilities to protect their child and a moral obligation to an honest open parent-child relationship.

A Future Conversation. This portion of the chapter discusses non-disclosing parents vision of a future disclosure conversation with their offspring.

The majority of study parents' described themselves as information seekers; consequently, 71% plan to connect with health organizations that they had previously consulted. For example, WRHA's Hereditary Breast and Ovarian Clinic, Breast Health Clinic, Breast Cancer Centre of Hope, and CancerCare Manitoba's Patient and Family Support Library. Additionally, in advance of conversations, the family's primary care physicians and the child's psychiatrist would also be consulted. Regarding to the remaining 29% (2 parents), one plans on conducting Internet searches. The second parent indicated confidence in her BRCA1/2 knowledge; consequently, preparation was not

needed. Parents noted their objective for self-preparation was directly related to sharing BRCA1/2 risk information with an offspring. The majority of parents also identified preplanning as necessary because, they envisioned an impromptu casual conversation in the presence of core family members. Similarly, Miesfeldt, Cohn, Jones, Ropka, and Weinstein's (2003) findings supported parents perceived themselves as the ideal people to present BRCA1/2 risk information. However, Segal et al.'s (2004) findings suggested only 20% of non-disclosing BRCA1/2 carriers have a disclosure plan. This may be explained because of the difference in the two studies eligibility criteria regarding the age of participants' children. In this study, participants were informed study conversations would be specific to children who were between 6 and 18 years of age. In comparison, Segal et al.'s (2004) study parents conversations pertained to offspring who were in the age groups from birth to 30 years of age and older. Regardless, a subgroup of parents intends to seek the assistance from a specific group of healthcare professionals. Therefore, it is essential that various clinicians need to develop expertise in the area of genetics and inter professional referrals needs to occur. More studies that specifically assess positive BRCA1/2 parents of minors and minors themselves will provide a greater insight into the needs of families with young children.

In contrast to Segal et al.'s (2004) findings, this study showed parents' actual and perceived disclosure content was comparable. In this study, disclosing parents topic of conversation clustered around the disclosure of a BRCA1/2 test results, family history, inheritance, risks, implications to parent and child, and management options. In comparison, non-disclosing parents perceived the topic of conversation would be inclusive of most all of the elements discussed by disclosing parents. However, notable

exceptions are non-disclosing parents did not acknowledge their intent to specifically share the BRCA 1/2 test results with minors. Parents who disclosed did not mention discussions included providing referrals to healthcare professionals. See Table 2.3 (page 138) for a comparison between this study's parents' actual and perceived disclosure content.

In contrast to Segal et al.'s (2004) findings, parents in this study did not stated the inclusion of the following topics: children and parents feelings, parents reason for testing, issues related to children's offspring, future technology, and illness concerns. The reason for the differences may be related to the study's eligibility criteria for the ages of parents' children. Furthermore, non-disclosing parents in this study may have not given much fore though regarding the content of a future disclosure conversation. The above information contributes to the body of research literature specific to the needs of BRCA1/2 carriers with children who are minors.

Studies have documented the association of parental distress with parents sharing inaccurate BRCA1/2 risk information which leads to erroneous uptake of information and potential childhood fears (Miesfeldt, Cohn, Jones, Ropka, and Weinstein, 2003; Bradbury et al. 2007). In this study, 43% (3 out of 7 non-disclosing parents) verbally acknowledged that life stressors accounted for the deferral of a BRCA1/2 disclosure. Moreover, one parent showed insight when she acknowledged a disclosure deferral because of concerns related to sharing inaccurate BRCA1/2 risk information specific to a male. This parent was concerned about the negative impact of the information on her son's anxiety disorder. Even though parents viewed themselves as the primary communicator of BRCA1/2 risk information to minor offspring a role exists for clinicians to assist parents

in preparing for the disclosure conversation. For example, clinicians can counsel parents and children before and after the initial disclosure conversation.

Knowledge Deficit

The sixth theme, *knowledge deficit*, addresses parents' deficit related to BRCA1/2 risk information.

Parental knowledge deficit was noted in 14% of the fifteen study participants' transcripts. Knowledge deficits were identified in the following areas: 1) BRCA1/2 risk factors, 2) inheritance, 3) consequences of a BRCA1/2 carrier status related to male offspring, life, critical, and mortgage insurance, and 4) testing eligibility. In agreement with other reports, parents who received counseling (identified as one BRCA1/2 test consult and one BRCA1/2 test result appointment) were identified as having a knowledge deficit in areas of BRCA1/2 risk information which presents a high risk for inaccurate knowledge transfer from parent to child (Bradbury et al., 2007; Miesfeldt, Cohn, Jones, Ropka, & Weinstein, 2003).

Parental Recommendations

The last theme, *parental recommendations*, discusses parents' recommendations to healthcare providers and words of advice to other positive BRCA1/2 parents. See Table 2.4 (page 145) for a list of parental recommendations to healthcare professionals

Disclosing and Non-Disclosing Parents Recommendations to Healthcare Providers. Ninety-three percent of study participants responded with recommendations for clinicians, despite the fact that approximately 45% of disclosing and non-disclosing parents indicated support was not necessary. Similar to other studies, parents collectively recommended that genetic practitioners 'take it a step further' (Miesfeldt, Cohn, Jones,

