"THE DIAGNOSIS IS JUST THE TIP OF THE ICEBERG": FAMILY STORYTELLING ABOUT HEREDITARY CANCER

A Dissertation

by

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ABSTRACT

Advances in science and genomic medicine are leading to more discoveries of genetic variations associated with diseases, making family health history and genetic testing important diagnostic tools for physicians. Family communication about the family's health history can alert individuals to their risks and facilitate prevention; however, these conversations can be difficult due to the emotional nature of the family's medical history. In families with a long history of hereditary cancer, individuals have often watched their close family members suffer or die, making the history of cancer for these families become highly integrated into the family's identity. Further, when members engage in these difficult conversations about the family history of hereditary cancer, they are also confronting their own risks of developing cancer. Telling stories can help family members make sense of and cope with their difficult and meaningful health experiences. The primary goal of this study was to explore the content of family stories by examining how narrative framing may contribute to coping, perceptions of risk, and medical decision-making. The second goal of this study was to examine how the process of joint storytelling about hereditary cancer influences coping, perceptions of risk, and medical decision-making. This study recruited 42 family dyads with a prevalent family history of hereditary cancer to participate in a phone interview in which they jointly told their family story of hereditary cancer. In exploring the content of these family stories, prevalent frames arose including empowerment, contamination, laissez faire, and competing frames. Each frame gives insight into how families are coping, their

perceptions of risk, and how they make medical decisions. Results examining the process of joint family storytelling found that families who were high in interactional sense-making behaviors such as engagement, turn-taking, perspective-taking, and coherence created family narratives that served as a reference point to help members exchange emotional support, share information about risk, and shape medical choices to better manage hereditary cancer risks. Findings from this study provide insight into how families with hereditary cancer make sense of their risks collectively and provides intervention points to help practitioners support patients as they communicate about hereditary cancer.

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CHAPTER I

INTRODUCTION

Advances in science and genomic medicine are leading to more discoveries of genetic variations associated with specific diseases, making family health history and genetic testing important diagnostic tools for clinicians (Rolland & Williams, 2006). To date more than 50 hereditary cancer syndromes have been identified for which individuals can test (National Cancer Institute, 2013). Inherited genetic variants, which dispose an individual to developing certain cancers, represent 5 to 10 percent of all cancers (National Cancer Institute, 2017). Although these hereditary cancer conditions may not represent a large portion of the population, those carrying these types of genetic variations have a significantly increased lifetime risk of developing cancer compared to the general population.

Currently, research is flourishing in diagnosis, prevention, and treatment among common hereditary cancers such as Lynch syndrome, hereditary breast and ovarian cancer syndrome (HBOC) and Li-Fraumeni (LFS) syndrome. The National Institutes of Health (2018) estimates that 3 to 5 percent of the 140,000 cases of colorectal cancer each year are caused by Lynch syndrome. Lynch syndrome, also commonly called hereditary nonpolyposis colorectal cancer (HNPCC), increases individuals' risk of developing cancers of the stomach, small intestine, colon, rectum, gallbladder, upper urinary tract, endometrium, brain, and skin. Further, it is currently estimated that 1 million people have Lynch syndrome, but only 5 percent are aware or have been diagnosed with the

condition (Jacks, Jaffee, & Singer, 2016). HBOC accounts for 20 to 25 percent of hereditary cancers and 5 to 10 percent of all cancers (Campeau, Foulkes, & Tischkowitz, 2008). Further, HBOC puts individuals at an increased lifetime risk for breast, ovarian, prostate, pancreatic, and skin cancers (Tai, Domchek, Parmigiani, & Chen, 2007). The cancers most associated with LFS include breast cancer, brain tumor, leukemia, adrenocortical carcinoma, osteosarcoma, and soft tissue sarcoma (NIH, 2018). Finally, men and women with gene variants related to these cancer conditions have a 50 percent chance of passing on the variant and inherited risks to their offspring (NIH, 2018). Family communication about the family's health history can alert individuals to their risks and facilitate prevention (Ashida et al., 2013). An individual's hereditary risk status also carries serious implications for close relatives (Sobel & Cowan, 2003), which makes family communication and sense-making an important area of research.

Communicating about family health history (FHH), or a family's medical history, can provide genetic risk information about a patient's relatives, which can alert healthcare providers to potential health risks they may be able to monitor, prevent, and treat (Koehly et al., 2009; Parrot & Hong, 2014). Although FHH can be an important tool in healthcare, Welch, O'Connell, and Schiffman (2015) found the percentage of Americans who seek FHH information only slightly increased from 29% in 2004 to 37% in 2014. As communicating about hereditary cancer is a family system level problem, how members communicate and interact plays an important role in how individuals within the family make sense of and manage their hereditary risk (Galvin & Young, 2010). Previous research demonstrates communication about hereditary cancer can be

challenging due to gender expectations (d'Agincourt-Canning, 2001; DeMarco & McKinnon, 2007; Koehly et al., 2003), family norms for communication and privacy (Rauscher et al., 2015; Thompson et al., 2015), closeness of relationships (Chivers Seymour, Addington-Hall, Lucassen, & Foster, 2010; Mesters, Ausems, Eichhorn, & Vasen, 2005), and the emotional nature of some family health histories (Gaff et al., 2007; Kenen, Arden-Jones, & Eeles, 2003). Although, much research focuses on how family members share or block genetic disease risk information (Forrest et al., 2003; Koehly et al, 2003; Koehly et al., 2009), far less research examines the persistent influence family communication exercises on health attitudes and behaviors regarding FHH.

One way families communicate to make sense of genetic cancer risk is through multigenerational family narratives (Werner-Lin, 2007). Indeed, families construct narratives to define and transmit family values, beliefs, and identity (Koenig Kellas & Kranstuber Hortsman, 2015). In families with a long and emotional history of hereditary cancer, individuals have often watched their close family members suffer and/or die (Forrest et al., 2003; Kenen, Arden-Jones, & Eeles, 2003), making the history of cancer for these families become highly integrated into the family's identity. Telling stories can help family members make sense of and cope with their difficult and meaningful health experiences (Trees, Koenig Kellas, & Roche, 2010). Thus, hereditary cancer and family members' experiences with hereditary cancers may become a focal point of family narratives (Frank, 1998), defining how individuals make sense of their risk and informing the medical choices they make. Furthermore, narratives families create to

make sense of the history and risk of hereditary cancer do not remain static, but may shift and change with each new diagnosis and illness experience, especially if more voices jointly share the story (Koenig Kellas, 2005). These stories may play a significant role in how newly diagnosed members come to understand their genetic disease risk and manage decision-making. Overall, family narratives and storytelling can influence family members' understanding and decision-making regarding the family history of hereditary cancer.

Exploring family communication and sense-making provides further insight into how families cooperate to coordinate meaning about hereditary cancer risks. Understanding how families communicate about a family history of hereditary cancer can help physicians provide family-centered care (Mendes et al., 2017). Providing family-centered care means physicians recognize the patient as a member of a family system and consider how family may facilitate or inhibit patients' hereditary cancer knowledge and patients' ability to take care of themselves (Mendes et al., 2017). Moreover, as "it is not possible to talk to a person about genetics without talking about family" (Koerner, LeRoy, & Veach, 2010, p. 187), a focus on how families manage hereditary cancer risks communally can contribute to developing strategies motivating patients to share FHH information with close and distant relatives. Encouraging patients to talk with their family about hereditary cancer risks, diagnosis, and treatment can help family members better manage their health and make informed medical decisions (Feetham & Thomson, 2006; Parrot & Hong, 2014). Indeed, knowledge of FHH is associated with engagement in exercise, healthy diet, participation in screenings, losing

weight, and can inform practitioners' recommendations for disease screening and prevention (Baptiste-Roberts et al., 2007; Guttmacher et al., 2004).

The primary goal of this study is to explore how families affected by hereditary cancer collectively make sense of their health history and risks through narrative. To achieve this goal, this study uses Communicated-Narrative Sense-Making (CNSM) theory (Koenig Kellas, 2005; Koenig Kellas & Tress, 2005) to first investigate the content of family narratives. The content of family stories can demonstrate how family members are coping, what they understand about their risks, and how they make medical decisions. Second, this study examines the narrative structures used by family dyads during joint storytelling about their hereditary cancer. CNSM posits families socialize one another through storytelling, which suggests family narratives about hereditary cancer influence how members make sense of and cope with their risks as well as how they make medical decisions to manage their hereditary cancer risks. Thus, by examining the narrative structures used in storytelling this study also aims to explore the outcomes of narrative sense-making related to coping behaviors, perceptions of risk, and medical decision-making.

CHAPTER II

REVIEW OF LITERATURE

As families communicate and manage hereditary cancer, family narratives may be an especially important way families make sense of the family history of cancer and cope with uncertainty and loss. These narratives can reflect aspects of family cohesion, support, and identity, which reveals the ways in which meaning is made in families regarding hereditary cancer risk and members' ability to cope in the face of hereditary illness (Koenig Kellas, 2018). Although much research on family narratives of illness provides insight on the content of individual stories, exploring both the content and process of family narrative construction may reveal the connections between narrative sense-making and outcomes such as coping, risk perceptions, and medical decisions-making. This chapter will review the clinical variables of hereditary cancer syndromes influencing family communication about hereditary cancer risk and the challenges family members face in managing a family history of cancer. Further, motivations and barriers to communicating about the family history of cancer will be explored to demonstrate the role family communication plays in managing hereditary cancer risks. Both clinical variables of hereditary cancer syndromes and factors in family communication about hereditary cancer can provide insight into the content of family narratives and how they are collectively constructed. An explanation of CNSM as well as how the theory is applied in this study will also be featured in this chapter. Finally,

this chapter poses research questions to explore the connection among narrative sense-making and health communication outcomes.

Managing Hereditary Cancer Risks

Clinical variables of hereditary cancer syndromes such as HBOC, Lynch syndrome, and LFS can shape how families communicate about hereditary cancer risks and influence how medical decisions are made (Rolland & Williams, 2006). These variables place psychosocial demands on individuals and families managing the family history of hereditary cancer, affecting individual well-being, relationships, and family identity (Rolland, 1994; Rolland & Williams, 2005). Specifically, how families make sense of hereditary risk is based on four clinical variables including the likelihood of developing the hereditary condition (penetrance), timing of onset in an individual's lifecycle, the existence of effective treatment or preventive medicine, and clinical severity (Rolland & Williams, 2006). Together these variables form a typology for categorizing the psychosocial demands individuals and families face in managing hereditary disease risk across the life span (Rolland & Williams, 2006). Overall, the typology of hereditary cancer syndromes can affect how families talk about and come to understand their risks and make decisions to manage this risk (McDaniel, Rolland, Feetham, & Miller, 2006). This section reviews the clinical variables forming the typology for how families communicate about and make sense of HBOC, Lynch syndrome, and LFS risks.

Penetrance. Penetrance refers to the likelihood a family member will develop HBOC, Lynch syndrome, or LFS related cancers during their life span. In the case of

HBOC, the *BRCA1/2* gene variants account for approximately 25 percent of HBOC cases, which currently makes them the most prevalent (Nielsen, van Overeem Hansen, & Sorensen, 2016). Women who inherit a *BRCA1* gene variant have a 55-65 percent risk of developing breast cancer by the age of 70, a 44 percent risk of developing ovarian cancer by the age of 80, and a 3.3 percent risk of developing pancreatic cancer (Antoniou et al., 2003; Cavanagh & Rogers, 2015; Chen & Parmigiani, 2007; Kuchenbaecker et al., 2017). Women who inherit a *BRCA2* variant have a 45 percent chance of developing breast cancer by the age of 70, a 17 percent risk of developing ovarian cancer by the age of 80, and a 6.6 percent risk of developing pancreatic cancer by the age of 50 (Antoniou et al., 2003; Cavanagh & Rogers, 2015; Chen & Parmigiani, 2007; Kuchenbaecker et al., 2017; Iqbal et al., 2009). Men with a *BRCA1* variant have a lifetime risk of 1-5 percent of developing breast cancer, a 3 percent lifetime risk of developing pancreatic cancer, and a 7-25 percent risk of developing prostate cancer (Cavanagh & Rogers, 2015; Lecarpentier et al., 2017; Liede et al., 2004; Mahon, 2014). Men with a *BRCA2* variant have a 5-10 percent lifetime risk of developing breast cancer, have a 3-5 percent lifetime risk of developing pancreatic cancer, a 15-62 percent lifetime risk of developing prostate cancer, and a 3-5 percent lifetime risk of melanoma (Cavanagh & Rogers, 2015; Lecarpentier et al., 2017; Liede et al., 2004; Mahon, 2014). Both men and women with a *BRCA1/2* genetic variant also have a 50 percent chance of passing on the gene variant to a child, which can be a threat to each generation of the family (Petrucelli, Daly, & Pal, 2016). Families can also be affected by HBOC without carrying a *BRCA1/2* gene variant, as not all pathogenic genetic variants predisposing individuals for HBOC have

been identified (Crawford et al., 2017). Recently, there have been additional gene variants identified for HBOC including *CHEK2*, *NBS1*, *ATM*, *BRIP1*, and *PALB2* (Kluska et al., 2017). New pathogenic gene variants are rare, which currently poses challenges for approximate estimations of risk (Nielsen, van Overeem Hansen, & Sorensen, 2016). Further, research shows some gene variants have been linked to both HBOC and Lynch syndrome-spectrum cancers.

Individuals diagnosed with Lynch syndrome have a 52-82 percent risk of developing colorectal cancer, a 25-60 percent risk of developing endometrial cancer, a 6-13 percent risk of developing gastric cancer, and a 4-12 percent risk of developing ovarian cancer over their lifetime (Kohlman & Gruber, 2014). Further, the risks for other Lynch syndrome-related cancers such as stomach, hepatobiliary tract, urinary tract, small bowel, brain/central nervous system, and sebaceous neoplasms is lower, but substantially increased compared to the general population (Lindor et al., 2006). Lynch syndrome is associated with a specific group of genetic mutations including *MLH1*, *MSH2*, *MSH6*, *PMS2*, and *EPCAM* (Baglietto et al., 2010; Kohlman & Gruber, 2014; Senter et al., 2008). Additionally, less than 1 percent of individuals diagnosed with breast cancer have a Lynch syndrome gene variant (Tung et al., 2014). Mean ages of diagnosis for Lynch syndrome-related cancers are between 40 and 62 years of age, but cancers may present sooner than these mean ages (Kohlman & Gruber, 2014). Unlike HBOC, men and women's risk of developing Lynch syndrome-related cancers, not including endometrial and ovarian cancer, are comparable across gene variants (Giardiello et al., 2014; Kohlman & Gruber, 2014). Both men and women diagnosed with Lynch syndrome also

have a 50 percent chance of passing on a gene variant to a child (Kohlman & Gruber, 2014).

Less risk information is known for LFS, but cancers associated with an LFS diagnosis include breast cancer, osteosarcoma, soft tissue sarcomas, brain tumors, leukemias, and adrenocortical carcinoma (NIH, 2019; Oliver et al., 2003). Further, these cancers tend to onset quite early, sometimes as early as childhood or young adulthood (Wong et al., 2006). Gene variants including CHEK2 and TP53 are associated with LFS (de Jong et al., 2002). Similar to HBOC and Lynch syndrome, parents also have a 50 percent chance of passing on a LFS gene variant to offspring. For individuals at risk for HBOC, Lynch syndrome, or LFS, family communication about health history can be important in making sense of and managing health risks before potential disease onset.

Statistical probabilities of disease onset can be difficult for the average patient to understand when facing general population level health risks (Gigerenzer et al., 2007). Probabilities given for women with a family history of HBOC can make their likelihood of developing breast and/or ovarian cancer uncertain (Dean, 2016; Rees, Fry, & Cull, 2001). Indeed, in Lloyd and colleagues' (1996) study many women failed to accurately recall risk figures provided by genetic counselors and perceived they were at a higher lifetime risk, which was associated with more intrusive thoughts worsening their anxiety. In contrast, men's probabilities of developing HBOC related cancers may seem low, especially in comparison to their female relatives' risks, which can make affected men feel ambivalent about managing their hereditary risks (Rauscher & Dean, 2017; Rauscher, Dean, & Campbell-Salome, 2018). Families managing Lynch syndrome face

the same difficulties in grasping complex disease information and disseminating risk information (Bartuma, Nilbert, & Carlsson, 2012; Peterson et al., 2018; Stoffel et al., 2008). Previous research shows family communication about an individuals' risk of developing hereditary cancer is not entirely informed by Mendelian patterns of inheritance, but rather perceived similarities between diagnosed family members (Rees, Fry, & Cull, 2001; Richards, 1996). For instance, family members may pre-select who will develop cancer based on their resemblance or similarity to an affected relative (Palmquist et al., 2010; Kenen et al., 2004; Wilson et al., 2004). Overall, the family's understanding of penetrance will influence members' expectations of their likelihood of developing hereditary cancer. Further, family stories can affect an individual's perceptions of their risks of developing a hereditary cancer and influence medical choices (Kenen et al., 2007). Perceptions of risk have been correlated with an increased demand for genetic testing, uptake of preventive screenings, pursuit of reproductive technologies to avoid passing a gene variant on, and perceived confidence in ability to cope (Codori et al., 1999; Lerman et al., 1994; Rich et al., 2014).

Severity. Expectations of clinical severity can create emotional or psychological distress when families talk about disease inheritance (d'Agincourt Canning, 2006; Hamilton, Williams, Skirton, & Bowers, 2009). Severity is the expected degree of disease burden based on the genetic condition's onset, course, and outcome as well as the degree of disability it may cause (Gaff & Metcalfe, 2010). For individuals with a family health history of HBOC, Lynch syndrome, or LFS, onset and trajectory of disease can be uncertain as well as the degree of burden if cancer does occur (Rolland &

Williams, 2006). In response to this uncertainty about disease onset and severity, family stories about illness memories and cancer experiences can be especially influential in helping at-risk family members make sense of their individual risks. Having an emotionally difficult family history of cancer may cause individuals to overestimate the severity of hereditary cancer and cause intrusive thoughts.

Interpretation regarding the severity of HBOC, Lynch syndrome, and LFS related cancers may depend on the severity of family health history. Previous research demonstrates communication about the family history of inherited cancer syndromes and illness experiences shape conceptualizations of risk at both individual and family levels (Gaff et al., 2005; McAllister, 2003; McCann et al., 2009). For example, Dean (2016) found individuals who described cancer as infiltrating their family trees felt memories of losing loved ones imprinted on them and made them more fearful of their risks. Furthermore, Dean (2016) found a positive *BRCA1/2* result triggers memories of family members who died of cancer. Similarly, Kenen, Arden-Jones, and Eeles (2003) found the strongest memories for women with a family history of HBOC were those of relatives suffering from cancer or cancer treatment, which affected perceptions of participants' own cancer risks and their severity. In a study on how three families of different ethnic backgrounds communicate about Lynch syndrome, results show family experiences and a prevalent family history shape risk perceptions and disease severity expectations (Palmquist et al., 2010). Families in this study shared the "cancer bond" based on other family members' experiences giving meaning to the family history, causing members to feel they were marked for the same kind of cancer experience in the

future (Palmquist et al., 2010). Essentially because these family members shared emotional memories of another's bad experience managing Lynch-related cancers, their sense of severity and risk was heightened. Individuals weave other family members' experiences with hereditary illness into their understandings of hereditary conditions, which shapes their outlook and how they communicate about the family health history and their hereditary risks (Etchegary, Dicks, Watkins, Alani, & Dawson, 2015; McCann et al., 2009). Thus, not only the severity of hereditary cancers, but also the severity of the family history of cancer and how families manage illness memories, contributes to members' sense-making.

Existence of Preventive Treatment. Existence of preventive treatment refers to the availability of options individuals with hereditary conditions may choose to prevent onset of the hereditary disease or treat the disease when it does onset (Rolland & Williams, 2006). The existence of effective prevention and treatment interventions can give at-risk family members a better sense of control. Indeed, previous research shows when preventive options are available, individuals with a gene variant for hereditary cancer tend to feel a better sense of control over their health and fate (Kenen Ardern-Jones, & Eeles, 2003; Lerman, Daly, Masny, & Balshem, 1994; Seppen & Bruzzone, 2013). Accordingly, family members who feel a better sense of control and coping through preventive medical options may communicate more with family about the efficacy of each of these options and encourage other members to consider making proactive medical choices to manage hereditary cancer risks.

Current medical guidelines for managing HBOC suggest women with a *BRCA1/2* gene variant consider prophylactic surgical procedures such as a bilateral mastectomy (removing both breasts) and/or an oophorectomy (removing the ovaries) to prevent onset of breast and ovarian cancers (NCCN, 2016). Other recommendations for managing hereditary cancer risk for women include chemoprevention and advanced screening (Petrucelli, Daly, & Pal, 2016). Family members with HBOC may be able to incorporate lifestyle changes related to diet, exercise, smoking cessation, and regular screenings under the guidance of a practitioner to attempt to prevent cancer development (Petrucelli, Daly, & Feldman, 2013). However, prevention and management recommendations are not as extensive for men. Guidelines suggest men perform self-exams for breast cancer and begin annual breast cancer screening at the age of 35, begin annual prostate cancer screening at the age of 45, and screen for melanoma at an individualized time based on the family history (NCCN, 2016). These prevention options may be the subject of family communication and family stories about members' experiences with prevention and treatment can influence how other relatives make medical decisions.

Patients with Lynch syndrome have similar recommendations related to prevention. For patients with Lynch syndrome, current guidelines recommend engaging in early preventive screening and surveillance in addition to preventive surgeries. Preventive screenings include undergoing colonoscopies every 1-2 years beginning between the ages of 20-25 or 10 years before the youngest relative was diagnosed and beginning between ages 30-35, undergoing annual pelvic exams with endometrial

sampling, transvaginal ultrasound, and urinalysis (Giardiello et al., 2013; Lindor et al., 2006). Current guidelines also recommend prophylactic hysterectomy and bi-lateral oophorectomy when female patients feel they no longer wish to have children (Kohlman & Gruber, 2014; NCCN, 2016). Further, patients may also engage in prophylactic colectomy prior to developing colon cancer; however, this recommendation is rarely offered if patients are regularly undergoing colonoscopies and doctors are removing precancerous polyps (Anele et al., 2017). Those with Lynch syndrome are also highly discouraged from smoking due to the higher risk of developing colorectal cancer (Kohlman & Gruber, 2014; Pande et al., 2010). Recent research has also explored the use of aspirin to reduce colon cancer risk, which may be somewhat effective, and the use of oral contraceptives may also reduce the risk of endometrial cancer for those with Lynch syndrome (Dashti et al., 2015; Rothwell et al., 2011). However, results from research using these medications is limited (Kohlman & Gruber, 2014). Further, knowing a patients' specific gene variant may aid in treatment of certain Lynch syndrome-related cancers as patients may respond differently to chemotherapy (Kohlman & Gruber, 2014). Family communication about genetic testing and risk plays a pivotal role in influencing health behaviors including preventive screening for patients with Lynch (Palmquist et al., 2010; McCann et al., 2009; Ersig et al., 2009). Thus, family narratives may be a way to share risk information for members and help relatives become aware of and manage their hereditary cancer risks as well as shape family perceptions about the available treatment and prevention options.

