

THE LIVED EXPERIENCE OF PROPHYLACTIC TOTAL GASTRECTOMY:

A PHENOMENOLOGICAL INQUIRY

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Abstract

Hereditary diffuse gastric cancer (HDGC) is associated with early age of onset and poor prognosis. Individuals who test positive for a CDH1 gene mutation are at a significantly increased lifetime risk of HDGC and face difficult proactive treatment decisions.

Currently, two risk management options are presented to those at risk of HDGC: (a) annual endoscopic surveillance or (b) removal of the entire stomach organ—prophylactic total gastrectomy (PTG). Little is known about how patients experience PTG. The purpose of this study was to gain an understanding of the reality of PTG as experienced by the patient from the time they realized their genetic risk through to their decision-making, hospitalization, recovery, and reflection upon the experience. Semi-structured interviews were carried out with seven individuals who had previously undergone PTG. Interview data was analyzed using van Manen's (1990) approach to phenomenology. Three substantive themes with supporting subthemes were identified: *playing the hand you're dealt*, *living a health–illness paradox*, and *moving forward*. Viewed together, the three substantive themes form the essence of the patient experience of PTG—choosing to be a previvor. This study is among the first to explore the patient experience of PTG, thus findings have implications for nurses and other health-care professionals caring for this unique patient population.

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Chapter 1: Introduction

This study is an examination of the experiences of individuals who have undergone prophylactic total gastrectomy (PTG) due to genetic risk of hereditary diffuse gastric cancer (HDGC). The advent of predictive genetic testing for hereditary cancer has provided a unique opportunity to patients. Patients who are at hereditary risk of cancer are armed with the knowledge of an increased lifetime risk of cancer occurrence while simultaneously presented with an opportunity to make proactive, preventative treatment decisions. Currently, individuals determined to be at genetic risk of HDGC are presented with two risk management options: (a) annual endoscopic surveillance or (b) surgical removal of the entire stomach—PTG (Ford, 2015; van der Post et al., 2015). Prophylactic removal of the stomach in a healthy individual is a radical decision for those who are faced with the dilemma of managing HDGC. Often, the health–illness journey and the impact of PTG are not fully understood by family, friends, or health-care providers. Using phenomenology this study aims to bring the unique lived experience of the patient undergoing PTG to light.

Background and Rationale

It has been estimated that 3,330 Canadians are newly diagnosed with stomach cancer each year, with 63% of cases ending in death (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Moreover, gastric cancer is a global health concern, ranking as the third leading cause of cancer-related death worldwide with a five-year survival rate at a dismal 20% (Chun & Ford, 2012). There are significant geographic variations in the distribution of gastric cancer. East Asia, East Europe, and South America have higher rates of stomach cancer in comparison to North America

which has among the lowest rates of stomach cancer (Jemal et al., 2011). Most gastric cancer research reflects the experience in high prevalence areas, patients with gastric cancer in North America have been understudied, resulting in limited understanding of their experience (Bae et al., 2006; Kim et al., 2008; Maeda & Munakata, 2008; Maeda, Onuoha, & Munakata, 2006).

In addition to the geographic variation of gastric cancer, there is also variation in the types of gastric cancer. Lauren (1965, as cited in Blair, 2012) classified and described two main subgroups of gastric cancer: intestinal gastric cancer and diffuse gastric cancer (DGC). Intestinal gastric cancer is often associated with environmental factors, whereas DGC is associated with traits of the individual and can be hereditary in nature (Blair, 2012; Caldas et al., 1999; Chen et al., 2011; Hebbard et al., 2009; Lynch et al., 2008; Mukherjee, McGarrity, Staveley-O'Carroll, Ruggiero, & Baker, 2009). While the majority of gastric cancer cases are sporadic in nature, a genetic predisposition can be confirmed in 1–3% of cases (Oliveira, Pinheiro, Figueiredo, Seruca, & Carneiro, 2015; Oliveira, Seruca, & Carneiro, 2006; van der Post et al., 2015).

The first description of a genetic mutation that places individuals and families at an increased risk for gastric cancer was provided by Guilford et al. (1998), who described a germline mutation of the CDH1 or E-cadherin gene. CDH1 gene mutation has an autosomal dominant pattern of inheritance and is associated with a lifetime risk of HDGC up to 70% in men and 56% in women (Hansford et al., 2015). CDH1 mutation also carries a 40% lifetime risk of lobular breast cancer (LBC) for affected women (Cisco, Ford, & Norton, 2008; Corso et al., 2014; Hansford et al., 2015; Lynch et al., 2008). After a genetic predisposition to gastric cancer was confirmed through identification of the

CDH1 mutation, HDGC has been a topic of interest in health research and practice. The International Gastric Cancer Linkage Consortium (IGCLC), comprised of a variety of geneticist, physicians, health-care specialities, and patient representatives, was formed to further evaluate the genetic basis of gastric cancer and to standardize clinical management of HDGC. According to IGCLC guidelines, clinical criteria indicative of HDGC include (a) two gastric cancer cases regardless of age, at least one confirmed DGC; (b) one case of DGC <40; (c) personal or family history of DGC and LBC, one diagnosed <50 (van der Post et al., 2015). Individuals meeting the IGCLC criteria are seen in approximately 10% of gastric cancer cases (Cisco et al., 2008; Oliveira et al., 2006; Oliveira et al., 2015). However, of the 10% of gastric cancers that are suggestive of familial inheritance, a known genetic mutation can be attributed to only 1–3% (Corso et al., 2014; Oliveira et al., 2015).

In a study of the genetic basis of HDGC by Hansford et al. (2015) only 19% of individuals meeting the clinical criteria for HDGC harboured the CDH1 gene mutation. Furthermore, only a fraction of HDGC can be accounted for by other hereditary cancer syndromes such as Lynch syndrome, Li-Fraumeni syndrome, or Peutz-Jeghers syndrome, which carry a lifetime risk of gastric cancer ranging from <3% to 47% (Corso et al., 2014; Setia et al., 2015). The majority of familial gastric cancer cases are due to, as of yet, unidentified genetic mutations resulting in significant clinical burden and a search for other HDGC susceptibility genes (Corso et al., 2014; Ford, 2015; Hansford et al., 2015; Oliveira et al., 2015; Tan & Ngeow, 2015).

Hansford et al. (2015) published the largest study to date investigating the genetic etiology of gastric cancer. Mutations in genes such as CTNNA1, PRSS1, PALB2, ATM,

MSR1, and SDHB have been linked to an increased incidence of gastric cancer (Ford, 2015; Hansford et al., 2015). However, until further genetic research is conducted to determine the pathogenicity and penetrance of these newly implicated genetic mutations, CDH1 remains the only genetic mutation for which PTG is advised (Colvin, Yamamoto, Wada, & Mori, 2015; Ford, 2015; Hansford et al., 2015; Tan & Ngeow, 2015).

Furthermore, in considering the incidence and penetrance of HDGC, it is thought to be higher in Newfoundland and Labrador (NL), where a founder mutation, or independent mutational events, have been suggested (Kaurah et al., 2007). If a founder effect can be attributed to the NL population then up to 40% of gastric cancer cases in the province could be hereditary (Kaurah et al., 2007).

HDGC is associated with early age of onset and can be fatal (Colvin et al., 2015; Lynch et al., 2008; Tan & Ngeow, 2015). Early HDGC has few or vague symptoms and can be asymptomatic. Often when symptoms of HDGC appear the cancer is advanced and prognosis is poor (Chen et al., 2011; Colvin et al., 2015; Ford, 2015). Discouraging is the finding that current methods of surveillance for HDGC—including endoscopy with biopsy, the computed tomography (CT) scan, and the positron emission tomography (PET) scan—are highly ineffective in early detection (Blair, 2012; Caldas et al., 1999; Chen et al., 2011; Cisco et al., 2008; Colvin et al., 2015; Corso et al., 2014; Fitzgerald et al., 2010; Ford, 2015; Hebbard et al., 2009; Huntsman et al., 2001; Lynch et al., 2008; Oliveira et al., 2015; Tan & Ngeow, 2015). Thus, physicians have advocated for early identification of genetic risk and have supported PTG as the superior risk management option (Chen et al., 2011; Colvin et al., 2015; Corso et al., 2014; Fitzgerald et al., 2010;

Ford, 2015; Hebbard et al., 2009; Huntsman et al., 2001; Lynch et al., 2008; Oliveira et al., 2015; Setia et al., 2015; Tan & Ngeow, 2015; van der Post et al., 2015).

PTG involves the complete surgical resection of the entire stomach with reconstruction to join the esophagus and small intestine. Approaches to PTG are largely physician dependent and can be performed either through laparotomy or laparoscopy and may or may not include removal of lymph nodes or the creation of a jejunal pouch, which in some cases improves food tolerance initially after surgery (Chung, Yoon, Lauwers, & Patel, 2007; Cisco et al., 2008; Fitzgerald et al., 2010). Removal of the entire stomach organ carries with it a nearly 100% risk of some form of morbidity, including diarrhea, dumping syndrome, weight loss, difficulty eating, abdominal pain, nausea, tiredness after eating, lactose intolerance, fat malabsorption, and vitamin deficiency (Cisco et al., 2008; Fitzgerald et al., 2010). In addition to the physical consequences of surgery, individuals undergoing PTG may also experience psychosocial implications. Those who have had prophylactic surgery for hereditary cancer syndromes have reported changes in identity or self-concept and post-surgical symptoms that impact quality of life (Brandberg et al., 2008; Etchegary, Dicks, Watkins, Alani, & Dawson, 2015; Fritzell, Persson, Björk, Hultcrantz, & Wettergren, 2010; Garland, Lounsberry, Pelletier, & Bathe, 2011; Kenen, Shapiro, Hantsoo, Friedman, & Coyne, 2007). Despite the consequences of PTG, it has also been described as a potential cure for otherwise highly fatal HDGC (Chen et al., 2011; Cisco et al., 2008; Huntsman et al., 2001). Thus, having PTG is a difficult decision and a significant undertaking.

Research into HDGC and PTG has been undertaken for a little over a decade. Research literature on PTG demonstrates the relatively new and evolving nature of the

surgical procedure, ranging from cautious optimism (Caldas et al., 1999) to full support for and recommendation of the procedure in more recent reports (Chen et al., 2011; Colvin et al., 2015; Corso et al., 2014; Fitzgerald et al., 2010; Ford, 2015; Hebbard et al., 2009; Lynch et al., 2008; Oliveira et al., 2015; Setia et al., 2015; Tan & Ngeow, 2015; van der Post et al., 2015). While research on PTG has found support for the efficacy of the procedure, data explicit to the patients' lived experience of the procedure remains largely unknown.

Purpose

The purpose of this research study was to better understand the experience of undergoing PTG to manage risk of HDGC. As a surgical nurse, my own clinical experience suggested that the decision and experience of PTG was complex and challenging with implications for both the individual and family. As a nurse researcher, I was interested in learning more about the experience of major prophylactic gastric surgery from the patients' perspective, including the physical, functional, psychosocial, and emotional challenges of the surgery as well as the health-care experience and the ongoing impact of the surgery on their life.

Findings from this study offer practice implications for nurses and other health-care professionals in providing optimum care to individuals and families both considering and opting for PTG. Enhanced understanding of the patient experience of PTG gained through this study can contribute to more supportive and effective therapeutic relationships in which individuals and their families may feel supported in their decision to undergo PTG. Furthermore, through the exploration of the experiences of patients

undergoing PTG—from genetic testing to follow-up—strengths and improvements in the delivery of health-care services to this unique patient population may be realized.

Research Question

This study was guided by the research question, what is the patient experience of PTG as a means of managing HDGC risk? The main objective of the study was to gain an understanding of the reality of PTG as experienced by the patient from the time they realized their genetic risk through to their decision-making, hospitalization, recovery, and reflection upon the experience.

Chapter 2: Review of Literature

A literature search was performed using two databases: CINAHL and PubMed.

Both databases were searched using the keywords *hereditary diffuse gastric cancer* (HDGC), *genetic testing*, *prophylactic surgery*, and *prophylactic total gastrectomy* (PTG) alone and then in combination with *patient experience*, *adjustment*, *psychological adjustment*, and *quality of life*. Articles were eliminated if the main focus was on various surgical or reconstructive approaches and if the publication was in a language other than English. Additional sources were obtained through references in the initial literature. This resulted in a thorough collection of literature on genetic testing and prophylactic surgery in general and a more limited compilation of literature specific to PTG which included physician case reports, quality-of-life research, and one qualitative study that explored gastrectomy from the perspective of both the palliative and the prophylactic patient.

Genetic Testing

The advent of genetic testing for familial cancers has been described as revolutionary in health care with the potential to lessen morbidity and mortality through early detection, informed decision-making, and individualized prevention strategies (Cameron & Muller, 2009; Heshka, Palleschi, Howley, Wilson, & Wells, 2008; Schwartz, Peshkin, Tercyak, Taylor, & Validimarsdottir, 2005). Genetic testing for several types of cancer, including breast and ovarian cancer, first began in the 1990s (Bleiker, Hahn, & Aaronson, 2003). Since that time extensive research has been conducted on the experience of genetic testing, allowing greater understanding of genetic testing decision-making and the impact on the individual and family. While most research on genetic testing for familial cancer has been conducted with populations at risk for breast, ovarian,

and colorectal cancer, findings may also provide insight into the experience of individuals and families at risk of HDGC.

Individual impact.

The decision to undergo genetic testing for familial cancer has been described as personal, complex, difficult, and potentially burdensome for the individual (LaTour, 2013; Meijers-Heijboer et al., 2000; Schwartz et al., 2005; Watkins et al., 2011). Due to the magnitude of the information revealed in genetic testing and the implications that it may have on the individual and family, all patients must participate in genetic counselling (Braithwaite, Emery, Walter, Prevost, & Sutton, 2006; Meijers-Heijboer et al., 2000). A 2006 systematic review of genetic counselling for familial cancer concluded that such counselling enhanced knowledge about genetic cancer, improved informed decision-making, and reduced cancer-specific worry and fear in the short term. However, genetic counselling did not result in a more accurate perception of risk (Braithwaite et al., 2006). In addition to genetic counselling, health professionals have also explored the use of decision aids in genetic testing for familial cancer (Iredale et al., 2008). A focus group study conducted in the United Kingdom revealed that supplementing genetic counselling with decision aids contributed to improved knowledge, informed decision-making, and a reduction in decisional conflict. Decision aids used in the study included self-study educational information in both paper and CD ROM format (Iredale et al., 2008).

While genetic counselling and decision aids may improve knowledge of genetic disease and assist with decision-making, the choice of whether or not to undergo genetic testing is ultimately that of the individual and may be influenced by a variety of personal factors. Research has identified several factors that motivate individuals to seek genetic

testing, including obtaining risk information for oneself and one's children (Fritzell et al., 2010; Jeffers, Morrison, McCaughan, & Fitzsimons, 2014; Meijers-Heijboer et al., 2000; Schwartz et al., 2005), physician recommendation (Hoskins & Werner-Lin, 2013; Kenen et al., 2007; Schwartz et al., 2005), relief of uncertainty and distress (Hoskins & Werner-Lin, 2013; Meijers-Heijboer et al., 2000; Schwartz et al., 2005), being knowledgeable regarding risk management options and plans to avail of them (Hoskins & Werner-Lin, 2013; Kenen et al., 2007; LaTour, 2013; Schwartz et al., 2005), previous experience with hereditary illness in family (Hoskins & Werner-Lin, 2013; Kenen et al., 2007), and younger age (Meijers-Heijboer et al., 2000).

Individuals may also experience deterrents to genetic testing including discrimination regarding life and health insurance (Cameron, Sherman, Marteau, & Brown, 2009; Iredale et al., 2008; Meijers-Heijboer et al., 2000; Schwartz et al., 2005). Cameron et al. (2009) also reported that the perceived severity and manageability of an illness may influence testing decisions with less uptake of genetic testing for illnesses considered untreatable.

The decision to undergo genetic testing is a very difficult one; however, the outcome is generally positive. In a study concerning the long-term implications of genetic testing for breast and ovarian cancer the majority of participants reported that genetic testing had been a positive choice (Hamilton, Williams, Skirton, & Bowers, 2009). Furthermore, there has been consensus in the literature that there are no long-term psychological consequences of genetic testing for either carriers or non-carriers (Broadstock, Michie, & Marteau, 2000; Heshka et al., 2008; Hirschberg, Chan-Smutko, & Pirl, 2015; van Oostrom et al., 2003). However, select individuals may experience

increased anxiety, distress, or coping difficulties (Esplen et al., 2013; Hirschberg et al., 2015; Watkins et al., 2013). Several authors have reported that the amount of pre-test emotional distress is predictive of distress after testing (Broadstock et al., 2000; Esplen et al., 2013; Hirschberg et al., 2015; van Oostrom et al., 2003). Watkins et al. (2011) found that genetic testing for Lynch syndrome is sometimes burdensome for the individual in relation to the lifelong management required and the unpredictable nature of cancer occurrence within the family. According to Bleiker et al. (2003), several other factors are associated with an increased risk of distress post-genetic testing, including previous caregiving for a family member with the genetic illness, previous or recent death of a relative due to familial cancer, negative experiences of family cancer during developmental years, and when test results are different than expected. Further factors relating to distress after genetic testing for cancer syndromes were identified by Hirschberg, Chan-Smutko, & Pirl (2015), including having a history of depression, use of avoidant or passive coping mechanisms, elevated risk perception, unresolved loss or grief, and being a parent. Non-carriers are also not exempt from feelings of distress post-genetic testing with studies finding increased distress relating to feelings of survivor guilt and doubt regarding accuracy of test results (Bleiker et al., 2003; Hamilton et al., 2009; van Oostrom et al., 2003).

Although most individuals adjust well to genetic test results, researchers in Canada have recently developed a brief screening tool to assess psychological risk and to determine the need for additional support (Esplen et al., 2013). The screening tool consists of a 20-item self-administered questionnaire that allows the health-care provider to determine the individual support needs of the patient. A local team of researchers

recently expanded upon the available tools to measure distress post-genetic testing (Watkins et al., 2013). Through a multi-phase project, the team developed a tool to measure psychological adjustment to hereditary diseases (PAHD). The self-administered scale consists of two inter-related subscales: burden of knowing and family connectedness. Preliminary testing of the PAHD scale revealed, as predicted, an inverse relationship between the two subscales with individuals reporting higher levels of family connectedness experiencing less burden of knowing. Initial testing of the tool with individuals affected by Lynch syndrome has confirmed the psychometric properties and clinical utility of the PAHD scale. However, it was acknowledged that further use of the tool is needed to confirm its ability to measure psychological adjustment in the long term (Watkins, 2013).