Ropka, & Weinstein, 2003; McGivern et al., 2004; Nycum, Avard, & Knoppers, 2009; Ratnayake et al., 2011; Reynier et al., 2000; Tercyak et al., 2002). Parents advocated for changes to BRCA1/2 clinical practice protocol. Parents believed genetic practitioners should initiate the topic of disclosure and non-disclosure with parents of minors. However, parents differed on when this should occur. Some indicated the best time is at the BRCA1/2 test result appointment while others felt time to adjust was required. An alternative recommendation was to offer a follow-up appointment. Essentially parents requested clinicians guidance and support directed towards the if, when, what, and how to disclose (Daly et al., 2001). Findings in this study regarding parental recommendations to healthcare professionals were reinforced by prior studies (Miesfeldt, Cohn, Jones, Ropkaa, & Weinstein, 2003; Ratnayake et al., 2011; Segal et al., 2004; Tercyak et al., 2002; Vadaparampil, Miree, Wilson, & Jacobsen, 2006). Interestingly, several educational tools and approaches to clinicians counseling have been suggested, but not implemented in various programs (Daly et al., 2001; Gallo, Angst, Knafl, Hadley, & Smith, 2005; Nycum, Avard, & Knoopers, 2009; Peshkin, DeMarco, & Tercyak, 2010; Ratnayake et al., 2011). For example, supportive aids are available which would assist BRCA1/2 carriers regarding the communication of genetic test results to minors (Ratnayake et al., 2011; Daly et al., 2001), however not all practitioners are actively not using aids. Additionally, guidelines are available to assist healthcare professionals regarding a developmental approach to genetic risk information sharing. Guideline principles can be applied in the development of a care plan which are made collaboratively with parents specific to a personalized disclosure conversations with minors (Daly at al., 2001; Gallo, Angst, and Hadley, 2005; Peshkin, DeMarco, and

Tercyak, 2010).

Disclosing and Non-Disclosing Parents Words of Advice to Other Positive BRCA1/2 Parents. Similar to other findings, parents involved in this study encouraged other parents to take a step-by-step approach to disclosure (Daly et al., 2001). A 100% of disclosing and 43% of non-disclosing parents offered a few words of guidance to other BRCA1/2 parents who have children that are minors. Together parents encouraged other parents to be honest and to prepare to engage in a series of disclosure conversations. Parents were urged to seek counsel with clinicians because it would facilitate a developmental approach to genetic information sharing. Parents voiced the need for other BRCA1/2 parents to remember that they know their children and family the best, and there was no right or wrong time to disclose. All of the parents in this study (disclosing and non-disclosing) advocated for disclosure because, BRCA1/2 risk information was deemed to be information that rightly belonged to all in the family.

Methodological Strengths and Limitations

This section discusses the study strengths and limitations related to the research design and research methods.

Hermeneutic phenomenology as described by van Manen (1990) allowed for a meaningful understanding of the lived experience of parental perceptions regarding the disclosure and non-disclosure of BRCA1/2 test results to minors. A qualitative phenomenological approach was appropriate for this research project because, additional clarity was needed due to the small number of publications on the subject. This methodology facilitated the essence of the collective voices of a subgroup of BRCA1/2 study participants which provided a deeper understanding of their lived experience

(Struebert & Carpenter, 2011).

In accordance with Streubert and Carpenter (2001) the researcher adhered to the rigors of qualitative trustworthiness which serve to strengthen the research findings. Credibility in the research findings is reflected in the researcher's continuous engagement with the subject matter. Moreover, it was achieved through participants' confirmation (member checks) of the accuracy of the researcher's interpretation of the participants lived experience as reflected in summary conversations. Summary conversations were forwarded to each participant after the initial research conversation. Credibility was further established with the researcher and two members of the researcher's thesis committee by engaging in the process of coding validation with a few transcriptions (Morse, Barret, Mayan, Olson, & Spiers, 2002). Furthermore, coded transcriptions were crosschecked with study participants confirmed conversation summaries. Dependability was achieved once credibility occurred. Confirmability was and can be further assessed through the researcher's study journal, conversation summaries, coding spreadsheet, and the researcher's study workbook. Confirmability was also assessed by the researcher's engagement with the hermeneutical circle from the onset of data collection to the end of data analysis. Reflecting on parts of the whole, then identifying patterns between transcripts, and applying an interpretation of the whole which assisted in a comprehensive understanding of the lived experiences of the study participants (Streubert and Carpenter, 2001). Users of the research findings can assess transferability. Additionally, it was assessed in chapter five between findings in this research study with other study findings.

Other strengths of the study included a zero drop out rate and a good response

interest from eligible participants at rate of *36% as only 47* individuals met the study's eligibility criteria in which 15 of 17 interested participants were interviewed. Data saturation was obtained when no new information (themes) emerged, which occurred with the 11th interview. However, the researcher conducted four additional interviews to confirm data saturation; consequently, this accounted for the final total of 15 study participants.

The primary purpose of the study was achieved in that it provided a rich understanding of the lived experience of parental perceptions regarding the disclosure and non-disclosure of BRCA1/2 risk information to minors. However, limitations to the study must be considered. The researcher does not believe the study findings are reflective of the larger BRCA1/2 population for a number of reasons. First, the retrospective nature of the study design accounted for a number of study limitations. Study participants were asked to reflect on events that happened in the past which naturally presented recall bias. A few parents openly admitted to the inability to recall full details of some information such as, the content of the disclosure conversation. Data was collected at one point in time, which limited study findings. Additionally, the study population was homogenous as it primarily reflected the views of an educated, middle to higher income, Caucasian female population. Consequently, the views of health care practitioners, children, males, gays, ethnic and cultural groups, and the lower socioeconomic segments of the community are not represented. Thus, the findings of this research study are not generalizable to the BRCA1/2 carrier population at large, which is intrinsic to all qualitative research studies (Streubert and Carpenter, 2001).

Implications

This chapter concludes with a discussion on the implications of the study findings related to nursing practice, nursing education, and nursing research.

Nursing Practice. Given the busy environment of genetic clinics along with the movement towards personalized healthcare and advancements in technology, meeting the needs of patients and families is challenging. This study serviced to provide a voice to the needs of a subgroup of BRCA1/2 carriers. The majority of study participants were aware that risk management and surveillance is not available prior to the age of 18 years, and generally is not recommended until the age of 25 (Bradbury et al., 2007). However, approximately 60% of participants choose to disclose and the other 40% intend to disclose around the age of 18 years. Furthermore, parents' viewed themselves as being responsible for sharing BRCA1/2 risk information with minors, but advocated for clinician assistance.