For patients with LFS, practitioners also suggest they engage in preventive screenings, but from much earlier ages such as 18 years old. Some patients beginning screening as early as age 5 (Kratz et al., 2017). Screening recommendations include blood tests every 3-4 months, routine physical exams, annual skin exams, breast MRI, mammograms, abdominal/pelvic ultrasound, and colonoscopies (Kumar et al., 2018). Doctors may also recommend whole-body MRI and brain MRI annually (Kratz et al., 2017). Additionally, patients with LFS may engage in prophylactic surgeries in adulthood similar to those recommended for patients with HBOC and Lynch syndrome. As individuals with LFS are at risk for highly aggressive forms of hereditary cancer in multiple areas of the body, family communication about preventive options available and the importance of engaging in screening from a young age may be especially important. These family stories not only alert members to their hereditary cancer risks, but can also inform individuals about the efficacy of preventive options or when to engage in preventive screenings.

In families with a multigenerational history of cancer, storytelling might serve to educate members about the risks of the condition and help them understand the prevention options they need to consider from a relatively early age (Frank, 1998; Kenen, Arden-Jones, & Eeles, 2004). For instance, a daughter who carries a gene variant related to HBOC, Lynch syndrome, or LFS might feel pressured to make reproductive choices early to take advantage of prophylactic surgeries after hearing her oldest sister tell stories about developing cancer after getting pregnant. A story of severe illness from a close loved one may motivate a family member to assess their hereditary cancer risks

more seriously and engage in more aggressive screenings and make healthier lifestyle choices. Previous research demonstrates communication about the family's health history is associated with engagement in exercise, healthy diet, participation in screenings, and losing weight (Baptiste-Roberts et al., 2007; Guttmacher et al., 2004). Further, family experiences with hereditary cancer management may be more influential in determining risk perceptions and health behaviors than objective information from medical sources (Douma et al., 2010; Mesters et al., 2005; Palmquist et al., 2010). Indeed, McDaniel and colleagues (2006) assert understandings of genetic risk and disease management likely "reflect a combination of medical information, family mythology, and cultural or religious beliefs" (p. 178). Family communication may be of particular importance in notifying members of their risks and motivating members toward specific prevention options.

Timing. Timing of expected onset of hereditary cancers related to HBOC, Lynch syndrome, and LFS can motivate family conversations about hereditary illness to help members come to terms with threatened loss, pursue genetic testing, and start making important health decisions (Rolland, 2006). Timing of onset for both HBOC and Lynch syndrome cases can be early-middle adulthood (20-60) and late onset (older than 60 years of age) (Gaff & Metcalfe, 2010; Kohlman & Gruber, 2014; Litton et al., 2012). For patients with LFS, onset can be as early as childhood (Kratz et al., 2017). However, there is no certainty as to exactly when cancer might appear even for those who test positive for a gene variant (Dean, 2016). As timing of onset can be uncertain and current treatment recommendations for HBOC, Lynch syndrome, and LFS emphasize

prevention and advanced planning, it is important to begin managing these hereditary cancer risks early. Timing of onset is also important because it may interfere with choices family members make regarding family planning and expected tasks for certain life stages (Rolland & Williams, 2006). For instance, receiving a diagnosis of HBOC, Lynch syndrome, or LFS may make a woman feel she should have children earlier in life due to the potential need for prophylactic surgeries (Dewanwala et al., 2011; Etchegary et al., 2015; Werner-Lin, 2008), which may conflict with original life plans. Timing of onset can create pressures for family members in deciding if and when to undergo prophylactic surgeries in tandem with planning for and raising children.

For families with a history of HBOC, timing of onset may be especially important for women because they are perceived to be the most at risk in comparison to male family members and their risk has implications for their family planning decisions (DeMarco & McKinnon, 2007; d'Agincourt-Canning, 2001). Women at risk for Lynch syndrome have comparable cancer risks to men, but also face endometrial and ovarian cancer risks, which puts pressure on their family planning decisions (Dewanwala et al., 2011; Douma et al., 2010; Rich et al., 2013). Thus, affected members might turn to family narratives to make sense of their uncertainty, especially as women try to determine when to have children and when to have preventive surgeries. Indeed, Werner-Lin (2007) found young women from families with HBOC based their risk perceptions off "danger zones" or times at which they expected to be affected by an HBOC related cancer. Previous family members' illness experiences and timing of onset determined female family members perceived "danger zones," and influenced their

medical decision-making (Werner-Lin, 2007). How narratives represent timing are especially important as women's reproductive decisions are deeply imbedded in personal and familial experiences of cancer (Donnelly et al., 2013). Moreover, women might not only be concerned with having children, but also living long enough to raise their children (Dean, 2016). Timing of onset may also cause uncertainty for men, but it may not carry the same type of pressures for men as women. Men in families with a history of HBOC often feel they need to support female family members, and may underestimate their risks or doubt if they will develop an HBOC related cancer (DeMarco & McKinnon, 2007; Hallowell et al., 2006). In contrast, men with Lynch syndrome face the same risks for non-gynecological cancers as women and may experience the same uncertainty regarding risk perceptions and timing of onset as women (Aktan-Collan et al., 2011). Thus, timing of onset can cause uncertainty and may influence perceptions of risk, family planning decisions, and when to consider preventive treatments.

How families talk about the clinical characteristics of HBOC, Lynch syndrome, or LFS inform perspectives toward risk and uncertainty, prevention and treatment efforts, support behavior change, and contribute to emotional adjustment (Palmquist et al., 2010; Bartuma, Nilbert, & Carlsson, 2012; Hurley et al., 2006). In essence, family communication about penetrance, severity, timing, and prevention and treatment options color members' interpretation of their hereditary cancer risks. For instance, families with a long emotional history of HBOC, Lynch syndrome, or LFS may create stories that produce a feeling of inevitability of developing cancer due to members

misunderstanding objective facts related to inheritance or due to the affectively charged interpretations of risk (Dean, 2016; Rees, Fry, & Cull, 2001; Palmquist et al., 2010). In contrast, learning a negative genetic test result in light of a long family history of cancer may produce feelings of confusion or guilt because that result does not fit within the family illness narrative (Carlsson & Nilbert, 2007; Diefenbach & Hamrick, 2003). Multigenerational family experiences with HBOC, Lynch syndrome, and LFS create schemas that influence how genetic risk information is received and used (Palmquist et al., 2010; Hurley et al., 2006). While clinical characteristics of HBOC, Lynch syndrome, and LFS influence how families communicate about hereditary cancer risks, family characteristics also contribute facilitators and barriers to family communication and sense-making about hereditary cancer.

Family Communication about Hereditary Cancer

Communicating about the family history of hereditary cancer is an integral step for an individual and the family to become aware of and better manage hereditary risks (CDC, 2016). Exploring factors contributing to or inhibiting family communication about hereditary cancer can provide insight into how these conversations impact the family and the individual's health. Previous research demonstrates sex (Aktan-Collan et al., 2011; d'Agincourt-Canning, 2001; Rauscher & Dean, 2017; Rauscher, Dean, & Campbell-Salome, 2018; Rees, Fry, & Cull, 2001), age (Ashida et al., 2013; Aktan-Collan et al., 2011; Chivers Seymour et al., 2010; McCann et al., 2009; Yamasaki & Hovick, 2015), and family characteristics (Bartuma, Nilbert, & Carlsson, 2012; Dancyger et al., 2010; Thompson et al., 2015) can act as both facilitators and barriers to

family communication about hereditary cancer. These factors may also influence which family members are more involved in constructing and perpetuating stories about hereditary cancer that contribute to the family's collective sense-making. This section reviews how sex, age, and family characteristics influence family conversations about HBOC, Lynch syndrome, or LFS.

Sex. Sex and gender expectations may complicate family communication and sense-making about hereditary cancer. For instance, as there is currently more information on risks and treatment for breast and ovarian cancer and men's risks are statistically lower than women's, there tends to be a bias toward focusing and communicating only about female relatives' HBOC related risks (Rauscher & Dean, 2017; Rauscher, Dean, & Campbell-Salome, 2018). Indeed, most research on how families communicate and share information about HBOC risk and genetic testing for *BRCA1/2* focuses on female family members, and finds women tend to be information disseminators and support providers (d'Agincourt-Canning, 2001; Hughes et al., 2002; Koehly et al., 2008; Koehly et al., 2009). Specifically, women tend to feel they have a responsibility or duty to find information about their hereditary cancer risks related to HBOC and to share this information with close and sometimes distant relatives (d'Agincourt-Canning, 2001).

In the case of Lynch syndrome and LFS, previous research has not found the same degree of sex differences as both women and men have comparable risks (Aktan-Collan et al., 2011; Carlsson & Nilbert, 2007; Peterson et al., 2003). However, research on how families communicate about Lynch syndrome does find women tend to take on

more responsibility for coordinating information dissemination and provide more support during disease disclosures relative to men (Aktan-Collan et al., 2011; Bartuma, Nilbert, & Carlsson, 2012). These feelings of responsibility and duty are also reinforced based on expectations for family structure and roles regarding gender that mark women as health gatekeepers (Jones, Beach, & Jackson, 2015). In contrast, men often report their intentions for undergoing genetic testing and communicating about hereditary cancer risks are based on alerting their offspring, and they tend to keep their communication to immediate family (d'Agincourt-Canning, 2001; Gaff et al., 2005; Mesters et al., 2005; Rauscher et al., 2018). Furthermore, female family members tend to communicate more with one another about their hereditary risks or genetic test results to provide and receive emotional support as well as to get advice on medical decisions (Gaff et al., 2005; Hughes et al., 2002; Koehly et al., 2008). However, sex is also a barrier to family communication about HBOC as men are often more passive in their communication or actively block and avoid conversations about the family history of HBOC (Koehly et al., 2009; Rauscher & Dean, 2017). As the research demonstrates, expectations related to sex may motivate women to be especially active in managing their own health risks in the case of HBOC and to alerting as well as supporting other family members coping with the family history of HBOC, Lynch syndrome, and LFS.

Age. Another important factor in family communication is age as older generations tend to know more of the family's health history, but are often not as open to having these conversations as younger family members. Families tend to view older generations as responsible for collecting and disseminating family health history

information to younger generations to facilitate preventive health behaviors (Forrest et al., 2003; Ashida et al., 2013). Older family members may feel it is their responsibility to alert younger family members to their risks and provide advice and suggestions on how to manage hereditary cancer risks (Forrest et al., 2003). However, research on family communication about family health history finds older generations can be reluctant to make disclosures about hereditary illness due to concerns regarding stigma or reliving negative memories (Hovick et al., 2015; Yamasaki & Hovick, 2014). Further, older generations may become frustrated if the information they share with younger generation isn't used or when young adults at risk don't go for testing or engage in cancer surveillance behaviors (Bartuma, Nilbert, & Carlsson, 2012). Indeed, younger generations may not have first-hand experiences with hereditary cancers and may not feel a strong sense of risk, which can limit the degree to which they act on information disseminated by older generations about hereditary cancer risks (McCann et al., 2009). However, research demonstrates younger generations have attempted to change older generations' patterns of interaction and secrecy regarding family health history (Hovick et al., 2015; Kaphingst et al., 2012). Younger generations tend to be more open about health information, which allows family health history information to flow more freely so close and distant relatives may act on it (Claes et al., 2003; Kaphingst et al., 2012). Problems arise when younger generations are the only family members sharing this information, which can create a bias in reporting family health history and becoming aware of hereditary cancer risks (Ozanne et al., 2012). Ashida and colleagues (2013) found older generations were more likely to share family health history information with

family members they were relationally and physically close to, and when they believed the information was important and could be acted upon. Thus, age alone is an important variable to consider in family communication about the history of hereditary cancer.

As age of onset for HBOC, Lynch syndrome, and LFS related cancers can be uncertain for family members at risk, how individuals consider when to share risk information with family members is also important to give members time to make reproductive and prevention choices, which are often intertwined for women (Donnelly et al., 2013; Rich et al., 2013; Werner-Lin, 2007). Based on previous research, young adult women with HBOC are motivated to collect information and communicatively make sense of their family history of HBOC to inform their medical decision-making regarding when to pursue prophylactic surgeries (Dean, 2016; Koehly et al., 2009). For Lynch syndrome, these sex differences in age are not as prevalent, but family members often feel a moral duty to disseminate risk information and communicate about Lynch-related health issues so other family members are alerted to their risks and can manage them early (McCann et al., 2009; Mesters et al., 2005; Peterson et al., 2003). Thus, age is an important and complicated factor in studying family communication about hereditary cancer risks. While some older family members may feel a sense of duty to disclose information about the family history of cancer to younger generations, others may prefer to not disclose this information to avoid stigma (Hovick et al., 2015; Peterson et al., 2003; Yamasaki & Hovick, 2014). Finally, younger generations may be motivated to make family communication more open about the family health history to improve information collection and dissemination among members.

Family Communication Characteristics. Finally, the ways in which families regularly interact when communicating about the family history of cancer may be an especially salient facilitator or barrier to family communication about hereditary cancer. First, how individuals define family informs to whom they will communicate with about their family health history (Thompson et al., 2015). Although biological relatedness carries important implications when talking about hereditary illness, individuals may also define family based on social ties, interactions, and proximity (Thompson et al., 2015). How an individual defines family can demonstrate with whom they will interact to share and receive health information and to whom they look to for support. Individuals who are not physically or emotionally close to their biological family may not have access to information regarding the family health history (Aktan-Collan et al., 2011; Ashida et al., 2013; Peterson et al., 2018). Thus, definitions of family and the degree to which members are close can determine who's involved in these conversations.

Beyond definitions and conceptions of family, important family factors also include how engaged and open members are to talk about the history of cancer in the family. Regarding genetic testing and disclosure, probands may be especially active in family communication about the family history of HBOC, Lynch syndrome, or LFS (Hughes et al., 2002; Koehly et al., 2009; Peterson et al., 2003). Probands tend to become information gatherers and disseminators in the family network, and may act as motivators for family members to talk more about their hereditary cancer risks (Koehly et al., 2009; Peterson et al., 2003). If families have members who undergo genetic testing

and openly disclose test results among family members, individuals may have a more accurate picture of their family health history and feel their relational environment encourages open communication and collective sense-making. Indeed, Dancyger and colleagues (2010) found families with a health history of HBOC were either strongly committed to testing or were ambivalent about testing. For the families who were committed to testing, all members had undergone or expressed interest in undergoing testing as a duty to helping the family better understand and manage risks (Dancyger et al., 2010). This sense of duty to the family to get tested and share results is also prevalent in research exploring how families communicate about Lynch syndrome (Palmquist et al., 2010; McCann et al., 2015; Mesters et al., 2005). How families communicate about hereditary cancer is likely related to family expectations for who is a member of the family and an individual's duty or sense of responsibility to participate in these conversations.

Overall, factors related to sex, age, and family characteristics act as facilitators or barriers to family communication about hereditary cancer. Based on previous research findings reviewed here, it is likely sex and age will be related to family communication environments and how members collectively make sense of their family history of HBOC, Lynch syndrome, and LFS through storytelling. Women may be especially important voices in storytelling in this context based on their risks of developing hereditary cancers and due to gendered nature of family health communication (Aktan-Collan et al., 2011; Bartuma, Nilbert, & Carlsson, 2012; d'Agincourt-Canning, 2001; Jones, Beach, & Jackson, 2015). Age is a complicated factor in conversations about

hereditary cancer as older generations tend to have the most information and may feel a sense of responsibility to share, while younger generations likely value and desire this information to manage their risks by engaging in preventive treatments (Forrest et al., 2003; Hovick et al., 2015). Finally, family characteristics regarding how individuals define family and how involved members are in actively managing individual and family risks can create expectations that form the foundation for schemas of family communication (Dancyger et al., 2010; Thompson et al., 2015). Characteristics of family communication about the history of HBOC, Lynch syndrome, or LFS can inform the content of individual retellings of family stories as well as the processes members engage in to jointly tell stories to help the family cope with and manage their risks.

Communicated Narrative Sense-Making

Narratives are communicative constructions including characters, attributing motives to characters, plot (rise and fall of action), and sequences of events situated in individuals' social, historical, and family contexts (Trees, Koenig Kellas, & Roche, 2010). Although stories can be told individually, people usually collaborate with others to jointly tell stories that construct and make sense of relationships and experiences with important relational others (Duck, 1994; Koenig Kellas & Trees, 2005). Indeed, family narratives provide a means for socializing members and creating identity, often in the face of difficult life experiences (Koenig Kellas & Kranstuber Hortsman, 2015). Family narratives can be especially important to study regarding the management of hereditary cancer risks, as family stories provide a way to understand and communicate a family health history (Trees, Koenig Kellas, & Roche, 2010). Patients may give a family health

history of hereditary cancer in a narrative form as stories help individuals organize important information and provide explanation as to the causes of present difficulties (Trees, Koenig Kellas, & Roche, 2010). Narratives not only help family members make sense of hereditary cancer risk, but can also provide an outlet to express emotions and create support with and for other family members. Although much previous work on narrative focuses on the content of stories, Communicated Narrative Sense-Making (CNSM) theory also explores the process and functions of storytelling and their connection to relational well-being and individual health (Koenig Kellas, 2018).

CNSM emphasizes communication as the means of storytelling and narrative sense-making and suggests this process takes place in patterned ways to construct meaning (Koenig Kellas, 2018). CNSM is guided by three heuristics including retrospective storytelling, interactional storytelling, and translational storytelling (Koenig Kellas & Kranstuber Hortsman, 2015). First, this study will explore the content of retrospective storytelling among families with a history of hereditary cancer to examine narrative content may connect to coping, perceptions of risk, and medical decision-making. Using retrospective storytelling, individuals hear and tell stories containing behaviors and values. The first proposition of CNSM theorizes the content of retrospective storytelling exposes individual, relational, and intergenerational mean-making, values, and beliefs (Koenig Kellas, 2018). These values and beliefs, for example, can inform female family members' decisions to pursue prophylactic surgeries and may also create pressure to have children early. For instance, Werner-Lin (2007) found women with a *BRCA1/2* gene variant used experiences with family and

communicated family histories to identify ages at which they would be at the highest risk for developing cancer to make prevention decisions. Moreover, Palmquist and colleagues (2010) found family members' risk perspectives related to Lynch syndrome were influenced by the family stories centered on the cancer history of the family. Further, the stories families create to make sense of their risk may be fragmented as some family members keep pieces hidden or perpetuate misconceptions from media, other family members, and health professionals (Kenen, Arden-Jones, & Eeles, 2003). As families tell stories to cope with and make sense of difficulty, the content of family narratives related to hereditary cancer may demonstrate how members are psychologically coping. Exploring the content of family stories and multigenerational narratives based on the family history of inherited cancer syndromes provides insight into how members are coping, making sense of risk, and how family stories may inform medical decision-making.

Retrospective Storytelling

As individuals face difficult life events such as losing generations of family members to hereditary disease or facing hereditary disease risks, they process, make sense of, and cope with these challenging situations through storytelling (Koenig Kellas, 2015; Pennebaker, Mayne, & Francis, 1997). Specifically, family stories individuals tell and remember are linked to individual and relational identity and well-being (Koenig Kellas, 2005; Koenig Kellas, 2018). Indeed, family stories individuals retrospectively share create personal myths of family, which teach essential life lessons regarding gender roles, family identity, emotions, illness, and self-worth (Koenig Kellas &

Kranstuber Hortsman, 2015; Stone, 1988). As individuals often share family health history as a story, it demonstrates how family members naturally organize family accounts regarding management of hereditary cancer related risks in narrative form (Trees, Koenig Kellas, & Roche, 2010). Exploring how individuals narratively make sense of their family history of hereditary cancer can highlight the stories that are meaningful and significant to the teller, story theme or tone, and how complete and coherent the story is (Koenig Kellas, 2018; McAdams & McLean, 2013). Indeed, stories are a way of expressing identity, making sense of and coping with difficult experiences, and can provide a window into family culture (Koenig Kellas & Kranstuber Horstman, 2015; McAdams, 1993). Overall, the content of family stories about the family history of hereditary cancer can provide links between narrative sense-making and psychological well-being (Baerger & McAdams, 1999; Chung & Pennebaker, 2012; Koenig Kellas & Manusov, 2003). Specifically, this study examines how narrative structures in the content of family stories, such as narrative tone and framing, are connected to coping, perceptions of risk, and medical decision-making.

Narrative tone. Narrative tone reflects the emotional expression or affective tone of the overall story and indicates how the individual is emotionally processing events in the story (McAdams et al., 2001; McLean & Pratt, 2006). Narrative tone can represent the storyteller's core beliefs about the nature of their world (McAdams, 1993). For instance, individuals with a family history of HBOC, Lynch syndrome, or LFS may see their likelihood of developing hereditary cancer as inevitable (Palmquist et al., 2010; Kenen, Arden-Jones, & Eeles, 2004), which may create a negative worldview and limit

their ability to cope. Indeed, Carlsson and Nilbert (2007) found that although family members suspected the hereditary nature of family cancers and believed they would likely get cancer, receiving a diagnosis of Lynch syndrome was still overwhelming, especially if the family health history was marked by multiple deaths. Further, if individuals feel their risk of cancer is inevitable and do not have the emotional resources to cope, they may have low efficacy in pursuing preventive care (Hurley et al., 2006; Koehly et al., 2008). Communicating about the family history of cancer can be a way of providing and receiving social support, which has been found to be negatively related to psychological distress for patients with hereditary cancer risks (Koehly et al., 2008). Emotions both shape and are shaped by narrative tone in retrospective storytelling, and emotions can indicate the perspectives and well-being of the storytellers. Narrative tone may also be predictive of the storyteller's personality and psychological state as narrative tone is related to identity formation, self-acceptance, and life satisfaction (Grossbaum & Bates, 2002; McLean & Pratt, 2006). Specifically, the narrative tone of the stories family members share when talking about their hereditary cancer syndrome can shape their ability to cope, perceptions of risk, and their level of efficacy in pursuing preventive medicine.