After at-risk status has been confirmed through genetic testing individuals must determine what to do with the information. Behavioral responses to genetic information has been studied among those at risk of hereditary cancer and other genetic-linked conditions. Several authors have reported that known genetic status has a positive impact on lifestyle changes and screening practices (Collins, Meiser, Gaff, St. John, & Halliday, 2005; Halbert et al., 2004; McBride, Koehly, Sanderson, & Kaphingst, 2010; Ozanne, Wittenberg, Garber, & Weeks, 2010; Senior, Marteau, & Weinman, 2000). Knowledge of familial cancer has even been shown, in some cases, to increase adherence to screening regimens among non-carriers (Kaphingst & McBride, 2010). Obtaining genetic risk information has been identified as a motivating factor in both screening practices and surgical risk management decisions (Bleiker et al., 2003; Collins et al., 2005; Etchegary et al., 2015; Frost et al., 2000; Halbert et al., 2004; Hallowell et al., 2016; Hamilton et al.,

2009; Kaphingst & McBride, 2010; Kenen et al., 2007; Lynch et al., 2008; McBride et al., 2010; McQuirter et al., 2010; Ozanne et al., 2010; Underhill et al., 2012; Underhill & Dickerson, 2011; Watkins et al., 2011). However, knowledge of genetic status does not result in more vigilant health behaviors for all affected individuals; a variation in behavioral responses to genetic information has been reported. In fact, Heshka et al. (2008) concluded that genetic testing had little effect on risk management behavior. Instead, risk management behavior was linked to individual motivation, highly motivated individuals frequently engaged in surveillance screening before testing and were more likely to follow screening recommendations. Adherence to surveillance regimens has also been found to vary across risk-reduction options, with less adherence to more invasive screening procedures (Kaphingst & McBride, 2010; Ozanne et al., 2010). Sivell et al. (2008) further suggested that inconsistency in uptake of surveillance recommendations can be related to an individual's perception of risk status. The authors found that individuals sometimes underestimate their risk status; however, there is a greater tendency toward overestimation of risk which may lead to inappropriate or hypervigilant preventative behavior.

Family impact.

Due to the hereditary nature of familial cancer, receiving a mutation-positive test result has significant implications not only for the individual but also for the family (Cameron & Muller, 2009; Hamilton, Bowers, & Williams, 2005). Bleiker et al. (2003) and Iredale et al. (2008) asserted that individuals selecting genetic testing must be cognizant that not all family members desire to know their genetic status. Being the first in the family to undergo genetic testing or being "the discloser" within the family can be a

very challenging experience (Bleiker et al., 2003; Hamilton et al., 2005). Throughout the literature, individuals and families have frequently reported feelings of discrimination or stigma associated with familial inherited illness (Cameron et al., 2009; Cameron & Muller, 2009; Fritzell et al., 2010; Frost et al., 2000; Heshka et al., 2008; Kenen et al., 2007; Vos et al., 2013). Thus, mutation-positive individuals often describe difficulties in communicating gene-positive test results to family members (Fritzell et al., 2010; Hamilton et al., 2005; Hamilton et al., 2009; LaTour, 2013; Schwartz et al., 2005). A grounded theory study by Hamilton et al. (2009) found that communication of gene-positive test results can negatively impact family relationships. Distancing in family relationships and failed expectations for support were experienced. Even when there was no negative impact on family relationships, participants were conscious that genetic information could skew family connections and worked to prevent it (Hamilton et al., 2009). Furthermore, negative family outcomes to genetic information were also identified in the systematic review by Wiseman, Dancyger, & Michie (2010), family responses included: distress, silence, confusion and blame. However, not all family communication of genetic information is experienced negatively, positive experiences have also been reported including feeling relieved and supported (Wiseman et al., 2010).

Family communication is a vitally important aspect of genetic testing that has been explored throughout the literature. Etchegary and Fowler (2008) suggested that genetic testing is an interdependent process rather than an autonomous and independent undertaking due to the coexisting sense of obligation and responsibility to the family. A range of family communication responsibilities in genetic testing were identified including responsibilities to future generations, partners, family members, and for future

planning. Beyond the responsibilities in family risk communication, Gaff et al. (2007) described such communication as a deliberative process rather than a one-time announcement. Three phases of communication along with inherent challenges were described; 1) deliberation before communication, 2) choosing communication strategies and 3) outcomes of communication. Factors underlying an individual's approach to sharing genetic risk information with the family were also identified by Seymour, Addington-Hall, Lucassen, and Foster (2010). Six key considerations were identified: informant's feelings about telling their family, perceived relevance of and reaction to the information, closeness in family relationship, family rules and patterns, timing of and amount of information to share, and the role of health professionals. More specifically, the authors found that individuals felt responsible to inform family of risk but did not want to harm them in the process. Individuals were more likely to inform first-degree relatives such as children and siblings than more distant relatives and the desired level of professional involvement in risk communication varied.

While family communication has been studied among various at-risk populations, there continues to be a lack of established guidelines on how best to communicate such information. A quantitative study by den Heijer et al. (2011) did find that open communication within the family regarding hereditary cancer is associated with less general and cancer-specific distress, greater perceived support, and better long-term adaptation to living with knowledge of hereditary risk. Alternately, lack of open communication is associated with increased worry and distress among mutation carriers (van Oostrom, 2003). Family dynamics may be particularly important to consider among young adults seeking genetic testing. In a multi-case report of young women seeking

breast cancer status, testing and prevention strategies were influenced by parental grief and fear resulting in decisions that were not always consistent with the preferences of the young adult (Hoskins & Werner-Lin, 2013). Due to the potential impact of genetic testing on the entire family, Cameron and Muller (2009) have advocated for an increased family focus in genetic counselling and testing.

Prophylactic Surgery

Prophylactic surgery, also known as risk-reducing surgery, is a surgical risk-management option offered to individuals at risk of hereditary cancer syndromes before the onset of disease. The research literature specific to PTG is fairly limited and mostly consists of physician case reports, as discussed below. However, other forms of prophylactic surgery including prophylactic mastectomy (PM), prophylactic colectomy, and risk-reducing salpingo-oophorectomy (RRSO) have been explored to varying degrees. Similar to selecting genetic testing, the decision to undergo prophylactic surgery is complex, multi-factorial, and influenced by both emotion and reason (McQuirter, Castiglia, Loiselle, & Wong, 2010).

Studies examining PM and RRSO have identified several factors that play a role in selecting prophylactic surgery, including preference for active involvement in health care (McQuirter et al., 2010), previous cancer experience in the family (Etchegary et al., 2015; Frost et al., 2000; McQuirter et al., 2010; Singh et al., 2013), physician recommendation (Etchegary et al., 2015; Frost et al., 2000; McQuirter et al., 2010; Schwartz et al., 2005), fear of getting cancer or dying with cancer (Etchegary et al., 2015; Frost et al., 2000; Kenen et al., 2007; McQuirter et al., 2010; Schwartz et al., 2005), family and spousal support (McQuirter et al., 2010), support from others who have lived

the experience (Kenen et al., 2007; McQuirter et al., 2010), and desire to be alive for children (Jeffers et al., 2014; McQuirter et al., 2010; Meijers-Heijboer et al., 2000; Singh et al., 2013). Additionally, McQuirter et al. (2010) found that the decision to undergo prophylactic surgery was profoundly influenced by a “pivotal point” that created a sense of urgency (p. 317). “Pivotal points” were described as emotion-laden events that made decision-making clearer, including learning of the genetic status or cancer diagnosis of oneself or within one’s family in combination with known genetic risk. Finally, in considering prophylactic surgery decision-making, many individuals with positive genetic status reported that heightened hereditary risk left them with no choice but to have surgery (Etchegary et al., 2015; Frost et al., 2000; Kenen et al., 2007; Underhill & Dickerson, 2011).

Until recently, the decision-making experiences specific to the PTG patient population had been minimally explored. One physician case report by Lynch et al. (2008) alluded to the decision-making experience of the patient. Specifically, a good support network and the loss of a loved one made the PTG decision easier. A greater struggle with the decision to have PTG was associated with insufficient educational information and the longevity of other family members with positive genetic status for HDGC. Most recently, Hallowell et al. (2016) identified factors that influenced decision-making specific to having PTG. In their qualitative study, the authors found that PTG decision-making was influenced by clinical, emotional, personal, and social factors. Specific reasons for choosing PTG included confirmed objective risk, family experiences, heightened perceived risk of cancer occurrence, observing others’ experiences with PTG, concerns with endoscopic surveillance, and being a parent (Hallowell et al., 2016).

Reports of the outcomes of prophylactic surgery are mixed, with both positive and negative reactions reported and with the outcomes described in terms of both gain and loss. Perceived outcomes of prophylactic surgery have been mostly positive among the PM and RRSO patient population. Studies evaluating the experiences of patients undergoing RRSO have reported that quality of life after RRSO is comparable with the general population, that there are no deleterious effects on physical or mental health, and that patients do not regret choosing the surgery (Etchegary et al., 2015; Finch et al., 2013). However, patients who had RRSO did report some unfavourable experiences related to surgery-induced menopausal symptoms and deficient information from the health-care team regarding hormone replacement therapy (Etchegary et al., 2015). Similar to the patient population electing RRSO, research has shown no negative impact on quality of life after PM, and individuals choosing PM also did not regret their choice (Brandberg et al., 2008; Kenen et al., 2007). Although, post-surgical symptoms were also an issue for PM patients: changes in body image, sexuality, and social relationships were reported (Brandberg et al., 2008; Kenen et al., 2007). Prophylactic colectomy for individuals at risk of familial adenomatous polyposis (FAP) was reported more negatively. Prophylactic surgery for the FAP patient population involves bowel resection with the creation of a rectal pouch or permanent colostomy, making the surgery difficult for patients to accept (Fritzell et al., 2010). In the study by Fritzell et al. (2010), patients at risk of FAP considered prophylactic surgery a turning point in their lives; participants reported feeling healthy until they had a prophylactic colectomy. As with RRSO and PM, patients at risk of FAP choosing prophylactic colectomy expressed feeling grateful for the

option of surgery, yet they were also bothered by post-surgical symptoms, specifically in relation to changes in eating and elimination (Fritzell et al., 2010).

Prophylactic surgery has been described as mutilating and irreversible (Bleiker et al., 2003) and the individuals who have selected prophylactic surgery report that surgery involves sacrifice (Fritzell et al., 2010; Hamilton et al., 2009; Kenen et al., 2007).

However, the majority of individuals report satisfaction with prophylactic surgery due to diminished anxiety and distress (Bleiker et al., 2003; Brandberg et al., 2008; Etchegary et al., 2015; Finch et al., 2013; Frost et al., 2000; Kenen et al., 2007) and due to comfort in knowing that everything possible had been done to diminish risk and improve their future (Kenen et al., 2007).

Prophylactic Gastrectomy: Physician Case Reports

Currently, research specific to the patient population undergoing PTG mainly consists of outcomes research from physician case reports. These case reports have a biomedical focus and are intended for physician audiences, but they also offer several important findings. In the case reports on PTG, early abnormal gastric cancer cells were identified in the majority of gastrectomy specimens, ranging from 76.5% to 100% of cases within sample sizes of five to 23 patients (Chen et al., 2011; Haverkamp et al., 2015; Hebbard et al., 2009; Huntsman et al., 2001; Lynch et al., 2008). Surprisingly, early stage carcinoma was even identified in the gastrectomy specimen of a 16 year old, the youngest recorded patient to have PTG (Wickremeratne et al., 2014). Only two case reports were identified in which no evidence of early malignancy was identified in the gastrectomy specimen; these case reports involved one and two patients (Daunton et al., 2012; Li et al., 2013). With such a high rate of early gastric cell changes identified in

asymptomatic patients and with the corresponding uncertainty of which specimens would have developed into gastric cancer, support is demonstrated for early genetic testing and PTG (Huntsman et al., 2001). Further support for early PTG was demonstrated in the case reports by Chen et al. (2011) which provided detail on the clinical experience of 18 patients who had undergone PTG, 13 patients without symptoms and five patients with symptoms. The authors found that the prognosis of patients without symptoms is significantly better than patients with symptoms, with two-year survival rates of 100% versus 40% in the study sample.

The consensus on PTG from physician case reports is that it is the only potential cure for previously fatal familial gastric cancer (Chen et al., 2011; Cisco et al., 2008; Huntsman et al., 2001). However, selecting PTG continues to be described as a significant undertaking and a difficult decision to make (Fitzgerald et al., 2010; Lynch et al., 2008). A major concern of patients considering PTG is weighing their risk of gastric cancer against the potential consequences of surgery (Fitzgerald et al., 2010; Garland et al., 2011). However, physician case reports have consistently indicated great efficacy of PTG with a low incidence of morbidity (Chen et al., 2011; Daunton et al., 2012; Haverkamp et al., 2015; Hebbard et al., 2009; Huntsman et al., 2001; Lynch et al., 2008) and no morbidity reported in the case of the youngest patient to have undergone PTG (Wickremeratne et al., 2014). Furthermore, case reports involving a laparoscopic approach to PTG have demonstrated safety and efficacy with improved morbidity through less intraoperative blood loss, early return of bowel function, and shortened wound healing (Daunton et al., 2012; Haverkamp et al., 2015; Li et al., 2013). An additional

concern of patients considering PTG is the risk of mortality, which has been reported at <1% (Oliveira et al., 2015).

Quality of Life After Gastrectomy

Quality of life after gastrectomy has been a growing area of interest since the development of a validated instrument to measure quality of life in this patient population (Vickery et al., 2001). Currently, studies pertaining to quality of life after gastrectomy have been mostly conducted with patients with a diagnosis of gastric cancer, with only one study identified that investigated the quality of life of patients who have had PTG.

The diversity of symptoms associated with gastrectomy has been collectively referred to as “post-gastrectomy syndrome” (Tyrväinen, Sand, Sintonen, & Nordback, 2008). Several authors have emphasized that the post-operative symptoms after gastric surgery, although sometimes temporary, can have a major and debilitating impact on quality of life (Avery et al., 2010; Fitzgerald et al., 2010; Vickery et al., 2001). A review of the literature identified that both changed eating habits and weight loss affected the quality of life of post-gastrectomy patients (Garland et al., 2011; Tyrväinen et al., 2008). Although weight loss is a significant issue for post-gastrectomy patients, Tyrväinen et al. (2008) found that the issue diminishes in importance among long-term survivors of gastrectomy. Problematic symptoms affecting quality of life in the long term after gastrectomy were identified as issues with sleeping, eating, elimination, and distress (Tyrväinen et al., 2008). In addition, a cross-sectional quantitative study of 391 patients by Bae et al. (2006) revealed that demographic factors may also have a role in quality of life after gastric surgery. The study found that older patients report better role and emotional functioning and less pain, anxiety, and eating problems. The study also

revealed that men often fare better than women in relation to post-gastrectomy physical and role functioning (Bae et al., 2006). However, it should be noted that this study was conducted in Korea and reflects the experience of gastric cancer patients, thus findings may not be representative of the experiences of those undergoing PTG in NL, Canada, or in North America.

Despite the overwhelming evidence of the negative impact gastrectomy may have on quality of life, Avery et al. (2010) found that this negative impact is short-lived. According to Avery et al. (2010), the greatest reduction in quality of life occurs in the first three months, with an approximate return to baseline quality of life by six months post-gastrectomy. The negative impact on quality of life after gastrectomy may be mitigated through patient involvement in decision-making. Findings from a quantitative study by Kim et al. (2008) indicate that patient involvement in decision-making is associated with greater satisfaction with treatment, decreased depression, and better health status and quality of life among post-gastrectomy patients. The study was limited by a low response rate, and thus outcomes may have been different for non-responders. Finally, better quality-of-life outcomes are expected among PTG patients than patients with a gastric cancer diagnosis because most patients undergoing PTG are relatively young and healthy (Caldas et al., 1999; Chen et al., 2011).

Quality-of-life findings specific to the patient population choosing PTG are limited. However, one study by Worster et al. (2014) found that problematic symptoms impacting quality of life among patients having PTG were similar to the symptoms that were problematic for those undergoing gastrectomy for treatment purposes. Symptoms identified to be problematic in the life of the patient having PTG included diarrhea,

fatigue, discomfort with eating, reflux, and eating restrictions. The authors found that physical functioning returned to baseline levels at 12 months. The greatest psychosocial concern reported was a change in body image. Reductions in mental health functioning were also noted but were short-lived, with a return to baseline levels between three and nine months after PTG (Worster et al., 2014).

Prophylactic Gastrectomy: Qualitative Research

While there is much to be learned from physician case reports and quality-of-life studies, there continues to be a need for explicit research on the patient experience of PTG. Qualitative study of PTG is nearly non-existent, with a Canadian study by Garland et al. (2011) representing the first and only study, which could be identified, that investigated the lived experience of total gastrectomy. The study consisted of three participants: two individuals who had PTG and one who had a palliative gastrectomy. Findings from the study were organized into three qualitative themes: making the decision, treatment impact, and life after total gastrectomy. The theme *making the decision* involved negotiating risks and benefits, educating oneself, and being impacted by a life event. The theme *treatment impact* described body image changes, physical changes, and the reaction of others. Finally, the theme *life after total gastrectomy* described a slow and continued challenge to recovery that resulted in a changed perspective on life. While this study provided insight into the patient experience of PTG, it also represents the only qualitative evidence on the topic; therefore, findings are preliminary and further research is warranted. The study also provided a comparison between prophylactic and palliative patient experience. Patients undergoing PTG

represent a unique patient population; yet, the empirical literature remains devoid of the accounts of the experiences of this group.

Summary

A review of the literature revealed that little is known regarding the experience of patients at risk of HDGC undergoing PTG. However, the experience of patients undergoing prophylactic surgery for genetic risk of breast, ovarian, and colorectal cancer has been explored to varying degrees and provides the basis for understanding decision-making regarding genetic testing and prophylactic surgery as well as for understanding the outcomes of the surgery. Research specific to the experience of individuals undergoing PTG is extremely limited. Physician case reports are the most common form of research published in relation to PTG. These case reports provide evidence on the complications and the safety of the surgical procedure but fail to address how patients experience this life-altering surgery. Quality of life after gastrectomy has also been empirically explored, mainly among those with a cancer diagnosis; however, only one study that explored quality of life among patients undergoing PTG was identified. Quality-of-life research has much to add to understanding how patients experience gastrectomy; however, it is quantitative in nature and outcomes of surgery are frequently reported in terms of functional status or symptom impact. Thus, what cannot be gained through quality-of-life research is an open-ended exploration of the meaning of the surgery for the individual. Qualitative research has the benefit of adding a humanistic perspective. To date, only one qualitative study exploring PTG, in which both prophylactic and palliative patient experience was reported, could be identified.

Understanding the reality of having PTG due to the susceptibility of HDGC lends itself to a phenomenological method of inquiry.

Chapter 3: Methodology

Hermeneutic phenomenology was the methodology chosen for this research study. This chapter will explore the phenomenological method of inquiry described by van Manen (1990) and detail the methods used to examine the experiences of individuals who have had prophylactic total gastrectomy (PTG) to manage hereditary diffuse gastric cancer (HDGC) risk.