Nurses can play a key role in meeting the complex needs of individuals and families that are specific to the BRCA1/2 high-risk population by supporting parents in the BRCA1/2 decision-making processes. An opportunity exists for inter professional collaboration. For example, geneticists and genetic counselors can offer referrals to parents of minors to further explore issues specific to parental BRCA1/2 deliberations and continued family support along the continuum. Parents specified the need for assistance and support in decision-making (i.e., the if, when, what, and how). Nurses can educate parents, help parents to explore their concerns and answer questions, and provide compassion toward parents during and after the decision-making process. Nurses can listen to parents' issues, desires, and in collaboration with parents assess children's

personalities, characteristics, and learning needs for the purpose of establishing a care plan. Ideally the care plan would be consistent with a developmental approach of parental communication of risk information to minors (Daly et al, 2001; Galllo, Angst, Knafl, Hadley, & Smith, 2005; Lynch, Snyder, & Lynch, 2009; Peshkin, DeMarco, & Tercyak, 2010). Additionally, nursing can establish ongoing support and education to BRCA1/2 carries and family members after the disclosure process. Nurses' skill set makes them appropriate to offer education and counsel to patients. Nurses possess excellent assessment skills; consequently they can facilitate referrals to allied healthcare professionals (e.g., psychosocial clinicians) as deemed appropriate. The involvement of nurses along the BRCA1/2 decision-making process may be tailored to accommodate individual BRCA1/2 carriers and family requirements. For example, nursing can be involved in offering personalized education and counsel to parents, in addition to consults with children. Moreover, sessions may be offered on a group basis. A close professional nursing relationship with a high-risk genetic patient population requires supplemental educational preparation which is available to registered nurses through various venues (e.g., Oncology Nursing Society Genetic Online Course, and university degree programs).

Nursing Education. Oncology nurses who are associated with a hereditary center are in an ideal position to offer health professionals in the genetics department support with the high-risk BRCA1/2 population. Advanced practice oncology nurses and oncology community nurses posses the skill set to optimally support the educational and counseling requirements of BRCA1/2 carriers and their family members. Nurses who practice in these settings need to maintain oncology knowledge relevant to hereditary breast and

ovarian education spanning across ages groups and genders. To advance one's expertise in oncology genetic, nurses are encouraged to continually review pertinent research literature, join genetic journal clubs, attend genetic meetings and conferences, and complete oncology and genetic certification and degree programs (Lynch, Snyder, & Lynch, 2009).

Nursing Research. Despite study limitations, this study has contributed to the existing body of literature by reinforcing the collective voices of a subgroup of BRCA1/2 carries and identified research gaps. The study assessed the perceptions of parents who are BRCA1/2 carriers, but it was limited to mothers due to an absence of interest from the BRCA1/2 male population. The role of fathers who are BRCA1/2 carriers in the communication of test results to children is important, and is in need of research. Furthermore, the general role of fathers in communicating BRCA1/2 risk information to children about their mothers would also inform the research literature.

Future research should be extended to include the perceptions of the lived experiences from the perspective of minors themselves which directly assess the impact of information sharing on children and family functioning. Short and long term studies are needed that specifically focus on minors in order to truly inform the research literature. Research related to parental communication with minors and the family dynamics is needed in order to further assist clinicians' understanding of how best to guide education and counsel to parents and minors.

The population sample in this study was primarily well-educated married, Caucasian females with a smaller number of participants from the Jewish and Icelandic community. More studies are needed with study populations from a variety of ethic and

cultural backgrounds, from the gay community, and various socioeconomic backgrounds in order to truly represent the needs of the community. The perceptions of the genetic and oncology clinicians who are direct care providers along the BRCA1/2 carriers' continuum warrant investigations.

Chapter Summary

This chapter presented a discussion of the research findings. The lived experience of BRCA1/2 parents regarding the decision to disclose or not to disclose BRCA1/2 test results to minors was outlined in the seven themes that arose from the study's findings. The methodological strengths and limitations were highlighted. The chapter ended with a discussion on the research findings as it applies to nursing practice, nursing education, and nursing research.

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APPENDICES

APPENDIX A
WRHA Request to Assist with Participant Recruitment

Helen Glass Centre for Nursing
Addressograph

UNIVERSITY OF MANITOBA

Faculty of Nursing

Dear XXXXXX,

My name is Kendra-Ann I. Seenandan-Sookdeo, and I am a graduate nursing student at the University of Manitoba, Faculty of Nursing. I am working on a research study that focuses on the experiences of parental perceptions regarding the disclosure and non-disclosure of hereditary breast-ovarian genetic test results to offspring. The study is entitled, ***Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors***.

The current research literature supports a gap exists in the area of parental communication and non-communication of genetic test results to younger offspring. A qualitative hermeneutic phenomenological study is designed to explore parent-child communications about genetic test results, information and support seeking needs, decision-making, and personal experiences regarding parent-child interactions. Due to the small sample size associated with qualitative inquiry, I anticipate approximately twenty participants will be required in order to gain rich descriptions of the lived experiences.

I am asking the permission of WRHA Research Resource Impact Committee for approval of Health Science Centre (HSC), Hereditary Breast and Ovarian Clinic healthcare professionals to assist with the recruitment of potential participants. I would ask that a HSC Hereditary Breast and Ovarian Clinic healthcare providers to identify, and offer recruitment packages to potential participants. The participants would be asked to contact me directly by telephone. Attached is a copy of the recruitment package which includes a letter of invitation, the informed consent form, and a demographic form.