Narrative framing. In contrast to overall emotional tone of the narrative, narrative framing is how emotion progresses through the course of the story (Koenig Kellas et al., 2015). Individuals may construct stories in sequences, which are framed as positive or negative. One common narrative frame in previous research is stories of redemption (Koenig Kellas et al., 2015; McAdams et al., 1997). Stories of redemption

may contain experiences involving sacrifices, recovery, and learning. For instance, receiving a positive genetic testing result for a gene variant related to a hereditary cancer syndrome may be perceived as bad news, but finding out risk status and successfully pursuing preventive measures to avoid developing cancer may be a story of redemption and survivorship (Dean, 2016). Indeed, feeling that family members could use genetic testing information to pursue their own genetic testing, surveillance programs, and preventive measures were often cited as reasons why probands shared information about their hereditary cancer syndrome (Aktan-Collan et al., 2011; Mesters et al., 2005). Looking at family communication and management of a hereditary condition as hopeful may promote genetic testing, disclosure, and engagement in preventive treatments. Family members with a health history of cancer may initially feel overwhelmed or upset by the news of testing positive for a gene variant for HBOC, Lynch syndrome, or LFS, but the presence of knowledge about these conditions and access to preventive measures may help families feel empowered and develop the narrative frame.

Another common narrative frame are stories of contamination in which good or benign events become negative (McAdams et al., 1997). For instance, undergoing a bilateral mastectomy to reduce risks of developing breast cancer might be a positive decision an individual makes, but if their family responds negatively and makes the individual feel ashamed, their story of prevention may be contaminated by stigma (Kenen et al., 2007). Further, the process of sharing positive gene variant test results for hereditary cancer syndromes can be burdensome for both the discloser and the recipient of the information (d'Agincourt-Canning, 2001; Leenen et al., 2016; Mesters et al.,

2005). While family members may initially feel relieved to know what is happening with their health, if they cannot access additional resources to understand how to manage their hereditary conditions and family communication is unsupportive, members may feel hopeless about their condition or resign themselves to the idea that they will get cancer (Carlsson & Nilbert, 2007; Peterson et al., 2018). Narrative frames can be linked to depression, life satisfaction, and self-esteem (McAdams et al., 2001). Essentially, narrative framing demonstrates how the storyteller organizes their emotions in the progression of the story. Exploring narrative frames can provide insight into how a family member is coping with their hereditary cancer risks based on if they feel hopeful and empowered or if they feel hopeless, fearful, or resigned. Moreover, narrative frame can reveal risk perceptions as family members may frame their hereditary cancer experience as positive or negative based on their perceived likelihood of developing cancer and their degree of control over their health. Finally, narrative frame can show family members' ability to manage hereditary cancer risks by pursuing preventive measures, as adhering to surveillance programs or pursuing surgeries may create a turning point in the story and shift a story from negative to positive.

RQ1: How do the narrative structures of tone and framing in family stories of hereditary cancer contribute to how families (a) cope, (b) perceive their risks, and (c) make medical decisions?

While content of family stories is important to exploring how family members process and make sense of their hereditary cancer risks, the processes families engage in when constructing family narratives demonstrates how families collectively make sense

of the family history of cancer. Exploring the process of joint storytelling can identify which family members contribute to the family narrative and how family dynamics contribute to narrative sense-making. Using the second heuristic of CNSM theory, this study investigates how family members collaboratively construct and share narratives about the family history of hereditary cancer.

Interactional Narrative Sense-Making

The second heuristic, interactional storytelling, explicitly calls attention to the communicative processes of telling stories. When families collaborate in telling stories and making sense of shared life events they are engaging in interactional sense-making (Koenig Kellas, 2018; Koenig Kellas & Trees, 2006). Interactional sense-making is a dynamic process of jointly or collaboratively telling stories that vary along dimensions including engagement, turn-taking, perspective-taking, and coherence. Exploring process in addition to content is important as, "not only do families tell stories, but storytelling is a way of doing family" (Langellier & Peterson, 2006, p. 100). Further, studies analyzing narratives over the life course find storytelling processes change over time, which changes how storytelling develops, maintains, and dissolves relationships (Jorgenson & Bochner, 2004; Koenig Kellas et al., 2010; Pratt & Fiese, 2004). Previous research finds higher levels of interactional sense-making predict higher levels of narrative sense-making as well as individual and relational health (Koenig Kellas, 2005; Koenig Kellas et al., 2010; Trees & Koenig Kellas, 2009). Thus, the interpersonal process of telling stories demonstrates how the family functions and reflects the relational health of its members (Trees & Koenig Kellas, 2009). For instance, if members are not included in

storytelling about the family history of cancer or their perspective is not acknowledged, they may not feel supported or informed enough to manage their hereditary cancer risks. As the process of creating family narratives about the family history of cancer are of interest to this study, dimensions of interactional sense-making are explicated below including engagement, turn-taking, perspective-taking, and coherence.

Engagement. Engagement reflects the degree to which relational partners communicate involvement and warmth (affection) during storytelling interactions (Koenig Kellas et al., 2010). Involvement includes the liveliness of the storytelling and the degree to which the family as a whole participates verbally in telling the story and shows interest nonverbally (Koenig Kellas & Trees, 2005). If a family member does not participate in discussions about new hereditary cancer diagnoses or blocks those conversations, they may not receive new diagnosis information or receive and provide social support (Koehly et al., 2009). This is an important dimension to explore in terms of genetic testing disclosures. Kenen, Arden-Jones, and Eeles (2004) found some families agree not to talk about cancer or loss of a family member to cancer, thereby directly or indirectly cutting off conversations. In this way, some families may try to hide past family cancer illness or avoid collectively managing hereditary cancer risks. The degree of involvement can also indicate supportiveness in conversations about problems (Koenig Kellas et al., 2010; Trees, 2000), which may provide insight into who in the family provides support and aids in helping members cope with hereditary cancer related risks. However, some family members may engage in blunting behaviors in which they distract or avoid threatening aspects of the story to avoid stress and try to

focus on moving on with life (McDaniel et al., 2006). Engaging family members more in communication and story-telling about hereditary cancer risks may help members pursue testing and bring the family closer. For instance, McCann and colleagues (2009) found younger family members who did not have colorectal cancer experiences did not take their risks as seriously; however, other family members encouraged them to stay involved in the conversation and pursue genetic testing with other relatives so they could go through the process of managing Lynch syndrome as a family.

Warmth on this dimension is the degree to which the family's interaction is characterized by affection and positive affect rather than negative affect or coldness (Koenig Kellas et al., 2010). Warmth may also facilitate collective sense-making as it can create an environment in which members can express themselves and receive positive reinforcement from family (Koenig Kellas & Trees, 2006). For instance, Ashida and colleagues (2013) found individuals tended to communicate about family health history with family members to whom they provide support and feel close. Communicating positive affect or warmth during joint storytelling about the family history of cancer may also demonstrate an environment of relational closeness and emotional support exchange. Further, Hughes and colleagues (2002) found sisters often communicated about *BRCA1/2* genetic test results to obtain emotional support and receive advice regarding medical decision-making. Similarly, Peterson and colleagues (2018) found probands' primary reason for sharing genetic testing information was also to receive support from relatives in addition to alerting relatives of their potential risks. Overall, engagement may facilitate communal coping in which families cooperate in a

reciprocal exchange of support, which can enhance family cohesion and individual as well as relational well-being. Thus, the following research question is posed:

RQ2: How does engagement in joint family storytelling about hereditary cancer shape (a) coping, (b) perceptions of risk, and (c) medical decision-making?

Turn-taking. Turn-taking focuses on how dynamic the process of storytelling is and can be marked by shifts in speech signaling segmented stories or mixed and free-flowing family conversations (Koenig Kellas & Trees, 2005). Turn-taking is likely based on how families view power and hierarchy. For instance, some families may have more segmented processes if parents' voices take precedence over children's voices when stories are told. Indeed, turn-taking has been shown to be important to how families tell stories about hereditary cancer risks. As Koenig Kellas and Kranstuber Hortsman (2015) argue, narratives provide a historical function of uniting family members under a common history, which shapes expectations about the world and the family itself. Hendry and Ledbetter (2017) in their study of genealogical communication and family kinkeepers found older generations (specifically older female family members) pass on meaning regarding family genealogy to younger generations. Similarly, previous research finds older family members tend to dominate family history conversations because they have lived longer and have more personal memories of deceased relatives than younger family members (Lenz, 2011). These findings regarding genealogical communication may also translate to family health history communication about inherited cancer syndromes as these stories contain memories older generations have

experienced. Thus, turn-taking may represent family hierarchy by identifying members who are expected to passively listen and those who are expected to actively participate.

As discussing the family history of HBOC, Lynch syndrome, or LFS can be pivotal in helping members learn of and manage their hereditary cancer risks (Hoskins et al., 1995), inaccuracies or missing pieces of the health history may be a result of a family member not adding their voice to the story (Kenen et al., 2004; Seppen & Bruzzone, 2013). For instance, family members may be left out of storytelling due to their emotional or physical distance from others as is a trend in disclosing HBOC and Lynch syndrome genetic test results (Ashida et al., 2013; Hovick et al., 2015; Hughes et al., 2002; Peterson et al., 2018; Stoffel et al., 2008). Further, previous research finds men in families with a history of HBOC do not often communicate about their own risks beyond passing the gene variant on to offspring (Hallowell et al., 2006; Rauscher et al., 2018). Female family members are more likely to disclose genetic testing results and talk to family members about managing hereditary cancer risks relative to men (Bartuma, Nilbert, & Carlsson, 2012; Koehly et al., 2009; Smith, Zick, Mayer, & Botkin, 2002). Further, Quillin and colleagues' (2006) found individuals tended to know and share more about their family history of cancer on the maternal side relative to the paternal side. Lack of information along the paternal side of the family related to the family history of cancer can limit practitioners' ability to diagnose a hereditary condition (Escher & Sappino, 2000). Findings from previous research exploring communication about the family history of HBOC suggest men may not engage in storytelling in the same ways female family members do, which may limit the accuracy of health history

information and drive men to be more passive in their management of HBOC related risks (Rauscher et al., 2018). Previous research on family communication of Lynch syndrome find men are just as likely to communicate about genetic testing and hereditary information, but often do so with their spouse to help provide support (Aktan-Collan et al., 2011; Bartuma, Nilbert, & Carlsson, 2012). These findings may suggest men are present during storytelling, but gendered family roles during communication about hereditary cancer may determine how involved men are in narrative sense-making beyond disclosing information. For example, women in Lynch syndrome families may take more turns to provide support and help members cope, whereas men may only take turns to simply share information. Limiting family members' turn-taking in storytelling may limit some members' integration with the narrative as their perspectives may not be included or acknowledged. Accordingly, the follow research question is posed:

RQ3: How does turn-taking in joint family storytelling about hereditary cancer shape (a) coping, (b) perceptions of risk, and (c) medical decision-making?

Perspective-taking. The extent to which families attend to and confirm one another's perspectives verbally and nonverbally is perspective-taking (Koenig Kellas & Trees, 2005). Being attentive to another member's perspective includes acknowledging their viewpoints and integrating their perspectives to create the story. Confirming perspectives is when family members make statements affirming the validity of the others' perspectives. Previous research links communicated perspective-taking to perceptions of support, family satisfaction, cohesion, and adaptability (Koenig Kellas et al., 2010; Trees & Koenig Kellas, 2009). An important distinction to perspective-taking

is family members do not necessarily agree with another's point of view, but rather try to empathize with how the other describes their perspective (Koenig Kellas & Trees, 2005). Previous research finds family communication about HBOC risk and genetic test results tend to occur among women and family health history reporting tends to be more representative of maternal relatives (Claes et al., 2003; Koehly et al., 2009; Ozanne et al., 2012), which may suggest men's perspectives are often not included or solicited in family communication about HBOC. If hereditary cancer narratives in families do not include multiple members' perspectives, they may have less validity or meaning to members. Indeed, Rauscher and Dean (2017) found women with a *BRCA1/2* mutation who encountered ignorance or insensitivity regarding their healthcare and family planning choices would shut down communication and no longer make disclosures to friends and family. These findings suggest members may avoid communicating about hereditary risks or invalidate different perspectives and create more conflict with emotionally distant family members. Creating room and sensitivity for multiple perspectives to be heard and incorporated in family storytelling regarding hereditary cancer may create family narratives that are more inclusive and have more weight in helping members make sense of their family hereditary cancer risks. To examine perspective-taking in family stories of hereditary cancer the follow research question is posed:

> **RQ4:** How does perspective-taking in joint family storytelling about hereditary cancer shape (a) coping, (b) perceptions of risk, and (c) medical decision-making?

Coherence. The family's ability to incorporate multiple perspectives into a cohesive narrative contributes to narrative coherence. Coherence is the extent to which the structural characteristics (characters, plot, sequence of events, attributions) of the story are integrated together in a way that makes sense (Koenig Kellas et al., 2010). This dimension of interactional sense-making is determined by the story's organization and how well the story is integrated into family communication. Organization refers to the extent the overall story is logically and sequentially organized, which includes distinguishable parts of the story with little jumping from one part to the other (Koenig Kellas & Trees, 2005). For example, family members may have a difficult time interpreting and accurately recalling their diagnosis when trying to communicate about risk to the family, which can create inconsistencies and confusion as family members try to joint tell stories about complex genomic medical information (Gallo et al., 2009; Lloyd et al., 1996). Confusing or incomplete risk information may distort the logical organization of family narratives about hereditary cancer as families come together to create a shared understanding and larger meaning for this health threat.

Integration refers to whether family members tell a single, intertwined story that makes sense or "hangs together." For instance, Kenen, Arden-Jones, and Eeles (2004) found families followed scripts including blocking and indirectly blocking, in which members censored conversations about HBOC. If members are engaged in blocking family narratives about hereditary cancer they are not integrating their stories with others in collectively making sense of hereditary cancer risks. Incoherent family narratives tend to be conflictual, with individually coherent stories competing with one another (Koenig

Kellas & Trees, 2005). Further if the family narrative is incoherent, it will not provide the existential explanations and ways of making sense of illness family members seek (Frank, 1998; Kenen, Arden-Jones, & Eeles, 2003). Indeed, Carlsson and Nilbert (2007) found experiences with genetic testing and family communication of risk had implications for how individuals coped by shaping whether they accepted their risk status. Additionally, competing individual narratives may confuse and overwhelm family members just beginning to understand their risks.

RQ5: How does coherence in joint family storytelling about hereditary cancer shape (a) coping, (b) perceptions of risk, and (c) medical decision-making?

Interactional sense-making behaviors provide a way to break down family narratives and better understand how family narratives of hereditary cancer form and change, as well as how individual members perceive their role in those narratives. For instance, with each new diagnosis or hereditary cancer experience in the family, the narrative may expand and shift to take in new perspectives from more family members (McDaniel et al., 2006). Further, receiving a diagnosis related to HBOC or Lynch syndrome may connect a family member more intensely and personally to the family narrative (Werner-Lin & Gardner, 2009). Previous research demonstrates family narratives can perhaps have a larger impact on medical decision-making than medical recommendations as these stories can help members manage complex medical options (Palmquist et al., 2010; Babb et al., 2002; Werner-Lin, 2007). Overall, family narratives and interactional sense-making can demonstrate family cohesion and support, which can improve mental and physical health outcomes (Koenig Kellas, 2005; Trees & Koenig

Kellas, 2009). Further, the process of narrative construction through interactional sense-making can represent patterns of communication and socialization in families as well as represent relational health.

Finally, the third heuristic, translational storytelling, uses both methods of meaning making through interactional storytelling and the content of the narrative from retrospective storytelling to create and test narrative-based interventions. Narrative-based interventions aim to improve quality of communication and relational functioning to improve well-being (Koenig Kellas, 2018). For instance, writing or talking about difficult life experiences as a family provides physical and mental health benefits (Charon, 2006; Koenig Kellas, Castle, Johnson, & Cohen, 2016; Frattaroli, 2006). In particular, researchers in narrative psychology and narrative therapy argue the chance to tell and reframe stories of stress, trauma, and difficulty promotes coping and resiliency (Pennebaker, 1997; White, 2007). Thus, this study can inform narrative-based interventions aimed at improving individual and family sense-making of the family history of HBOC, Lynch syndrome, or LFS. Specifically, this line of research can provide practitioners with insight into how families can shape individual perceptions of risk and decisions as well as how to communicate and counsel families with HBOC, Lynch syndrome, or LFS. Further, exploring the connections between family narrative sense-making and health outcomes can help practitioners identify the ways in which family influences individual health behaviors.

CHAPTER III

METHODS

Participants

Upon receiving Institutional Review Board approval, this study used purposive and snowball sampling to recruit subjects who have a prevalent family health history of hereditary cancer (Biernacki & Waldorf, 1981; Lindolf & Taylor, 2011). Participants were asked to recruit a family member to complete a joint phone interview. According to the National Cancer Institute (2013) an individual has a prevalent family health history of hereditary cancer if s/he has three or more blood family members with specific types of cancer that seem to be inherited (especially early onset) or if an individual has cancer at an early age (especially multiple forms of cancer in the same person). A prevalent history can also include a known pathogenic gene variant in a cancer susceptibility gene within the family (NCI, 2013). Thus, subjects were recruited through advocacy organizations that aim to bring people with hereditary cancer together for informational and support purposes such as FORCE (Facing Our Risk of Cancer Empowerment), Bright Pink, Lynch Syndrome International, Colon Cancer Alliance for Research and Education for Lynch Syndrome, Li-Faurmeni Syndrome Family and Friends Support Group, and the Hereditary Cancer Foundation. These advocacy groups shared recruitment information about the study on their social media pages and through regular email newsletters. Further, subjects were also recruited from the 7th Annual Hereditary Breast and Ovarian Cancer Patient Conference at the Baylor College of Medicine

Medical Center in Houston, Texas as well as the 11th Annual FORCE Conference in San Diego, California.

In total, 42 family dyads (84 individuals) completed joint phone interviews and follow-up surveys. Participants were 63 females and 21 males ranging in age from 18 to 76 years old (M = 46.13, SD = 13.88). Family dyads consisted of 12 husband-wife pairs, 9 mother-daughter pairs, 5 father-daughter pairs, 1 mother-son pair, 1 father-son pair, 9 sisters, 1 brother-sister pair, 2 aunt-niece pairs, 1 cousin pair, and 1 pair of close friends who identified one another as family. Of the 42 family dyads in the study, 22 dyads were composed of two affected family members and 20 dyads were composed of an affected family member and an unaffected family member; however, 3 of the affected-unaffected dyads had a member who had not yet been tested. A large majority of participants were Caucasian (89.30%), with 8.3% self-identifying as Hispanic, 1.2% as Asian, and 1.2% as Middle Eastern. Participants reported an annual household income of less than $25,000 (7.10%), $25-50,000 (13.10%), $50-75,000 (14.30%), $75-100,000 (11.90%), more than $100,000 (38.10%), and 15.50% preferred not to answer. Six percent of participants reported having graduated high school, 14.50% had some college, 12% had an associate's degree, 25.30% had a bachelor's degree, 37.30% had a graduate or professional degree, and 4.80% preferred not to answer. Of the 84 individuals in the study, 67 participants had been tested for a pathogenic gene variant. One participant reported having an *NBN* variant, 14 had *BRCA1*, 11 had *BRCA2*, 1 had *PALB2*, 4 had *TP53*, 3 had *CHEK2*, 11 had *EPCAM*, 4 had *PMS2*, 5 had *MSH6*, and 3 had *MLH1*. Participants also reported having breast cancer, fallopian tube cancer, endometrial

cancer, uterine cancer, ovarian cancer, prostate cancer, colon cancer, bladder cancer, kidney cancer, ureter cancer, melanoma, squamous cell carcinoma, adrenal cancer, and rectal cancer. Nine participants reported having more than one type of these cancers in their personal health history. Time since diagnosis for participants who had cancer ranged from 2 months to 240 months (M = 87.72, SD = 70.97).

Procedures

After agreeing to participate in the study, subjects recruited a family member and scheduled their joint phone interview at their convenience. In-depth phone interviews were conducted in a semi-structure format beginning with the prompt, "Please tell the story of your family's experience with hereditary cancer, and try to tell it to me as if I'm a family member who does not know much about this history." Answers to this question helped establish that participants had a prevalent family health history of hereditary cancer and encouraged dyads to share the family narrative of hereditary cancer. Previous research demonstrates individuals often talk about their family history of hereditary cancer as a story (Trees, Koenig Kellas, & Roche, 2010; Kenen, Arden-Jones, & Eeles, 2003). When applicable, dyads were asked to tell a story that they may have told together at some point to increase ecological validity (Koenig Kellas et al., 2010). Thus, open-ended questions were constructed to capture family health history information and motivate participants to provide information in a story format. Other interview questions included, "Can you each describe an important memory you have about how you or a family member managed cancer or the risk of cancer?" and "How have you seen the history of hereditary cancer affect your family members emotionally?" Probing

questions supported a conversational yet structured interview with family dyads. Dyadic interviews were audio-recorded and transcribed, lasting an average of 38 minutes. Transcripts resulted in over 500 pages of single-spaced interview data. At the end of interviews, participants were debriefed and thanked for their participation. Further, once the family dyad completed their interview they were each sent a link to an online follow-up survey to answer demographic and background questions. Upon completion of the survey, each family member received a $20 Amazon Gift Card. Appendix A contains the interview schedule and survey items used in the online follow-up survey.

Data Analysis

As this study focuses on both narrative content and the process of joint family storytelling about hereditary cancer, data was analyzed qualitatively using a phronetic iterative approach that alternated repeatedly between emergent data and past research (Tracy, 2012). This inductive approach focuses on refining analysis over time to narrow explications and situate findings in the current literature, adding to understandings of the phenomena (Ellingson, 2013). This approach was further informed by definitions of the narrative components of retrospective storytelling and interactional sense-making provided from previous research on CNSM (Koenig Kellas & Trees, 2005; Kranstuber Hortsman et al., 2015). The goal of this data analysis was to provide rich descriptions of each narrative construct and overarching themes without fracturing narrative accounts (Riessman, 2008). This is a novel approach in the CNSM literature, as previous research rates narrative behaviors from participant accounts to quantitatively test relationships between narrative and relational outcomes (Koenig Kellas et al., 2010; Kranstuber

Horstman et al., 2015). By examining themes and trends for both content and the process of storytelling, this study explicates how components of narrative sense-making contribute to coping, perceptions of risks, and medical decision-making. This approach worked well for discovering how narrative tone contributed to framing, defining themes among narrative frames, and examining trends between frames and outcomes (RQ1). Additionally, open-coding for interactional sense-making behaviors in dyadic interviews provided insight in examining trends among psychological and physical outcomes and joint family storytelling (RQ2-5).