Phenomenology

Hermeneutic phenomenology was used to answer the research question, what is the patient experience of PTG as a means of managing HDGC risk? Phenomenological research has been broadly defined as the study of lived experience (van Manen, 1990). It aims to reveal meaning, to enrich our understanding of human experience, and to provide a unique perspective by bringing us closer to the reality of an experience rather than focusing on what we know of the experience (Flood, 2010; van Manen, 1990). Furthermore, hermeneutic phenomenology is interpretative, requiring an in-depth exploration of the structure and meaning of an experience, thus offering greater insight than mere description can (Flood, 2010; van Manen, 1990).

While various approaches to phenomenology exist, including those described by Colaizzi (1978), Giorgi (1985), and van Manen (1990) (as cited in Streubert & Carpenter, 2011), the goal of each method is to refrain from controlling, defining, or theorizing an experience and, alternately, to describe the experience holistically, as lived (Flood, 2010; Streubert & Carpenter, 2011). The phenomenological method as described by van Manen (1990) was chosen to guide this research study.

Van Manen (1990) described six research activities for conducting phenomenology; however, Streubert and Carpenter's (2011) succinct summary of van Manen's approach into four procedural steps best describes my use of it. These are reflective of the research activities described in van Manen's (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*.

The first step of van Manen's (1990) approach to phenomenology is orientating to the phenomenon. Van Manen described this step as "turning to the nature of lived experience," and it involves formulating the research question and explicating assumptions or pre-understandings (van Manen, 1990, p. 35).

Van Manen (1990) described identifying an interest in a phenomenon as the starting point to phenomenological research. In this study, I identified, or turned to, the experience of having PTG due to risk of HDGC as a research interest. My assumptions and pre-understandings of the experience of PTG were formed from the unique and somewhat limited perspective of a health-care provider. As a surgery nurse, I witnessed multiple PTG experiences: from a young adult receiving support from a parent who also had the procedure, to the patient who came to hospital well but struggled with post-operative complications, to the young parent who was in hospital for weeks, away from family for this preventative procedure. I questioned what it is like to know that you and your family are at such a great risk for stomach cancer and what it is like to undergo such an extensive surgery to improve your future. This study attempted to answer these questions and was the basis of formulating the research question, what is the patient experience of PTG as a means of managing HDGC risk? Based on this question, a literature review and a research proposal were completed. As an interpretive

phenomenological researcher one cannot separate or bracket what is already with one (van Manen, 1990, p. 47). As I had assumptions and pre-understandings of the phenomenon under investigation and did not want them to unduly influence the interpretation of the data, I wrote them down to bring them to the fore. I continually questioned my interpretation by asking myself, “Is this the experience, or is this this how I imagine it?” and “What assumptions are present in this text?”

The second procedural step identified by Streubert and Carpenter (2011) is to engage in existential investigation. Van Manen (1990) referred to this as “investigating experience as we live it” (p. 53). Exploring a phenomenon and gathering data are essential to this research phase. Van Manen identified various data sources including biographies, observations, artwork, and personal life stories gained through conversational interview.

Phenomenology is based on the premise that all we can know or understand must present itself to consciousness. Thus, if we are interested in a life experience that we, ourselves, have not lived, we must engage others in descriptions that bring us closer to the reality of the experience (van Manen, 1990, p. 62). To this end, I conducted semi-structured, conversational interviews. Informants were invited into a reflection on the reality and meaning of an experience as it occurred, what van Manen (1990) termed the “lifeworld” (p. 7). The bringing forth of the lifeworld to consciousness was communicated through lived experience descriptions. Consistent with van Manen’s method, these descriptive interviews were transcribed and represented the raw data on which I worked.

The third step is to engage in hermeneutic phenomenological reflection (Streubert & Carpenter, 2011). This step involves conducting thematic analysis and engaging in collaborative analysis. Van Manen (1990) asserted that we can only gain knowledge of the nature or essence of a human experience by first knowing the particulars of that experience. Phenomenology strives for precision and exactness by aiming for interpretive descriptions that are rich and complete and that get at the very meaning of the everyday life stories being addressed in the text (van Manen, 1990). Through examination of the unique and collective experiences contained in the lived experience descriptions, or the transcripts of each participant, the essence of having PTG to manage HDGC risk was brought forth. A detailed description of thematic analysis is included in the data analysis section of this chapter. Van Manen described collaborative analysis as a formal or informal process in which research themes are examined, articulated, re-interpreted, omitted, added, or re-formulated. Sharing the research text with an advisor was identified by van Manen as one manner of engaging in collaborative analysis and was the method used in this study.

The fourth and final procedural step described by Streubert and Carpenter (2011) is to engage in phenomenological writing. This stage involves creating a phenomenological text with varying examples through writing and re-writing. In this research step, findings from the research study were summarized and structured to share the experience of having PTG in a more meaningful way. The essence of the experience of having PTG due to genetic risk is presented in themes and subthemes that are supported with short interview excerpts. The complete phenomenological text is presented in the findings chapter.

Recruitment

Participants were recruited to the study based on their first-hand experience of having PTG due to a confirmed risk of HDGC. The target population consisted of men and women who had PTG and were available to be interviewed in the greater St. John's area. The ability to communicate in English was a mandatory criterion for participation.

The decision to participate in the study was voluntary and occurred by participant self-referral by contacting the researcher. There were no incentives or identified benefits for participation. Potential participants were informed of the study through various means, including information posters and letters of invitation. These explained the purpose of the study and the data collection strategies, and they provided the contact information of the researcher (see Appendix A and B).

During the first week of January 2014 I obtained approval from the Health Research Ethics Authority (HREA) and the Eastern Regional Health Authority (Eastern Health). Study posters along with research packages that included letters of invitation were delivered to the inpatient general surgery units and outpatient clinics at St. Clare's Mercy Hospital and the Health Sciences Centre in St. John's, NL, and Carbonear General Hospital, Carbonear, NL. Outpatient areas of hospitals throughout the Avalon Peninsula of Newfoundland were also provided with research posters and packages, including Placentia Health Centre, Placentia, NL; Dr. A. A. Wilkinson Memorial Health Centre, Old Perlican, NL; Dr. Walter Templeman Health Care Centre, Bell Island, NL; and Dr. Wm. H. Newhook Community Health Centre, Whitbourne, NL. The manager of each unit or outpatient clinic was contacted first by email and then by an in-person visit or by follow-up phone call. The purpose of the study and the inclusion criteria were explained

to the manager, and they were provided with a package that included research posters and letters of invitation. Each manager was asked to display the research poster and to have staff provide a letter of invitation to potential participants who inquire about the study. The Provincial Medical Genetics Program at the Dr. H. Bliss Murphy Cancer Centre was also provided with study materials at this time, including posters and research packages. The manager of the genetics program was asked if clerical staff in the department could mail letters of invitation to individuals who had been followed in the department for genetic counselling and who had opted to have PTG; letters and postage-paid envelopes were provided (see Appendix C).

Participant response was minimal after initial recruitment efforts. Thus, after one month an additional recruitment strategy was used: the research poster was distributed to all users of the Eastern Health internal email system. This recruitment strategy proved most effective as colleagues throughout the organization referred potential participants to the study. Snowball recruitment then occurred though initial participants wherein two participants provided others in their social network with study contact information, resulting in three participants joining the study by contacting the researcher.

There was no predetermined number of participants. Data was gathered using semi-structured interviews and analysis began after the first interview. Therefore, participant recruitment continued during initial data collection and analysis. Participants were recruited until both repetition and variation of themes were identified in interviews that had been transcribed or analyzed.

Description of Participants

A total of seven individuals who had previously undergone PTG were interviewed. All participants had previously participated in genetic testing and were identified as carriers of the CDH1 genetic mutation placing them at risk of HDGC. Five women and two men participated in the study. Five participants had PTG in the previous six to nine years and two participants had PTG in the previous two to five years. Participants' age at time of surgery ranged from 35 to 52. Marital status of all participants was married/common law and all participants had children.

Data Collection

Upon initially meeting each participant, I first introduced myself and provided a brief background of my career. I then proceeded to verbally review the study, including the purpose, the demographic sheet and the interview components as well as how findings would be reported, their ability to withdraw from the study, and the measures used to ensure confidentiality and anonymity. After verbal explanation of the study, participants were given the opportunity to ask questions, and consent was obtained using a written consent form (see Appendix D).

Before interviews began, participants were asked to fill out a short demographic profile consisting of five questions (see Appendix E). Demographic questions did not include any identifying information but addressed broad categories pertinent to understanding group characteristics and contextual factors in the experience of PTG. Participants were reminded to avoid placing their name or other identifying information on the demographic sheet.

One audio-taped semi-structured interview was conducted with each participant. A flexible interview guide that supported open dialogue was provided to each participant prior to beginning the interview (see Appendix F). Through review of the interview guide, participants were given an overview of the study, and I was able to conduct open, semi-structured interviews that provided rich detail of the personal experiences with PTG: from genetic risk to life since the surgery. All interviews were recorded and transcribed. During each interview I took notes in order to capture impressions and ideas about meaning to guide a deeper analysis of each participant's description.

Data collection occurred over a four-month period from January to April 2014. Interviews ranged from 21 to 50 minutes, with the average interview lasting 36 minutes. Length of each interview was completely dependent upon the amount and content of data revealed by the participant. Follow-up was arranged with participants to confirm study findings.

Setting

Each interview was conducted at a time and place convenient for the participant. All interviews were conducted in-person in the greater St. John's area. Interview location was determined by the participant and all locations were quiet and private with minimal distractions. Of the seven interviews, four were conducted at the participant's home, two were conducted at the participant's workplace office, and one was conducted in a conference room at my workplace.

Data Analysis

In phenomenological research, data analysis occurs during the data collection phase of the study. I began data analysis by first becoming familiar with the experiences

presented. Shortly after the completion of each interview I transcribed the audio interview data. Each transcript was reviewed and compared to audio data to ensure accuracy. Transcripts were then read thoroughly numerous times to become familiar with the data. Multiple readings of the data in its entirety was an important first step in the analysis process to become immersed in the data, to reflect on the experience as presented in each interview, and to grasp the meaning of the experience.

The next step in data analysis involved breaking the data down into more meaningful, interpretative pieces using the selective reading approach described by van Manen (1990, p. 94). During the first level of thematic analysis, descriptive statements or phrases essential to the experience were highlighted to determine what seemed particularly revealing in these statements or phrases (van Manen, 1990, p. 93). Furthermore, each of the highlighted statements and phrases were given short qualifying statements to capture the “geist” of the specific experience (Dilthey, 1976, as cited in van Manen, 1990, p. 3). Geist has been defined as the thoughts, consciousness, values, feelings, emotions, actions, and purposes contained in language (van Manen, 1990, p. 3).

During the second phase of thematic analysis, the short qualifying statements were reviewed and grouped to create themes within each interview. Van Manen (1990) described a theme as an aspect of an experience that gives it special significance, providing structure to the interpretation and reporting of lived experience. Interview notes were consulted and aspects of the experience that might be hidden were searched for, and the question, “What is it like for these individuals?” was repeatedly asked (van Manen, 1990). I considered whether the themes possessed that which made them essential to

making the experience of PTG what it was for the participants and would it lose its meaning if the theme was omitted.

The third step of thematic analysis required that themes within each interview were compared and contrasted across interviews to identify final, exhaustive themes that best described the reality of having PTG. During this step of the analysis I worked closely with my thesis supervisor. As themes developed, the meaning of the experience was understood in relation to the existential world through lived body, lived time, lived space, and in relation to others (van Manen, 1990, p. 101).

The creation of a textual description of the experience of PTG was the final step of data analysis. Van Manen (1990) described writing as a fundamental process in phenomenological research. Phenomenological researchers are challenged to create a narrative that explains the major themes identified while remaining true to the experience of each participant. Providing examples of several participant experiences creates transparency in the research process and allows one to connect with the deeper meaning of the experience of another (van Manen, 1990). Thus, the final product of this research study is a textual, interpretative description that consists of multiple interrelated themes supported with participant examples.

Ethical Considerations

Ethics review board approval.

Ethics approval was obtained from the HREA, the governing body for research conducted through Memorial University (see Appendix G), and from Eastern Health. Additional permission was also obtained from managers at each hospital site or unit used in participant recruitment.

Informed consent.

Individuals were interviewed once with consent obtained at the beginning of the interview. The written consent document developed for the study was based on the HREA standard consent template. The consent form included written explanation of the study purpose, the data collection methods, including the possibility of a second interview, the level of risk or potential benefit, the ability to withdraw at any time by stopping the interview, and the measures to ensure confidentiality and anonymity (see Appendix D). As the primary researcher, I verbally reviewed the content of the consent form and answered any questions regarding the study. Consent was obtained through signing the written consent form prior to commencing each interview.

Access to data.

Printed data or hard copies of the data obtained in the research process have been stored in a locked briefcase in my home. Data that has been entered into computer files has been stored on a password protected flash drive. Access to data was limited strictly to individuals directly involved in the research, including myself and my thesis committee. My thesis advisors and I adhered to the research standards of Memorial University, safeguarding the privacy, confidentiality, and anonymity of information obtained through the research process. After completion of the study, hard copies of transcripts, coded data, and the final report will be retained for a period of five years, as required by Memorial University. The stored data will not contain any personally identifying information on the participants.

Level of risk and interventions.

Participation in the research was of minimal risk to participants. The *Tri-Council Policy Statement* (2010) defines minimal risk as the equivalent likelihood and seriousness of harm existing in everyday life (p. 23). Difficult emotions in the recalling of events surrounding PTG was the only identified risk. Participants did display varying degrees of emotion throughout the interview process; however, no participant requested to stop an interview, and the use of pre-arranged mental health nurse services was not required.

Data quality.

Scientific rigour and data quality of this phenomenological study was assured by adhering to the criteria for trustworthiness as described by Streubert and Carpenter (2011, p. 406–407.). These criteria include fit, understanding, generality, and control.

Fit is described as the process of ensuring that the execution of the research study adequately represents the phenomenon of study and the method of inquiry (Streubert & Carpenter, 2011, p. 406). Ensuring methodological “fit” requires a persistent and conscious reorientation to the original research question throughout each phase of the research study. Regular consultation with an assigned thesis advisor during participant recruitment, data collection, data analysis, and reporting of findings ensured that I, as a novice researcher, had access to a methodological expert who assisted with methodological “fit” through consistent guidance, feedback, and continual assurance that methodological expectations were met.

The criteria of understanding requires demonstration of originality in data and logical explanation of findings that can be easily interpreted by others (Streubert & Carpenter, 2011, p. 406). According to van Manen (1990), data collection and data

analysis are not separate but joint processes that assist with understanding. The data quality principle of understanding was achieved by summarizing key points during participant interviews and seeking clarification. Three of the seven participants were also provided with the findings of the study to ensure accurate interpretation of the lived experience of PTG. The liberal use of quotes from participants were included to enable the reader to validate and establish the adequacy of the study.

Generality refers to the usefulness of findings to others (Streubert & Carpenter, 2011, 406). Through the selective reading approach described by van Manen (1990, p. 94), themes were identified and supported with statements from participant transcripts. It is hoped that the use of short quotations to support themes in the study report will assist readers to make connections between the research and their own work or life experience. Although my background is in nursing, study findings may also prove to be useful for individuals impacted by hereditary cancer risk, other health-care professionals, and special interest groups.

Control provides evidence of the work completed by the researcher and contributes clarity to the analysis process that would enable the study to be replicated (Streubert & Carpenter, 2011, p. 406). Control was demonstrated through documentation of interview transcripts and three levels of thematic analysis that illustrate how themes were extracted from interview data. I also made notes about my observations, documenting verbal and nonverbal cues as well as how I arrived at my interpretations so that my advisors or others replicating the study could follow my “decision trail” (Sandelowski, 1986).

Chapter 4: Findings

The findings of this study will be discussed as themes around which an interpretation of the data is presented. Interpretation of the data was carried out in accordance with van Manen's (1990) approach to phenomenology whereby all human beings experience the world existentially through lived space, lived body, lived time, and lived human relation. Furthermore, it must be noted that lived experience has a temporal structure; it cannot be grasped in its immediate but only reflectively as past experience (van Manen, 1990, p. 10). Therefore, the experiences of prophylactic total gastrectomy (PTG) were revealed as memories from when the participants became aware of their "at risk" status to the present time. The experience of having PTG is not a usual life experience; it is an intense and complex experience that penetrates all areas of life for those selecting the surgery. To fully grasp the experience of PTG it must be viewed holistically. The full experience of PTG is comprised of many separate yet interrelated experiences. Events leading up to PTG, the process of undergoing surgery, and the outcomes of PTG are all important parts of the whole experience; they cannot be completely separated and must be considered together. While it must be remembered that human experiences are always more complex than what is captured by writing alone (van Manen, 1990, p. 18), themes function to bring experiences closer to us.

Three substantive themes were identified from the data: (a) playing the hand you're dealt, (b) living a health-illness paradox, and (c) moving forward. Each substantive theme is comprised of subthemes that further enrich the meaning of the lived experience of PTG. Each of the themes and subthemes is described below, along with exemplifying quotes from the participants.

Playing the Hand You're Dealt

The participants' narratives all began with stories of life prior to PTG: a time when they first learned of their genetic risk. Being at risk for a hereditary cancer is a life situation in which one has no control; however, the participants in this study did exert control over how they chose to react to their risk. The narratives were stories of bravery, whereby they chose to face their risk head-on. However, to the participants, they were simply doing what they had to do. They were playing the hand they were dealt. *Playing the hand you're dealt* emerged as the first theme of the patient experience of having PTG for genetic risk of hereditary diffuse gastric cancer (HDGC). Subthemes included (a) being faced with difficult and far-reaching decisions and (b) preparing the mind and body.

The circumstance of "at risk" status for HDGC was "handed" to the seven individuals in the study. Participants initially learned of potential genetic risk in a variety of ways. Most learned of genetic risk through family history or experience. One participant's journey with PTG began when his sister was diagnosed with stomach cancer and subsequently died. Due to the high number of extended family members with stomach cancer, the participant's sister knew that something was not right, and she questioned the frequency of stomach cancer in the family. This initial question marked the starting point of the entire family's HDGC and PTG experience. He recalled, "It started with our family, my younger sister . . . she passed away when she was 40 years old. . . . She said to the doctor . . . there's something not right about this in our family, there is too many people dying with this disease." Another participant shared a similar story; for him, hereditary risk of cancer was brought to the fore by a cousin's diagnosis and their shared parental history of the same cancer.

My cousin, she got sick. . . . They discovered it was gastric cancer. So when she told the history of her mom and my dad, they were just after discovering . . . that there was a hereditary cancer. . . . She just passed the information on to us, me especially. She said, you know, your dad died of gastric cancer . . . there's a . . . chance that you got it.

As immediate and extended family members learned of hereditary risk they shared this information with each other.

My sister sent me some information. . . . [I] just sort of read it, didn't really pay much attention to it to be honest. . . . We talked about it some more and there was some research that was found and that was presented.