At the end of the study, the healthcare professionals at HSC Hereditary Breast and Ovarian Clinic will be invited to attend a presentation which will discuss the findings of the study. The study findings will also be presented at local, national, and international conferences, and disseminated in professional and scholarly journals. Findings will be presented / published as grouped data as to not identify individual participants.

Please note permission is presently being sought from the Education Nursing Research Ethics Board to conduct the aforementioned research study.

I look forward to your response.

Sincerely,

Kendra-Ann I. Seenandan-Sookdeo RN, BN, MN (c)

APPENDIX B
CCMB Request to Assist with Participant Recruitment

Helen Glass Centre for Nursing
Addressograph

UNIVERSITY OF MANITOBA

Faculty of Nursing

Dear Dr. XXXXX and RRIC Committee Members,

My name is Kendra-Ann I. Seenandan-Sookdeo, and I am a graduate nursing student at the University of Manitoba, Faculty of Nursing. I am working on a research study that focuses on the experiences of parental perceptions regarding the disclosure and non-disclosure of hereditary breast-ovarian genetic test results to offspring. The study is entitled, ***Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors***.

The current research literature supports a gap exists in the area of parental communication and non-communication of genetic test results to younger offspring. A qualitative hermeneutic phenomenological study is designed to explore parent-child communications about genetic test results, information and support seeking needs, decision-making, and personal experiences regarding parent-child interactions. Due to the small sample size associated with qualitative inquiry, I anticipate approximately twenty participants will be required in order to gain rich descriptions of the lived experiences.

I would like to request the permission of CCMB Research Resource Impact Committee for approval of Breast Cancer Centre of Hope healthcare professionals to assist with the recruitment of potential participants. I would ask that a Breast Cancer Centre of Hope (CCMB-BCCH) healthcare providers to identify, and offer recruitment packages to potential participants. The participants would be asked to contact me directly by telephone. Attached is a copy of the recruitment package which includes a letter of invitation, the informed consent form, and a demographic form.

At the end of the study, the healthcare professionals at Breast Cancer Centre of Hope will be invited to attend a presentation which will discuss the findings of the study. The study findings will also be presented at local, national, and international conferences, and disseminated in professional and scholarly journals. Findings will be presented / published as grouped data as to not identify individual participants.

Please note permission is presently being sought from the Education Nursing Research Ethics Board to conduct the aforementioned research study.

I look forward to your response.

Sincerely,

Kendra-Ann I. Seenandan-Sookdeo RN, BN, MN (c)

APPENDIX C
FON Request for Interview Rooms

Helen Glass Centre for Nursing
Addressograph

UNIVERSITY OF MANITOBA

Faculty of Nursing

Dear XXXXX,

As a graduate student at the University of Manitoba, Faculty of Nursing, I am working on a research study that focuses on the experiences of parental perceptions on the disclosure and non-disclosure of hereditary breast-ovarian genetic test results to offspring. The study is entitled, ***Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors***.

The current research literature supports a gap exists in the area of parental communication and non-communication of genetic test results to younger offspring. A qualitative hermeneutic phenomenological study is designed to explore parent-child communications about genetic test results, information and support seeking needs, decision-making, and personal experiences regarding parent-child interactions.

I would like to request the permission to book interview rooms (as required), at the Faculty of Nursing for the purposes of conducting semi-structured conversations. I anticipate approximately twenty interviews will be required in order to understands the structures of the participants lived experience.

At the completion of the study, the academic staff and graduate students at the Faculty of Nursing will be invited to attend a presentation which will discuss the findings of the study. The study findings will also be presented at local, national, and international conferences, and disseminated in professional and scholarly journals.

Please note permission is presently being sought from the Education Nursing Research Ethics Boards and appropriate impact committees to conduct the aforementioned research study.

I look forward to your response.

Sincerely,

Kendra-Ann I. Seenandan-Sookdeo RN, BN, MN (c)

APPENDIX D
Study Package Invitation Letter

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

Dear Family Member,

My name is Kendra-Ann, and I am a graduate student at the University of Manitoba, Faculty of Nursing. *On my behalf,* your healthcare provider at WRHA – Hereditary Breast and Ovarian Clinic is sharing this information package with you to offer you the opportunity to take part in a study I am working on which is called **'**Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors.' Please note, I am not aware of your name, and do not have any information about you.

I am interested in learning more about parents' feelings and thoughts regarding the disclosure or non-disclosure of hereditary breast and ovarian test results (BRCA1/2 results) to their child(ren). Very little is known about parental communication and non-communication of genetic test results to children who are younger than 19 years of age. Thus, by sharing your experiences, you are helping healthcare professionals to better understand the needs of families who choose to disclose and who choose not disclosure genetic test results to minors.

If you are interested in *learning more* about the study, and you are:
1) Able to speak and read English
2) Male or female who is 18 years of age and older
3) Received a BRCA1/2 positive diagnosis from Health Science Centre Hereditary Breast and Ovarian Clinic within the past 4 years
4) A parent with at least one child who is between the ages of 6 and 18, and who at the time of disclosure is younger than 19 years of age
5) Within one year of receiving test results you have disclosed or choose not to disclose BRCA1/2 test results to a minor

Then I would like to speak with you!

If you are aware of anyone who you feel may qualify to participate in this study, and who you feel would be interested in taking part please have them call me at (xxx) xxx-xxxx.

For more information on the study please read the enclosed consent form, and call me at (xxx) xxx-xxxx.

With appreciation,
Kendra-Ann I. Seenandan-Sookdeo RN, BN, MN(c)

APPENDIX E
Informed Consent Form

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

Research Project Title:	Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors
Sponsor:	Canadian Breast Cancer Research Foundation (Prairies / NWT)
Principle Researcher:	Kendra-Ann I. Seenandan-Sookdeo RN, BN, MN(c) Email: xxxxxxxx@umanitoba.ca
Research Supervisor:	Dr. Thomas F. Hack PhD, CPsych Principal Investigator, Psychosocial Oncology & Cancer Nursing Research; Professor, Faculty of Nursing, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, it is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more about something mentioned here, or information not included here, you should feel welcome to ask. Please take the time to read this carefully.