While CNSM uses rating schemes for both the content and process of narrative sense-making, the data in this study was not scored or quantitatively linked to outcomes. Rather, previous CNSM rating schemes provided in-depth and thick descriptions of narrative sense-making behaviors, which were used to openly code family narratives for themes. In this way, themes were not imposed on the data and rather emerged from family narratives (Charmaz, 2014). Open coding began by journaling initial thoughts regarding emerging themes, prevalent family storytelling behaviors, and health outcomes after interviews (Tracy, 2012). After all interviews were transcribed, the author read through each dyadic family narrative to gain a holistic understanding of the stories participants constructed, noting further key examples and emerging themes (Smith, 1995). Then the researcher both read and listened to dyadic family interviews again to identify first-level and second-level themes related to narrative sense-making and individual as well as family well-being outcomes such as coping, perceptions of risks, and medical decision-making (Tracy, 2013). Themes were selected and explicated below

using Lindolf and Taylor's (2002) data management, reduction, and conceptual development process to stay focused on the most important themes for the goals of this study. Using the constant comparative method, the researcher made sure codes fit the data and were representative of family narratives within and across family interviews (Charmaz, 2014). Open coding based on narrative sense-making behaviors and themes are detailed further below. Open coding led to a hierarchy of themes using code books to manage data for this study (Ryan & Bernard, 2003). Data collection ended upon reaching theoretical saturation, in which participant interviews provided rich contributions to the research goals of the study and responses became similar with no new or emergent data (Glaser & Strauss, 1967; Tracy, 2013).

Retrospective Storytelling Analysis. The content of dyadic family interviews was openly coded using the retrospective storytelling dimensions of *narrative tone* and *narrative frame* (Kranstuber Hortsman et al., 2015). *Narrative tone* was assessed using Kranstuber Hortsman and colleagues' (2015) code book of individual narrative sense-making for retrospective storytelling. First, the content of family stories was coded for the degree to which participants expressed positive affect or negative affect. For instance, a story that had a higher degree of negative affect was defined as one with a depressed or despondent feel, in which participants expressed negative emotions such as crying or yelling while jointly telling their stories. On the other side of the spectrum, stories with a higher degree to positive affect were defined based on content that was cheerful or glad, in which participants were laughing or upbeat during interaction.

Family narratives were not scored, but rather categorized based on the degree to which they communicated positive or negative affect.

Narrative frame refers to the way in which participants frame or shape the story (i.e., a story of redemption or survival, and a story of contamination). Using definitions of positive and negative frames created by Kranstuber Hortsman and colleagues' (2015), redemptive sequences are defined as stories that end on a positive or hopeful note. In contrast, stories using contamination sequences are those in which a storyteller may begin positive, but the story concludes in a negative light. Stories that are neither redemptive nor contaminated are defined as ambivalent (Koenig Kellas et al., 2015). Although these definitions were used to classify frames as redemptive, contaminated, or ambivalent, findings during open coding for frames led to developing and refining more nuanced framing categories that best fit the emergent data. Appendix B includes the codebook for retrospective storytelling behaviors.

As the researcher examined the emotional sequence of events in joint family stories, general categories of frames that were prevalent across dyadic family stories about hereditary cancer were developed. These prevalent frames include empowerment, contamination, laissez-faire, and competing frames. Important themes for frames were determined using Opler's (1945) description that important themes occur often, are pervasive, and challenge dominant themes. During second-level coding, the author drew from the theory of CNSM to refine first-level codes such as redemptive frames, into overarching themes and labels such as empowerment (Tracy, 2013). Labels for these framing categories were developed as participants described feelings, behaviors, and

ideas that fit certain themes and sub-themes. This labeling system moved analysis from first-level codes to second level-codes with rich descriptions of themes given below anchored by specific narrative examples to provide transparency for the reader (Tracy, 2012). Further, in examining prevalent frames among dyadic interviews, the researcher also identified trends between the ways in which families were framing their narrative and psychological and physical outcomes.

Interactional Sense-Making Analysis. As Gubrium and Holstein (2009) contend, narratives are constructed in discernable patterns and formats. Thus, data from participants' joint storytelling was analyzed using definitions from the Interactional Narrative Sense-Making Rating System (Koenig Kellas & Trees, 2005). To explore the degree to which family members engaged in interactional sense-making behaviors, the author listened to audio-recordings of family interviews in addition to studying the transcript to determine the trends in *engagement*, *turn-taking*, *perspective-taking*, and *coherence*.

Each interactional sense-making behavior was openly coded based on the definitions provided by Koenig Kellas and Trees (2005) to examine sense-making trends and themes related to coping, perceptions of risk, and medical decision-making. *Engagement* is made up by the degree of involvement and warmth expressed by each member of the dyad. *Turn–taking* is comprised of the dynamism of the turn-taking between members of the dyad and the distribution of turns. *Perspective–taking* includes the degree to which each individual is attentive to and confirming of the other's perspective. *Coherence* includes how logically organized the narrative is and the degree

to which it integrates multiple stories. Thus, each family interview was analyzed and openly coded based on how high or low dyads were in each sense-making behavior during storytelling. Rich descriptions of each behavior in interactional sense-making are given below with examples from the data to explicate how joint family storytelling trends were connected to themes in coping, risk perceptions, and medical decision-making. In this way, analysis alternates consistently between theoretical definitions of interactional sense-making behaviors provided by previous research and family storytelling interview data. This inductive analysis method helped the researcher better categorize dyads based on their sense-making trends and themes related to the outcomes they communicated in the narrative. Appendix C includes the codebook for ISM definitions.

CHAPTER IV

RESULTS

The purpose of this study was to explore the ways in which families tell stories about hereditary cancer, results first illustrate how family members use narrative tone and framing during retrospective storytelling about their hereditary cancer experiences. Further, this study draws connections among the narrative tone and frames families use that shape how individuals cope, perceive their risks, and make medical decisions (RQ1). Developing a better understanding of how families use emotions and develop frames can better help in designing interventions to help families re-frame stories to promote improved health outcomes related to psychological and physical well-being. Next, this study looks at the process of collaborative storytelling in family dyads. Using interactional sense-making behaviors such as engagement (RQ2), turn-taking (RQ3), perspective-taking (RQ4), and coherence (RQ5), this study explores how these sense-making behaviors shape coping, perceptions of risks, and medical decisions. Exploring trends among each behavior of interactional sense-making in joint storytelling can help practitioners identify the dominant storytellers in the family, when families need psychological resources to communicate about hereditary cancer experiences, and how to create narrative interventions to help family members better manage their risks.

Retrospective Storytelling

The ways in which family members construct the content of family stories can show how members are emotionally processing their risks of hereditary cancer and

constructing a larger narrative to give meaning to their experiences and feelings. Narrative tone, or the affective tone of the overall story, can contribute to how family members frame their hereditary cancer narrative (Koenig Kellas et al., 2015; McAdams et al., 2001). These narrative structures can provide insight into storyteller's psychological state and what they understand regarding their risks for developing a hereditary cancer. Such content can also show how family members make medical decisions to manage their risks such as pursuing genetic testing, engaging in preventive screenings, and undergoing prophylactic surgeries. Common frames throughout the results included empowerment, contamination, laissez faire, and competing. Each frame speaks to how the family is coping, perceiving their risks, and making medical decisions to manage their hereditary cancer syndrome.

Empowerment. Families engaging in the empowerment frame during storytelling tended to stress how knowledge about their gene variant and hereditary cancer syndrome gave them power and a sense of control over their risks, which helped them to better cope with their diagnosis. Families that stressed empowerment often spoke about becoming their own advocates with their doctors to make sure they were getting their necessary screenings and helping educate other family members about their risks. For example, Susan (mother, 58, *BRCA2*) and Charlotte (daughter, 33, *BRCA2*) talked how knowing about their risks and being proactive helped them cope better:

> Susan: There's the good thing about knowing, obviously, in the knowledge that we have to be able to go out and research the different treatments and screenings that are available, and to find those care providers that are specific in just the

> BRCA gene. I feel it's more important than just finding somebody who is well known within just breast cancer or ovarian cancer. Someone that understands the genetics behind, the causes, and the reactions of what we have and how one interrelates into the other. To be proactive with your screening is, unfortunately, but fortunately, how I found that not only did I have the genes but then discovered that I had a very aggressive tumor, hence, the breast cancer from them. We would never have known if we did not have genetic counseling.
>
> Charlotte: My response would be pretty similar. Just knowing that you have it, I feel like it's more than half of the battle because it's not something that I think about every day. But I am glad that we have doctors that are looking out for us and are very knowledgeable with the topic and are constantly keeping up with new research so that I don't necessarily have to. Just knowing that I'm being screened and that there are preventative measures that we can take to decrease the risk is helpful.

In this example, Susan, Charlotte's mother, feels emotionally conflicted because the diagnosis of a BRCA gene variant and Susan's cancer diagnosis were emotionally difficult, but having answers about their hereditary condition and having the ability to be proactive creates more positive emotions and better coping. Overall, Susan and Charlotte's narrative had positive narrative tone, which created the empowerment frame. This frame motivates family members to get genetic testing, to learn more about their risks, to be proactive about their preventive care, and find doctors they feel suit their needs. Indeed, both Susan and Charlotte pursued genetic testing right away when their

doctors recommended genetic counseling. Charlotte also pursued preimplantation genetic diagnosis to eliminate future risks for her children.

Overall, this frame of empowerment is also passed on to younger generations who may be just coming to understand their risks. For instance, Blair (daughter, 27, no gene variant) discussed this frame as something she grew up hearing from Liz (mother, 55, *BRCA2*) when they talked about Blair's future risks before she got tested:

> Blair: I think my mom's approach was very like, "Learn, as much as you can about it. And know as much as you can about it and make an informed decision about it."
>
> Liz: Information is power. That's my motto. Information is power.

Learning and gathering more information is a form of coping for Liz as it gives her a sense of control because she often talked about a BRCA gene variant as previously being a "death sentence" in her family. Liz also says, "I was always really vigilant if I had a lump, I went in, I got mammograms when I was 20 something" and pursuing other preventive screenings before she knew she had a gene variant. Further, Liz pursued prophylactic surgeries after her breast cancer and *BRCA2* diagnoses, and talked about warning her children about their risks. Indeed, Liz successfully passed this information on to Blair and stressed the importance of knowledge to her daughter through such framing. Throughout the story, Blair discussed speaking with a genetic counselor about testing and the implications of having a positive result years before testing for a BRCA gene variant to better prepare herself. Now that Blair knows she does not have the gene variant, Liz and Blair said they believed "the risk stops here." Having this type of frame

used in family narratives about hereditary cancer can help future generations be proactive in learning about and managing their risks.

Finally, beyond knowing about gene variants and having preventive options in general, some family members were thankful that they were the ones to get hereditary cancer to help alert other members to their risks. Many family members felt empowered that they had overcome cancer and became an advocate in their family for sharing risk information. For instance, Casey (32, sister, *EPCAM*) said to Laura (32, sister, *EPCAM*) that she was glad she got cancer and feels she saved Laura's life:

> Casey: I think that there's going to be some anxiety involved. I have a little PTSD every year when I wake up for my scope being like, "Oh my God, are they going to find something?" Because the first time I ever had one they found something. I think it's just like you need to be your own advocate and make sure that you're getting the testing and probably be a healthier person because of it.
>
> Laura: I think being really proactive about testing and knowing the hand we were dealt-
>
> Casey: I know it's frustrating for me when family members don't take that approach. I want to do something about this. I want to be proactive and look for it and get screened appropriately or get tested. I'm like, "What's wrong with you? This isn't a death sentence." If you don't know, it could be because you're not--I remember telling my mom one time, not that I'm glad I had cancer, but if somebody had to have it among our siblings, I'm glad it was me because I'd already had my kids. Financially and local support, [my husband and I] were

> probably in the best position to have people help us. Me finding out probably it's like, it saved Laura's life because she could have had another kid been pregnant and had no idea.

In this example, the frame Casey and Laura use echoes the importance of becoming your own advocate and getting informed to better manage health risks as seen in previous examples. However, Casey also talks about feeling frustrated with family members who don't actively manage their risks because they feel it's a death sentence. While she and her sister feel anxiety about when they might get cancer, their narrative tone overall is positive because they focus on being proactive and taking control in the face of that anxiety. Moreover, not framing this condition as a death sentence reflects their perceptions of risk for Lynch syndrome. While this condition absolutely increases their risks of developing a Lynch-related cancer, it does not mean that they will die, especially if they manage their risks through prevention. Casey followed her doctor's recommendations to undergo a proctocolectomy (removal and reconstruction of the small intestine) and a prophylactic hysterectomy after receiving her colorectal cancer and Lynch syndrome diagnoses. After Casey's genetic test results and surgeries, Laura chose to undergo genetic testing. Near the end of their story both Casey and Laura agree that they are lucky to get a Lynch syndrome diagnosis because with their preventive screening options available they feel "better off than the general population." Casey goes further by framing her colon and endometrial cancer experiences as something positive for the family since she feels she and her husband were the best equipped to manage the cancer diagnoses and she was able to alert her sister and other members to their risks.

Among family narratives using the empowerment frame, members focus on knowledge, being proactive, and focusing on positive emotions such as gratitude. While narratives tended to start with negative emotions such as anxiety, shock, and fear, they reached a turning point when family members felt they could control their risks by being proactive. These narratives also tended to have positive narrative tone, which suggests these families are coping well. Further, as this frame stresses being proactive and making preventive medical decisions to control risks, these narratives motivated family members to follow recommendations regarding prevention and treatment and to make healthy choices. Indeed, being medically proactive and informed about risks helped these family members to feel they had more control and better manage their anxiety. Thus, the empowerment frame helps family members better cope emotionally with their health risks and motivate informed medical decision-making.

Contamination. Families using a contamination frame told stories about how their perceptions of risks caused (1) intrusive thoughts about developing cancer and (2) how cancer had consumed and ruined their lives. These families expressed their difficulty in coping with their lifetime hereditary cancer risks and often felt overwhelmed by anxiety, which motivated family dyads to be proactive or avoidant in managing their risks. Families that engaged in this frame had often watched generations of family members suffer or die due to their hereditary cancer, which made the risks of developing a life-threatening cancer seem almost certain.

Feeling that a cancer diagnosis was certain, even if participants were engaging in preventive screening and prophylactic surgeries, often made at-risk family members feel

helpless in controlling their risks and caused intrusive thoughts. For example, both Paige (sister, 48, *TP53*) and Nancy (sister, 48, negative for gene variant) felt certain that they were going to get cancer, but when Paige lost her daughter and found out she had Li-Fraumeni syndrome it increased their anxiety:

> Paige: I think, for me, cancer wasn't anything surprising, and I knew I was always going to get cancer. I just had that feeling, and I ended up getting cancer, a breast cancer, in 2013. It was just caught very early during a mammogram, and actually, it was stage zero. I elected to have double mastectomy, which is probably the best decision I could have made, because last year my daughter, who was 29, she had just given birth to her third son, my third grandchild. A few weeks later she was diagnosed with stage four sarcoma. That was very unexpected, very surprising, and it happened very quickly. She passed away 10 weeks later. That's when we found out we had the genetic mutation, and my immediate family basically got tested, and I'm positive, my brother's positive, my nephew is positive, and my grandson is also positive, one of my grandsons.
>
> Nancy: Just to pick up on some of the things that Paige said. She said that we have a lot of history on both sides of the family. I always felt the same way she did. I haven't had any cancer, but I always feel like, and I still feel like, even though now that I know that a lot of the cancer in my family was caused by this Li-Fraumeni syndrome I still feel like it's probably inevitable that I might get some sort of cancer at some point in my life.

Since Paige's cancer and her daughter's death, Nancy and Paige have experienced intrusive thoughts about their risks of cancer, which was why Paige chose to have a double mastectomy and reduce her risks of a breast cancer reoccurrence. Further, Paige's anxiety about her hereditary cancer risks were confirmed through a traumatic experience in which her daughter developed an aggressive cancer and died. As Paige shares her family story of hereditary cancer the narrative tone is very serious and melancholy with Paige crying while explaining what happened to her daughter. Nancy too feels the threat of cancer is inevitable even though she does not have a gene variant for LFS, which also shows she is still experiencing intrusive thoughts about cancer with a negative result. This frame motivated both Paige and Nancy to make proactive medical choices to reduce their risks of developing cancer or improve their chances of catching cancer early. While they have each other to talk about their emotional hereditary cancer experiences, both were having difficulty emotionally coping with their future risks. They both discussed feeling worried about other member's risks and who else they might lose to cancer. Other family dyads such as Britney (niece, 41, *BRCA2*) and Sarah (aunt, 71, *BRCA2*) also felt developing cancer was inevitable due to their family health history:

> Britney: I think that it's something that like my cousin and I have always said. Growing up we knew that we were going to get it one day.
>
> Sarah: I didn't know that growing up. But after my mother and all of her first female cousins, every one of my mother's first female cousins had breast cancer on her mother's side. My mother's sister had it also. I also like Britney at that point waited, knowing. When I first felt a little pain in my breast, it was amazing

because it was just a little pain. I said, "I have breast cancer", and I called the doctor and said, “I have breast cancer.” I don't know if it's fulfilling-

Britney: -No, I mean the same thing. At one point I knew once when I was positive for the mutation and then I went, I was having my screening done and I had a mammogram, is the first time ever, they called me back in for a second round of, then they said we’re going to do an ultrasound and I was like, “Well, that's it.”

Although Sarah did not share Britney’s expectations in her youth for developing cancer, when she did get breast cancer the diagnosis did not surprise her. Further, they have both watched generations of female family members develop breast cancers, which increased their perceptions of risk. Moreover, both later talked about engaging in preventive screenings and prophylactic surgeries because the risks of developing additional cancers felt so real to them. Overall, their narrative had a more negative emotional tone because although this is a diagnosis they have come to terms with, they still experienced persistent negative emotions regarding their personal health experiences such as anxiety and loss. For example, Sarah and Britney go on to describe how they feel their bodies are betraying them and how their worry about developing cancer is always in the back of their minds:

Sarah: -but it's always in the back of your mind, especially if somebody has something, all of a sudden it yanks you back in, "All right. This is something I'm going to have." And because the BRCA mutation does allow more aggressive recurrence, when people ask me how long ago I was diagnosed, I do this very

idiotic thing where I go, "I don't remember. I don't know the date." Of course, I know the date. I have the exact minute. "I don't know how long it's been." Because it's like saying to me, "You're still alive? How much longer do you have?" I know that if it does recur, we have a very high rate of recurrence. It's going to be more aggressive. My brother's cancer is incredibly aggressive. It's like your body is betraying you-

Britney: -I say that all the time. I always say that. I always say, "I feel like my body is betraying me." I also feel like my body is trying to age me so much beyond-- 36 years-- now I'm not 36 but I was 36 and I had a hysterectomy and I mean I had my ovaries removed and I was 36 years old and all of the things that go along with that where-- and I feel like my body has just aged so far beyond my actual years.

In this example, Sarah discusses lying about if she remembers when she was diagnosed because she feels like the questions from friends and family about the time since her diagnosis brings up her mortality. As Sarah points out, the risk of reoccurrence is great for those with an HBOC-related gene variant so she and Britney are not only dealing with emotions from their previous breast cancer diagnoses, but also with emotions about their future risks of developing more cancers as well as the physical and emotional toll prophylactic surgeries have taken on them. Although they discussed making proactive medical choices such as prophylactic surgeries to prevent the onset of cancer, they did not feel in control of their bodies or their risks. They both discussed the feeling that their

bodies are letting them down, which illustrates they are not coping well emotionally with their hereditary cancer risks.

Beyond experiencing intrusive thoughts, some families using a contamination frame frequently discussed the feeling that cancer and the fear of developing cancer was consuming and ruining their lives. For example, Clair (daughter, 33, *EPCAM*) discussed with Hank (father, 63, *EPCAM*) how learning she had Lynch syndrome and endometrial cancer threatened her dreams of having a family and changed her as a person:

> Clair: Now, kind of like what my dad was saying, I feel like I'm always just waiting for something else bad to happen. For me everything's really new right now, I'm trying to be positive even though I don't think I'm doing a really good job with it. It's just hard because I feel like I've changed as a person. I don't know if it's just temporary because of everything but I just don't know if I'll be able to, in a way I guess, live my life the same because I'd like to think with most people that typically you're not going around worrying about the next time you're going to get sick. I didn't feel that way before all this and now I do accept to a point, am I doing something that's going to maybe cause cancer? I'm trying to control it as much as I can, even though I know I probably can't. It's just weighing on my mind all the time.

Clair was recently diagnosed a few months after getting married and got tested only so her physicians could rule out a hereditary condition, but she was not emotionally prepared for a positive Lynch syndrome result. Much like her father was recounting earlier, she now tends to expect bad things to happen to her since being diagnosed and is

waiting for the next struggles to come. Overall, she and her father had a negative narrative tone because of their difficult and unexpected cancer experiences and how those diagnoses significantly changed their lives and expectations for the future. While Clair was still early in coming to terms with and managing her diagnosis, this narrative frame in her family story limits her psychological adjustment and ability to cope long term, especially if "something else bad" happens. As Clair brings up "the concern weighing on her mind all the time" illustrates the intrusive thoughts a hereditary cancer diagnosis can cause and further demonstrates the sense of helplessness in the contamination frame. The feelings this frame reflect are why some family members might put off genetic testing or other medical decisions related to managing hereditary cancer risks. In another family dyad, this hesitancy to get tested was justified using the contamination frame. For example, Nicole (niece, 50, not yet tested) and Beth (aunt, 68, variant of uncertain significance) have relatives with Lynch syndrome along with a prevalent family health history of breast and endometrial cancers. However, Nicole did not want to get genetic testing though she had ovarian and colon cancer diagnoses at a young age because she could not bear dealing with more cancer and the worry it brings:

> Nicole: At some point, there was some discussion about there being a genetic link given family history and the type of cancer. They talked to me about doing some genetic testing, and I talked to one of the nurses who was going to be my contact person for that. Some extended family had gotten the testing done, genetic testing, and there was some mention of Lynch syndrome. They talked to me about that specifically and about my feelings about testing and I asked, "What

> would be the pros of that? What would be some other reasons that that would be helpful to me?" They talked about, well, then we could do screeners to look for additional cancers within that syndrome I guess. I decided not to do it because I felt like I didn't want cancer to just be this consuming thing for my life. I just didn't want it to be this all-consuming thing where I'm constantly screening for cancer, I mean, with the anxiety, I had some symptoms. I've noticed some symptoms in myself, it was like post-traumatic stress and so just having to really work through that to kind of begin to feel safe again and feel okay, so that when my body is feeling some little twerk, I'm not like, "Oh my gosh, what's going on?" If that makes sense. I just felt like the screening, that whole process was going to lead to cancer being this all-consuming thing, and it's constantly going to be a part of my life.