Once participants learned of potential risk for HDGC, they were then charged with the overwhelming responsibility of what to do about it. They had to make decisions about whether to have genetic testing, whether to use surveillance or surgical risk management, when to have surgery, and for women, how to manage the corresponding increased risk of breast cancer.

Being faced with difficult and far-reaching decisions.

From the existential-phenomenological perspective, the individuals in this study were in a situation that was imposed on him or her. Yet, they still had the freedom and responsibility to make choices within the situation and to actively control their own lives. Being "handed" the potential for genetic risk of stomach cancer resulted in a multitude of decisions that participants needed to make. Decisions were difficult and far-reaching; there were short-term decisions and long-term decisions that carried implications for them and their families.

The first decision in the PTG experience was choosing whether or not to undergo genetic testing. Participants varied in their desire to undergo genetic testing. Two individuals described feeling eager to know their genetic status. They saw genetic testing as an opportunity to take control and actively do something. “I was happy. . . that I could actually get something done . . . that they could test and see whether or not . . . I had this type of gene.” However, most participants expressed less certainty about undergoing genetic testing. For them the decision was influenced mainly by fear, perceived risk, and family.

The decision to undergo genetic testing can be very complex. The meaning of any experience is tied to the individual’s life world, influenced by individual and situational factors. For one woman not knowing was a defense mechanism, a way to protect herself from a harsh reality—a reality she was not prepared for. It was mentally easier not knowing her genetic status and to continue living life not having to deal with the fact that she might test positive.

If you don’t have the test then you don’t know. . . . So it’s easier to live in oblivion. . . . I might have been longer than most people. . . . Some people decided fairly early to have the test done. And I think those people are probably people who had siblings who had died.

The meaning of the decision to undergo genetic testing was quite often tied to participants’ “lived relation to the other” (van Manen, 1990, p. 104). They described how the fear stemming from watching family members die of stomach cancer caused them to be consumed with their own future morbidity and mortality. One participant, who did not want to die like her sibling, stated, “I . . . started to feel I was having stomach problems

myself. . . . I always found that I was scared, always felt that I might end up with it.”

Another who also observed suffering from stomach cancer within the extended family also feared what might happen if she were not tested. She stated, “A couple of the relatives didn’t have the test, chose not to. . . . And they got cancer . . . and they died. . . . So you don’t want to be one of them.” The risk to other family members was also an important aspect of the decision-making experience. The choice of whether or not to be tested for genetic cancer included “living toward a future” (van Manen, 1990, p. 104). The future was seen as already beginning to take shape. Choices were seen to have consequences—not only for themselves, but also for others. As one participant pointed out, “You can’t not [get tested], for me, I have children. . . . You have a responsibility to them to do that.”

Reactions to positive genetic status varied and a wide range of emotions were described including shock, fear, relief, and optimism. One participant described the shock of a positive test result, “I was really shocked that I had it. . . . It was like something hit me in the gut.” Despite the fact that she knew there was a chance she would test positive, it was difficult for her to acknowledge and accept this reality. She was happy and considered herself to be so lucky and blessed in life that she could not imagine something so bleak happening. Testing positive and learning of her genetic status soiled the fortunate, content life that she knew. Learning of her at risk status for hereditary cancer also meant reconsidering her life view: Life is not always good; bad things can happen to those with good lives. At that moment, the reality of the future did not look as bright and promising as it had before.

Within the range of emotions that were experienced, another participant described feeling simultaneous relief and fear: “She told me that I was positive. . . . There was . . . if it makes sense, almost like a relief . . . came over me . . . scared . . . of the unknown but a relief that at least I know.” This participant felt empowered by the positive test result. She could do something to mitigate her risk but not knowing what might transpire in the process was unnerving. Similarly, another woman felt optimistic regarding her positive genetic test result: “It was an opportunity. Knowledge is power.”

Still, for two participants playing the hand you’re dealt meant focusing on the practical implications of a positive genetic test result. Their minds automatically began calculating the steps ahead for themselves and/or their children. Being pragmatic was the focus of one participant’s reaction: “I wasn’t devastated, I wasn’t relieved that I knew, it was just, ‘Okay, if this is what it is . . .’ and I knew immediately that I was going to have the surgery.” For another participant the next step was to learn what impact her genetic status would have for her children: “My immediate reaction . . . was my two kids. . . . I knew that they would need to be tested.”

For some, the decision to have PTG came easily and was even described as a “no brainer.” Those that reported ease of surgical decision-making often decided upon surgery before a definitive genetic test result. One participant described the relative ease of the decision: “I pretty much knew . . . if I tested positive I was going to have it done.” Making the PTG decision was easier when it could be shared with a loved one. As one participant recollected,

I can't remember how long it took to get the results. . . . But I can remember when she told us [sisters] I knew . . . we both had our minds made up in that length of time that if we were positive then we were going to have surgery.

She further elaborated, "For us it was an easy decision, but you wouldn't believe how some are struggling with it." Others in the study did describe a greater struggle with the decision to have PTG. They felt that the decision was difficult and complex, they were uncertain regarding PTG and insulted that the term "no brainer" was used by others to describe the decision. Those who struggled with the decision to have PTG had difficulty accepting the necessity of such surgery and were skeptical: "I wasn't so convinced, to be honest with ya, because it is pretty dramatic. . . . [I was] healthy up to this point. . . . Why would I think it would change?" The participant further described a search for validation that it was okay to wait: "[I was] trying to find somebody, basically, who'd say, 'Just slow down, there's no, there's no rush.'" Similarly, another participant discussed the struggle and the skepticism experienced in PTG decision-making:

I thought they were crazy . . . to be honest. Because . . . they said "remove your stomach" and . . . at the time there wasn't a lot . . . only two or three done here on the island. . . . There wasn't a whole lot of research . . . [because] this was fairly new. . . . Everything they told me . . . nothing seemed good. Because they told me . . . I would lose weight . . . my quality of life probably wouldn't be as good . . . probably wouldn't be able to tolerate a lot of foods . . . could probably develop chronic diarrhea. . . . So everything seemed, nothing seemed good.

Skepticism for another participant resulted from a lack of immediate family affected by gastric cancer. She explained, "My mother died young of breast cancer . . .

but she didn't have stomach cancer. And no siblings had stomach cancer. . . . I think that's why you take a longer time deciding."

Those who were skeptical regarding PTG acknowledged the possibility of an unplanned and unfavourable outcome. "It's preventative. . . . It's a healthy individual going in and having a major organ removed, not knowing what's going to come out at the other end." Another participant shared this concern: "And it might mean that you're going to be miserable for the rest of your life. . . . We had some people who were very, very ill after surgery." Furthermore, those who expressed worry regarding the surgical procedure also went a step further to consider the risk of dying: "You know, so you go in, you might not come out."

Whether the decision to have PTG was viewed as quick and easy or lengthy and difficult, in the end, participants chose surgery for similar reasons. The primary reasons they chose PTG included perception of risk, fear, mistrust in screening, family, and health factors.

Participants' understanding of their genetic status and increased risk of HDGC impacted PTG decision-making. An apt description of playing the hand you're dealt was provided by one participant who related increased risk of HDGC to a game of chance:

And there's a 70 or 80 percent chance it was gonna happen, so you don't like those odds in any game. . . . You can only do what you know. What I knew was I had this particular gene; what I knew was there was a good chance it was gonna present.

Participants feared getting stomach cancer and dying of stomach cancer. Living in fear of getting HDGC was a thought that could not be escaped; it was as if they were

living under a dark cloud. The majority of participants described fear as a motivating factor in selecting PTG. It was a fear that, if they let it, could stop them from living life. One participant recalled, “you start to wake up in the middle of the night and think . . . ‘What if I got cancer now?’” Fear was echoed by another participant: “I use to say, ‘No, I have to do it.’ Because . . . if I got a pain in my stomach, I’d have myself worked into that [panic].” This woman overcame fear by believing, “we were told it for a reason.”

In addition to fear, the majority of individuals also described a lack of trust in screening methods as a factor in choosing PTG. Based on experience from within their own family and personal research, they did not believe that stomach cancer could be identified in a timely manner through endoscopic screening methods. One participant discussed, at length, mistrust in screening:

Even though the scopes were always negative . . . I always knew that the scopes were not always one hundred percent. . . . The scopes were a way to detect it. . . . You could have them and it not be able to be seen. . . . For me, that’s what scared me the most . . . every, you know, fear that, “Oh my God, they’re going to find something,” or “Oh my God, they’re not gonna find it.”

In several cases, endoscopic screening had been ineffective in the early detection of stomach cancer for a family member. Therefore, when it came to making the decision between PTG and endoscopic surveillance participants had little faith in surveillance and did not want to fall victim to family history repeating itself. As one individual recalled, “Dad had that [endoscopy] done in February. Of course it showed up nothing. . . . That November, he was diagnosed, stage three, nothing could be done.” For another, mistrust

in endoscopy was based on both family experience and perceived shortcomings of the procedure:

That's the only option that I had . . . get scoped every six months. . . . And from what I'd read of that, that was sort of useless. . . . I know of some people who got scoped and three months after they were dead. . . . You can go in, and you can take a spot and the cancer could be, you know, millimeters away, and you missed it, and then all of a sudden, six months after, it's too late.

Due to mistrust in endoscopic screening and genetic risk, another participant chose PTG because, in their words, "I don't feel I had a choice."

Family roles and family history also factored into PTG decision-making and reflected the far-reaching nature of the decision. The role of parent influenced several participants in their decision to have surgery. They wanted to be alive for their children and also realized that their children looked to them as role models. "It was really important that I was there for my daughter. . . . I wanted to be around for her." Another participant added, "I thought . . . 'What kind of behavior do I model?' You have to be what you want them to be. . . . You have to try to model those behaviors. . . . I don't know what I would've done. . . . If I didn't have children, it would have been a lot different."

Events encountered in the past stuck with the participants, influencing the present and their thoughts of the future. The difficult decision of choosing PTG reached into the roots of the participants' families. Family history of gastric cancer played a significant role in PTG decision-making. They reflected on the age of loved ones when they were diagnosed with stomach cancer or passed away, and they made connections with their own lives. "My mom died when she was 36. I know it was not relevant, but I'm thinking,

like, I'm almost that age. . . . I don't want that to happen to me." Likewise, another participant explained, "so many of our cousins in our gene pool have been diagnosed with full fledged cancer, before the age I was when I had my surgery. . . . We had a cousin who died . . . who was like late 30s." Yet another shared, "Dad died of cancer when he was 62 . . . his sister . . . when she was 31." The gastric cancer experiences of loved ones remained imprinted in their memories and influenced PTG decision-making.

I will say to you now . . . if my dad had not died and I had not seen him suffer, I might carry the gene, I might never have had the surgery. . . . He suffered. He was only a month from diagnosis to death. . . . I'd never want, I didn't want my family to see me like that. . . . I would rather die trying to prevent something than suffer like he did.

In choosing surgery, participants often validated the decision by believing that loved ones would have approved of or chosen PTG themselves: "I wish a million, million times over that my sister had that choice. . . . She would have picked it. She would have done it, no time. . . . She would have made her decision just the same as I did." Another echoed, "It always goes back to him [father] because . . . if it had been there for him, he would've had it done, day 1."

Health factors including physical symptoms, valuing prevention, and advice from the health-care team also impacted the PTG decision. For one participant, his own health and physical symptoms aided in decision-making: "At the time, I was having a little bit of trouble with my stomach. . . . I had *H. pylori*. . . . And [the doctor] . . . did tell me that . . . my stomach was inflamed." Another participant discussed the value placed on prevention: "If you could do something to prevent lung cancer . . . or any type of disease . . . you'd do

it.” Still others were influenced by advice from the health-care team. They trusted health professionals and wanted to follow their advice—not in a paternalistic manner but because they believed the team to be genuine and the suggestions to be in their best interest.

When you’re making up your mind and you’re listening to all these people [health-care professionals] . . . you need their honest opinion and they all gave it to me. That’s what I liked about all of them. They weren’t . . . they didn’t, like, sugar-coat it. . . . They told it like it was. And offered you their best piece of advice. And most all of them was to have it done.

Once the decision to have PTG was made, the difficult and far-reaching decisions continued: participants then had to decide when to have surgery. Those who described greater ease and certainty in decision-making were also more likely to prefer surgery as soon as possible. These individuals were more fearful of being at risk. As one woman recalled, “So [the doctor] gave me those results and [I said], ‘So when can I schedule my stomach surgery?’ , like immediately, like same sentence.” Conversely, those who described greater hesitancy and skepticism in PTG decision-making were also more comfortable with postponing the surgery. These individuals were less concerned about their at risk status and wanted to enjoy life in the present, leaving illness for later. “It took me a long time to have the surgery, mainly because . . . I was busy. . . . I had intended to forget about it for a while. . . . I was going to wait until I retired. . . . I didn’t want it interfering with my life.”

Despite having PTG, participants continued to have thoughts of cancer and faced difficult decisions regarding cancer screening. Women most often discussed thoughts of

cancer and cancer screening because CDH1 mutation is also associated with breast cancer. While participants continued to have thoughts of a legitimate risk of breast cancer, most were comfortable with the decision to adhere to screening regimens.

We're still at risk for breast cancer and I've been screened for that. And I'm comfortable with that because MRI . . . can pick up . . . something that a mammogram is not going to pick up . . . with breast cancer, knock on wood, don't want it. . . . But nevertheless . . . there's good preventative measures, more so than endoscopy [for stomach cancer].

For the CDH1-positive women in the study, breast cancer was the lesser of two evils; gastric cancer was of greater concern because they did not feel they could trust the screening tests and they associated gastric cancer with a greater risk of dying. Women in the study believed that breast cancer was easier to detect and was therefore a lesser threat.

Preparing the mind and body.

Being told you are at genetic risk of cancer and deciding to undertake drastic, life-altering surgery never happens at a good time. Part of playing the hand your dealt involved a sense of preparing the mind and body for such an enormous undertaking. As one participant stated, "Not only your mind but your body has to be in a state of preparedness." Participants prepared both mind and body for PTG in a variety of ways.

Preparing the mind for surgery involved talking with others and creating a positive mindset. In preparing for surgery, participants valued talking to others who would understand: "I think it is important that people talk to other people . . . who have had it [PTG]." Individuals also recalled physicians recommending talking with others who had the surgery preoperatively: "I did contact [the doctor] . . . and he put me onto a few

people that had had it [PTG] done.” Creating a positive mindset was also important in mentally preparing for surgery. As simply stated by one woman, “Mindset is all. . . . positive attitude. And go from there.” Yet another described personal methods of preparing one’s mind for surgery through “relaxation before and . . . meditation.” The participant also consulted self-help books: “I did some . . . reading . . . about coping, coping with pain and illness.” This individual elaborated on personal methods to create a positive mindset: “The least emotion I could feel the better. . . . I wanted as little fuss, I wanted calm . . . staying away from people who would upset me.”

Participants prepared the body for surgery by being active or gaining weight. Being physically fit was recognized as one aspect of preparing the body for surgery. “[I was] active, worked out. . . . I was in good shape.” Participants were advised preoperatively of the potential for significant weight loss. Thus, most prepared the body for surgery by gaining extra weight beforehand: “I did put on a little extra weight intentionally.”

Living a Health–Illness Paradox

During the interviews the participants told stories about their operation, their hospital stay and their recovery. Once the decision to have PTG was made and the operation was complete, they soon realized there was no turning back. Overall, participants were healthy individuals electing to have major prophylactic surgery. As a result, they experienced an abrupt change in their lives. They were dropped into a world of hospitals, tests, and doctor’s appointments; they were placed into a “sick” role, yet they were never actually sick. They were living a health–illness paradox. One participant provided a vivid description of this unique situation: “The next day it was like a truck ran

over ya. . . . You couldn't raise your head . . . can't sit up . . . it was so, you know, cause you were so healthy . . . not sick and then . . . this is smacked on you." *Living a health-illness paradox* emerged as the second theme of the patient experience of PTG for genetic risk of HDGC. Subthemes included (a) dealing with the symptoms every day, (b) learning to eat and drink again, (c) having coping strategies at hand, (d) experiencing a slimmer self, and (e) perceptions of interactions with the health care team.

Dealing with the symptoms every day.

Living a health-illness paradox meant that participants had to endure various physical symptoms after their prophylactic surgery. The actual number and severity of physical symptoms varied; however, participants felt sick—they were fatigued, nauseated, experienced dumping syndrome, and lost weight. They were forced into dealing with the symptoms every day.

Fatigue was the most frequent symptom discussed. Participants described their initial and ongoing struggles with fatigue. PTG is not an easy fix for HDGC; at times the surgery took all their energy. One woman shared the exhaustion she experienced after surgery whereby bedtime became a highly regarded and much anticipated time of day. "I use to go to bed 8 o'clock after my surgery, I'd take all my medication 8 o'clock, it was bedtime, and I couldn't wait for 8 o'clock to come." This change was new and in the absence of an ailment it was difficult for others to understand. "My daughter use to say, 'Dad, how come she sleeps so much?' . . . She's probably just up out of bed and I'd be here and I'd be dropping."

Just getting through an ordinary day became a struggle. Fatigue was experienced to the point that it impacted simple activities that others might take for granted. As one

participant recalled, “I can’t go to the bank and stand up if there’s a big lineup. . . . I can’t, my legs. I just can’t do it.” The consequences of fatigue were further illustrated by another:

A typical day in the hospital . . . I wanted to sleep. I want to sleep all the time . . . and I still want to sleep all the time. Always, always, tired. Always . . . I push myself every day to go to work. . . . I push myself to go to the mall, to get groceries.

The experience of such extreme and ongoing fatigue presented an obstacle to a physically active lifestyle. “I don’t exercise now. . . . I probably should. . . . I’m not motivated to exercise whatsoever.” For one person, physical activity was an important part of life that was impacted by PTG. However, with perseverance he was able to overcome the fatigue. At first the fatigue was discouraging, “I was running a lot before I had my surgery. . . . And by the time I got out of hospital . . . I couldn’t walk 10 minutes. . . . I was all in. . . . So that was hard.” Through identifying goals and targets, the limitations imposed by fatigue eventually improved: “What I started doing, some days trying to walk 10 minutes . . . Then I’d come home and I’d probably have to lie down for a couple of hours, then I’d walk 10 minutes again, then 10 minutes became 15 . . . 15 became 20.”

Overall, participants remained positive and persevered despite limitations imposed by fatigue: “You got to push [yourself] because if you give into it [fatigue] then it’s not going to work.” Another participant echoed, “I gets up and goes on . . . because if you sits down and gets thinking . . . and gets in that mindset, you’re bringing on a whole new set of problems.” She further explained, “You’ll never have the same energy . . . but you’re

functioning. . . . How many people are not? . . . And you got to look at it like that.”

Presented with threats to the human condition they made the conscious choice to persevere and oftentimes did so by looking at the positive.

The post-operative complication of nausea was another example of living a health–illness paradox. Nausea ranged in severity and was experienced both initially and years after surgery. Nausea was relentless initially and required much trial and error to find a solution.