What is the study about?
For my Master of Nursing thesis project, I am doing a study which explores parents' views about the sharing and not sharing of hereditary breast-ovarian genetic test results with their children. I hope to gain a better understanding of parent-child communications regarding genetic test results, information and support seeking needs, decision-making, and personal experiences about the parent-child interaction.

What am I being asked to do?
You are being asked to take part in a study and to willingly share your experience about your decision to tell, or not to tell your child(ren) about your positive BRCA1/2 test result.

Participation in the study involves signing this consent form, and completing the demographic form in the Hereditary Breast and Ovarian (HBO) information package that your healthcare provider gave you. The consent and demographic form is to be mailed back in the pre-addressed stamped envelope that is in the HBO information package given to you by your healthcare provider, or it will be collected at the time of the first interview.

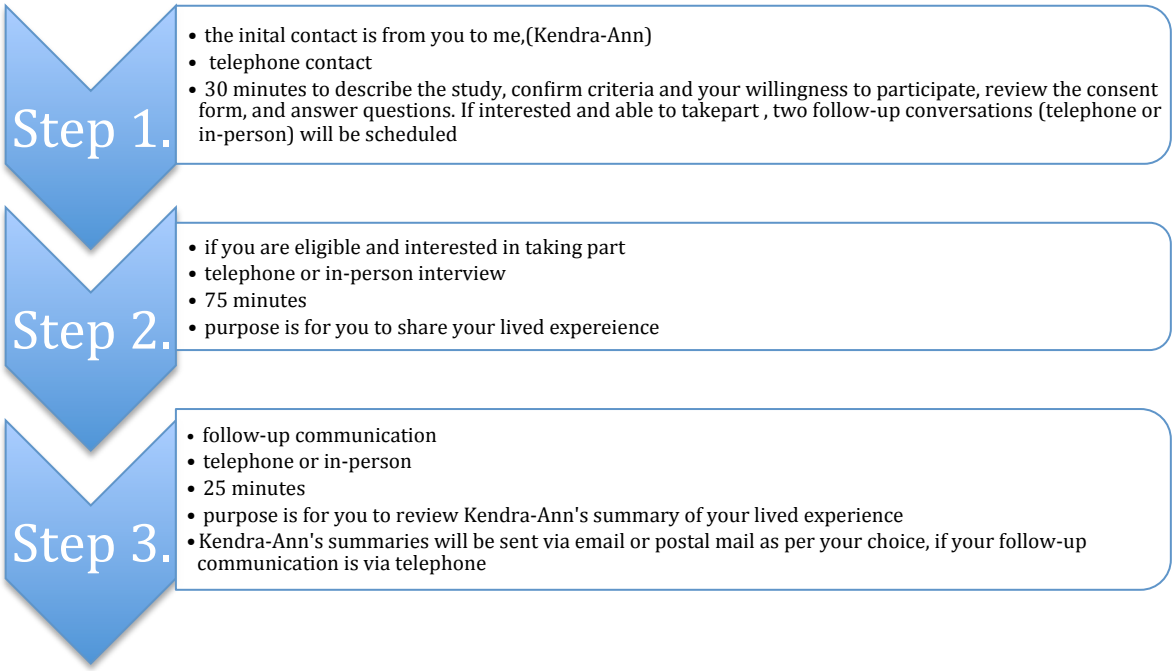
Participation also involves two interviews which are in the form of semi-structured conversations either on the telephone or face-to-face. The interviews will be recorded using an audio-recorder. A professional transcriptionist (who has signed a confidentiality form) will transcribe your interview.

If you are interested in participating, the first interview will be scheduled at a place that works best for you (i.e. your home, office, or an interview room at the University of Manitoba, Faculty of Nursing). At this interview, you will be asked to share your feelings and thoughts about disclosing, or not disclosing your BRCA1/2 test results to your young child or children. At this interview, you will be asked to think about how you made your decision to share, or not to share your test results with your child(ren). If you disclosed this information to your child(ren), you will be asked to share how you disclosed the information, and what you disclosed. Additionally, I would like to hear about your information and support seeking needs, and your thoughts as to how healthcare providers can help other parents regarding the decisions to share, or not to share genetic test results with their children.

You are free to choose not to answer any questions.

Do I have to take part in this study?
No, you do not have to participate. If you choose not to participate, it will not impact the care you receive from members of your healthcare team. If you choose to participate you may cancel your participation at any time.

How much time involved?
The first interview (as described above) will take about 75 minutes of your time, and the second interview about 25 minutes. The purpose of the first conversation is for you to share your lived experience. The second interview is to provide you with my summary of what you shared with me at our first interview. This will offer you a chance to add and / or clarify what was shared.



Will I be paid for my time?
As a thank-you for your time and for sharing your story, you will be receive a $10.00 coffee gift card at the time of the first interview, or it will be mailed to you if the interview is done by telephone. Parking fees will be paid for you if you choose to be interviewed at the University of Manitoba, Faculty of Nursing.

Does the study involve any risks?
No risks are expected as a result of taking part in the research study. However, speaking about personal experiences may bring up uneasy feelings. If this happens during our conversation, the interview will be stopped. The audio recorder will be paused, and you will be provided with a chance to decide if you wish to continue or stop. If you decide to go ahead with the interview, the audio recorder will be turned back on. If you decide to stop, the interview will end, and you will be offered the opportunity to have your data removed from the study. In both cases, and based on your needs; you will be provided with a referral to CancerCare Manitoba Psychosocial Oncology Department.