Nicole's persistent anxiety while dealing with these cancers were traumatic for her and the thought of having life-long hereditary cancer risks made it challenging to cope. Because she perceives the outcome of the genetic testing results will be difficult to cope with, Nicole is motivated to avoid genetic testing although she knows other family members have Lynch syndrome. Interestingly, after Nicole's explanation as to why she does not want to get genetic testing, Beth disclosed to Nicole that she recently had genetic testing after dealing with uterine cancer and received a variant of uncertain significance result but that, "I really appreciate the process, and I did meet with the genetic counselor twice. I have to say it was very, very thorough and a good experience." Nicole never responded to Beth's disclosure during the interview, which

further demonstrates her avoidance of this topic due to her fear of testing positive. The narrative tone throughout their family narrative is quite negative and highly emotional as Nicole recounted her experiences and feelings managing multiple cancers at a young age. The tone and frame throughout Nicole and Beth's hereditary cancer narrative demonstrate how too much fear and a lack of feeling able to cope prompted Nicole to avoid information about her risks and limits her ability to engage in prevention methods. Similarly, other family dyads also discussed avoiding information about their risks when their contamination frame stressed how much cancer ruined lives and how the fear was overwhelming. Feeling overwhelmed and choosing to be avoidant of information limited these family dyads' ability to make proactive medical decisions to manage their risks. One aspect that Nicole does not verbally connect in her story is that even if she is not aware of her hereditary cancer risks, if she is positive for Lynch syndrome there is a high likelihood that more cancers will occur or reoccur even if she continues to avoid the information. Thus, when families use a contamination frame in their narrative and discuss low coping efficacy, their avoidance suggests a need for an intervention to aid in better emotional adjustment that can facilitate proactive risk management.

Families operating under the contamination frame generally had negative narrative tone throughout their stories, in which they were either motivated by anxiety to be proactive about their health because they believed cancer would occur or they became avoidant about hereditary cancer risk information because the anxiety was too overwhelming. Families using this narrative frame are especially be in need of a narrative intervention to help them become more proactive about their risks and they

also need outside help such as counseling services to better cope with the fear of developing a hereditary cancer. Additionally, these findings demonstrate an opportunity for health care providers to take a more directive approach in stressing the importance of knowing about hereditary cancer risks so avoidant family members can better manage their future risks through preventive medical decision-making. Thus, families using a contamination frame need additional resources to aid in their coping and help them be more proactive in their medical decision-making.

Laissez Faire. The third frame that frequently came up during family narratives of hereditary cancer was a laissez faire frame, in which participants were not emotionally involved with their diagnosis and were often misinformed about their risks. While CNSM suggests narratives may have an empowered, contaminated, or ambivalent frame, this frame was different from ambivalence (Koenig Kellas et al., 2009; McAdams et al., 1997). Ambivalence suggests storytellers are experiencing mixed or contradictory feelings while telling the story. Among family dyads with this frame, members did not have mixed feelings about their hereditary cancer risks and history but rather a "it is what it is" attitude of acceptance. Overall the narrative tone in these family stories was unemotional and distant. Often family dyads who shared this narrative frame and unemotional tone also discussed that they had never had to confront cancer in their immediate family. For instance, Kevin (husband, 32, not yet tested) and Danielle (wife, 25, no family history) discussed Kevin's family health history of HBOC and how they have responded when his extended family members have received HBOC-related cancer diagnoses:

> Kevin: Obviously, we're very sensitive to cancer and we know that's the battle that [my extended family] have to go through as soon as it's caught and how much more preventive care they have to go through to try to catch it early. To some degree it's like, "Well, here's the next time [my extended family are battling cancer]" and we just know the drill and hope things work out. Obviously, no one in my immediate family has actually had to go through it so it hasn't [had] as quite as [big of] an effect to me as it [has on] some of the extended family members that have all watched very close family of theirs pass or deal with [cancer].

Although Kevin has witnessed cancer experiences among his distant family members and talked about how the family rallies behind that person, he has not yet experienced cancer more personally in his immediate family. Indeed, even when he talked about battling cancer and preventive care he was always talking about other members of his family engaging in those behaviors, but did not mention that he personally was proactive. When asked how Kevin and Danielle feel about Kevin's potential risks of having a gene variant related to HBOC and managing those cancer risks Kevin responds unemotionally while his wife is more concerned about the future of their family:

> Kevin: I guess I try not to really feel positive or negative one way or the other. It's just a gene that you may or may not have and there is absolutely nothing you can do about it. I try not to let it really bother me or get to me, it's just more about how we can use the knowledge to make decisions in the future and knowing that [right now it's] unknown on whether I have the gene [like] the rest of my family.

> Just knowing that at some point I'll probably have to get tested and that'll really change. Once we know that'll change how we make decisions.
>
> Danielle: Yes, Kevin like I said earlier, is a lot more relaxed about it than I am, I would say. I mean I do want him to get tested if we have kids but also for him. I haven't researched it a ton so I really have no idea the effect it can have on men if they have the gene. I have assumed that it could be harmful to them other than just passing it on, but Kevin doesn't feel that way. We haven't looked into it too much and I've been wanting to more recently. The more that we've talked about this [the more I think about] the effects it could have on him because I am not as good at separating emotion from logic and he is.

Kevin's attitude about possibly having a gene variant was that there is not much he can do to change that fate so he unemotionally just accepts it, while not actively pursuing genetic testing or more information. Indeed, Kevin's motivation to get genetic testing was more based on his wife's requests that he get tested before they start having children. Further, Danielle wanted Kevin to get tested to also better manage his own health; however, Kevin and Danielle were unaware of the potential risks for men with the gene and the importance of Kevin to get tested for himself. While men with a gene variant such as *BRCA1/2* do not face the same risk levels of women with the gene, their risk of developing an HBOC-related cancer is significantly higher than the general population. To not be aware of the increased risks for men shows Kevin was operating under misinformation. However, this overall narrative tone and frame do not motivate Kevin to become more active in managing his risks. Kevin was either not aware of or

ignoring his risks and this attitude of acceptance helps him emotionally cope, but it limits his ability to make medical decisions such as pursuing testing and regular screening to better manage his risks.

Parent-child dyads using this frame were consistent in using the laissez faire frame to discuss their narrative and risks. Sharing a laissez faire frame can be problematic because not only is the parent not necessarily being proactive about their hereditary cancer risks, but the next generation is matching this behavior. For instance, when Steven (father, 62, *BRCA2*) discussed his health decisions and risks with Ashley (daughter, 22, not yet tested), she repeated what he said while explaining why she does not want to get tested at the recommended age of 25:

> Steven: I like the idea that I can just take care of myself on my own. So I feel like, what would I be doing differently knowing [my genetic testing results]? This is before I got tested and I didn't think that I really would do anything differently, so I don't know. I wasn't worried. I remember, I was concerned about my kids and I think it's also-- I just feel like that was the reason why I got tested. I felt this reason was important because if I was negative, then my kids, if they get tested or not, that probably they'll be negative, I assume, because I don't think their mom has it. If she doesn't have it and I don't have it, then they won't have it. I thought, "Oh okay, well, maybe instead of them figuring out for themselves at some certain time, let me get tested, and if I'm negative, then they don't have to think about doing it." My oldest did get tested and she was negative, but none of my other kids have gotten tested yet. In fact, I think, she got tested but she hasn't

really-- Ashley and her sister also wanted to get tested and the woman that tested me said, "Oh no, they're too young."

Ashley: I was going to say, I think I was at least 18 or older than 18. And yeah, the woman that tested my dad. She just recommends you like, "She's young. There's no reason she should get tested now. If she wants to, she could get tested in mid to late 20s, but now there really wouldn't be a point to it." Also, with that, my dad was saying now like, just again, will this make a difference in my life. For now, I don't think I'm going to get tested. Maybe, one day I'll want to, if I end up having children, then I want to know. Maybe, that will be a reason for it. I'm not in a rush to do it, but I'm also not against it. Maybe, getting tested just to at least know this affects like I said, my children or-- Maybe, it could affect me. For now, I don't think I'll get tested.

Ashley used the same frame and tone as her father when discussing why she wants to wait on getting tested. Both her and her father feel that finding out they have *BRCA2* should not change how they are currently managing their health and are relying on their healthy lifestyle choices regarding diet and exercise to prevent cancer. However, this narrative frame did not motivate them to engage in preventive screenings and justifies Ashely's decision to continue avoiding information as she continues to put off genetic testing. Indeed, both Steven and Ashely are unemotionally accepting of their *BRCA2* risks, which is unusual and uncharacteristic especially for women managing these HBOC-related cancer risks. What is problematic about this frame and tone is that Steven's HBOC-related cancer risks as a man are significantly less serious than Ashely's

potential risks if she also has a *BRCA2* gene variant. Thus, to not get tested or to wait until later in life when she has children to get tested could be a risky decision as Ashley will not be engaging in preventive screenings such as mammograms and MRIs or considering prophylactic surgeries to prevent cancer if she does have the gene variant. Further, Ashley tends to go back and forth about when to get tested and why, and seems somewhat indecisive about testing. Ashely's indecision suggests that if Steven told the story differently to her about their *BRCA2* risks and stressed the medical options available for his daughter, Ashely might be persuaded to get testing at the recommended age. For instance, Steven's narrative took a turn when he started discussing who might be next to get cancer in the family, which surprised Ashely and suggests this is not a part of the story he's shared with her before:

> Steven: Only three got tested out of four of my sister's kids and I think two are positive. I've only had one of my kids tested and it was negative. The woman who did my test said, "Wow. You guys are like not always 50/50, but you guys are like way heavy on the positive side", like a lot more than she would expect. I thought about that like, does that mean that from the number of family members that I know that are positive, including myself, does that mean we can expect over the next whatever years that people are going to show up with cancer? I've thought about it and I'm like, "Who's the next one?" [laughs]
>
> Ashley: For real?
>
> Steven: Yeah, I thought about that. I thought about it.

> Ashley: I don't know. I just forget about that. I haven't really thought about it. I'm one of the younger grandchildren, but I haven't got tested. I haven't thought through it more. More, I haven't thought about cancer as much as you have, but I don't like to think often about the risk of it. I know in those cancers, many people get it, even the general population. I could get it from something else. It's not like I fear the rest of it, even with all of our family health issue history, and a good majority of us do have the chance.

This story caught Ashley off guard and is a perspective from her father that she had not heard before when they had previously discussed the family history and their personal risks. Moreover, this was the only time in Steven's narrative in which he sounded more emotionally worried about his family's future risk of HBOC-related cancers. However, Ashely continued using the original laissez faire frame of accepting the potential risk unemotionally and choosing not to think about it further. Steven and Ashely did not have intrusive thoughts about their future risks of hereditary cancer, but that's likely because this frame and tone support avoidance. Overall, Steven and Ashley were acting under misinformation about the differences between their risks, were not emotional when telling their story, and had an attitude of acceptance that their diagnosis would not change anything for them.

Those family dyads using the laissez faire frame generally felt an unemotional acceptance of their risks and in large part felt a diagnosis would not substantially change their lives. However, families using this frame did not experience hereditary cancers in their immediate family and often these family members were putting off genetic testing

and avoiding risk information. While these families might be coping somewhat well emotionally as they rarely experienced intrusive thoughts, it's largely due to their avoidance of this topic and the emotions it causes. Further, these families did not always recognize or were not aware of their risks or what medical options were available to them to prevent and manage hereditary cancer. These families need an informative intervention to introduce important risk information into their family narratives so members have an accurate understanding of their risks and can make proactive medical decisions before cancer onsets.

Competing. Finally, other family dyads were telling the same overall story but had competing narrative frames and tones throughout the telling. Thus, while the story overall was the same and both added in their accounts to create a clear narrative, each made comments representing they did not agree on the story's tone and frame. These competing frames represent some conflict amongst family members such as trying to get a family member to take their risks more seriously or encouraging avoidant family members to more proactively manage their risks. Indeed, family dyads with competing frames most often had a member using a laissez faire frame to remain unemotional and accepting, while the other talked about feeling strong emotions such as anxiety or empowerment in managing their hereditary cancer risks. For example, when Melissa (mother, 53, not yet tested) discussed the prevalent family healthy history of cancer in her family with Amy (daughter, 24, not yet tested) she felt that because her daughter was still young and healthy that she wasn't taking her health seriously:

Melissa: It's not really funny exactly but it is kind of a joke. If I get cancer, where is it going to show up? I think for me, I'm encouraging my daughters to go get their Pap smears, annual exams and stuff. Young people, I'm worried because sometimes I don't think they realize that they could get it too.

Amy: I think what she said is pretty accurate. For me, it was a little different because not that I don't pay attention to it but a lot of the times when a family member had gotten cancer, I was young. It's just not something that's really had that much effect on me but I do remember when my Papa got the last time and how difficult that was for everybody, especially my mom. I know that especially on my dad's side that there's been cancer and on mom's, like breast cancer. I honestly can't remember the other ones but I think it makes me more aware of the fact that it's definitely even more possible for me to get cancer because of the history in our family. We do joke about it a lot. You're going to get cancer. You're going to have some of these diseases. We kind of all know that eventually, it might happen because of how much it is in our family history.

Although, Amy said she is aware of the risks of getting cancer because of the long family history of cancer on both sides of her family, her tone in responding is unemotional about this risk compared to her mother, who was often crying or becoming highly emotional during storytelling. Indeed, Melissa mentioned that she worries that her children are not actually taking their risks seriously or being proactive because they are young and feel invincible. It is likely that the family joke about who will get cancer next and what type of cancer it will be has desensitized family members to their risks. The

competing frames bring Melissa and Amy to an impasse on how and when Amy should start screenings.

These type of conflicts between empowerment and laissez faire frames also happened when a child was trying to stress the importance of being proactive to a reluctant parent. For instance, Crystal (daughter, 31, *PMS2*) talked about feeling empowered by continuing to screen for Lynch-related cancers while Sandra (mother, 61, *PMS2*) felt reluctant to do anything more to manage her risks:

> Crystal: It's a locus of control. You can say you have some ownership over it, even just having the doctor say, "You need a uterine biopsy every year, you need a colonoscopy every year, you need an endoscopy every year, you need this bloodwork and ultrasound every six months." There is a protocol and there is a reason, and having some order. None of those are fun things. There's comfort in that.
>
> Sandra: Honestly, for me, ever since I had, it was a shock and you felt like, "Oh, my gosh, I'm damaged." In the beginning, you go around like, "Why me?" After I had the colon cancer removed, I didn't need chemo, I didn't need anything. It was just removed and I was done. After I had the preventive hysterectomy, honestly, it doesn't affect my daily life at all, I am not as good as Crystal.
>
> Crystal: Mom needs to do an endoscopy and a colonoscopy yesterday.
>
> Sandra: She is really very good and I feel like, "I've scooped out practically every part that might be-
>
> Crystal: [laughs]

Sandra: -affected. Do I really need to be as diligent?"

Crystal explained how having a protocol for her screenings gives her a better sense of control and comfort, fitting an empowerment frame. In contrast, Sandra still remembers the intense emotional response she had to her colon cancer diagnosis and colon resection surgery. Sandra felt like she had "scooped out" everything that could put her at risk and no longer follows up on her screenings like her daughter does. Sandra is using a laissez faire frame in which she's already dealt with her risk and her diagnosis no longer affects her life. Similarly, when Hannah (sister, 29, *BRCA1*) discussed her perceptions of risk and getting tested she is engaged in a laissez faire frame, but pressure from Helen (sister, 34, *BRCA1*) and the guilt she feels about what her mother would have wanted created an emotional conflict for her in managing her risks and staying consistent with Helen's narrative frame:

> Hannah: I've never really wanted to get the test, or even sometimes I don't think about it because I feel like if I get it, I just get it. It is what it is. That's just what it is and so I sometimes I avoid emotional conversations about it, but then I feel selfish about that because like we said, my mom never got the opportunity to find that out and if she would have it would have saved her life, so I feel selfish at times about that too so that's why I just go and do it. We don't really talk about it too much but we do say like me and my sister try to motivate each other to go and get-- Be on top of that. It just sometimes it's just the way it happened. It's just chaotic. Life hits us hard sometimes and so-- But nobody's really scared or afraid

to talk about it too much, so it's just there but we do talk about a little bit but not like too crazy.

Helen: Yes, so like I would tell my sister, you need to get it together, you need to go, you really need to go. I got her. We both stayed on each other to get the Aflac, so she has Aflac. We both have Aflac cancer policy and so I've been telling her she has to go and she'll remind me and we'll remind each other about trying to call and get things set up. She just needs to get set up back again.

Hannah felt conflicted between what she wants and what she feels she owes to her mother and other family members. By the time Hannah and Helen's mother learned of her cancer and *BRCA1* gene variant, it was too late for her to do more than hospice care. Hannah and Helen witnessed their mother's loss first hand and support each other in making medical decisions about their risks. Although Hannah felt pressure from the guilt of losing mother and has her sister frequently checking in, she still had an "it is what it is" attitude about her risks and did not want to actively engage in prevention because she did not want to think about the topic or deal with the emotions it brings up. It's also Helen that was driving prevention behaviors while Hannah would prefer to avoid getting screenings because each time it brought back emotional memories. Thus, competing frames demonstrate different coping mechanisms and the tension competing frames can create. Without Helen and her attempts to pull Hannah back into the empowerment frame, Hannah might further put off screenings and avoid thinking about her risks. Competing frames in this dyad did not create relational conflict, but did put more pressure on Helen to take care of her sister.

While at-risk family members might differ in how they want to manage their risks, there were also instances when competing frames illustrated relational conflict between family members. Some family members had stopped communicating with one another because a member wanted to avoid receiving risk information or getting tested. For example, Olivia (mother, 47, *PMS2*) discussed with Jack (son, 18, not yet tested) how her aunt told her off and stopped communicating with her because she was trying to motivate her aunt to get tested:

> Olivia: One time my one aunt just told me off, she goes, "I don't want to get tested. That's your thing and if I get it then fine." I was like, "Okay." I thought I had come at it gently, but different people respond differently. I don't know why she doesn't think about her kids, that if she would find out she had it then her kids would need to know that information, but some people just don't respond the same way as we do, that we believe knowledge is power.

Although Olivia's aunt was not involved in the story she and her son shared about becoming aware of risks and managing risks through proactive medical decision-making, how Olivia approached the family history of Lynch syndrome caused conflict with her aunt. To continue avoiding managing risks and getting involved in the family narrative about Lynch syndrome, her aunt ended communication with Olivia and her side of the family. Relational conflicts in narratives were also caused when competing frames led a family member to be dismissive of another's health experience. For instance, when Abigail (sister, 62, *BRCA1*) talked to Grace (sister, 57, variant of

uncertain significance) about how another family member treated her after her prophylactic surgeries she explained:

> Abigail: Sometimes it feels like an us and them kind of situation [with previvors and those who have survived breast cancer]. I try not to make it a competition over who deserves the pink t-shirt. Did I tell you about this Grace? I was in the car with my aunt, while my mother was in hospice with cancer, and my aunt went for a mammogram and came back with a stage zero cancer diagnosis and she had a lumpectomy and a week of radiation and no chemo. So she was very lucky that she was able to find it early. But at that point I was recovering from a hysterectomy and double mastectomy and reconstruction, which I had all done within the space of 3 months. I'm in the care with my aunt and she was already through her cancer treatment and she referred to what I had gone through as a flu shot.
>
> Grace: I don't think I heard this story.
>
> Abigail: And I know it was 6 years ago, but that made me feel really bad.
>
> Grace: It dismisses your experience.

Abigail felt that her aunt's comment about her prophylactic surgeries was dismissive and unsupportive of her experience, and challenged Abigail's empowerment frame. Grace was also upset about her aunt's reaction to Abigail's prevention efforts. As Abigail later explained, "It felt like she was saying 'Well, I had cancer and you had a flu shot. You're not in the same category as me and your mother.'" Abigail and Grace's narrative was generally one of empowerment by becoming more aware of their hereditary cancer risks

and managing those risks through preventive screenings and surgeries. However, their aunt felt Abigail's experience in preventing cancer was not as important or serious as her experience in treating cancer. Abigail added later that her aunt's comment has affected their relationship and now she censors some of what she shares about her experiences as a previvor with family. While Grace and Abigail shared an empowerment frame, their aunt's challenge to that frame caused relational conflict and limited Abigail's storytelling with other family members. Indeed, lack of support for another member's medical decisions was often a source of competing frames in family dyads. For instance, Ben (husband, 47, no family history) often talked about believing Betsy's (wife, 46, *CHEK2*) gene variant was "not a problem. It's a red flag" and not something she should get upset about or go to extreme measures for:

> Ben: Well, Betsy's hysterectomy stuff is what really got me. When we found out that she had the genes, she's like, "I'm going to get a hysterectomy and bla, bla, bla and the doctors were recommending it." I was like, "Wow, that seems like a really drastic thing to do. Like is this the right thing to do or I'm just--?" I couldn't get that out of my head but the doctor was like, "Listen, if you're not having any more kids," and we're obviously not, "we should have it done." I mean Betsy was listening and running right head long for that and I was like, "Holy shit." I was like, "I can't believe she's going to do this just because they're recommending it." Then after she had the surgery and she said she got the pathology back and found that she had the precursors, I was like, "Well, I guess

they're right," but man, I could see other people, women and men, having to take that kind of preventive measure, really balking at it.

Betsy: I was older. Well, it was like two years ago. I'm 46 or 44 and I can understand someone who is in her late twenties or early thirties, that's so young [to get a hysterectomy]. [The hysterectomy] will save your life. You really need to do it. I can understand what Ben is saying, but—

Ben: I mean the surgery in it of itself is drastic to me. I mean that's-- I would call it highly invasive and then the hormonal problems and everything after that even is like lifelong, so scary.

While Betsy was moving forward with the doctor's recommendation to get a hysterectomy, Ben was questioning if surgery was necessary and felt this level of prevention was drastic. Although the doctors found the precursor to sarcoma in Betsy's pathology after her hysterectomy, Ben was not focusing on the surgery as having saved her life. Rather, Ben was focusing on how the surgery complicated their lives as Betsy continued to advocate for her prophylactic surgery and believed that surgery was lifesaving. Both family members were talking about the same event, but their narrative tone and frame about Betsy's hysterectomy and medical decisions were quite different. Betsy later said when Ben complained about the medical bills for her annual colonoscopies, "I'm sorry. I'm just at the point where like I don't care if they have to charge it every year and that in a long term, a year. It has to be done." Even if Ben was not emotionally supportive of her medical decisions to manage her risks, Betsy was determined to continue being proactive about her health. In this example, Betsy's

empowerment frame was competing with Ben's laissez faire frame, which created some tension in their marriage. On the other hand, if Ben had more influence over Betsy and the story his views could have limited her medical decisions to pursue preventive screenings and prophylactic surgery. Beyond how Ben and Betsy talk about her medical decisions and risks, Betsy also felt unsupported and often dismissed by Ben's behavior when she was having difficulty coping:

> Betsy: I felt like I wasn't supported because it was just his way of trying to be like, "Okay, get off the ledge. Step back a little bit. Get back into the house." Be a little bit more calm about this and I felt a little bit different like, "Okay, well you don't understand. This is what's going through my mind a thousand miles a minute and it could be this." He would be like, "No." I would be like, "Well, but it could be," and it's festering up there and I just-- I always kind of felt more like he was pushing things off a little bit more.
>
> Ben: I tend to-- I don't know. I tend to internally process things before I vocalize them.