I was nauseated for the first, I have to say, constant—six to seven months . . . couldn’t eat anything. . . . I’d urge and urge . . . And [the doctor] was really concerned about that. . . . We tried everything . . . and the only thing that really worked for me was Gravol. . . . That kind of settled it down.

Participants provided severe descriptions of nausea and personal ways to cope with the symptom. “If you’ve ever been seasick, that’s what it felt like . . . nauseous to no end . . . and you’d be like that for an hour. . . . I still get it every now and then, but now it’s like 20 minutes.” The participant learned to tolerate the nausea: “I know it’s gonna happen [nausea], so I just sit there and wait for the clock to tick to fifteen, twenty minutes and then it’s okay.” Likewise, another participant detailed, “there are certain things that . . . cause me to get . . . violently nauseous, you never throw up, however, you feel like you’re going to. . . . That’s all new since the surgery. And that, the nauseous feeling, happens every day.” She has also learned to cope with nausea:

It just takes me, like, lie down for a half hour, let the food go down, and then I can jump back up and go. . . . But I sometimes have to . . . put the pillow over my head. I’m out for like 45 minutes to an hour . . . can’t even think about

anything to eat. No food. Nothing. . . . But, you know, 45 minutes to an hour . . .

I'm up again.

Others had a limited experience of nausea after PTG.

I've had episodes [of nausea] but nothing worth talking about in the grand scheme of things in five and a half years. . . . Never thrown up . . . I think I did once . . . that's only because I ate too fast, that was kinda my own fault.

Dumping syndrome was another symptom that was experienced after PTG. For one woman the first dumping syndrome experience was unforgettable. She was scared, her family was scared, and they were unsure of what to do or how to handle this new symptom.

I had a lot of dumping. A lot of dumping . . . I remember one night . . . I was home from hospital and you don't really know . . . like, should I go to the hospital. . . . And my husband was frightened. My daughter was crying. . . . I was just shaking and I was throwing up and I just kept shaking and sweating and sweating and it was just really, really bad dumping.

Similarly, another participant's experience of dumping syndrome was so frequent and severe that it became a physical and psychological burden that impacted their view of the future.

The dumping was very severe . . . sharp pains. . . . You get this logy feeling, like you can't move. . . . You just get sweats, rapid heartbeat. . . . The first couple of months that was constant . . . a lot of things going through your mind . . . I didn't know if I could provide for my family. . . . At the time I thought this [severe dumping syndrome] was going to be for life.

In time, participants could occasionally identify causes of dumping syndrome including greasy foods and sweets. However, despite years since surgery, dumping syndrome continued to reinforce the health–illness paradox which they continued to live: “I can have something today, and this is really weird too, and . . . everybody says it, that have had it done . . . had that today, hmm, not bad, I could have that next week and, ‘Oh my God, I’m going to die!’”

Learning to eat and drink again.

The task of learning to eat and drink again further enforced the health–illness paradox participants were living. Participants were never diagnosed with gastric cancer, yet they faced some of the same challenges. They coped with difficulties eating, learning new eating strategies, and recalibrating their intake of alcohol.

The severity and length of eating difficulties varied between individuals. One participant provided a powerful description of the day-to-day eating difficulties initially experienced:

In the beginning, I can remember . . . this was my diet for the first six months . . . I’d get up in the morning . . . have a cup of tea and a cream cracker with butter . . . lunchtime I’d have a fruit cup. That was my lunch . . . then whatever [my husband] had for supper I would try. . . . It was just so hard. . . . Then, before I’d go to bed I’d try to have crackers. . . . They’re the one thing I can eat that don’t do me any harm.

Undergoing PTG meant lengthy eating difficulties and varying degrees of sickness for most participants. “It took me a long, long time . . . to be able to eat solid foods. I couldn’t even drink water . . . without struggling. . . . I struggled for a full year, eating

anything . . . I went through a full year of suffering.” Another participant described their struggle with eating.

Some of them compared . . . [eating] to, like, you’re starving to death but food brings you no pleasure. . . . And that must be bad. . . . I mean it got to be bad . . . when you have to eat out of necessity, not out of enjoyment. . . . That ought to . . . suck the fun right out of everything.

Eventually participants learned to adjust their diet. Similar to those undergoing gastrectomy for treatment purposes, participants were advised to eat smaller portions and more frequent meals. One participant described her eating habits when first home: “I use to try to eat every hour, every hour and a half for sure.” Similarly, another participant recalled having a rigid eating schedule, “I would eat every 2 hours. . . . I would eat 8, 10, 12—steady like that. . . . If I was in church, if it was my time to eat, I would haul out a sandwich and eat it.” Participants were also advised to avoid drinking fluids with meals. Some of them commented on this new approach to eating: “I met with a dietitian. . . . They were saying . . . don’t drink with your meals. . . . I did all that.” Another participant shared, “not drinking while you’re eating . . . that was hard adjusting to.” Recording dietary intake and calories was also recommended by the health-care team. “They said, ‘Keep a diary.’ And that’s how I learned. I kept a journal of everything that I ate and how it agreed with me or how it didn’t.”

In addition to following the recommendations from the health-care team, several of the participant’s also added vitamin and mineral supplements to their diet. They reported receiving little guidance from health-care professionals on which, if any, supplements were necessary. One participant started a vitamin and supplement regime

from her own research: “I take Materna because . . . it’s high in iron and vitamins, I take . . . vitamin D, calcium and B12 . . . but I don’t think there’s really any protocol, what to do after, you know. And not just for six months, but lifelong.” Another explained the confusing experience surrounding whether or not to supplement and the lack of clear direction from the health-care team on the matter: “No one had answers. . . . Like, the vitamins . . . I didn’t, I don’t even know to this day, if I [should take any vitamins]. . . . I talk to some people, they do. . . . Some people don’t.”

Over time, participants realized personal eating tactics that worked for them. One participant explained the importance of eating slowly, “You have to learn that, chewing, 50 times, and swallowing. A whole new way [of eating] . . . and after . . . years eating, you have a tendency to forget.” For another, eating foods that were cold seemed to help: “The one thing that worked with me was cold food. . . . I could have a sandwich or a salad or fruit or crackers but give me anything hot, oh my God, I’d die . . . I love everything ice cold.” Another participant spoke about prioritizing certain foods: “Protein is my biggest thing, make sure I get protein and iron, those are my . . . top-of-the-list things. . . . I’ll eat . . . my meat first, and then I’ll eat . . . vegetables . . . not a whole lot of carbs. . . . We have some problems with that.”

Even years after PTG, participants continued to face challenges with eating.

I, even now, I over eat, and I go, ‘Gee, you’d think I’d know by now’ . . . You think after six years I’d learn that I can’t eat . . . certain foods, right. . . . But it was so delicious . . . and so I ate it . . . and I was miserable . . . then I was crooked all night . . . mostly because I’m like, ‘How stupid for you to do.’

Participants also discussed the need to adjust alcohol consumption after PTG. They suggested that drinking alcohol is more complex than the physical ability to consume it. As one participant explained,

[People] figures that if [they] can physically put it inside of [them] then okay. . . .

You know, if I drink a dozen beer then I'm ok because I've been drinkin', it can go down but then [you will] feel really miserable.

Another discussed alcohol consumption after PTG: "It [alcohol] affects you differently . . . or quicker, I don't know if it's different . . . but I know that you do have to recalibrate your drinking." The participant elaborated on concerns related to alcohol consumption and the lack of attention given to it by the medical community:

I remember the first meetings that we went to with [the doctors who are familiar with HDGC and PTG] . . . people would always ask . . . 'What about drinking, will we be able to drink after this surgery?' . . . And it was a big ha ha. . . . It wasn't treated seriously, it was like . . . alcohol is like, Brussels sprouts, you know, maybe you'll be able to have it, maybe you won't, like chocolate . . . but it's not like chocolate. Right. The effects of over-drinking are a little different than eating too much chocolate. . . . I think it's a factor that deserves more attention. . . . We need to talk about it . . . include it in the conversation.

The participant had observed ill-effects of alcohol after PTG and suggested that the issue may be worthy of future research:

I would say that there are increased . . . issues with alcohol, post-op, with this surgery. . . . I would like to see a study done on that . . . If there's no research

done on it then it's hard to convince people that it's not just a . . . isolated incident. . . . But I feel strongly that it's not.

Having coping strategies at hand.

Having PTG in the absence of illness put participants in a unique situation that was difficult for others to understand. They had to deal not only with the physical consequences of surgery but also mental, psychosocial, and emotional consequences. Having coping strategies at hand was an important part of surviving the health–illness paradox. When discussing coping, the magnitude of the surgery and the effect on life became apparent. One participant stated, “[It’s] a big surgery. It’s not for everybody. . . . If you don’t think it’s for you, why would you get into something over your head, if you don’t think you’re able to cope with it.” Alternately, one participant discussed coping with PTG as if it were commonplace, “it’s . . . probably like anything else . . . you have something wrong with you, you just find ways to cope, to deal with it.” Participants in the study had readily available coping strategies, including relying on support from others, maintaining a sense of humor, and keeping positive.

One of the strongest supports available to the participants was their family. All praised the support that they received from family: “I would never, ever, ever, in a million years have been able to do it without the support of my husband and my family.” Similarly, another participant recalled, “I definitely had support from my immediate family. Other people thought I was crazy, but that’s fine.” Family members were a source of instrumental support for participants by tending to their physical needs. One woman found comfort in having her husband help after PTG: “My husband stayed with me. . . . He fed me . . . he was at my beck and call.”

For one participant, being among the last in the family to undergo PTG had a beneficial impact because he could depend on family for anticipatory guidance.

I think that was probably how I got through it. . . . My mother and my sister had had it done . . . and they came through. So that was . . . a positive thing for me.

At least I knew there was light at the end of the tunnel. Cuz I seen when they had their surgery . . . they struggled too, getting back on their feet. . . . Eventually things got better. . . . So at least I had that to look forward to, I knew that it's not going to be this bad all the friggin' time.

He further commented on the support and encouragement from family: "The family . . . that's the only thing that really kept us all going in the right direction, I think. . . . We all seem to know, the right thing to say at the right time." The support received from family served to reinforce family connections. Participants commented that PTG brought family closer together. One woman remembered talking with her brother during a time when both were recovering from PTG. As part of the conversation she recalled, "Just before I hung up the phone, I said, 'You know something, I love you.' He said, 'I love you too, sis.' And I don't know if I ever said that to him." Similarly, another participant explained how PTG brought both affected and unaffected family members closer: "The experience, I think, brought us all a lot closer, there's no question. My older sister . . . she was negative. But I think it even brought her closer because . . . she's got the other side of the story."

Support networks with others who had PTG were also an indispensable coping resource. One woman discussed the supportive relationships formed with others who had

PTG. People she met through having PTG were not only a source of support, they became a tight-knit extended family, forever linked by a mutual experience.

But the biggest support, I would have to say is from— the doctors were really, really good but, from others who had it done because they knew first hand, what I was describing . . . somebody that's been there, I think that that'll be what will help you the most. . . . All of them came to see me in the hospital and [someone] actually came to see me cuz she was waiting to have hers done . . . and that's how we met. . . . So that group of people are wonderful. . . . We'll be friends forever. . . . We all have such a . . . bond, I guess.

Another participant commented on how difficult it must have been to be among the first to undergo PTG without a local support network, "I pitied the people who had no support team, the first of the people who didn't know . . . people in Newfoundland that had it done."

Online support groups were also used as a coping strategy. One participant explained the supportive, collegial relationships formed through online support groups:

There's a group, No Stomach for Cancer. . . . There's a little chat line for anyone that was having problems. So I use to go in on that a lot . . . even getting on the group and just venting . . . you know, "Geez what a crummy day." You know someone's listening, like I know, I had days like that but it gets better.

While support from family and others who had PTG was a common and helpful experience, participants did acknowledge that the experience is individual. "There's worst-case scenario, there's best-case scenario . . . And everyone that you've interviewed, I'm sure they all has their own story. . . . Everyone is different. It's the same but

different.” Another participant recalled the difference in PTG experience between sisters: “Funny how we’re different but we’re alike. . . . We’re sisters, both with the gene, identical surgery but . . . her health and my health are completely different.”

Humor and making light of the PTG experience was also used as a coping method. Participants made light of many of the health–illness situations in which they found themselves, even joking about the genetic status itself: “[Our family are] all really musical. . . . I never got any of that . . . the only gene we got was the murky one that nobody wanted!” Participants also joked about their post-surgery symptoms. One woman made light of post-surgical weight loss and nausea: “You’ll need a new wardrobe . . . that’s one of the good perks of this . . . and when you get kind of sick after dinner, you get away from cleaning up after.” Another found a way to laugh through the burden that significant weight loss had caused: “I was going to put rocks in my shoes and everything before all that was over.”

Finally, staying positive was important in coping with PTG. Participants focused on moving forward despite adversity because they believed that, through PTG and recovery, wellness could be achieved. “I got in the mindset and said, ‘I’m doing this . . . for– save my life.’ And I think it did.” The participant elaborated: “You got to get in that mindset and you got to stay there. Everything is going to be alright, everything is going to be alright, and it do.”

Experiencing a slimmer self.

All participants had lost weight as a consequence of PTG. The new, slimmer self was an outward sign of the health–illness paradox they experienced. Weight loss affected individuals differently, impacting them not only physically but also requiring

reorganization and acceptance of a new self-image. Their familiarity with their body and their self-perception changed.

The pattern of weight loss and the total amount of weight lost was different for each participant. One individual recalled being very nonchalant regarding weight loss in the beginning but grew more concerned as weight loss exceeded expectations. “When I was in hospital I lost only about five pounds, so I’m kind of saying . . . I’m going to be the one who’s not going to lose the weight. . . . I got home and I was losing weight . . . a significant amount of weight.” Another participant recalled feeling taken aback by early and rapid weight loss: “Physically, I started losing a lot of weight. . . . Like, I knew I would lose weight . . . but it was just melting off me. . . . It was probably 25 or 30 pounds that first 35 days.” Still another recalled a concerning, gradual weight loss: “I lost 40, then 45, and then 50, then 55, 60. I said, ‘My God, I’m going away to nothing.’ . . . I ended up losing 63 pounds. Looking back at pictures now I was . . . sickly looking.”

A negative impact on self-image from weight loss was frequently reported: “My face is the worst. . . . You look slimmer in the face. . . . If you look at pictures I had more weight in my face . . . if I lose a pound or two . . . my mom will say you look sick looking.” Another participant commented, “I was gross. . . . I was looking all skinny and bony.”

Some participants related weight loss to illness and their new body weight served as an ever-present reminder of the health–illness paradox they were forced to live. One participant stated,

When I started getting the B12 injections with our public health and I use to be weighed and, like, you’re only after gaining three ounces in a month . . . that

really use to play up on me because in the back of my mind I use to say, “Okay, heaven forbid something with the breast.’ . . . And I said . . . would they do a surgery on me [at this weight]? . . . It played up on me for the longest while. . . . But I had to get over that because that was causing me grief. . . . So now I don’t know what I am . . . and if I goes to see [the doctor] and I has to get weighed I still do be there in fear . . . I wanted to get to [my ideal weight] . . . but, like, I’m never getting there . . . I goes to see [the doctor] and she says you’re the exact same weight you were last year. And I’m just grateful that I’m not after dropping.

In contrast, for some participants the slimmer self was accepted and they reported a favorable self-image. “Now I’m probably what a good weight would have been for me before.” Likewise, another participant stated, “the weight that I lost . . . I’m probably healthier now than before I went into the surgery . . . I was carrying more weight then.”

Perceptions of interactions with the health-care team.

Participants were required to have many consultations and interactions with professionals in the health-care system. They were well versed in the terms related to their condition and managed multiple interdepartmental tests and appointments.

First in their journey through the health-care system was the genetics department. All participants recalled a favorable experience with the genetics department. The team in the genetics department were praised for being organized, informative, and supportive. “The geneticist or . . . genetic researcher . . . the whole group was really wonderful . . . in terms of expertise.”

Some consultations with the health-care team during preparation for PTG were not perceived as helpful. However, several of the participants acknowledged that they underwent PTG at a time when the surgery was still new, resulting in a shared learning process for both the patient and the health-care team. For example,

I met with a dietician. . . . They were saying do this and do that but I don't think that no one really knew. . . . She was giving me information that I found it was . . . not helpful . . . you know, nothing to them . . . but I don't think no one knew.

Participants also recalled consultation with a psychologist prior to surgery, however, this was also perceived as minimally helpful.

I did see a psychologist beforehand. She was alright. . . . It was almost like you'd see on TV. I felt, it was kind of like, 'So how do you feel about that?' I'm kind of going, like, 'Oh my God, are you kidding me?'

Participants also acknowledged the role of nurses in their experience of PTG.

While nurses were appreciated, they were most often mentioned in the context of tasks they performed. Several examples of the direct-care role of the nurse were provided. Most prominently, nurses were remembered for pushing participants to get out of bed and ambulate in the early post-operative period. "[The nurses] wanted me to get up and move." Another participant echoed, "The nurses were trying to get me up and sit up and stuff like that." Nurses were also tuned into changes in vital signs: "I always had a problem with blood pressure. They [nurses] were a bit more concerned about it than I was." Participants felt that they received the care they needed from nurses. "When I came back after my surgery, when I needed the care I got it . . . and then of course, when you starts to get better . . . you're not going to see a nurse every 10 minutes." This participant

noticed the heavy workload on frontline nursing staff and felt that workload sometimes limited the quality of care they could provide.

I had nurses who were— that floor, as you know, busy, busy, busy . . . nurses who were worked to death . . . But I really didn't have a bad experience. There were times I had pain and you might ask for pain relief and you mightn't get it for two hours . . . but apart from that [the care was good].

Overall, participants reported a favourable relationship with nurses. "The nurses I had were so good, they knew exactly what to do."

Family doctors also played an important role in the PTG experience. Most participants reported having a positive relationship with their family doctor. They were pleased with their family doctors when they perceived them to be interested in the genetic condition, open to collaborating with them, and attentive to their needs.

I have a fabulous family doctor too and I attribute a lot of my post-op to him . . . because . . . when I got the news, that I had the gene, [my family doctor] was . . . right intrigued by it. . . . Everything I could find out he wanted to know. . . . So everything that I got [from the genetic research team] was forwarded to him. He read about it. . . . He's so good like that.

Alternately, having a family doctor who was dismissive of concerns after PTG was described as a more negative experience: "Even my family doctor, I didn't find very . . . not that he wasn't helpful but . . . I remember going to him, shortly after . . . and . . . I just didn't feel well . . . the only thing I kinda got from him was, 'Geez, you know, you look pretty good.'"