Does the study involve any benefits?
There are no direct benefits to you for taking part in this study. The findings of the study will help healthcare providers to better understand how to assist parents who are seeking help as to if, how, what, and when to share HBOC test results to young children.

How will my privacy be protected?
To protect your privacy and identity during the interview I will address you based on your wishes i.e. by their first name or Mr., Mrs., Miss, or other. You may choose to have your interviews on the telephone, or in person. If you choose the telephone a digital recorder adapter will be used to ensure conversations are directly taped into the digital recorder. To ensure exact and timely transcriptions, a professional typist will transcribe all conversations word or word, and I will review them to make sure they are correct. The typist will sign a confidentiality agreement. To safeguard your privacy individual names, place of employment, and any personal identifiers will be not be included on transcribed records. All communications as it relates to this thesis (text and oral) will not disclose your identity, or anyone's identity. A coded number will be used.

All study material related to you will be kept confidential in accordance with the Personal Health Information Act of Manitoba. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes. All study material will be securely stored in a password protected computer, except the signed consent forms. Signed consent forms will be securely stored in a locked filing cabinet. I will be the only individual to have access to study related materials. Only the transcribed interviews and the reflective log will be shared with my thesis advisor (Dr. T Hack). Transcribed interviews will have no personal information i.e. your name, contact information, etc. At no time will your name and/or contact information be shared with my thesis advisor, or anyone.

Seven years after our first interview, the printed transcribed interview, demographic form, and any written information with your name and contact information will be

shredded, and recycled as confidential material. The audio-recorded interview will be deleted nine months after our first interview

How will the results of the study be used?
Study findings will be shared with you if you return and fill in the form called 'research summary study findings' which is in your HBOC study package. Findings will also be shared with members of the academic and healthcare worlds in the form of oral and/or poster presentations. Presentations may be include local, national, and/or international talks. In addition, this plan is to share study findings by publishing in peer-reviewed journals. Stories will be referred to base on a coded number, or information will be discussed as group data.

How can I get a copy of the study results?
At the time of the first interview you will be asked if you would like a copy of the results of the study. This form is included in your HBOC study package and you will be asked to give either your mailing address, or email address if you wish to have a summary of the study results.

Who do I call if I have questions?
This research study has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. You are free to call me, Kendra-Ann at (xxx) xxx-xxxx if you have any questions that directly relates to the study. If you have any concerns, or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat, Maggie Bowman, at (xxx) xxx-xxxx.

Do not sign this consent form unless you have had a change to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the chance to discuss this research with Kendra-Ann I. Seenandan-Sookdeo. I have had my questions answered to me in a language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced to take part in this study. I understand that I will be given a copy of this consent form. I understand that my participation in this study is voluntary, and that I may chose to withdraw at any time. I freely agree to participate in this research study. I understand that information regarding my personal identity will be kept confidential in accordance with the Personal Health Information Act of Manitoba. The University of Manitoba Research Quality Management / Assurance office may require access to my research records for safety and quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant Printed Name: _____

Date (month/ day/ year): _____

Participant Signature: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant understood and has knowingly given their consent.

Printed Name: _____

Date (month/ day/ year): _____

Participant Signature: _____

Role in Study: _____

APPENDIX F
Telephone Script Regarding Potential Participant Calls

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressorgraph

Hello my name is Kendra-Ann. Thank-you for your interest in my research study which is part of my Master of Nursing thesis project.

The name of the study is *Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors*.

The purpose of the study is to explore parents lived experiences about disclosing, or not disclosing their BRCA1/2 test results to their children who are under 19 years of age. I hope to gain a better understanding of parental decisions about sharing and not sharing genetic test results, information and support seeking needs, decision-making, and personal experiences about the parent-child interaction.

The study involves two interviews. The interviews will be set-up at a place that works best for you. For example, I would be happy to meet you at your home, place of work, or an interview room at the University of Manitoba, Faculty of Nursing. The first conversation will be about 75 minutes, and the second will be about 25 minutes.

During the first conversation we would speak about your experiences of sharing, or not sharing your BRCA1/2 test results with your young children. Do you feel you would be interested in participating is this study?

[If the potential participant answers yes, then I would proceed to confirm eligibility criteria as noted below].

[If the potential participant answers no, then I would thank them for their time, wish them great day, and say good-bye].

[If interested] Thank-you for your interest in this study. I do need to ask you a few questions to make sure you are able to take part in the study. Can you answer the following questions:
1) Are you able to speak and read English?
2) Are you older than 18 years of age and older?
3) Have you received a BRCA1/2 positive test result from Health Science Centre Hereditary Breast and Ovarian Clinic within the past 4 years?
4) Are you a parent with at least one child who is between the ages of 6 and 18, and who at the time of disclosure is younger than 19 years of age

5) Within one year of getting your test results have you disclosed, or chosen not to disclose your BRCA1/2 test result to a minor?

[If the potential participant met all the eligibility criteria, I would now review the contents of the informed consent form]. (See Appendix F)

[For those who are still interested after the entire consent form has been reviewed and all questions answered, I would book the two interview appointments].

Before we end this telephone call I will ask, if you are aware of anyone who you feel may qualify and may like take part in this study; please have them call me at (xxx) xxx-xxxx.

I appreciate your time and interest in the study. Are you comfortable with sharing your telephone number with me just in case I need to call you to rearrange our interview meeting? I would only do so in an emergency situation.

Please remember to complete your consent and demographic forms, and return them to me in the pre-addressed stamped envelope which is in the study information package [for those who choose a telephone appointment].

I look forward at meeting you at [stating the agreed on location, date, and time]. If you have any further questions please feel free to call me at (xxx) xxx-xxxx.

Enjoy your day. Good-bye.