Betsy and Ben's different outlooks and different forms of coping created some relational problems when Betsy was first learning about her diagnosis and going through her surgery. Overall, Betsy was receiving little support from her spouse and still deals with intrusive thoughts with little outlet to discuss these feelings at home. Thus, while Betsy might have positive outcomes related to her proactive medical decisions based on her perceptions of risk, the competing frames and outlooks about her hereditary cancer risks contribute to poor coping and adding to the couple's relational strain.

Among narratives using competing frames family members did not have the same interpretation or outlook to their stories about hereditary cancer risks. Indeed, during the telling of these stories there was often conflict and tension when a member was not taking their risks seriously, did not support another member's prevention decisions, or was not providing emotional support to help another cope. Most often the frames that were competing were empowerment and laissez faire. Members using the empowerment frame stressed being proactive and often tried to take on the role of family advocate by persuading or scolding another member about their risks. Further, the competing frames also seem to show a mismatch in how the dyads were supporting each other either by downplaying or dismissing a member's experience and anxiety or by not addressing why a member felt such anxiety or emotional burden. Families with competing narrative frames and tones may need additional counseling resources to better hear and understand shared stories from a different point of view to find ways of bringing members on the same page. Further, these families may need more help in finding ways to provide the emotional support a family member needs and conflict resolution resources to manage the tension and relational strain that competing narrative frames cause.

Interactional Sense-Making

Beyond analyzing the content of family narratives of hereditary cancer, the second aim of this study is to examine how the processes of joint storytelling shape coping, perceptions of risks, and medical decision-making. Overall, when there was more engagement, turn-taking, perspective-taking, and coherence family dyads were

engaging in better collective sense-making about their hereditary cancer risks. Collective sense-making better facilitated coping through emotional support exchange during storytelling and family dyads whose narratives achieved collective sense-making talked more about how other members' stories influenced their medical decisions. Family dyads lower in these behaviors often had members "check out" of storytelling while another member dominated the narrative, which limited the support members could receive and the level of meaning some drew from the narrative.

Engagement. When family members are more engaged during narrative storytelling they are both highly involved in telling the story together and communicate warmth or affection as they construct the narrative (Koenig Kellas et al., 2010). Indeed, when family dyads were engaged they were both active in storytelling and even discussed how they influenced each other's decisions about managing their hereditary cancer risks. For instance, when April (sister, 28, *BRCA1*) explained how watching Rachel (sister, 28, *BRCA1*) go through breast cancer influenced her decisions to get a double mastectomy both are actively involved and exhibit warmth in telling the story:

> April: Like I said, I think she was stronger than us. [laughs] How was that for me?
>
> Rachel: I feel like I put a lot of pressure on you to do things.
>
> April: No. I think I felt a lot of peace too to see her at peace and then a lot of family really did come out. The family support was definitely important. I think seeing how strong she was and seeing she couldn't have a choice--
>
> Rachel: We didn't know that we were BRCA positive at that time.

April: I think that really pushed me to do my own surgery, a thing that she couldn't have. It was too late for her to have a choice. Everything that she was going through like losing her hair and what our mom had gone through, as well. It gave me a lot of peace in my decision. I was surprised at how clear and how sure I was about my condition to have surgery-

Rachel: -because you're a very indecisive person.

April: Because I am a very indecisive person. Yeah. [laughs]

Both sisters were involved in telling the story and adding on to each other's responses. April was communicating warmth by reflecting on Rachel's experience in going through treatment for breast cancer and how watching her sister respond to that diagnosis gave her peace about her own prophylactic surgery decision. Rachel demonstrated warmth by recognizing April's part in helping her go through treatment and through joking and laughter near the end of the quote. It is clear from this example as well that this family dyad has a strong bond and their shared narrative of managing HBOC risks was important to them and helped give more meaning to their decisions. Further, during their storytelling they were also talking about feelings of peace and feeling supported, which indicates that they are coping well as they look back on treatment and prevention decisions they made together. These patterns were similar across jointly constructed family narratives of hereditary cancer that were high in engagement overall.

When family dyads were low in involvement and warmth it was often because one member did not actively tell the story, or attend to the story with positive affection. Rather, this family member would "check out" or fade into the background while the

majority of the story was told by another, who often had to call the avoidant family member back into the conversation. For instance, as Helen (sister, 34, *BRCA1*) told the story of her mother's diagnosis Hannah (sister, 29, *BRCA1*) took more of a backseat role during the interaction and throughout the interview she was not as involved in storytelling as Helen:

> Helen: So when all this came down and our mom got the gene and we found out she had the gene but her cancer was too far advanced to cure. It was just treatable not curable. It became really hard on us because we started putting all the pieces of the puzzle together and we felt that the medical professionals should have been more on top of catching the patterns for my great grandma having colon and then my grandma having breast, which we felt that if the medical professionals would have caught that pattern then my mom would have been able to be tested sooner and then her cancer would have been actually, hopefully curable instead of treatable. We wish that they would have put that pattern together because then my mom would have been able to find out she has a gene when she was in the earlier stages of her cancer and she would've been like, "Yes, please give me a hysterectomy." She would have been able to go through all those things and hopefully have had a better chance, but also it's so new that people don't really put-- Even my mom and my grandma's doctors weren't even able to correlate that those two, the colon and the colon with the breast and ovarian cancers.
>
> Hannah: They said that we don't have any family history of it.

> Helen: Yes, they said we don't have any family history of colon cancer, so it didn't make sense that there would be a pattern of cancer at all, so that's our negative story with it because we wish that they would've been able to put together the pattern and then, in the end, would have hopefully saved our mom's life or given us more time with her.

Throughout this example, Helen often spoke for Hannah and throughout the interview Hannah was rarely the first to answer questions and rarely added much information to the story unless she was directly asked. Further, Helen tended to be the more proactive member in her family when it came to making preventive medical decisions while Hannah tended to be more avoidant, which she further explained saying, "Sometimes I don't care, I'd rather just not deal with it and I know that's not the best way but sometimes I just shut down so I haven't been in probably a year and I'm supposed to be doing every six months." Overall, Hannah often checked out of the storytelling and communicated emotional distance during storytelling by not actively telling her story, discussing how this is a topic that shuts her down emotionally, and not positively attending to Helen's parts of the story. Not only does Hannah's avoidance inhibit her during storytelling, but Hannah also avoided thinking about her risks and put off her preventive screenings. Further, Hannah's explanation about her avoidance demonstrates that she is not coping well emotionally with her family's past hereditary cancer experiences or her own future risks of cancer. This was a common theme among multiple family narratives that had low engagement.

In essence, family stories that were high in involvement and warmth showed more support for family members to aid in coping, families were open and active in discussing risks, and influenced each other's medical decision-making. Indeed, Koenig Kellas and Trees (2006) contend involvement and warmth can facilitate sense-making by creating an environment for emotional support exchange, which can help family members better overcome problems. However, when families were low in involvement and warmth, one member was avoidant during storytelling and emotionally distant throughout. When avoidant family members did add to the story they often discussed their desire to continue avoiding the topic because they were struggling to emotionally cope with their risks and the memories of losing family members. Indeed, avoidant family members also tended to put off genetic testing, additional screenings, and other preventive procedures. Narrative interventions might look at how to increase engagement during family storytelling to help avoidant members become more involved in the story and more active in managing their hereditary cancer risks. Finally, more emotional engagement can create a space in which they can better receive and provide emotional support.

Turn-Taking. Turn-taking refers to the degree to which family members are dynamic when telling the story together. Families who were high in turn-taking often interrupted each other, added in parts of the story while another member was talking, and had an even distribution of turns throughout joint storytelling. For instance, George (son, 38, *EPCAM*) and Ron (father, 68, *EPCAM*) discussed evenly with multiple

additions from one another how they and their family responded to Ron's colon cancer and Lynch syndrome diagnoses:

> George: That's why my dad originally ended up getting tested, just because he never thought-- At first it was denial, because mainly the family was thinking it was- trying to say it can be my mom's side of the family, even though she has no history of colon cancer. Like my brother, I guess he's still in denial. I guess, he just doesn't want to face facts, the 50/50 chance that you have this autosomal dominant genetic condition. It exists and some people were receptive, and some were not. Then, we all have had a couple of cousins that contacted me asking for another copy of that letter and my test results. They still, at this point, haven't gotten tested.
>
> Ron: They've got colon tests.
>
> George: Yes, they've all gotten colonoscopies. Nobody's gotten actual genetic testing itself.
>
> Ron: It was hard, but when you have a diagnosis, you've got to go ahead and take care of it surgically, through oncology treatments. I put my faith and trust in Jesus Christ. I prayed a lot throughout this whole process, I give all the glory to God for all that was done for me. I feel the same way with George. It's just amazing how many people were praying for you and thinking about you all the time.
>
> George: I guess, a lot of it, you just do what you've got to do to get through that point in your life. During my second and third semester of nursing school, I was

> trying to become a nurse when I had my diagnosis. I had to drop out of nursing school for a whole year. I had chemo. I had two surgeries. It's scary, but I did what I had to do and I started back to nursing school, finished nursing school. I'm now a nurse and I'll have my bachelors. I just did what I had to do and fought through the fear, and had my family by my side, thank God. That was my strength through this. My parents, they went to every appointment with me. My dad was at every chemo with me. I'm glad we have a very strong family.
>
> Ron: In more ways than one.

Both George and Ron actively told the story and added on to each other's responses in a steady turn-taking pattern. Further, George and Ron tested positive for Lynch syndrome and experienced a cancer diagnosis, which made them both active in telling the story of their family's experience with Lynch syndrome. Turn-taking can reflect who in the family has power over constructing the narrative by how many turns are taken and if there's space in the conversation for others to add to the story. Both George and Ron equally contributed and thus have comparable power in constructing the narrative. Among family narratives, turn-taking was often decided by who had been more affected by cancer such as being diagnosed with a hereditary cancer or receiving a positive genetic test result. As George and Ron were both affected by Lynch-related cancers and tested positive for *EPCAM*, they contribute equally. However, as they talk about other family members like George's brother, they both make it clear that he is not often active in conversations about the family's health history and does not actively manage his own hereditary cancer risks. Further, George and Ron talked about relying on their family to

help them cope and George especially explains how much he relied on his father. Indeed, George later said, “I definitely feel a stronger bond with my father because of that fact, that we both come out on the other side of cancer diagnosis, as well as a genetic mutation.” Their sense of a shared experience and the support they gave each other in coping gives them an equal stake in storytelling. Thus, turn-taking in interactional sense-making is an indicator of how active family members are in providing support, discussing risks, and making medical decisions to manage those risks.

Families low in turn-taking rarely interrupted each other and instead told stories through structured and separate turns, often with one member dominating the telling of the story. Further, the family member who often dominated storytelling was the member who had a cancer diagnosis and/or a parent or elder in the family structure. When turn-taking was low and storytelling was dominated by one family member, that family member became the key storyteller and had the most control in constructing the meaning of the family narrative. For example, when Sophia (mother, 54, *BRCA1*) and Chelsea (daughter, 25, negative for *BRCA1*) were asked how they have emotionally responded to their family health history Sophia decided who will speak first and takes the majority of the turn:

> Sophia: You can start Chelsea.
>
> Chelsea: I'm relieved. I'd probably be a lot more upset if I was positive, but it was a relief that I don't have it and now that my mom has been through everything and it's done, my aunt's done, I'm kind of like, it's all done, hopefully.

> Sophia: I do feel that way on a lot of it. I think, as anybody who had cancer can say that it never goes away. You always have that in the back of your head, what if it comes back? I mean I've always had anxiety as Chelsea can tell you, especially about my children. I'm very careful with them, I'm worried about them. Now it's funny, I've almost kind of let go of that, now I'm just more worried about me, what if it comes back? Every time I have an ache or a pain, I'm like, "Oh God, is that anything I should be worried about?" I also kind of feel that I may not live to be 90 and that's okay. The side of family that has this mutation, they don't make it much more than 70 and I'm like, "Well, the good news is that I don't have to save a whole lot of money for years and years of retirement." [laughs] Which is probably kind of a fatalist attitude, but I always try to seem positive. It's definitely changed the way I look at things. I still keep up with all of my follow-ups, but every time I have a follow-up, it's a few days of not sleeping and anxiety.

In this example, Sophia is both the parent to Chelsea and the family member who has a genetic variant as well as fallopian tube cancer. As Chelsea explained briefly, she feels like the risks for her and other family members of getting additional cancers are done and this part of their lives is over. Indeed, Chelsea did not add much to the story after this comment possibly representing that this narrative is more for her mother than for her. For Sophia, the risks do not necessarily end since she has the gene variant and so the narrative and her part in telling the story do not end either. Further, Sophia is struggling with anxiety about her future risks of developing cancer and not living a long life, which

motivates her to tell more of the story to share these feelings as an outlet. However, if Chelsea isn't attending to her mother's feelings and aiding in coping, Sophia may not receive the support she seeks from storytelling.

Not only were family members who tested negative taking less turns, but unaffected family members such as spouses did not take as frequent or lengthy of turns. For instance, when Peter (husband, 53, *BRCA2*) and Taylor (wife, 48, no family history) were talking about their daughter's future risk of testing positive for *BRCA2*, Peter took more turns and contributed more to the story of how they plan to tell their daughter about her risks when she's older:

> Peter: Probably as you think about it, we don't want to pass on this order of eating, out of what may appear obsessive, for my part. We are trying to adhere to this model of healthy living, in general. Your activities and diet and when it comes to genetic testing, which I'll strongly encourage her to do when she's 25. I think it's just the age to do it. We'll see. If she is negative, she can go back to her milkshakes, and if she's not, I'm going to try pass on everything I have learned.
>
> Taylor: We are hoping by then, there is something better offered--
>
> Peter: Well they are making tremendous strides, at least to the cancer or not, and it's not prevention but-- I think for breast cancer, there are some breakthroughs.
>
> Taylor: That's what we're hoping to. By the time she has to make decisions, there are better options out there.
>
> Peter: And if they can't, she'll have to consider prophylactic you know, breast and … in that case then we'll—

Taylor: Oh gosh.

Peter: I'll encourage her to get pregnant, certainly, a lot sooner than we did. Then, take care to prevent, so.

Taylor: Ya, I haven't thought that far with her. It's hard enough-

Peter: -No, we don't talk about that. I, certainly, don't want her, at this age-- Just on the verge, she wouldn't need to think, that, being with the breasts, their emerging, are going to have to be taken off, or something, that point. We're not going out there at all.

In discussing their daughter's risks, Peter took more turns, regularly interrupted Taylor, and had more to say on how he plans to prepare his daughter if she is positive. Taylor was almost taken aback that her husband had thought so much ahead about their daughter's future diet choices, the age she will get genetic testing, her need for prophylactic surgeries, and family planning decisions. Peter's turn-taking also points to the more active role he plans to take in directing his daughter's health decisions and the content of the hereditary cancer narrative that will be stressed to his daughter to help manage her potential risks. Furthermore, this example demonstrates how family narratives of hereditary cancer can be inherited and influence the next generation's ability to cope, risk perceptions, and medical decisions.

Essentially, turn-taking often reflected who in the family had the most power in constructing the hereditary cancer narrative. Across family dyads, those who took the most turns were members who had cancer or a gene variant. Unaffected family members often took less turns and were briefer in their responses. Family dyads who were more

dynamic were able to contribute to the story equally to jointly construct meaning and were emotionally involved in the stories they were sharing. For family dyads lower in turn-taking, the family member taking the most turns dominated the narrative and had the most control in constructing meaning, largely influencing the risk perceptions and medical choices of other members. This might be especially important for spouse dyads raising children who might have inherited a gene variant because it can provide insight into how parents will discuss children's risks and medical choices. Narrative interventions focused on helping families manage future risks might focus on aiding parents in the stories they tell and the awareness they pass down to children with a 50 percent chance of inheriting a gene variant. For families lower in turn-taking, interventions could explore how to create opportunities for other family members such as unaffected family members to get more involved in storytelling to collectively make sense of risks to better cope.

Perspective-Taking. Perspective-taking refers to the extent to which family members are attentive to and confirming of one another's perspectives verbally and nonverbally (Koenig Kellas & Trees, 2005). Attentiveness in perspective-taking is different from engagement, as perspective-taking captures how attentive family members are to one another's perspectives and not just the overall story as engagement defines attentiveness. Family dyads that were high in perspective taking confirmed each other's perspectives and created stories with a clear shared perspective, which reflected the degree to which family members had a close relationship with one another that included regular emotional support exchange. For instance, Ron (father, 68, *EPCAM*)

and George (son, 38, *EPCAM*) were on the same page in understanding their risks and felt their shared experience had brought them closer together as they've been a source of support for each other:

> Ron: I'm just thankful that George, he immediately called to go have a test. He could've just denied it and run away from it, not ever worry about having a test. If he hadn't have caught it when he did, it would've been too late. Very possible. That's the memory I have of it. I feel like that was definitely necessary at that time to have that done.
>
> George: You know in a twisted way, it makes me feel like I'm closer to my dad, because we have something genetically in common that not many other people have to deal with. We both have cancer, I definitely feel a stronger bond with my father because of that fact, that we both come out on the other side of cancer diagnosis, as well as a genetic mutation. We've also helped, possibly, down the road any other family members. At least they have the knowledge whether they want to do something with it or not to go through what we've gone through. They have the ability to possibly keep themselves from having cancer through knowledge.

In Ron's response, he explained that he is thankful and proud that George faced his risks head on and pursued genetic testing rather than avoiding it like his other children. Ron and George shared the same perspective on being proactive about hereditary risk information and they confirmed one another's perspectives throughout their storytelling. Sharing the gene variant and cancer experiences makes George and Ron closer and

facilitates their perspective-taking and emotional support exchange. Feeling their perspective was attended to and confirmed, often helped family members better manage their negative emotions related to hereditary cancer risks. For example, when Agnes (cousin, 41, *MLH1*) discussed her knowledge of hereditary cancer risks, Monica (cousin, 44, *NBN*) confirmed her perspective:

> Agnes: It's a blessing because knowing, having that knowledge that I have this gene helped me to get all the tests done that I have to do. It's also everyday worrying and having it on my mind like, "Oh my goodness, when I go in to get a scan done this year, what's going to come up on the MRI?" I had a biopsy last summer and thankfully it was benign. I put it off too long, and it grew very big. I'm very blessed that it was not malignant. Now, every little thing I see, I think, "Oh gosh is it cancer?" I have to always be on the lookout, but it's good having the knowledge that I have to get tests done.
>
> Monica: I mean, it took me longer to have the gene testing done. I was hesitant, I think just because I was scared as well. I would just agree I think 100% with what Agnes said. It is knowledge, I think from both aspects, whether you do get testing or you don't, I think there's a psychological component to it.

As Agnes and Monica discussed their health history and their perspectives on knowledge about their hereditary risks, Monica explicitly confirmed Agnes' perspective. Agnes went on to add that she when she first learned of her gene variant "there was some anger going on. There was a little bit of depression," but talking to family like Monica helped her "bounce back." Families high in perspective-taking created a conversational space in

which storytelling not only provides a catharsis to talk about difficult emotions, but also helps families exchange emotional support. Finally, these family dyads constructed a shared perspective on how best to manage their hereditary cancer risks such as acquiring more knowledge to make proactive choices.

In contrast, family dyads low in perspective-taking tended to be less attentive to other's perspectives and had conflicting perspectives during storytelling. When family members had conflicting perspectives they often assessed their risks differently and were not on the same page regarding their medical decisions. For instance, when Crystal (daughter, 31, *TP53*) and Sandra (mother, 61, *TP53*) were discussing their future risks, they did not share the same perspective on Sandra's risks:

> Sandra: I don't know. I am naively sitting here, thinking, "I'm done. I've had my cancer risk and nothing else is going to happen to me. [chuckling]
>
> Crystal: You know when you have cancer, your likelihood of having cancer again goes up exponentially? Yes? No? You're not going to the doctor ever? Fabulous.
>
> Sandra: That is probably the wrong way for me to be looking at it.

Sandra admitted her perspective might be naïve, but she does not believe she is at risk since she's already had her cancer. Crystal explicitly negated Sandra's perspective and even mocked her mother's view, which demonstrates some conflict as they tell their story. However, after Crystal negates and makes fun of her mother's perspective, Sandra considered that her perspective on risk may be incorrect. Their conflicting perspectives on risk during storytelling may cause Sandra to change her perspective to see her risks as

Crystal does and make more proactive decisions. However, if a family member feels their perspective is being disrespected or mocked by another, they might not change their views but instead withdraw from the conversation and lose some of the coping benefits of storytelling. Dyads with an affected family member and an unaffected family member also told stories with conflicting perspectives. For example, after Liz (mother, 55, *MSH6*) discussed her views of the family's future risks, Blair (daughter, 27, no gene variant) shared different sentiments and concerns:

> Liz: I think that the risk stops here, just about. I still am at high risk and so is my dad, but we're the only ones left. Well, actually, that's not true. I have a cousin who I totally always worry about, too, who's about the same age as me. Her grandmother was my grandmother's sister, the one that died of breast cancer. To me, her grandmother also had only sons and no daughters, so it could have been handed down from her dad. It could have been handed down from my dad. Her dad died of cancer and her uncle also died of cancer. Everybody in her family has died of cancer, men and women.
>
> Blair: I have a little bit of a different perspective just because I tested negative. Than you do obviously, so I don't have the same positive perspective. I think that for me it's almost dangerous knowing that I'm negative because I feel like I've gotten a lot lazier about preventative things. I don't like performing breast self-examination. I just don't. They're not fun. I don't like getting clinical breast self-examinations. It's not something that I enjoy doing.

While Liz said she felt like the risk stops with her in her immediate family and discussed engaging in screenings and prophylactic surgeries, Blair had a different perspective and felt learning that she does not have the gene variant makes her less likely to engage in general population screening behaviors. After Blair explained her perceptions of risk, Liz did not attend to or confirm Blair's perspectives and instead talks about her risks due to her dense breast tissue. Both of these family members had different perspectives and while they respond back and forth in the story, they do not explicitly respond or confirm each other's perspectives. Their perspectives in the story did not converge, but rather created separate perspectives and separate stories. When family members are neither attending to nor confirming one another's perspectives, they are not creating a story that reflects shared understanding or that can act as a reference point for members about risks. Families low in perspective-taking have differing views on risks and the right medical choices to manage those risks, and by not attending to one another's views these families have limited emotional support exchange.