Relationships formed with the surgeon were also perceived as helpful. Participants had confidence and absolute trust in their surgeons. “You trust your doctors, and I did, I trusted [the surgeon].” Another stated, “[The surgeon] was excellent. . . . He’s right up there. . . . I knew I was in good hands.” Participants described surgeons as attentive: “He was back and forth every single day.” They believed the surgeons were knowledgeable: “The way that [the surgeon] spoke to us and the information— how she provided the information to us was . . . top-notch.” Surgeons were also a source of reassurance: “They [surgeons] knew what I was going through and they knew what the next step would be, so at least I knew . . . there wasn’t anything . . . they couldn’t deal with.” Similarly, another participant shared, “I kept asking [the surgeon] every day, ‘Am I as good as I’m supposed to be at day 2?’ . . . And so long as he was saying . . . ‘Yes, you’re good.’” Yet another reflected positively on the compassion shown to her by the surgeon: “[The surgeon] sat down next to me . . . said, I got your results back . . . there was extensive cancer in your stomach . . . I started to bawl . . . [the surgeon] patted my hand . . . put an arm around me.”

Finally, follow-up after PTG was one area in which participants reported a negative perception of the health-care team. They felt that there were no standard follow-up protocols and some participants were unable to find answers to their questions.

I don’t think there’s really any protocol, what to do after, you know. And not just for six months, but lifelong . . . for the rest of my life I’m not going to have a stomach, so all these things can happen. . . . [my doctor] was like, ‘Okay, well we’ll do it [blood work] every two years . . . just to . . . keep on track.’ But

nobody is telling . . . my brother that . . . there's no protocol in what you should be doing. . . . I believe that there should be something like that.

Another participant described lack of follow-up and a feeling of disconnect following PTG:

Health care was . . . I can't say nothing bad, I guess, but . . . I don't think no one really understood . . . When I first met with 'em . . . [they] said we'll have people you could call upon . . . but there wasn't really . . . because I know at first, I have a thyroid problem and at first . . . I couldn't get my thyroid regulated . . . and then I was asking questions like, "Is it because I have no stomach that the pills are not getting absorbed right?" . . . And no one could seem to answer that. . . . I don't find that I get good follow-up. . . . It would have been nice if they had . . . say, pick up the phone. . . . No one had any answers.

An additional participant discussed improvements that are needed to follow-up care. "Yes, we need people to do the surgery but we also need them to follow up with their family doctors. . . . This should be checked. That should be checked because that's not happening." Speaking in relation to the care provided to a family member, one participant believed health care after PTG could be improved by a more coordinated team approach.

We met with all [the health-care team] prior to the surgery. . . . [My family member] didn't have any of that. . . . You're lost. . . . You have a surgeon that goes in and does your surgery . . . you're cared for in the hospital and you're sent off. . . . I never fell between the cracks. . . . I had these focus of people, were

surrounding me from the time I found out I had it [CDH1 mutation] and decided to have it [PTG] done, right up until I was completed. . . . That's lost.

Moving Forward

The participants' narratives concluded by reflecting on how life has changed since having PTG. Due to the life-altering impact of PTG, there was no definite end to the experience. However, eventually individuals who had PTG were able to move forward. *Moving forward* was the third and final theme revealed in the exploration of the patient experience of having PTG. Subthemes included (a) the new normal, (b) seeking affirmation that PTG was the right thing to do, and (c) paying it forward.

The new normal.

The struggles of the initial recovery period went on for quite some time but eventually things got better and participants could see their way forward. They described feeling better and being able to move forward once they reached a new normal. Reaching a new normal was achieved when participants recovered from surgery, had fewer or less bothersome symptoms, and no longer dwelled on their genetic risk of gastric cancer or their risk-reducing surgery. The new normal was, in its own right, a form of self-actualization, a sense of mastery over illness. As one woman stated, "It's a new normal that we end up, kind of, living. I think it takes a solid year before you are like—okay." Moving forward after reaching a new normal was summarized well by one participant:

The further you get along, the less you really think about it. . . . You know, it's done. . . . You can't really . . . change anything. . . . I think you get a new normal. . . . You will never be the same. . . . You'll never be exactly the same. . . . It's different . . . I don't think I suffer or anything. . . . I'm to a point now . . .

like at first I was, on the Internet trying to research and look for articles and read and read and read and I contacted this one and that one but . . . it's behind me now . . . you know. I can function, I guess normally. . . . It took me, I'd say, a full year, a year and a half . . . almost two years I guess, to get some what you call normal. . . . Well, it's not a normal . . . it's a new normal.

Seeking affirmation that PTG was the right thing to do.

In the process of moving forward participants discussed different sources in seeking affirmation that PTG was the right thing to do. At the time of this study participants had PTG two to nine years ago and had reached a time in their PTG experience where they were better able to reflect objectively on their total experience. These reflections became a part of the process of moving forward.

Perhaps the greatest struggle in seeking affirmation that PTG was the right thing to do was mentally evaluating the what-ifs. Several participants were left wondering what life might have been like without PTG. One participant pondered,

I'm not sorry I had it. . . . I would do the same thing again. . . . I don't think I was stupid to be so cautious . . . [but] we still don't know what the consequences are . . . in the long term . . . the quality of my life, how does it compare with if I didn't have it, who knows? . . . Maybe I'd be dead and maybe I'd be . . . top of the world. I don't know, there's no way to know. . . . I am healthy. . . . But I don't know . . . I really don't know the difference.

This simultaneous incertitude and acceptance was experienced by others: "If I didn't have it done . . . I could be . . . I could be gone now, who knows . . . or I could've lived to be 90, I don't know." Another participant acknowledged, "In the long run . . . I'm glad . . . I

did it now. . . . But I went through a couple of years of not being too sure it was the right thing to do. . . . I just go through life believing now that the odds were good I was gonna get this. . . . So now I'm not."

To some, a pathology report that was positive for precancerous changes resolved some of the what-ifs and provided affirmation: "I'd say, five years later . . . with having seven spots and how aggressively it grows we probably wouldn't be here now." Another described the validation that resulted from the final histology report: "I figures that if I had waited . . . I would've had the cancer. Because when my pathology came back . . . I did have beginning cells." However, this was not the case for everyone. Some found little solace in histology results.

My stomach was taken and . . . samples taken and sent and I said I don't want to know . . . if I have any yet to present. . . . I don't need to know, why do I need to know? . . . The stomach's gone now, I don't need to know that. . . . What's knowing going to do? . . . Just because it wasn't there then doesn't mean that it's not gonna be there next, wouldn't be there next year, or the year after, or the year after that.

In seeking affirmation that PTG was the right thing to do, the majority of participants expressed hope in their health and future by having the surgery. A new and favorable perspective on body and health was expressed by several participants: "I'm wonderful. . . . I'm healthier than I was prior to the surgery." Another described a greater awareness of one's body and feeling empowered in moving forward: "You know, through all of it . . . that's one of the things that I think I know . . . and [the doctor] would say this every time we see each other . . . you know your body so well." Likewise, another voiced

a greater respect for health and life after PTG: “You don’t want to do things that are unhealthy because you’re so lucky you have your health. And you’re lucky to be here. So, I think you appreciate life a little bit more.”

Overall, individuals in this study reflected positively on the benefits of surgery and did not regret choosing PTG. A sense of optimism was inherent in participants’ statements: “If there’s a bonus and I think there is . . . I know I can never get stomach cancer.” This sentiment was repeated by others: “Do I feel like I have gained anything? Oh, my life! Absolutely . . . I feel that I was given a gift. I was given the gift of choice.” Another participant reflected positively on PTG in this manner: “If all cancers you could do that [have prophylactic surgery] there’d be so much less sadness and hardship for families.”

Paying it forward.

Now that their surgery was complete and they were able to move forward, participants’ thoughts shifted to their children and how their experience could be of benefit to those who might have PTG. They had conquered PTG and now wanted to pay it forward to the next generation and to the research community.

All of the participants had children and expressed concern for the next generation as they moved forward in their PTG experience. “The thing I think about most now is . . . my son’s situation . . . cuz for me it’s done.” Worries regarding the unknown genetic status of children were echoed by other participants: “My thing now is my kids might have it, that’s in the back of my mind . . . and they’ll get tested when the time comes. . . . But I’ll pray to God that they don’t [test positive for genetic mutation].”

Participants discussed the genetic testing decisions of their children. Choosing the timing of genetic testing was often associated with life milestones that included finishing university, getting married, and having children. For one participant, concern regarding genetic status had shifted to heartbreak. “That was a bigger regret for me, when [my daughter] was tested and found out that she carried the gene. My hope was that it had stopped at me. . . . It hurt me more that day that she carried it.”

Participants were uncertain regarding the option of PTG for their children: “I don’t want [my child] to go through what I went through.” They had hope that through research their children would have more time and more options. Paying it forward meant participating in research and holding hope that their children and others would reap the benefits of such research. One participant stated, “I’m hoping . . . that maybe they’ll [researchers] find a way if not to cure it, to slow it down, so that [my child] . . . can get to 48 before he has to decide [regarding PTG].” Another related, “This is eight years now [since my own PTG]. . . . I know eight years is not a long time in research but . . . back then they just discovered the gene . . . so I’m sort of hoping that it’ll be a little further along [for their children’s generation].” Participants also discussed the desired benefits of genetic research: “Hopefully . . . through their studies . . . they’ll find a pill that they can give somebody and say, ‘Okay, you can take this,’ and it would be the same effect as what a prophylactic gastrectomy is.” Another wished that “they’ll be able to come up with a better screening . . . cuz it [PTG] is drastic.”

While acknowledging that advancements in genetic research are needed, participants believed that they had benefited from the genetic research and were happy to be able to pay it forward to the research community. “You know, you got to be grateful . .

. somebody took the time . . . investigating. Genetic research, I'd do anything to help them . . . only because somebody chose to look into it. I always say, that's why we're alive today.”

Essence: Choosing to Be a Previvor

The study of the experiences of individuals at risk of hereditary cancer remains a new and evolving area of health research. To date, breast cancer has been the most widely studied form of hereditary cancer. In the literature on hereditary breast cancer, the term *previvor* has been applied to unaffected carriers who have selected prophylactic mastectomy (PM) (Hoskins & Werner-Lin, 2013) or regular surveillance (Mahon, 2014). The term previvor was developed and promoted by the group FORCE (Facing Our Risk of Cancer Empowered) (Friedman, 2008). The term has a positive connotation and reflects the self-advocacy and proactive treatment decisions of those faced with hereditary cancer. Broadly, a previvor is an individual who is a survivor of a predisposition to cancer (Friedman, 2008). While the term previvor originated among those at risk of hereditary breast cancer, it also applies to individuals at risk of HDGC. *Choosing to be a previvor* is the common thread that binds the experiences of the study participants individually and as a whole, and it forms the essence of the experience of having PTG.

Ultimately, life is about choices. The participants in the study decided to make a choice—to take a chance and to actively do something to mitigate their risk of cancer. Being confronted with the knowledge of an increased risk of HDGC represented a crossroads in their lives; only the participants could determine the path forward. They were given the opportunity to mold their future, and their fate rested with them. Choosing PTG provided a sense of security for the future. The participants did not know what the

end result would be, but for them doing something was better than doing nothing. It was not an easy choice; each theme and subtheme described represented a decision, consequence, interaction, or outcome that occurred in the experience of having PTG. Their bodies and lives were forever changed. However, by choosing PTG they were choosing something bigger, they were choosing to be a previvor and to re-write the gastric cancer story of their family.

Summary

Through thematic analysis of participant interviews, the findings of this study unveiled the meaning of a specific life experience: undergoing PTG due to confirmed risk of HDGC. Phenomenological inquiry allows one to be brought closer to the lifeworld, or lived experience, of another. Thus, phenomenological nursing research allows us as nurses and health-care providers to identify with the experiences of those who form the basis of our practice—the patient. Through the present research study one is better able to grasp the feelings, actions, and meaning within the experience of having PTG. In the phenomenological text presented in the findings, the participants allowed the reader to join in the PTG experience in its fullness. Three phenomenological themes were used to frame the lived experience of PTG. First, playing the hand you're dealt spoke to the unpredicted presentation of genetic status in the participants' lives and the difficult and far-reaching decisions and efforts to prepare the mind and body that followed. The second phenomenological theme, living a health–illness paradox, was used to describe the challenging and ironic situations in which the participants found themselves. Dealing with the symptoms every day, learning to eat and drink again, having coping strategies at hand, experiencing a slimmer self, and perceptions of interactions with the health-care team

were subthemes that highlighted the paradoxical PTG situation. The third and final theme, moving forward, captured the transformation that occurred in participants through having lived the PTG experience. Moving forward involved the new normal, seeking affirmation that PTG was the right thing to do, and paying it forward. Collectively, the three phenomenological themes form the essence of the patient experience of PTG—choosing to be a previvor. The participants chose to persevere in the face of an adverse and potentially fatal hereditary cancer syndrome, HDGC. However, when the participants chose PTG they were not fully aware of what that would mean for their bodies and lives, but they did know they were choosing something bigger—they were choosing life; they were choosing to previve.

Chapter 5: Discussion

Consistent with the study findings, the following discussion will expand on the three substantive themes identified: (a) playing the hand you're dealt, (b) living a health-illness paradox, and (c) moving forward.

The experience of prophylactic total gastrectomy (PTG) is more than the process of undergoing and recovering from major surgery; it is a solution to an existential quandary. People who choose PTG are faced with questions of life and death. They are forced to confront the reality that one's existence has a defined beginning and end. In choosing PTG, individuals are given an opportunity to re-write their future and to change the preconceived ending implicated by hereditary diffuse gastric cancer (HDGC). At the very root of the PTG journey, one is forced to consider the meaning and value of life. Phenomenology was a well-suited research method to explore the PTG experience within an existential framework. According to van Manen (1990), the lifeworld, or the world as it is presented before thought or reflection, is comprised of four existential pillars: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality). The following interpretation and discussion of the lived experience of PTG is grounded in these four existentials.

Playing the Hand You're Dealt

The first theme of the lived experience of PTG was *playing the hand you're dealt*. Within this theme participants described the short-term and long-term decisions surrounding PTG and the actions they engaged in prior to having surgery.

The first experience in playing the hand you're dealt was the realization that they were at potential risk of HDGC. This realization occurred relationally, through their

interactions and relationships with others. Participants either questioned the history of gastric cancer within the family or were informed of potential risk by a sibling or relative who had already undergone predictive genetic testing. In studies investigating hereditary illness, the first in the family to undergo genetic testing are charged with the role of being the “discloser,” the means by which other family members learn of the hereditary condition (Bleiker, Hahn, & Aaronson, 2003; Hamilton, Bowers, & Williams, 2005). In the current study, none of the participants were the discloser within the family. Potential risk was disclosed by other family members, which initiated “illness talk” within the family. Such illness talk sparked self-reflection within the participants and they began to consider what a diagnosis of HDGC would mean in the context of their own lives. Participants thought about what they valued most in life. They thought about their spouses, children, careers, and future. They were shocked and perturbed to know that all of that could be potentially taken away. The potential that something serious was happening within their body was acutely realized. Feelings of shock and acute awareness of impending changes in one’s life and body were also experienced by BRCA positive women. In a qualitative study by Underhill and Dickerson (2011) women used words such as eye-opening and shocking to describe their newly discovered risk status (p.690).

Potential risk of HDGC was felt in every part of their being—corporally, spatially, temporally, and relationally—which ultimately led them to seek genetic testing. The initial realization of potential genetic risk was felt spatially: hearing the news of their genetic status suddenly made their world feel smaller. Instantly, what was important in life came sharply into focus; their life, health, and family was all that mattered. Participants realized their lives were coming to a crossroads: there was their potential

diagnosis, their future, and their person. In hermeneutic phenomenology the person is viewed as “being in the world,” which includes the ways in which people describe themselves, such as a “woman,” “man,” “parent,” “child,” “sister,” “brother,” or “professional” (van Manen, 1990, p. 105). Participants considered who they were in the context of their possible illness. Participants discussed their professional roles including their plans to retire as well as their parental roles, including the desire to be alive for their children. Women at hereditary risk of breast cancer also defined themselves through family and work experiences and sought to maintain health to continue their purpose in life (Underhill et al., 2012). Likewise, participants in the current study considered questions of life purpose in their risk management decisions. Participants considered if their life would be cut short. Would they see their plans for life through? Would they see their children grow? Would they have to endure the suffering they witnessed among family? These fears weighed heavily upon the genetic testing decision. Fear and family relationships have been shown to motivate individuals to seek genetic testing (McCann et al., 2009; Underhill et al., 2012; Underhill & Dickerson, 2011).

At the very root of the genetic testing decision was the participants’ need for answers to the existential questions that troubled them. Their unknown genetic status was an uncertainty that clouded the future; participants could no longer picture what the future may hold. The plans they held for the future were overshadowed with images of illness and possible death. Participants realized they were losing control; however, through genetic testing they could write their future and change the ending implied in HDGC. Participants had the freedom and ability to make a choice: to undergo genetic testing and make certain what may be happening within them.

All participants within the study harboured a CDH1 genetic mutation. Playing the hand you're dealt also meant that participants had to confront the reality of their fears being confirmed—that their potential risk was actually a legitimate risk. This was sobering news for all participants. It was not what they had hoped to hear. The process of genetic testing and knowledge of at-risk status can be a source of distress for some individuals undergoing genetic testing (Hirschberg et al., 2015). However, distress after genetic testing has been described as short-lived, decreasing throughout the first year and often fails to reach a clinically significant level (Braithwaite et al., 2006; Heshka et al., 2008; Hirschberg et al., 2015; van Oostrom et al., 2003). A systematic review by Broadstock et al., 2000 further concluded that distress after genetic testing decreased for both carriers and non-carriers; however, the decrease in distress was greater and more rapid among non-carriers. While the news was shocking to participants within the study, none of them experienced distress. After the initial shock participants began to accept the news, to them, at least there was an answer and they knew with certainty what they were dealing with. There was power in knowledge and that was the silver lining in the dreaded news. Individuals undergoing genetic testing need time to absorb the information (Seymour et al., 2010; Etchegary et al., 2015).

Temporally, participants knew they had to make a plan. Underhill et al. (2012) reported that once hereditary risk of cancer was known individuals felt driven to do something (p. 498). For some participants, the plan was to forget about their genetic status for a while. But for most, the plan was to take action, to decide upon surgery.

All participants within the study ultimately decided to have PTG to manage their HDGC risk. The greatest variation among participants was in relation to the existential

pillar of temporality. Variation in the immediacy of PTG was also reported in the case report by Lynch et al. (2008). The group was divided between those who sensed an immediate threat to their lives and those who felt that it was okay to wait. Participants who planned to put off having PTG wanted to enjoy life in the present and to deal with their genetic status later. These participants were worried more about the potential outcomes of surgery: Would they suffer? Would they be able to function after? Would they die? Alternately, those who sensed a more immediate threat preferred surgery sooner; the possibility of getting HDGC was a greater concern than the potential outcomes of surgery. These findings corroborate those of Garland et al. (2011) who found the immediacy of surgery was related to the perception of risk.