APPENDIX G
Reminder Letter

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

Dear Family Member,

My name is Kendra-Ann, and I am a graduate student at the University of Manitoba, Faculty of Nursing. *On my behalf,* your healthcare provider at [WRHA – Hereditary Breast and Ovarian Clinic] [CCMB – Breast Cancer Centre of Hope] is sending this *reminder letter* regarding an information package you previously received about the chance to take part in a study called **'**Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors.'

If you are interested in *learning more* about the study, and you are:
1) Able to speak and read English
2) Male or female who is 18 years of age, and older
3) Received a BRCA1/2 positive diagnosis from Health Science Centre Hereditary Breast and Ovarian Clinic within the past 4 years
4) A parent with at least one child who is between the ages of 6 and 18, and who at the time of disclosure is younger than 19 years of age
5) Within one year of receiving test results you have disclosed, or choose not to disclose BRCA1/2 test results to a minor

Then I would like to speak with you!

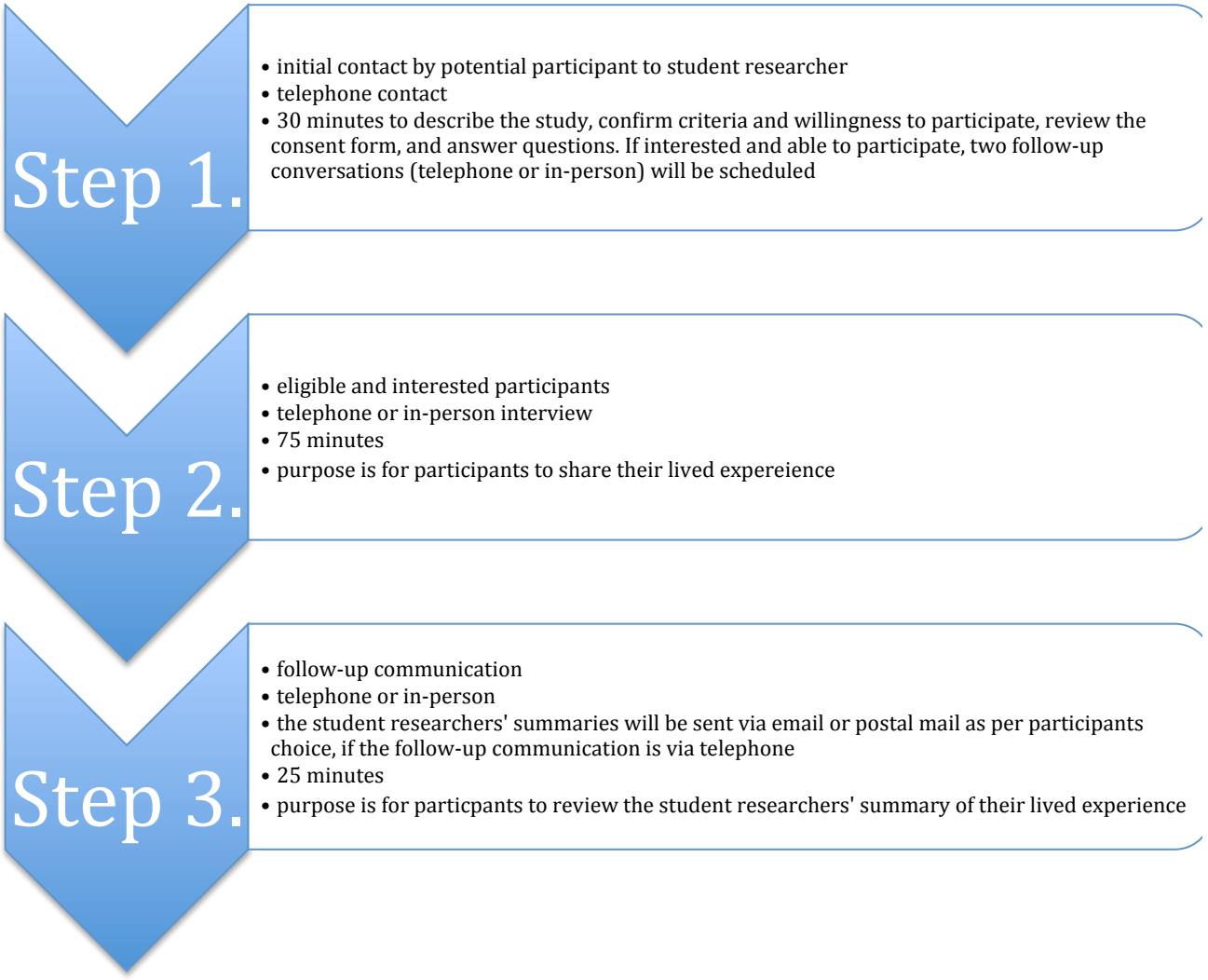
If you are aware of anyone who you feel may qualify to participate in this study, and who you feel would be interested in taking part please have them call me at (xxx) xxx-xxxx.

For more information on the study please read the enclosed consent form, and call me at (xxx) xxx-xxxx.

With appreciation,

Kendra-Ann I. Seenandan-Sookdeo RN, BN, MN(c)

APPENDIX H
Participants Involvement Chart



APPENDIX I
Demographic Form

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

The data gathered on this form will help the researcher (Kendra-Ann) to get to know you and your family, and compare your family circumstances with those of other families in this study. All data gathered will be kept private (confidential).

Please *circle or write* the answer that best reflects you.