Overall, perspective-taking in joint storytelling was important in shaping family's coping ability, risk perceptions, and medical decision-making. For family dyads high in perspective-taking, members constructed a single-shared perspective, creating stories based on shared understanding to help make sense of hereditary cancer risks. Often these families discussed being proactive in managing their risks and members agreed on the best prevention choices. Family dyads low in perspective-taking tended to not only have conflicting perspectives but also gave little attention to differing perspectives. Competing perspectives or the disconfirmation of a perspective limited the

amount of support a family member received in managing their risks. Perspectives on risks were especially disjointed among unaffected-affected family dyads, which limits the degree to which these family dyads can support one another and aid in coping. Finally, perspective-taking can inform narrative interventions by highlighting the support and coping resources available in families based on which members are willing to openly discuss hereditary cancer, whose perspectives are valued and heard, and how family members judge certain medical choices.

Coherence. Finally, coherence refers to the family's ability to incorporate their various turns and perspectives into a cohesive narrative, which is logically organized and intertwines member's stories (Koenig Kellas & Trees, 2005). Most family dyads told stories that were relatively easy to follow and started off by discussing the family health history of hereditary cancers. Often this foundational information was told by the elder family member or the member who had a gene variant for hereditary cancer, as they were often referred to by the other member as the expert on this material. Having one family member guide narrative construction improved organization, but it curtailed collective sense-making by limiting the degree to which other family members could integrate their stories into the larger narrative. For instance, Sophia (mother, 54, *BRCA1*) detailed the family history and the family myths that have been passed down:

> Sophia: Yes. One was a myth. [chuckles] There was two myths actually, in our family. The first one was that it's like the guys didn't have it. It passed from mother to daughter. The doctors-- The oncologist or medical doctors at that time, told my aunt and my father, that they didn't believe that this was for real-- They

> thought it was all coincidental. One of my aunts has now tested and it's BRCA negative. Two remaining aunts still alive on that side of the family. She was a nurse, an oncology nurse and she had kept all of the family records because she knew there was something going on. We have all of our records from the '50s and '60s. Which is kind of cool. I'm also a nurse, but I was not an oncology nurse. That was the myth. The other myth was, if you can get your girls over to 50, they would be okay. As we were growing up, my aunts were always very-- I wouldn't say pushy, but aggressive about making sure that we all followed up as we got older and started having kids, with our gynecologist to check us. To go for your mammogram, to go for early screenings.

Sophia told foundational pieces of the family narrative independently with little to no input from Chelsea (daughter, 25, negative for *BRCA1*), which makes the family history and common family beliefs coherent and easy to follow. When Chelsea was asked if she had anything to add she said, “I can't keep track of all the relatives. Mom laid it out better than I ever could. I just know a lot of people had it and that it ran in the family, it was very prevalent but mom is better at the specifics.” As Sophia is the dominant one telling the story and knows the details, it is clear this is an important narrative to Sophia and does not seem as important to Chelsea. While Sophia told a well-organized story, there is little addition from Chelsea or integration of Chelsea’s points into the overall narrative. Families low in integration are achieving less collective sense-making in their narratives because stories are told separately without much overlap into a larger coherent narrative.

Overall, family dyads low in coherence reported difficulty coping and often felt overwhelmed or emotionally shut down, which suggests their family stories do not provide space for healthy emotional support exchange. For instance, when Kayla (daughter, 42, *PALB2*) and Evelyn (mother, 76, not tested) were discussing their family history of cancer and Kayla's cancer experience, they were telling separate stories that rarely overlapped into a larger narrative. Kayla was discussing with Evelyn why she used to go for chemo and surgeries on her own she explained, "I watched people that have come with me. They're always-- My mom came to one chemo and she was, I could tell, she was nervous and upset the whole time. It just gets me upset." During storytelling, Evelyn rarely integrated her story of losing family members with Kayla's story of going through cancer treatments. Further, in Kayla's responses she talked about going through treatments and making medical choices alone because her family could not emotionally cope, let alone support her. Although there is an overall family story about hereditary cancer being told, Kayla told a separate story from Evelyn in which she went through hereditary cancer management by herself with little input or support from others. Evelyn and Kayla's stories were never clearly tied together in their interview to create a larger family narrative incorporating both stories. Not only can this diminish the therapeutic benefit of storytelling for coping, but it can create confusion when family members' stories are not integrated to create a narrative that could aid in medical decision-making. For example, when Betsy (wife, 46, *CHEK2*) and Ben (husband, 47, no family history) were asked to discuss Betsy's family health history of Lynch syndrome, Ben pulled focus from the larger narrative about hereditary cancer in the

family to talk about his own viewpoints on death and mortality, thereby making the narrative less coherent:

> Ben: I've had a couple small medical scares here and there. I think I came to grips with my mortality much younger than Betsy. If I live past 70, I'll probably be feeling okay, will be happy with that. Obviously, I'd like to live longer than that and do retirement things, but if it's not in the cards to me there's nothing you could do about it. Take care of yourself the best you can and enjoy it while you're here. I try to put that type of a feeling on Betsy, but I know that's not how she thinks. To be honest with you, I don't know how to handle it. I can tell she's getting upset about these things. I try but we don't have a lot of super deep conversations about it.
>
> Betsy: Sorry to say this, I don't know if we've ever really said this. Not that I feel like he didn't support me, but I felt that he didn't understand and was just dismissive about it. I think he was just trying to say, "Don't worry about it. Don't let it fester in your head. You still have a life to live. Don't be planning your funeral right now."

Ben discussed his own health concerns, interrupting the story about Betsy's family health history. However, as part of this deviation in the story both Ben and Betsy discussed the problems they are having exchanging support related to Betsy's Lynch-related cancer risks. Shifting focus away from Betsy's health history story to how Ben felt can create confusion in storytelling and interfere with the coherence of their narrative. Further, it cut short Betsy's discussion of her emotions to focus more on how

Ben felt, which limited her ability to receive support from her spouse in addition to drawing focus away from a coherent story.

In contrast, families high in integration and organization were constructing stories that "hang together" and aid in family members' collective sense-making. For example, when Karen (mother, 59, *BRCA2*) and Amanda (daughter, 29, *BRCA2*) were asked to describe the history of BRCA-related cancers in their family, they told that story together, which was sometimes hard to follow due to the back-and-forth nature of their conversation, but integrated their points into a cohesive narrative:

> Karen: Anyway, she had decided she wasn't going to do the testing for a while and then as the years went by, she finally decided just this year, 20 years later. She decided, "You know what? I think some of the other people in the family need to know how prevalent the gene is, even though I don't have kids that will be directly affected by it. Other of the children could benefit from knowing this information." She did get tested and she is positive. Though she has not that breast cancer. The study that or the, what are you calling it Amanda in Seattle she goes to?
>
> Amanda: The surveillance program is a high-risk surveillance program.
>
> Karen: Anyway they recommended years ago when she got into the program, which was soon after my sister and I were tested or got cancer.
>
> Amanda: Tested or diagnosed? That's when you were diagnosed.
>
> Karen: Diagnosed pardon me, diagnosed, thanks for clarifying. Anyway, she did get into the surveillance quickly after and within a few years they said, "You

haven't gotten breast cancer but really what you need to do is to get your ovaries out." She did and to what extent, that made the difference for her not to get breast cancer. I don't know whether she never would have or she would have. Who knows? Anyway, we were all shocked that she tested positive because I know we were all convinced that she must not have the gene, because she's the oldest one of us and she never got it.

Amanda: Just to interject there, there is research that says when you do have your ovaries removed, it reduces your breast cancer risk by 50%. That is not surprising that my eldest aunt has had that outcome. If we can say it that way. Yes, that's a really good summary mom. Was there anything else you wanted to say because there was a couple of things I was going to add.

When Karen and Amanda discussed part of the family health history they are adding in points simultaneously and clarifying pieces of the narratives as well to create a more logically organized narrative that intertwines both of their stories and perspectives. Higher levels of coherence in joint storytelling show that this narrative is important and meaningful to both Karen and Amanda. In particular, higher integration shows a degree of harmony in which Karen and Amanda are coming together and working through their story as a unit, influencing how the narrative is interpreted. Thus, family dyads like Karen and Amanda were engaging in better collective sense-making about their hereditary cancer risks. Further, Karen and Amanda made preventive decisions together to try to change the narrative and risks for future generations:

> Amanda: My mom and I haven't talked about this, because again I haven't thought about this, but potentially if we decide to tell him that. We show that he would be BRCA negative, I don't know but I would want to share that, that was thanks to his grandparents. That they were a part of that legacy that he wouldn't have to deal with that. Again that is contingent upon what I decide for other children but I think that it will be important for him to know that his parents and his grandparents loved him that much that they didn't want that to be something he'd have to deal with.

From this example, Karen played a big role in the decision for Amanda to pursue preimplantation genetic diagnosis to eliminate her son's future HBOC-related risks. Families with narratives high in integration were involved in each other's medical decision-making in addition to providing emotional support.

Overall, coherence provides insight into the degree to which family dyads were engaging in collective sense-making in their hereditary cancer narratives. Families were all generally organized in sharing their stories; however, the degree of integration varied among dyads. Family stories with lower integration did not coherently incorporate two stories or points of view into an overall narrative. Rather, participants told separate stories that rarely if ever overlapped to create a shared narrative that could aid in coping, perceptions of risk, and medical decision-making. When there was less coherence, family members reported having difficulty coping and feeling more intrusive thoughts about their risks. When there was more coherence in joint storytelling, family dyads helped each other tell their parts of the story, discussed how the other members' story

influenced their medical decisions, and intertwined individual stories to create a family narrative. Families low in coherence need an intervention to help families incorporate one another' stories into a larger narrative so members can better engage in collective sense-making.

CHAPTER V

CONCLUSIONS

The focus of this study was to examine how family storytelling shapes coping, perceptions of risks, and medical decision-making for families with a prevalent health history of hereditary cancer. First, this study explored the content of family stories of hereditary cancer based on narrative tone and frame. Identifying narrative frames and their relationship to coping, perceptions of risks, and medical decision-making can help practitioners develop narrative interventions to help families re-frame how they discuss their hereditary cancer risks. Second, this study investigated the process of family storytelling about hereditary cancer using interactional sense-making behaviors such as engagement, turn-taking, perspective-taking, and coherence. Based on study findings, interventions focused on family narratives of hereditary cancer can attempt to improve the processes of storytelling to help keep members engaged and provide conversational space for multiple points of view and additions to the story, while helping members integrate their stories together to achieve better collective sense-making.

Review of Findings on Retrospective Storytelling. Narrative frames about hereditary cancer gave insight into the family's psychological well-being, how they understand their risks of developing cancer, and whether the family engaged in proactive medical decision-making. The empowerment frame in family narratives better supported coping and proactive medical decision-making as these family stories stressed the importance of knowledge to better manage hereditary cancer risks. In contrast, families

using a contamination frame had difficulty coping and reported intrusive thoughts about developing hereditary cancer, which sometimes motivated them to pursue preventive medical options. However, the feeling that cancer had ruined their lives often overwhelmed family members using this frame, motivating them to avoid making proactive medical choices. Differences in outcomes from the contamination frame may be related to the degree of perceived threat of hereditary cancer and perceived efficacy in managing hereditary cancer risks (Witte, 1992). The contamination frame has message components similar to fear appeals that stress the severity of and members' susceptibility to hereditary cancer. As Witte and Allen (2000) contend, the more individuals experience perceived threat, the greater fear they will feel. However, the degree to which efficacy is addressed in this narrative frame can explain why some family dyads chose to make proactive medical choices while others felt overwhelmed and avoided these medical options. Families using the contamination frame who engaged in proactive medical decision-making experienced fear, but their narratives also stressed efficacy regarding members' ability to prevent or catch cancer early through screenings and surgeries (Witte, 1992). In contrast, family dyads who reported avoiding recommended medical options had less efficacy in performing recommended preventive choices and believed these options would not reduce their risks or fears (Witte & Allen 2000). Thus, practitioners working with patients and families using a contamination frame need to stress the efficacy of genetic counseling, preventive screenings, and prophylactic surgeries to prevent the onset of cancer and mitigate fears. Additionally, practitioners also need to provide counseling resources to help these families manage their negative

emotions and re-frame their narratives to stress the importance of information and prevention so they may move toward better coping like families using the empowerment frame (Trees, Koenig Kellas, & Roche, 2010).

Equally important, Family dyads with competing narrative frames experienced relational conflict, which limited members' ability to exchange support and created tension regarding risk perceptions as well as the best medical decisions to manage risks. As Werner-Lin and Gardner (2009) found, competing family narratives cause challenges for family members regarding how they maintain relationships when there is narrative conflict and how they reconcile multiple perspectives to create shared understanding for medical decision-making. Results on competing frames found conflict in family dyads was caused when one member was using an empowerment frame while the other was using a laissez-faire frame. Family members using an empowerment frame tried to provide information to change their relative's risk perceptions and influence their medical choices. Nevertheless, family members using a laissez-faire frame continued to underestimate their risks using inaccurate information. Essentially, these family dyads were having problems collectively managing information. Those using the empowerment frame provided what they saw as helpful information, but relatives using the laissez-faire frame often felt this information provision was insensitive to their desires to avoid information (Shumaker & Brownell, 1984; Skirton & Bylund, 2010). As Brashers (2007) posits, the ways in which individuals manage information is based on their cognitive and emotional appraisals of uncertainty. Individuals may wish to reduce uncertainty about hereditary cancer because they appraise uncertainty about their genetic

condition as a danger and gathering information helps them better cope and manage their health (Hogan & Brashers, 2009), like those using the empowerment frame. Alternatively, individuals may also wish to maintain or increase their uncertainty about hereditary cancer risks because they see uncertainty as an opportunity to maintain hope so they avoid information (Hogan & Brashers, 2009), like those using the laissez-faire frame. Theories of uncertainty often examine uncertainty management from an individual perspective; however, results from this study show how competing goals for uncertainty and information management create competing narrative frames and contribute to family conflict. Practitioners can use these findings to develop interventions aimed toward helping laissez-faire patients re-appraise their uncertainty about hereditary cancer as a danger to promote more proactive medical decision-making. Practitioners can give these family members more information to accurately assess their risks coupled with discussion about medical options to prevent and treat hereditary cancers, which may motivate these members to re-frame their hereditary cancer narrative. For the best medical results, practitioners can use these findings to examine how to help family members with competing frames re-frame their narrative to better facilitate emotional support exchange and psychological well-being.

Beyond sharing information, family dyads with competing frames often experienced problematic emotional support exchange as competing frames led relatives to be dismissive of one another's experiences and feelings. Families with competing frames may be providing incongruent emotional support, which can limit psychological well-being and reduce the emotional health benefits of storytelling (Holmberg, Orbuch,

& Veroff, 2004; Koenig Kellas, 2018; Trees, Koenig Kellas, & Roche, 2010). Often laissez-faire family members communicated emotional distance to the topic of hereditary cancer and would downplay or dismiss another family member's health experience and emotions. Feeling dismissed or unheard by a family member can motivate someone using the empowerment frame to no longer tell their story to those using the laissez-faire frame, which can create rifts among family members and limit communication. Relational conflict and poor emotional support exchange among family dyads with competing frames can create coping problems for families with hereditary cancer. Further, previous research shows social support exchange not only decreases anxiety, but also facilitates family health history communication (Ashida et al., 2013; Koehly et al., 2003; Koehly et al., 2008; Koehly et al., 2009). Consequently, competing frames and the relational conflict they may cause can inhibit future family communication about hereditary cancer risks. Under these conditions, practitioners need to recommend additional counseling resources such as individual and family therapy to give members an outlet to feel heard. As families with a history of hereditary cancer are often adapting to chronic uncertainty (Skirton & Bylund, 2010), practitioners and counselors need to have continued conversations with patients and families about their on-going uncertainty and the emotions that accompany such uncertainty. Further, family therapy can help members better understand why one another frames their narrative differently and how they can start to overlap their emotional interpretations of the narrative. This type of narrative intervention can aid in both information and emotional support exchange,

improving coping and helping members accurately assess and proactively manage their hereditary cancer risks.

Review of Findings on Interactional Narrative Sense-Making. Joint storytelling behaviors such as engagement, turn-taking, perspective-taking, and coherence facilitate collective sense-making about hereditary cancer risks. When family dyads created a shared understanding through collective sense-making they experienced better emotional support exchange and coping, shared information to develop joint perceptions of risk, and influenced one another's medical decisions to manage hereditary cancer risks. First, family members who were high in engagement communicated more support to one another during storytelling. Indeed, engagement can indicate supportiveness in conversations about how to manage problems such as the risk of developing hereditary cancers in the family (Koenig Kellas et al., 2010; Trees, 2000). These family dyads communicated reciprocal support exchange and their engagement in storytelling demonstrated their cohesion and relational well-being, which better facilitated coping with increased risk and making challenging medical choices such as pursuing prophylactic surgeries. Conversely, family dyads low in engagement often had one member "check out" of storytelling and remain emotionally distant. Less engaged family members were using blunting behaviors, in which they avoid threatening aspects of the story such as discussing the loss of family members or more directly speaking about their risks to avoid emotional stress and try to move on with life (McDaniel et al., 2006). Previous research finds that "blunters" not only avoid threatening health information, but they may be less likely to seek information in the face of a health threat

or visit a physician (Miller, 1996; Galvin & Young, 2010; Wilson & Etchegary, 2010). Accordingly, family members who were less engaged in storytelling often reported putting off screenings and prophylactic surgeries, suggesting family dyads with low engagement in telling the family's story about hereditary cancer need an intervention to overcome these blunting behaviors. Practitioners such as genetic counselors should encourage patients who are blunters to express their emotions motivating their avoidant behaviors, acknowledge the validity of those feelings, and help to restructure the patient's thoughts (Gaff, Galvin, & Bylund, 2010). Further, genetic counselors may be in a situation to work with multiple family members as some relatives prefer to attend genetic counseling sessions together. In these situations, genetic counselors can identify when a family member is blunting conversations about risk and the family story. Helping these patients manage their negative emotions about risk and helping them approach their hereditary cancer risks from an altered perspective may help these reluctant family members engage more in storytelling and become more active in managing their risks.

Second, turn-taking indicated which member in the dyad had the most power in telling the family story of hereditary cancer. By having more control over narrative construction, this family member also had the most influence in determining risk perceptions and medical decisions for other relatives managing their hereditary cancer risks. Dominant storytellers were most often affected (those who have a pathogenic gene variant and/or personal cancer history) family members, who spoke over and interrupted unaffected family members when sharing their narrative. In previous research on how

individuals and families manage hereditary cancer, the focus has been on the affected individual, which may underestimate the role unaffected family members can play in the patient's ability to cope, their perceptions of risks, and medical decision-making (Aktan-Collan et al., 2011; Gaff et al., 2007; Hughes et al., 2002). While it makes sense that affected family members have the most to tell and share regarding the hereditary cancer narrative, quieting unaffected family members' voices during storytelling can be a missed opportunity for additional support exchange. Although affected family members are managing a significant emotional burden related to their risks and ultimately are the ones who make decisions on how to best manage those risks, unaffected family members are also managing emotions such as worry and anxiety for their family member and can provide emotional as well as tangible support (Galvin & Young, 2010). Previous research finds family members with a pathogenic gene variant often discussed their test results and health burdens with unaffected family members such as spouses and partners (Koehly et al., 2003; Koehly et al., 2009). Further, research on disclosure of genetic risk information finds affected family members tend to disclose results and discuss health risks more frequently with relatives they feel emotionally close to, who provide them emotional support, and who they frequently see (Ashida et al., 2013). Unaffected family members often fit these characteristics facilitating further communication and their voices in storytelling can help alleviate some of the informational and emotional burden that affected family members often experience. Moreover, spouses may not only be concerned for their partner, but may also be worried about the genetic risks their offspring may face and likely will play an active role in disclosing to children and

helping the next generation manage risks (Forrest et al., 2003; Holt, 2006). Accordingly, interventions for families with low turn-taking should focus on creating opportunities for unaffected family members to become more active in storytelling and collective sense-making about familial hereditary cancer risk. Practitioners can design interventions that give unaffected family members recommendations and tools to better support their affected family members as they're managing emotions related to risk and make prevention and treatment decisions. Moreover, practitioners may need to stress to affected family members the importance of bringing unaffected family members into family storytelling about hereditary cancer.

Next, families high in perspective-taking constructed a narrative that served as a reference for other members, reflecting close relational support as well as a shared understanding of risk and medical decision-making. In narrative sense-making literature, perspective-taking in joint family storytelling acts as a consistent, positive predictor of relational cohesion and perceptions of familial support (Koenig Kellas, 2005; Trees & Koenig Kellas, 2009). Families low in perspective-taking often disconfirmed one another's perspectives, causing relational conflict and withdrawal. When family members felt their relative did not understand or confirm their perspective, they would often shut down and stop adding in their points of view during joint storytelling. Similarly, previous research in the contexts of HBOC and Lynch syndrome found when family members are insensitive to individuals' perspectives about how they manage their hereditary cancer risks, communication shuts down limiting disclosures and old disputes can resurface (Rauscher & Dean, 2017; Carlsson & Nilbert, 2007). When perspectives

are disconfirmed and communication is shut down, there was a dominant perspective. Low perspective-taking in families may reflect a chilling effect during family storytelling in which members do not share their perspectives due to the coercive power of the family member with the dominant perspective (Afifi & Olson, 2007). Family members may choose to quiet their perspectives during storytelling for fear of judgment or aggression from others during storytelling if their perspective conflicts with a more dominant storyteller. The chilling effect not only causes secret concealment in families limiting information exchange, it can also negatively affect relational closeness (Afifi & Olson, 2007). Indeed, results demonstrated families low in perspective-taking expressed different perceptions about risks and problems with coping, which may be due in part to limitations in emotional support exchange. Practitioners should develop interventions to help families low in perspective-taking work together to share and respect each person's views on their hereditary cancer risks. Genetic counseling appointments may be an especially important time for family members to individually share their perspectives about their risks and the family's history with a professional. During this time, genetic counselors can help patients problem solve as patients consider how to talk about hereditary cancer with their family (Gaff, Galvin, & Bylund, 2010). If practitioners assess families are low in perspective-taking or a patient feels their voice is not respected in family conversations about hereditary cancer, it can be especially beneficial to recommend psychological counseling to provide a space the patient can feel heard as well as family therapy to help more perspectives be included in joint storytelling to improve coping and collective sense-making (Trees, Koenig Kellas, & Veach, 2010).