Either immediately or in time, participants' known genetic status created an uncomfortable space in their lives. The risk of developing HDGC began to invade their thoughts, it began to consume them and to take up their time and energy. Participants feared getting stomach cancer and they did not believe surveillance methods were sensitive enough to find the cancer early. Mistrust in surveillance testing was also identified in PTG physician case reports (Huntsman et al., 2001; Lynch et al., 2008). For one participant, physical symptoms, including a diagnosis of *H. pylori*, contributed to the fear of developing gastric cancer and led to the PTG decision. The presence of health issues has been shown in other studies to impact prophylactic surgery decision-making (Frost et al., 2000; Huntsman et al., 2001; Lynch et al., 2008; McQuirter, Castiglia, Loiselle, & Wong, 2010).

In the current study, the participants' relationships with others had the greatest impact on the PTG decision. In a qualitative study by Etchegary & Fowler (2008),

relational responsibility, or participant's obligations to others, was also identified as a key factor in genetic testing and risk management decisions. Participants thought of their children; they wanted to see their children grow up, and they wanted to be there for them. Participants' thoughts also drew to their family members who had cancer. Individuals at risk of hereditary illness have been shown to draw conclusions about their own future through comparison with family experiences (McQuirter et al., 2010). In the phenomenological study by Underhill et al. (2012) women at risk of breast cancer frequently compared themselves to family and feared they were "heading down the same path." The authors concluded that comparison to previous family experience can have a greater impact on self-care and experience than risk information from health care providers. Participants often related their age at the time of PTG to the age of a loved one's diagnosis or death. In making the PTG decision, participants grieved for their loved ones, they wished the option had been presented to them, and they believed that their loved one would have chosen PTG also. Alternately, when individuals lack family members affected by the hereditary condition, the decision to have prophylactic surgery becomes more difficult (Lynch et al., 2008). Participants who did not have a family member affected by HDGC perceived risk to be less and felt they had ample time. Relationships with the health-care team also impacted the PTG decision with participants recalling, as consistent with established guidelines (Fitzgerald et al., 2010; van der Post et al., 2015), the health-care team recommending PTG.

Once the decision to have PTG was made, participants then began to prepare themselves. Participants had to decide on the timing of surgery and had to create a space for surgery and recovery in their life. Participants prepared their minds and bodies for

PTG. Participants gained weight and focused on physical fitness to prepare their bodies for PTG. Preparing the mind was more difficult. How could one be calm when they could not be sure of the outcome of the surgery? Creating calm in the face of adversity required mindfulness. Mindfulness is a well-studied concept in cognitive and behavioural therapy. Mindfulness is defined as intentionally paying attention to present-moment experience (physical sensations, perceptions, affective states, thoughts, and imagery) in a nonjudgmental way and thereby cultivating a stable and nonreactive awareness (Grossman, Niemann, Schmidt, & Walach, 2004). The use of mindfulness has been shown to improve stress, pain, and overall well-being (Carmody, 2009). Some participants in the study used mindfulness to cope with the stress of a positive genetic test result and the impending major surgery, PTG. Participants in this study used mindfulness by focusing on being positive, consulting self-help books, relaxation, meditation, and avoiding people who were opinionated or negative. Talking to the health-care team and others who had “been there” also contributed to mindful preparation for PTG.

Due to family history of other cancers and the genetic risk of breast cancer among CDH1 positive individuals, participants continued to have thoughts of cancer and to engage in cancer screening even after PTG. Data relating to the effect of risk management approaches on cancer worry is mixed. Underhill et al. (2012) reported that women’s cancer worry was not completely relieved after prophylactic mastectomy (PM). Similarly, women undergoing risk reducing salpingo-oophorectomy (RRSO) continued to experience cancer worry after surgery, albeit reduced from 34.4% of participants reporting moderate to severe worry pre-operatively to 18.6% after surgery (Finch et al., 2013). Cancer worry was less in the study by Hamilton et al. (2009) in which participants

reported feeling less vigilant and anticipating a longer life after PM and RRSO. Individuals at risk of familial adenomatous polyposis (FAP) who selected either surveillance or surgical risk management also did not identify cancer as a threat to future health (Fritzell et al., 2010). Continued thoughts of cancer after engaging in medical or surgical risk management may be related to the individual's estimation of risk as it has been found that at-risk individuals often overestimate their cancer risk (Cameron et al., 2009; Kaphingst & McBride, 2010; Silvell et al., 2008). Thoughts of other cancer, among participants of the current study, primarily involved breast cancer which participants described as less distressing than stomach cancer. Participants were comfortable with the screening provided for breast cancer and therefore did not perceive it as a threat to their immediate future. They believed that if breast cancer were to occur it would be caught early and they would have a chance; with stomach cancer, they did not believe they had a chance. They believed that stomach cancer would mean death.

Living a Health–Illness Paradox

The second theme of the lived experience of PTG was *living a health–illness paradox*. This theme uncovered the day-to-day challenges of recovering after PTG. Initial recovery was marked with complications and daily trials both at hospital and at home. PTG has been associated with a nearly 100% risk of some form of morbidity (Cisco, Ford, & Norton, 2008). During the recovery period, surgically-induced illness pervaded the participants' lived space. They were forced to deal with the symptoms every day. For some, symptoms were so persistent and severe that, in a temporal sense, their lives were placed on hold. Participants wondered if symptoms would ever relent or if they would go on forever. Participants questioned whether they would ever be able to function and live

their life again. Time passed slowly when sickness hindered usual activities; weeks felt like months.

Dealing with the symptoms every day was commonly described corporally. Their bodies were going through many new, unfamiliar, and unwelcome changes. In some ways they felt disappointed and discouraged by what was happening with their bodies. Their bodies were failing them. Most days they were too fatigued to function. It has been reported that over 70% of patients experience fatigue lasting greater than six months after gastrectomy (Avery et al., 2010). Participants were too tired and weak to do many daily tasks that are taken for granted, such as shopping for groceries. They were constantly exhausted, unable to engage in physical activities or sports, and needed to rest periodically throughout the day. Even years after surgery, participants reported not having the energy they once had. Coping with such fatigue required perseverance and a positive attitude. Participants set goals for themselves, pushed themselves, and eventually accepted their new level of functioning.

Dumping syndrome and nausea were common and problematic symptoms after PTG. Nausea was an issue for many. Nausea was an offensive and bothersome symptom that was described as violent and was compared to seasickness. Participants took great caution to avoid foods that made them sick. When participants did eat, they feared dumping syndrome. Dumping syndrome was described corporally through rapid heart rate, sharp abdominal pains, sweating, and lethargy. Initially, dumping syndrome made participants feel as though they were dying. Participants were scared in the moment that dumping syndrome occurred and were also scared for their future. At times, dumping syndrome was debilitating and participants worried that it would be a part of their life

forever. Clinical guidelines for CDH1 carriers acknowledge that eating difficulties after PTG are an anticipated symptom that may present a discouraging hurdle to some (van der Post et al., 2015). Gastrointestinal symptoms were also experienced by those having a PTG in the study by Worester et al. (2014). Dumping syndrome symptoms including diarrhea, discomfort with eating, reflux, and eating restrictions were reported to varying degrees in the study sample; while symptoms often persisted after PTG with time and personal adjustments symptom experience improved (Worester et al., 2014).

Relationally, it was difficult for others, even for family who had PTG, to completely understand the experience of the participants. Fitzgerald et al. (2010) stated that each patient is different and that it is impossible to predict how any one individual will be affected by PTG. Family and friends were genuinely concerned and shared worry and fear, but they could never fully know the experience of another. Having PTG was as unique an experience as the individuals who participated in the study. No two people had the exact same experience. This was particularly true in relation to dealing with the symptoms every day.

Learning to eat and drink again was also part of living a health–illness paradox. Like the symptoms they experienced, focusing on eating and training oneself to eat took a lot of time and energy. In the early days after PTG, learning to eat and drink again dominated their life; days were spent eating at regular intervals and journaling about calories and the effect of food. Learning to eat and drink again was a slow and tedious process that involved much trial and error. Similar challenges and experimental approaches to re-learning how to eat were provided in other accounts of PTG experience (Garland et al., 2011; Worster et al., 2014). Physicians have advised that diet

accommodations can take up to one year post-PTG (Lynch et al., 2008). Participants gradually learned over 12 to 18 months what their bodies needed and what they could tolerate, including eating slowly, eating cold foods, eating smaller portions, prioritizing certain foods, limiting fluids and carbs, and avoiding greasy foods and dairy. Despite finding the right dietary fix, at times participants still looked to the past; they missed eating like others could. Occasionally they would treat themselves or eat more than they should, but their body quickly reminded them of the changes inside. Participants did not feel as though they suffered, but eating was definitely different than before PTG.

Learning to eat and drink again also involved a relational element. Family and friends were helpful in assisting with meals, encouraging participants, and understanding newly imposed eating routines and restrictions. The health-care team, however, was less helpful than expected. Dietary information provided held little practical value, and guidance on vitamin and mineral supplementation was nearly non-existent. Clinical guidelines for the management of HDGC have consistently reported the need for monthly B12 injections, a daily multivitamin, and a ferrous sulfate supplement (Blair, 2012; Fitzgerald et al., 2010; van der Post et al., 2015). Participants were also confused regarding any necessary changes to alcohol consumption after PTG. Again, recent guidelines suggest that patients should be advised that tolerance to alcohol will reduce after PTG (van der Post, 2015). While participants in this study underwent PTG before the development of the aforementioned guidelines, support is demonstrated for widely distributing and implementing HDGC and PTG guidelines, particularly among primary health-care providers.

Having coping strategies at hand was an important component of recovery after PTG. Participants' relationships with their family were the most important source of support after PTG. Family was unconditional; they knew they could always depend on family. Family members provided encouragement and tended to participants' physical needs. The outpouring of love and support during the PTG experience served to bring the entire family closer together, whether or not family members were impacted by the hereditary condition. Family camaraderie was also noted in PTG physician case reports (Lynch et al., 2008). Snyder, Lynch and Lynch (2009) also reported that families at risk of hereditary cancer often support each other and proceed through the risk assessment and management process together. Furthermore, family connectedness has also been associated with better psychological adjustment to hereditary disease (Watkins et al., 2013).

However, from a perspective of lived space, participants needed to expand their circle of support beyond family. Participants connected with the PTG population both locally and online. The network of PTG survivors understood each other in ways no one else could. They vented to each other, shared stories, provided reassurance, and encouraged one another. Over time, the PTG network became an extended family. Together they coped with the changes inflicted by PTG and transformed the way they thought and communicated about health and illness. Most developed a sense of humor toward PTG, joking about their genetic status, surgical preparation, and post-surgical symptoms. Several authors have also found that humour can be used to deal with a genetic predisposition to cancer and lifelong surveillance or to deal with consequences of prophylactic surgery (Fritzell, Persson, Björk, Hultcrantz, & Wettergren, 2010; Underhill

et al., 2012; Underhill & Dickerson, 2011). Creating and maintaining a positive mindset also helped participants cope with PTG and provided a positive lens for the future. Participants coached themselves to believe that things would work out, and eventually they did.

One outcome of living a health–illness paradox that was experienced by all participants was a slimmer self. Some participants lost weight quickly after surgery, and for others weight loss was more gradual. Individuals undergoing PTG can expect to lose approximately 10-20% of their original body weight (Corso et al., 2014) which most often occurs within the first 3 months (Tyraväinen et al., 2008). Most participants were concerned by the weight-loss experience. Corporally, their bodies were changing both inside and out. The familiar shape and appearance they knew was slipping away. Weight was “melting off” them, they were “going away to nothing,” and there was little they could do about it. Participants were losing weight despite their best efforts to avoid it. Participants began to see themselves differently; they were “bony,” “sick looking,” even their face was not the same. Changes in body image were also reported in the study by Garland et al. (2011) in which weight loss was described in terms of failing to recognize oneself and becoming a “different person” (p.310). The new, slimmer self was an outward sign of the health–illness paradox they lived and a persistent reminder of the cancer that had threatened their lives. They were worried about the impact their new weight would have on their health and future. Participants feared what would happen if they got ill or required surgery in the future. Weight loss exceeded their expectations; participants had to get to know their own body again. They were challenged to find a level of acceptance with their slimmer self, which eventually happened for all

participants. For some, maintaining ideal body weight was a continual struggle and the slimmer self was accepted as a surgical consequence. Still others embraced the slimmer self, believing their new weight was healthier.

Finally, participant perceptions of interactions with the health-care team helped shape the experience of living a health–illness paradox. Spatially, the participants’ lives became crowded with appointments, post-surgical symptoms, medications, and health-related routines. Most had undergone endoscopic screening prior to surgery; all participants had genetic counselling, predictive testing, and surgical consultation. Participants attended information sessions on PTG, met with various health disciplines, and continued to meet with the family doctor and community nurse after PTG. There were many steps to work through in selecting PTG. Medical tests and appointments added demands to their already busy lives. All participants worked and had children at the time of PTG. Their schedules were full and their days were busy; yet they chose to fit surgical prophylaxis into their lives.

Participant perceptions of interactions with the health-care team were primarily experienced relationally. Participants were mostly satisfied with their health-care providers and felt that they received good care overall. Relationships formed with the surgeon and family doctor were frequently depended upon. Physicians were viewed as attentive, knowledgeable, skillful, and compassionate. Implicit trust in the surgeon has also been reported by women opting for PM (McQuirter et al., 2010). Participants in the current study had confidence in physicians and sought reassurance from them. Physicians who were dismissive of concerns contributed to negative perceptions of physician interactions.

Perceptions of nurses were also mostly positive. Participant memories of the nurse centered on the physical care provided, including assisting to ambulate, monitoring vital signs, and administering medications. The perception of the nurse has been traditionally influenced by how they are seen and not what they know. Often the knowledge behind the skills that nurses perform does not get communicated (Price & McGillis-Hall, 2014; ten Hoeve, Jansen, & Roodbol, 2014). It is difficult to determine if participants viewed the nurse as both skillful and knowledgeable. Nurses were also recognized as being busy but providing the necessary care when it was needed.

The importance of a dietitian consult and follow-up was stressed throughout the PTG literature (Blair, 2012; Fitzgerald et al., 2010; Lynch et al., 2008). However, participants found dietary information provided by the dietitian generic and unsatisfactory for their needs. Inadequate dietary information was also identified in the study of gastrectomy patient experience by Garland et al. (2011). Interactions with other health-care team members, including the psychologist, were perceived as having little to no benefit. Participants acknowledged that, at the time of PTG, the surgery was still new and health-care providers were learning along with them.

In terms of lived relation, the health-care team did fail in one major area—follow-up. Most participants felt somewhat abandoned in the follow-up provided by the health-care team. They felt alone; at times, they could not find the answers to their questions, and they were uncertain regarding the lifelong management of PTG. Participants wished the health-care team was more accessible and that there was a consistent protocol that could be followed. This is supported by other studies that show that health-care providers

are perceived to lack knowledge related to the management of hereditary cancer (Fritzell et al., 2010; Underhill & Dickerson, 2011; Watkins et al., 2011).

Moving Forward

The third theme of the lived experience of PTG was *moving forward*. This theme provided detail on the open-ended nature of the experience. Eventually there was a sense of closure to the PTG experience; however, due to the life-altering changes, there could never be a definite end.

Participants were able to move forward after PTG once they reached the new normal. The new normal was experienced temporally, spatially, and corporally. Participants realized that time brought healing, after 12 to 18 months participants could see a brighter future. Finding the new normal was a rite of passage, a milestone in their experience. Spatially, their world began to open up again. They realized that there was life after PTG. The sense of mastery over illness was liberating. They had overcome the trials of having PTG and could now live life fully. The new normal was felt corporally; their body was not the same but they were going to be okay. Physically, their symptoms were less; and mentally, they were freed of the worry of having stomach-cancer.

In moving forward, participants sought sources of affirmation that PTG was the right thing to do. Participants looked to the past, present, and future and compared their situation with that of family. In looking to the past, participants recalled family suffering and believed that PTG was easier to live with than stomach cancer. They wished that family who had died of gastric cancer could have had the option of PTG. This sentiment has been echoed throughout the prophylactic surgery literature. Women who have engaged in risk management for familial breast cancer have also recalled generations of

suffering and loss in their journey through both surveillance and surgical management (Kenen et al., 2007; Underhill et al., 2012; Underhill & Dickerson, 2011). As similarly voiced by a participant in the current study a women in the qualitative study by Underhill et al. (2012) stated, “I wouldn’t wish what I saw my mother go through on anyone” (p.498). As suggested by Etchegary & Fowler (2008) the relational context of a hereditary condition translates into an interdependent process in genetic testing and risk management.

Those who have experienced risk-reducing prophylactic surgery have reported feeling lucky to be alive and have a new appreciation for life (Brandberg et al., 2008; Fritzell et al., 2010). In the present study, participants were empowered by PTG and believed that it had saved their lives. The surgery had given them a second chance. Life, health, and body took on new meaning. They were motivated to make healthy choices and enjoy life more.

When participants thought of the future, they acknowledged the unknown. They no longer feared gastric cancer but were also unsure of what life would have been like without PTG. Participants thought of the next generation—their own children. Existentially, the dreaded future they had once faced was now applied to their children’s situation. They were stricken with worry at the very thought of their children having to experience the reality of PTG first-hand. Worry regarding their children’s potential risk and how it would be managed was also experienced by those at risk of FAP, breast, and ovarian cancer (Fritzell et al., 2010; van Oostrom et al., 2003). In a study of psychological distress 5 years after prophylactic surgery among BRCA1/2 carriers,

having children younger than 15 at the time of surgery was associated with significantly more distress 5 years after surgery (van Oostrom et al., 2003).

In seeking affirmation that PTG was the right thing to do, participants considered their gastrectomy pathology report in the context of lived body and lived time. A pathology report indicative of early gastric cancer changes provided reassurance in the decision to have PTG to some who viewed cell changes as a potential cancer growing within them. Others believed early cell changes might take years to develop or never develop into cancer at all. Such participants did not feel validated in their decision by gaining pathology information and viewed such information as counterintuitive after PTG was complete.

Once participants had settled into life after PTG, they wanted others to benefit from their experience; they wanted to pay it forward. Likewise, women at hereditary risk of breast cancer also expressed a desire to give back to future generations which was cited as a motive for participating in research (Underhill et al., 2012). Paying it forward was rooted in lived time and lived relation. Participants' thoughts drew to their children, extended family, and others who might have PTG in the future. They were happy to share their experiences, to connect with others considering PTG, and to support them in the process. While their own experiences were not all negative, they held hope for future generations that research would provide more options. Through contributing to research, they hoped to give upcoming HDGC individuals and families a PTG-free future.

Chapter 6: Limitations, Implications, and Summary

The final chapter of this thesis outlines the limitations of the research study; identifies implications for nursing administration, practice, education, and research; and provides a comprehensive summary of the study.