1. Your age _____
2. Gender
    a. Female
    b. Male
3. Carrier status
    a. Positive for BRCA 1
    b. Positive for BRCA 2
4. Number of children _____
5. Age of each child _____
6. BRCA1/2 test results received
    a. Month _____
    b. Year _____
7. Test result shared with children who are under the age of 19
    a. Yes (specify month and year) _____
    b. No
8. Cancer status
    a. Affected (specify breast, ovarian, other) _____
    b. Unaffected
9. Marital status:
    a. Single / Never Married
    b. Married / Common Law
    c. Divorced / Separated
    d. Widowed
    e. Other (specify) _____
10. Highest education:
    a. Less than high school
    b. High school
    c. Community / Technical college
    d. University
    e. Other (specify) _____
11. Employment status

a. Full-time
b. Part-time
c. Unemployed
d. Disability / Medical Leave

Participant's code _____

12. Ethnic background
    a. Caucasian
    b. Ashkenazi Jewish
    c. Icelandic descent
    d. Eastern European (specify) _____
    e. Other (specify) _____
13. Do you live inside the city of Winnipeg
    a. Yes
    b. No (specify where) _____

Participant's code _____

APPENDIX J
Permission to Forward Summary of the Lived Experience

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

I would like to have my follow-up communication with Kendra-Ann to be done by telephone. Therefore, I would like to receive Kendra-Ann's summary of our initial conversation about my lived experience to be sent to me so I may have time to review the summary before our telephone contact.

Participant Printed Name (first and last): _____

Date (month/ day/ year): _____

Please send me a copy of the summary of the initial conversation by:

- _____ Email to the following e-address: _____
- _____ Post to the following address *(please include a postal code)*:

  Full Canada Post mailing address is:

  _____

  _____

  _____

  _____

APPENDIX K
Script for Second Communication

Script for Telephone:
Hello may I speak to [first name of participant].

[If it is the participant]. It's Kendra-Ann calling. Thank-you for agreeing to speak with me regarding the summary of your lived experience. Have you had a chance to review the summary?

[If yes]. Please share with me any additional thoughts, and clarifications you may have regarding the summary.

[For participants who have not retuned the Request for Research Summary Study Findings]. I have not received a copy for your request for the research summary study findings to sent to you. As a friendly reminder, if you would like a copy please complete and return this form.

Thank-you very much for taking the time to participate.

Good-bye.

Script for In-Person:
Hello [first name of participant].

It's nice to see you again. Thank-you for agreeing to speak with me regarding the summary of your lived experience. Here is a copy for a summary of our previous conversation. Please take your time to review it, and when you are finished you may share your thoughts with me regarding the summary.

[When participant has indicated review is complete]. Please share with me any additional thoughts, and clarifications you may have regarding the summary of your lived experience.

[For participants who have not retuned the Request for Research Summary Study Findings]. I have not received a copy for your request for the research summary study findings to sent to you. As a friendly reminder, if you would like a copy please complete and return this form at a later date, or you may complete and return it to me now.

Thank-you very much for taking the time to participate.

Good-bye.

APPENDIX L

Request for Research Summary Study Findings

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

Yes, I would like to receive a summary about the findings of the study entitled 'Parental Perceptions Regarding the Disclosure and Non-Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors.

Participant Printed Name (first and last): _____

Date (month/ day/ year): _____

Please send me a copy of the results by:

- _____ Email to the following e-address: _____
- _____ Post to the following address *(please include a postal code)*: Full Canada

  Post mailing address is:

  _____

  _____

  _____

  _____

APPENDIX M
Interview Questions

UNIVERSITY OF MANITOBA
Faculty of Nursing
Helen Glass Centre for Nursing
Addressograph

The primary research question framing the study is, what are Manitobans' parental perceptions regarding the disclosure, and non-disclosure of BRCA1/2 carrier status to offspring who are between the ages of 6 and 18, and who at the time of the initial research conversation are less than 19 years of age. The following research questions will help to answer the overarching research question:

A. Research Questions: *Disclosure BRCA1/2* Test Results

1. What was involved in your decision making to disclose your genetic test result to your child(ren) who is (are) between the ages of 6 and 18?

2. Why did you choose to disclose your test results to your child(ren)?

3. What did you tell your child(ren)?

4. How did your child(ren) react and respond to the disclosure?

5. How did you feel after disclosing your genetic information to your child(ren)?

6. What kind of supports were provided to you during your decision-making process?

7. What recommendations do you have for healthcare providers regarding how best they can assist and support parents who choose to disclose BRCA1/2 test results to young children?

8. What recommendation do you have for parents regarding the communication and non-communication of genetic test results to their child(ren)?

B. Research Questions: *Non-Disclosure* BRCA1/2 Test Results

1. What was involved in your decision-making not to disclose your genetic test results to your child(ren) who is (are) between the ages of 6 and 18?

2. Why did you choose not to disclose your test results to your child(ren)?

3. At this point in time, how do you feel about your decision not to disclose your test results your child(ren)?

4. What kind of supports were provided to you during your decision-making process?

5. What recommendations do you have for healthcare providers regarding how best they can assist, and support parents who choose not to disclose test results to young children?

6. What recommendations do you have for parents regarding the communication and non-communication of their genetic test results to their child(ren)?

APPENDIX N

Transcription Service Confidentiality Agreement

UNIVERSITY OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing
Addressograph

"I, _____, transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documents received from Kendra-Ann I. Seenandan-Sookdeo related to her Master of Nursing study on Parental Perceptions Regarding the Disclosure of Hereditary Breast and Ovarian (HBO) Test Results to Minors. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews
2. To not make copies of any audiotapes
3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession
4. To return all audiotapes and study related documents to Kendra-Ann in a complete and timely manner
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and / or files to which I will have access."

Transcriber's Name (printed): _____

Transcribers Telephone Number: _____

Transcriber's Signature: _____

Date (month/ day/ year): _____

Student Researcher's Signature: _____

Date (month/ day/ year): _____

Source: https://secure.myunion.edu/Forms/IRB/IRB016.doc

APPENDIX O

Certificate of Completion

This document certifies that

Kendra-Ann Seenandan-Sookdeo

has completed the Queen's University online Course in Human Research Participant Protection (CHRPP).

Date of Issue: September 18, 2010

UNIVERSITY OF MANITOBA