Limitations

This study described the lived experience of seven individuals who had previously undergone prophylactic total gastrectomy (PTG) for risk of hereditary diffuse gastric cancer (HDGC). However, as with any phenomenological research, results are reflective of the experience of study participants and should not be generalized to others. Another phenomenological study on the topic with different participants could yield different findings. All participants in the current study were married, parents, and Caucasian. Thus, a similar study that included single, childless, and non-Caucasian participants could possibly reveal different PTG experiences. Of the seven participants in the study, five were female and two were male. With small numbers of each gender, the differences between the PTG experiences of men and women could not be differentiated. All participants within this study were also from the city of St. John's, NL, and surrounding area. It is difficult to determine if individuals from more rural areas of NL would have a similar experience. It could be expected that individuals from rural communities may experience less access to health-care resources or support in their home community and would be required to travel to access the care they needed, which may impact their experience of the same surgery. Finally, individuals in this study had PTG two to nine years prior to participating in this study, with the time since surgery greater than five years for most. The International Gastric Cancer Linkage Consortium (IGCLC) has

developed and revised clinical guidelines for the management of HDGC including PTG within in the past six years, such guidelines may have an impact on patient experience (Fitzgerald et al., 2010; van der Post et al., 2015).

Implications for Nursing

This study unveiled the patient experience of PTG throughout the continuum of care from genetic counselling to operation to recovery to follow-up. Registered nurses (RNs) have a diverse skill set and work in all areas of the health-care system including outpatient clinics, acute care, and community settings. Thus RNs are in an important position to support individuals in their journey through hereditary risk of cancer and prophylactic surgery. Findings from this study have several implications for nursing administration, practice, education, and research.

Nursing administration and practice.

Nurse administrators are influential in the practice setting of RNs; therefore, implications for nursing administration and practice are difficult to separate. The findings from this study could be used in combination with established clinical guidelines (Fitzgerald et al., 2010; van der Post et al., 2015) to develop and implement patient-centered, standardized care maps for PTG. In recent years, health-care agencies have been challenged to find methods to provide effective and efficient quality care. To this end, there has been an increased use of standardized care maps in clinical settings (Jakobsson & Wann-Hansson, 2013; Rycroft-Malone, Fontenla, Bick, & Seers, 2008). Standardized care maps are guides to clinical decision-making based on scientific evidence that outline what should be done, when, and by whom (Miller & Kearney, 2003; Turunen-Olsson, Petersson, Willman, & Gardulf, 2009). The individuals in this study identified the lack of

a standard protocol for PTG patients as a concern. Participants were unsure of what supplements or surveillance were necessary after PTG. A standardized care map that outlines exams, supplements, and follow-up, with specified parameters and frequency, would ensure consistent, evidence-based practice. A standardized PTG care map would also formalize the treatment plan for patients and health-care providers, including RNs and family physicians, who may have less exposure to IGCLC guidelines. Furthermore, participants in this study suggested that the health-care experience of those undergoing PTG could be improved by having a more coordinated team approach throughout the continuum of care. A standardized care map may help to outline health-care processes and to ease transitions; however, assigning a patient navigator or case manager may also be beneficial. The role of the RN as a caregiver and coordinator for those at risk of hereditary cancer has been described (Snyder et al., 2009; Lynch, Snyder, & Lynch, 2009). Additionally, due to the current and anticipated demand for hereditary cancer counseling, testing, and management; the advanced practice oncology nurse has been identified as having other important roles such as counselor, consultant, educator, researcher, and administrator (Snyder et al.; Lynch et al., 2009).

From a practice perspective, it is also important for RNs to understand that being a healthy individual undergoing PTG is a difficult and unique experience that others in the patient's life may not understand. While every individual experiences PTG differently, a general understanding of the range of symptoms and support needs will benefit RNs and the interdisciplinary team. In the current study, the presence and severity of symptoms varied and included fatigue, nausea, and dumping syndrome. Participants were also challenged with learning to eat and drink again as well as with weight loss.

In relation to support, it is also important for RNs to understand the complex and far-reaching implications of PTG. Participants in this study voiced concerns about their health, future, and family. RNs who understand the existential and relational concerns of the patient undergoing PTG will be better prepared to empathize with their situation and to connect them with the coping resources they need. Participants in this study identified family and others who had PTG as the greatest source of support. Current HDGC guidelines also recommend that individuals who are considering PTG have access to someone who has already had the surgery (van der Post et al., 2015). The findings from this study support that recommendation.

Nursing education.

As the genetic basis of illness is uncovered, nurses and other health-care providers are likely to encounter an increasing number of patients making proactive treatment decisions. Understanding the experiences and care needs of those at risk of hereditary cancer will have increasing importance to current and future generations of health-care workers. Post-graduate certification courses in genetics are available to nurses; however, undergraduate programs could benefit from increased content specific to genetics and hereditary cancer. Nursing and other health discipline students would benefit from exposure to managing hereditary cancer in entry-level education programs.

Interdisciplinary case-based study in health care undergraduate programs may assist in clarifying the roles of various disciplines in managing hereditary cancer. Such case-based study could also foster understanding of the difficult decisions that those with a predisposition to cancer face and the biopsychosocial implications of risk management. Activities that foster team building and critical evaluation of hereditary cancer risk

management will result in clinicians that are better prepared to care for this population of patients in the practice setting.

Nursing research.

This study examined the experiences of those at risk of HDGC who chose PTG; as such, the experiences and reasons for failing to choose PTG have not been identified here. Lynch et al. (2008) indirectly found that those failing to choose PTG were influenced by the lack of affected family members, and they had hope for improved screening, diagnosis, and treatment options. Further exploration of the experiences of those who decline PTG is an interesting avenue for future research. Participants in the study were also curious regarding quality-of-life comparison between PTG and non-PTG patients; a concept that has been minimally explored empirically. Participants also had lingering questions about the effect of alcohol after PTG, which could also lend itself to empirical inquiry.

This study revealed that having PTG is a significant life event with a profound effect on the individual and their family. Further study of the social impact, social support needs, symptom impact, psychological adjustment, and effect of weight loss after PTG is warranted. As previously identified within the limitations section, studies that evaluate the experiences of men and childless, non-Caucasian, and/or rural patients could also offer new insights into the PTG experience. However, research pertaining to the patient population at risk of HDGC or those having PTG is limited by the rarity of the condition and the limited number of people affected.

Summary

This study aimed to answer the research question, what is the patient experience of PTG as a means of managing HDGC risk? Hermeneutic phenomenology was the method used to answer this question. Participants were recruited to the study based on their first-hand experience of having PTG. A total of seven people participated in the study through self-referral by contacting the researcher. Each participant participated in one semi-structured interview that was recorded and transcribed. Interview data was analyzed using the selective reading approach described by van Manen (1990).

The findings of the study uncovered the patient experience of PTG through three substantive themes with supporting subthemes. The first theme, playing the hand you're dealt, described the initial realization of genetic risk of HDGC and the steps that followed. Participants experienced many difficult and far-reaching decisions and engaged in preparing the mind and body for major prophylactic surgery. The participants were forced to make decisions and take life-altering actions; however, to them, they were merely doing what needed to be done. The second theme, *living a health–illness paradox*, revealed the daily challenges and ironic situations the participants faced throughout their surgical recovery. The participants were healthy individuals that encountered many illness situations on their journey through PTG. Subthemes including *dealing with the symptoms every day*, *learning to eat and drink again*, *having coping strategies at hand*, *experiencing a slimmer self*, and *perceptions of interactions with the health-care team* were used to highlight the paradoxical PTG experience. The third and final theme, *moving forward*, illustrated the open-ended nature of having PTG. Due to the life altering impact of PTG there was no definite end to the experience; yet participants were able to

reach a point where they embraced their new life after surgery. *The new normal, seeking affirmation that PTG was the right thing to do, and paying it forward* were the subthemes used to describe the experience of moving forward. Viewed together, the three substantive themes form the essence of the patient experience of PTG—*choosing to be a previvor*. *Choosing to be a previvor* speaks to the self-advocacy and proactive treatment approach by participants to re-write the future. *Choosing to be a previvor* is the common thread that binds the experiences of the participants individually and collectively.

Discussion of the findings highlighted the study themes within an existential framework of lived space, lived body, lived time, and lived human relation and related the findings to the literature. Finally, limitations of the research study were outlined, and implications for nursing administration, practice, education and research were identified.

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Appendix A

Research Poster

STOMACH SURGERY RESEARCH

The experience of stomach removal surgery

I am looking for people who had a surgery to remove their stomach for preventative reasons:

Are YOU or SOMEONE YOU KNOW:

- **At genetic risk for stomach cancer and had preventive stomach removal surgery?**
- **Willing to participate in an interview to share your experience?**

Participation will involve one interview of about 30-90 minutes.

You may be invited to a second follow-up interview.

If you are willing to share your story or have any questions please contact:



Jenelle Hodge BN RN
Memorial University
School of Nursing
u62jep@mun.ca or 728-6837

Appendix B

Letter of Invitation

STOMACH SURGERY RESEARCH:

The experience of stomach removal surgery for those at genetic risk

D/M/Y

Dear Possible Participant,

Hello, my name is Jenelle Hodge. I am a registered nurse and I work full time in the area of general surgery. I am currently completing my master's degree in nursing. As part of my master's I am carrying out a research project. I chose my research topic based on my practice as a surgery nurse. In my time as a surgery nurse I have cared for patients that have had their stomach out because of genetic risk for cancer. In my research study I want to learn more about the experience of people who select stomach removal surgery due to genetic risk. I want to learn about the full experience of preventive stomach removal surgery from knowledge of genetic risk, through decision-making, surgical experience, recovery, and life after surgery.

I am looking for people to share their story of having their stomach removed due to genetic risk of stomach cancer. The research project will involve one interview in which you are free to decide the length and type of information to be shared. Taking part in the research will be of little risk to you. Possible risk may include difficult emotions that are recalled in sharing your experience with family risk of stomach cancer, surgery, or complications. It is up to you to take part in an interview and you may end the interview at any time. If you do not want to be in the study it will **not** affect your health care or the health care of your family members.

Thank you for any help you can give me in my research of stomach removal surgery. If you are able to share your story or if you have questions about this study please contact me at (709) 728-6837 or u62jep@mun.ca.

Sincerely,

Jenelle Hodge BN RN
Memorial School of Nursing

Appendix C

Letter to Genetics Department

STOMACH SURGERY RESEARCH:

The lived experience of prophylactic gastrectomy

D/M/Y

Dear Department of Genetics

I am a Master of Nursing student at Memorial University. I have worked in the area of general surgery for five years and have cared for patients who have selected prophylactic gastrectomy. Understanding the unique experience of individuals who select prophylactic gastrectomy is of interest to me. I am conducting a phenomenological research study on the lived experience of prophylactic gastrectomy from knowledge of genetic risk, through decision-making, surgical experience, recovery, and life post-prophylactic gastrectomy. The purpose of this research is to better understand the patients' first-hand journey through the experience of having a prophylactic gastrectomy. It is hoped that by understanding the complex nature of the experience, nurses and other health care professionals will be able to provide optimal care to patients opting for prophylactic gastrectomy surgery to manage genetic risk of gastric cancer.

I would appreciate your help in recruiting participants for this study. The Provincial Health Research Ethics Board in NL specifies that the researcher may not be the initial study contact and a professional providing care is advocated as an appropriate initial contact. I am looking for individuals older than 18 that have previously undergone a prophylactic gastrectomy and are willing to share their experience. Participation will involve one interview of approximately 30-90 minutes with a follow-up interview if necessary. Could you or your secretary please mail the provided letters of invitation to potential participants? Also, it would be greatly appreciated if you could display the enclosed research poster in your office.

Thank you in advance for your help with my thesis research. If you have any questions or concerns please contact me at (709) 728-6837 or at u62jep@mun.ca.

Sincerely,

Jenelle Hodge BN RN
Memorial School of Nursing

Appendix D

Consent Form



Consent to Take Part in Research

TITLE: The Lived Experience of Prophylactic Gastrectomy: A Phenomenological Inquiry

INVESTIGATOR(S): Jenelle E. Hodge BNRN, Master of Nursing Student, Memorial University, u62jep@mun.ca

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. This will not affect your usual health care.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researcher will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

1. Introduction/Background:

Individuals who are at a genetic risk for stomach cancer may choose to have their stomach removed to prevent future cancer. Little is known about their experience and the many factors involved in their experience of preventive surgery. I want to hear the stories of people who have had preventive stomach removal surgery so that health care needs of this group can be appropriately supported.

2. Purpose of study:

To increase understanding of the experiences of people who undergo preventive stomach removal surgery

3. Description of the study procedures:

You will be asked to fill out a short personal profile consisting of 5 questions. Then you are invited to tell me your personal story of having preventive stomach removal.

4. Length of time:

You will be expected to take part in an interview once for about 30-90 minutes. A second interview may be requested by you or the researcher to clarify the first interview or to confirm the findings of the study. The second interview will last between 20 to 60 minutes. Interview time and location will be determined in discussion with you.

5. Possible risks and discomforts:

Taking part in the research is of minimal risk to you. The only identified risk is the possible experience of difficult emotions that may occur in recalling family experiences with gastric cancer, the genetic testing process, or the surgical and recovery experience. If the emotional impact creates discomfort you can stop the interview and arrangements can be made for you to see a nurse counselor if you wish.

6. Benefits:

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify you by name.

Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study. This information will include your

- sex
- brief family history
- preventive stomach removal surgery information including age at time of surgery and how long ago you had the surgery
- information from study interviews and questionnaires

This information will only be used to describe the overall group of participants, not any individual.

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored at Memorial University School of Nursing. Jenelle Hodge BNRN is the person responsible for keeping it secure.

Your access to records

You may ask the researcher, Jenelle Hodge BNRN, to see the information that has been collected about you.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Jenelle Hodge BNRN

Jenelle Hodge BNRN, u62jep@mun.ca, 728-6837

Dr. Karen Parsons BN MN PhD, karenp@mun.ca, 777-6528

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office

Health Ethics Research Authority

709-777-6974 or by email at info@hrea.ca

After signing this consent you will be given a copy.

Signature Page

Study title: The Lived Experience of Prophylactic Gastrectomy: A Phenomenological Inquiry

Name of principal investigator: Jenelle E. Hodge BNRN, Master of Nursing Student, Memorial University, u62jep@mun.ca

To be filled out and signed by the participant:

Please check as appropriate:

| | | |
|--|---------|--------|
| I have read the consent. | Yes { } | No { } |
| I have had the opportunity to ask questions/to discuss this study. | Yes { } | No { } |
| I have received satisfactory answers to all of my questions. | Yes { } | No { } |
| I have received enough information about the study. | Yes { } | No { } |
| I have spoken to Jenelle Hodge BNRN and she has answered my questions | Yes { } | No { } |
| I understand that I am free to withdraw from the study | Yes { } | No { } |
| • at any time | | |
| • without having to give a reason | | |
| • without affecting my future care | | |
| I understand that it is my choice to be in the study and that I may not benefit. | Yes { } | No { } |
| I understand how my privacy is protected and my records kept confidential. | Yes { } | No { } |
| I agree to be audio taped. | Yes { } | No { } |
| I agree to take part in this study. | Yes { } | No { } |
| I would like to receive a copy of the final research report. | Yes { } | No { } |

Signature of participant

Name printed

Year Month

Day

To be signed by the investigator or person obtaining consent

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator

Name printed

Year Month Day

Telephone number: _____

Appendix E

Demographic Profile

1) At what age did you have a preventative gastrectomy?_____

2) How long ago was your preventative gastrectomy?

<1 year_____

2-5 years _____

6-9 years_____

> 10 years_____

3) What is your marital status?

Single_____

Married/Common-law_____

Divorced/Separated _____

Widowed _____

4) Do you have any children? Yes/No

5) Please indicate your gender: Male_____ Female_____

Appendix F

Interview Guide

Please tell me about your personal experience with preventative gastrectomy.

- 1) How did you know about your family risk? (What age? How were you told? How did you feel?)
- 2) What has been your family experience with hereditary cancer? (Did you lose parents or grandparents due to this disease? Are there many family members affected by the gene mutation? How do you/your immediate family and extended family feel about the genetic cancer? genetic testing? prophylactic surgery?)
- 3) Tell me about your decision to have surgery. Were there other options presented to you? What factors impacted your decision? (family, experience, future, etc).
- 4) How was your surgical recovery? (Did you have any complications? Did you feel you had adequate support from your health care team, your family? Did you experience sadness, anxiety, fear? What was a typical day in the hospital like for you?)
- 5) How did you cope once home? (Did you notice any changes in yourself physically, emotionally?)
- 6) How do you feel looking back on the surgery? (Do you have any feelings of loss from your surgery? Do you feel you have gained anything from surgery? Would you do it again? Was it a positive or negative experience? What would you tell others deciding to have the surgery?)

Appendix G

Ethics Review Board Approval



Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure Avenue
St. John's, NL
A1B 2X5

November 29, 2013

Ms. Jenelle Hodge
312 Windgap Road
Flatrock, NL
A1K 1C3

Dear Ms Hodge

Reference #13.251

RE: The Lived Experience of Prophylactic Gastrectomy: A Phenomenological Inquiry

This will acknowledge receipt of your correspondence.

This correspondence has been reviewed by the Chair under the direction of the Board. **Full board approval** of this research study is granted for one year effective **November 14, 2013**.

This is to confirm that the Health Research Ethics Board reviewed and approved or acknowledged the following documents (as indicated):

- Response Letter, approved
- Letter to Physician Offices and Genetics Department, approved
- Letter of Invitation, approved
- Research Poster, approved
- Consent Form dated November 2013, approved
- Proposal, approved

This approval will lapse on **November 14, 2014**. **It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HREB office prior to the renewal date; you may not receive a reminder, therefore the ultimate responsibility is with you as the Principle Investigator.** The information provided in this form must be **current to the time of submission** and submitted to HREB **not less than 30 nor more than 45 days** of the anniversary of your approval date. The Ethics Renewal form can be downloaded from the HREB website <http://www.hrea.ca>.

email: info@hrea.ca

Phone: 777-8949

FAX: 777-8776

The Health Research Ethics Board advises THAT IF YOU DO NOT return the completed Ethics Renewal form prior to date of renewal:

- Your ethics approval will lapse
- You will be required to stop research activity immediately
- You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again

Lapse in ethics approval may result in interruption or termination of funding

It is **your responsibility to seek the necessary approval from the Regional Health Authority or other organization as appropriate. You are also solely responsible for providing a copy of this letter, along with your application form, to the Office of Research Services should your research depend on funding administered through that office.**

Modifications of the protocol/consent are not permitted without prior approval from the Health Research Ethics Board. Implementing changes in the protocol/consent without HREB approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HREB website) and submitted to the HREB for review.

This research ethics board (the HREB) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Health Research Ethics Board currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; ICH Guidance E6: Good Clinical Practice* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as defined by *Health Canada Food and Drug Regulations Division 5; Part C*.

Notwithstanding the approval of the HREB, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,



Dr Fern Brunger, PhD (Chair Non-Clinical Trials)
Ms. P. Grainger, (Vice-Chair Non-Clinical Trials)
Health Research Ethics Board

For Office Use only: December 12, 2013