Finally, narrative coherence showed overall how well family dyads were engaging in collective sense-making to create a logical narrative that incorporated each member's individual side of the story (Koenig Kellas & Trees, 2005). Coherence not only reflects consistency in family stories about hereditary cancer, but it can also demonstrate if the family is creating a "master narrative" that overlaps family stories into an ideological force (Trees, Koenig Kellas, & Veach, 2010), which creates the basis for shared understanding of risk perceptions and medical decision-making. While results found most family dyads told organized and logical stories, for families with low coherence a larger narrative was not created. Lack of a master narrative integrating family stories demonstrated less collective sense-making (Koenig Kellas, 2018), and family members experienced more intrusive thoughts when thinking about their hereditary cancer risks. These families have multiple, individual stories competing for attention, which potentially caused confusion and uncertainty among members on how best to manage their lifetime risks. More coherent family storytelling may not only help create a larger narrative for the current generation, but it can also aid in collective sense-making as the narrative is passed across generations (Trees, Koenig Kellas, & Veach, 2010). Practitioners can benefit from using narrative therapy or narrative medicine in which they encourage family members to work collectively against the problem, and thus stress to patients the importance of family members coming together to discuss risks, share information about medical options to manage those risks, and aid in one another's coping. Using narrative medicine would re-focus recommendations from just disclosing genetic test results and risk information to family members, which has been

heavily studied (Aktan-Collan et al., 2011; Claes et al., 2003; Mesters et al., 2005), to helping patients orient themselves to an on-going family conversation and story that will change and grow as more voices are incorporated. Helping patients prepare for on-going family storytelling and stressing the importance of purposefully creating a multigenerational family narrative can help members be more deliberate and reflective as they collectively make sense of their hereditary cancer risks.

Theoretical Implications. Findings support and expand research using CNSM theorizing by examining how both the content of narratives and the process of storytelling in families are connected to outcomes related to psychological well-being and medical decision-making. First, results on narrative tone and framing support Propositions 1 and 2, which contend "the content of retrospective storytelling reveals individual, relational, and intergenerational meaning-making, values, and beliefs" and when family narratives are framed positively they are positively related to relational health and well-being (Koenig Kellas, 2018, p. 65). This study both builds on previous findings on framing and complicates theory behind retrospective storytelling by providing a new frame that may be particularly salient in health contexts. The laissez-faire frame differs from the theorized ambivalent frame as the laissez-faire frame did not reflect mixed or contradictory feelings about the story topic (Koenig Kellas et al., 2009; McAdams et al., 1997). Rather the laissez-faire frame was characterized by unemotional acceptance based on inaccurate risk information. Further, when family members had conflicts in their story it was due to the competing nature between the empowerment and laissez-faire frames. Currently, CNSM does not account for family members

communicating competing frames, causing conflict in narrative sense-making. Second, while CNSM holds that storytelling can influence health outcomes related to psychological and relational well-being, far less research examines how stories may contribute to medical decisions (Koenig Kellas, 2005; Trees & Koenig Kellas, 2009). Findings from this study not only link narrative framing to psychological well-being and risk assessment, but also finds connections between frames and the medical choices. Thus, this study begins to make additional connections between narrative sense-making and health outcomes.

Findings on the communication processes of joint storytelling further support Propositions 3 and 4 of CNSM as higher levels of interactional sense-making (i.e., engagement, turn-taking, perspective-taking, and coherence) support higher levels of collective sense-making, individual and relational health, and well-being (Koenig Kellas et al., 2010; Koenig Kellas, 2018). In the context of hereditary disease, families tell stories not only to cope with and share risk information, but they also tell stories to socialize members toward taking specific actions to better manage their risks such as pursuing genetic testing, engaging in regular screening, and undergoing prophylactic surgeries. Results from this research can expound on the dark side of joint family storytelling in which some family members' stories are dismissed, voices are muted, and family members resist inherited narratives (Koenig Kellas, Willer, & Kranstuber Horstman, 2010). Families with lower interactional sense-making during joint family storytelling about hereditary cancer not only engaged in less or incomplete collective sense-making (Koenig-Kellas, 2018), but there was often a family member establishing

narrative dominance. This family member often defined the larger narrative meaning for others, which can silence individual voices, subvert individual identity (Stone, 1988), and open non-dominant voices up for critique by other family members (Koenig Kellas, Willer, & Kranstuber Horstman, 2010; Langellier & Peterson, 1993). These type of family stories can thus be a point of conflict and contribute to poor coping and family relationships. While previous research using CNSM has investigated the dark side of retrospective storytelling, far less research has been done on the dark side of interactional storytelling (Koenig Kellas & Trees, 2005). This study begins to fill an important theoretical gap by examining the dark side of joint storytelling (Koenig Kellas & Kranstuber Horstman, 2015). As storytelling is connected to coping and relational well-being, problems in the process of interactional storytelling can have serious implications for health outcomes of storytellers as well as for the type of narrative created that may help or hinder family members as they manage hereditary cancer risks.

Practical Implications. Findings from the current study can be used to develop narrative interventions targeting efforts to help families re-frame their narratives to support improved coping, accurate risk perceptions, and proactive medical decision-making. The third heuristic of CNSM, translational storytelling, examines how narrative research can be used to develop interventions to improve outcomes of storytelling for families (Koenig Kellas, 2018; Koenig Kellas & Kranstuber Horstman, 2015). Genetic counselors and practitioners need to be aware of how narrative frames can influence patients' and family's health decisions and directly discuss these frames during consultations. In particular, practitioners need to probe into how patients are feeling

about their risks and practice narrative medicine, in which physicians provide patient care with empathy and appreciation for how patient stories affect health (Charon, 2001). Practitioners, when diagnosing patients with a hereditary cancer condition, can provide information about the health condition, risks and treatment; however, it may be beneficial for practitioners to also use the empowerment frame as they are helping patients make sense of a new genetic diagnosis. For instance, as genetic counselors are explaining the implications of genetic testing to patients pre-diagnosis they can explain how learning more about their potential condition is a way to better manage their health and protect other family members by alerting relatives to their risks. Further, at the time of diagnosis practitioners also need to give patients tools to think more deliberately about how they will frame their story, especially for probands as they are the first to be diagnosed in the family and their story is likely to be particularly impactful on the family (Hughes et al., 2002; Peterson et al., 2003). Helping patients construct their narrative before leaving the clinical consultation can help patients better organize their thoughts and express their emotions in a story that alerts others to risk and equips family members to make proactive medical choices.

Second, narrative interventions should target interactional storytelling to improve the process of family storytelling to better facilitate collective sense-making that supports coping, accurate risk perceptions, and proactive medical decision-making. Previous research has found families managing hereditary conditions often feel they lack resources from professionals on both what to communicate and how to have family conversations about genetic risks (Metcalfe et al., 2008; Peterson et al., 2018; Wilson &

Etchegary, 2010). Genetic counselors need to have a continued relationship with patients not only to improve continuity of care, but to better support patients and their families as they learn more about their hereditary condition, make sense of their risks, and interact with affected and unaffected family members across generations. Continued genetic counseling appointments can help practitioners provide information and support resources to help patients and their families manage their narrative over time, as each new family diagnosis can motivate more narrative sense-making and possibly change the family narrative over time (Werner-Lin, 2007). In these follow up appointments practitioners can ask patients about how they and their families are adjusting to the diagnosis and how they are communicating to better understand how families are making sense of their hereditary cancer risks and what new sense-making tools families may need. Further, family members often see the same genetic counselor, which can better facilitate family system interventions to improve storytelling (Gaff, Galvin, & Bylund, 2010). Genetic counselors can advise patients and give them tools not only on how to frame their stories, but also on how to bring a "checked out" member back into the conversation and how to respectfully communicate when there are different perspectives. Genetic counselors can also provide suggestions on therapists for individuals and families to seek additional help as families work through narrative conflict during sense-making about hereditary cancer.

Limitations & Future Directions. Although this study presents interesting findings regarding family communication and storytelling about hereditary cancer, the sample is limited as it is predominantly made up on Caucasian, well-educated

participants. These diversity limitations are important to discuss as family is nested within cultural norms, which can influence how relatives discuss health (Bochner, 1976) as well as their ability to access health resources and services such as genetic counseling (Hall & Olopade, 2005). However, it stands to reason that if the families in this study who have resources face family communication and information management challenges, these problems can be exacerbated in families with limited access to practitioners and information. Second, participants were recruited through advocacy organizations and social media support groups for patients and families managing hereditary cancers so there may be a selection bias as participants may be more active in managing their risks than the rest of this population (Collier & Mahoney, 1996). Further, family members could choose a relative to recruit to complete the dyadic interview, which can further limit generalizability as there are some dyadic family relationships that are not represented in this data and a small representation of others. However, family members often recruited a reluctant relative to tell their family story as evidenced in results of the study, which may suggest selection bias was not as prevalent of a problem. Despite these limitations, this study aims to show the connections between family communication and storytelling about hereditary cancer and health outcomes.

Future research should continue examining how families tell stories about hereditary conditions to make sense of and manage their risks. One area researchers should investigate is the relationship between family communication environments and narrative sense-making. In particular, the process of narrative construction through interactional sense-making can represent patterns of communication and socialization in

families as well as represent relational health (Koenig Kellas, 2018). As CNSM contends, storytelling is a way of enacting family and family narratives help define both individual and familial identity (Koenig Kellas & Kranstuber Hortsman, 2015). Accordingly, researchers can naturally link family communication patterns to the process of family storytelling (Thompson & Schrodt, 2015; Wittenberg-Lyles, Goldsmith, Demiris, Oliver, & Stone, 2013). Based on this study's findings on the links between family storytelling and psychological and physical outcomes, examining the relationship between typologies of family and interactional sense-making can establish a model for predicting family communication environment's relationship to outcomes through interactional sense-making. Such a model examining a possible mediation or moderation relationship of interactional sense-making between family communication environment and health outcomes may also be applied to other long-term, chronic health conditions. Moreover, certain frames may be more prevalent in specific family types, which can further help in developing interventions to aid families in communicating about hereditary cancer risks. By categorizing patients based on family types and frequently associated health outcomes, practitioners can establish clinical conversational tools specific to the patient's family environment (Koerner, LeRoy, & Veach, 2010).

Conclusions. As the science and clinical applications of genomic medicine continue to advance, more families will be diagnosed with hereditary disease and will turn to practitioners as well as family to make sense of their lifetime risks. Examining how families with a prevalent history of hereditary cancer come together to construct illness narratives gives more insight into why some patients and families proactively

manage their risks while others may be more avoidant. Developing narrative interventions to help families re-frame narratives and to improve the process of joint storytelling to better facilitate collective sense-making can aid in helping families cope with their lifetime cancer risks and make proactive medical decisions to better manage those risks. These family narratives can be multigenerational and may change over time as more family members add their voices to stories of hereditary cancer (Werner-Lin, 2007). Family narratives not only help family members cope with and make sense of their hereditary cancer risks, but can also define individual and family identities (Frank, 1998; Koenig Kellas & Kranstuber Hortsman, 2015; Trees, Koenig Kellas, & Roche, 2010). Thus, these narratives are important to continue studying and need to be incorporated into clinical care for patients and families facing hereditary cancer.

REFERENCES

Afifi, W. A., & Morse, C. (2009). Expanding the role of emotion in the theory of motivated information management. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty, information management, and disclosure decisions: Theories and applications* (pp. 87-105). New York: Routledge.

Babrow, A. S., & Striley, K. M. (2014). Problematic integration theory and uncertainty management theory: Learning to hear and speak to different forms of uncertainty. In D. O. Braithwaite & P. Schrodt (Eds.), *Interpersonal communication: Multiple perspectives* (pp. 103-114). Los Angeles: Sage Publications, Inc.

Barbour, J. A., Rintamaki, L. S., Ramsey, J. A., & Brashers, D. E. (2012). Avoiding health information. *Journal of Health Communication*, *17*, 212-229.

Barry, C. L., & Huskamp, H. A. (2011). Moving beyond parity—mental health and addiction care under the ACA. *New England Journal of Medicine*, *365*(11), 973-975.

Bawden, D., & Robinson, L. (2009). The dark side of information: overload, anxiety and other paradoxes and pathologies. *Journal of Information Science*, *35*(2), 180-191.

Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication*, *51*, 477-497.

Brashers, D.E. (2007). A theory of communication and uncertainty management. In B. Whaley & W. Samter (Eds.), *Explaining communication theory* (pp. 201-218). Mahwah, NJ: Lawrence Erlbaum Associates.

Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding

in health contexts. *Human Communication Research*, *28*(2), 258-271.

Brashers, D. E., & Hogan, T. P. (2013). The appraisal and management of uncertainty: Implications for information-retrieval systems. *Information Processing & Management*, *49*(6), 1241-1249.

Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). "In an important way, I did die": Uncertainty and revival in persons living with HIV or AIDS. *AIDS Care, 11*, 201–219.

Brashers, D. E., Neidig, J. L., Haas S. M., Dobbs, L. K., Cardillo, L. W., & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs*, *67*, 63-84.

Bylund, C. L., Fisher, C. L., Brashers, D., Edgerson, S., Glogowski, E. A., Boyar, S. R., Spencer, S., & Kissane, D. (2012). Sources of uncertainty about daughters' breast cancer risk that emerge during genetic counseling consultations. *Journal of Genetic Counseling*, *21*(2), 292-304.

Dauner, K. N., & Thompson, J. (2014). Young adult's perspectives on being uninsured and implications for health reform. *The Qualitative Report*, *19*(4), 1-15.

Cantor, J. C., Monheit, A. C., DeLia, D., & Lloyd, K. (2012). Early impact of the Affordable Care Act on health insurance coverage of young adults. *Health Services Research*, *47*(5), 1773-1790.

Cegala, D. J., McClure, L., Marinelli, T. M., & Post, D. M. (2000). The effects of communication skills training on patients' participation during medical interviews. *Patient Education and Counseling*, *41*(2), 209-222.

Centers for Disease Control and Prevention. (2014, January 17). National Prevention Strategy: America's Plan for Better Health and Wellness. Retrieved July 24, 2015, from http://www.cdc.gov/features/preventionstrategy/

Cohen, R. A., & Martinez, M. E. (2012). Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey, January–March 2012. Atlanta, GA: Centers for Disease Control and Prevention.

Gostin, L.O., & Garcia, K.K. (2012). Affordable Care Act litigation: The Supreme Court and the future of health care reform. *The Journal of the American Medical Association*, *307*(4), 369-370.

Gray, N. J., Klein, J. D., Noyce, P. R., Sesselberg, T. S., & Cantrill, J. A. (2005). Health information-seeking behaviour in adolescence: The place of the internet. *Social Science & Medicine*, *60*(7), 1467-1478.

Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., & Viswanath, K. (2005). Trust and sources of health information: the impact of the Internet and its implications for health care providers: Findings from the first Health Information National Trends Survey. *Archives of Internal Medicine*, *165*(22), 2618-2624.

Hogan, T. P. (2007). *Information and the management of treatment in chronic illness: A qualitative study of people living with HIV-disease*. ProQuest.

Hogan, T. P., & Brashers, D. E. (2009). The theory of communication and uncertainty management: Implications from the wider realm of information behavior. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty, information management, and*

disclosure decisions: Theories and applications, (pp. 45-66). New York: Routledge.

Kaiser Family Foundation. (2013). *Kaiser health tracking poll.* http://kaiserfamilyfoundation.files.wordpress.com/2013/09/8487-t.pdf

Lazarus, R. S. (1991). *Emotion and adaptation*. Oxford: Oxford University Press.

McCroskey, J. C. (1966). Scales for the measurement of ethos. *Speech Monographs*, 33, 65-72.

Mishel, M. H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship*, *20*, 225-232.

Moldovan-Johnson, M., Tan, A. S., & Hornik, R. C. (2014). Navigating the cancer information environment: The reciprocal relationship between patient–clinician information engagement and information seeking from nonmedical sources. *Health Communication*, *29*(10), 974-983.

Monaghan, M. (2014). The Affordable Care Act and implications for young adult health. *Translational behavioral medicine*, *4*(2), 170-174.

Pasek, J., Sood, G., & Krosnick, J. A. (2015). Misinformed about the Affordable Care Act? Leveraging certainty to assess the prevalence of misperceptions. *Journal of Communication*, *65*(4), 660-673.

Pecchioni, L. L., Thompson, T. L., & Anderson, D. J. (2006). Interrelations between family communication and health communication. In L. H. Turner & R. West (Eds.), *The family communication sourcebook*, (pp. 447-468). Thousand Oaks: Sage Publications, Inc.

Rains, S. A., & Tukachinsky, R. (2015). An examination of the relationships among uncertainty, appraisal, and information-seeking behavior proposed in uncertainty management theory. *Health Communication*, *30*(4), 339-349.

Sommers, B. D., Buchmueller, T., Decker, S. L., Carey, C., & Kronick, R. (2013). The Affordable Care Act has led to significant gains in health insurance and access to care for young adults. *Health affairs*, *32*(1), 165-174.

Thompson, N. M., Bevan, J. L., & Sparks, L. (2012). Healthcare reform information-seeking: Relationships with uncertainty, uncertainty discrepancy, and health self-efficacy. *Journal of Communication in Healthcare*, *5*(1), 56-66.

U.S. Department of Health and Human Services. (2015). Preventive Care. Retrieved from http://www.hhs.gov/healthcare/rights/preventive-care/

APPENDIX A

JOINT STORY-TELLING INTERVIEW GUIDE

Welcome. Please try to interact together as you normally would. There are no wrong of right answers and we are interested in how you answer questions together. Please be as detailed as possible in your responses.

1. Please tell the story of your family's experience with hereditary cancer. Tell it to me as if I'm a family member newly diagnosed and looking for advice about what to do for my health next.
    a. Is there are significant story told in your family regularly? If so, can you tell it to me as if we are at a family gathering?
2. Can you provide a description of the history of cancer in your family?
    a. How have you seen this history and its health issues affect members in your family?
3. How did you learn about your family's health history?
4. Have either/any of you been diagnosed with cancer?
    a. If so when?
    b. How did you manage it?
    c. How did the family respond?
5. Have either/any of you undergone genetic testing? Why/why not?
6. Can you describe an important memory you have about how you or a family member managed cancer or the risk of cancer?
7. How do you feel about your family's health history and risk of cancer?
8. Is there a certain story often told in your family regarding hereditary cancer?
9. Are there family members who do not share your perspectives? If so, who? And why do you think that is?

Follow-Up Survey Items

<u>Demographics</u>

1. What is your age?
2. What is your sex?
    a. Male
    b. Female
3. What is your ethnicity?
    a. Caucasian

   b. Black/African American
   c. Asian/Pacific Islander
   d. Native American
   e. Hispanic
   f. Middle Easter
   g. Other
4. What is your annual household income?
   a. Less than $25,000
   b. $25-50,000
   c. $50-75,000
   d. $75-100,000
   e. more than $100,000
5. What is the highest level of education you have received?
   a. High School Graduate or GED
   b. Some college education
   c. Associate's degree
   d. Bachelor's degree
   e. Graduate or professional degree
   f. Prefer not to answer
6. Have you undergone genetic testing?
   a. Yes
   b. No
7. If yes, do you carry a gene mutation related to hereditary breast and ovarian cancer syndrome?
   a. Yes, BRCA1
   b. Yes, BRCA2
   c. Yes, PALB2
   d. Yes, MLH1
   e. Yes, MSH2
   f. Yes, MSH6
   g. Yes, PMS2
   h. Yes, EPCAM
   i. Yes, CHEK2
   j. Yes, TP53
   k. Yes, not sure of gene variant
   l. No
   m. Uncertain results
8. Has anyone in your family undergone genetic testing?
   a. Yes
   b. No
   c. Not sure
9. If yes, who? (check all that apply)
   a. Mother
   b. Father

    c. Maternal Grandmother
    d. Maternal Grandfather
    e. Paternal Grandmother
    f. Paternal Grandfather
    g. Sibling
    h. Maternal Aunt
    i. Maternal Uncle
    j. Paternal Aunt
    k. Paternal Uncle
    l. Cousin
    m. Other, please specify:
10. Have you ever had cancer?
    a. Yes
    b. No
11. If you have been diagnosed in the past, how long has it been?
12. What type(s) of cancer were you diagnosed with?

APPENDIX B

CODEBOOK

Retrospective Storytelling Ratings

Tone

Assess the extent to which the storyteller expresses positivity vs. negativity in the story. Those expressing *positive affect* in their story may note that they are cheerful, glad, or content with the experience. They may refer to the "positive aspects" of their difficult experience and use positive affect words (e.g., hopeful, happy, encouraged, peaceful, satisfied). These storytellers express that they feel hopeful, optimistic, or upbeat about the situation.

Stories with *negative affect* will have a depressed, despondent, or gloomy feel. Storytellers may mention that they are troubled or frustrated by the event and that they get upset or emotional about the experience. The storyteller may feel helpless or dejected, expressing little hope that the situation will turn out well. Storytellers may mention other negative feelings such as sadness, anger, anxiety, frustration, hopelessness, unhappiness, discouragement or irritation that accompany their discouraged feeling.

Frame

Assess the extent to which storytellers conclude their stories in positive (redemptive) or negative (contaminated) ways. This element of narrative tone examines the *progression* of affect throughout the story, from beginning to end of the narrative. Redemptive sequences are those that the storyteller begins the story in a neutral or

negative way, and then concludes in a positive manner. *Redemptive sequences* also include those that end of a positive note, especially if the storyteller describes their experience as overall negative or beginning negatively. The overarching quality of redemptive stories are that the storytellers recognize the good that comes out of a difficult or challenging situation.

Contaminated sequences are those that the storyteller begins in a positive or neutral way, and concludes the story in a negative light. Stories that transitioned from positive to negative, or if the story was generally negative will be coded as contaminated. Stories that are neither particularly redemptive nor contaminated will be coded as *ambivalent*. The storyteller does not describe his/her emotions through the story, including a neutral or ambivalent end to the story.

Appendix C

CODEBOOK

Joint Storytelling ISM Ratings

Engagement

Involvement (Uninvolved to Involved)

- Involved: All family members are both verbally and nonverbally engaged in the telling of the story. Each person shows interest in both telling and listening to the story. Family members are consistently animated, interested, and engaged verbally and nonverbally and are involved throughout the telling.
- Relatively Involved: All family members are animated and engaged for most of the telling with infrequent occurrences of family members "turning out" at certain points in the story. Or, two members are highly involved throughout and one member is involved through part of the story and not involved at other times.
- Neutral: There is either a balance between involvement and uninvolvement or moderate involvement throughout. Family members are at times verbally and nonverbally engaged in the telling and at times seem to "tune out" from involvement in telling or listening. Or, one member is highly involved in the telling and listening of the story and the other is sometimes involved and sometimes uninvolved. Alternatively, family members may be moderately involved, somewhat lively but not highly animated.
- Relatively Uninvolved: Family members are less animated and interested in the telling. They less frequently engage in involvement behaviors while telling or

listening to the story. One family member might be involved, but the other appears uninterested or is moderately involved or quite uninvolved in the story telling.

- Uninvolved: Family members do not seem interested in telling the story (e.g., seem bored and uninvolved) or in listening to other members (e.g., no eye contact or back channeling). There is little to no liveliness; telling the story seems like a chore.

Warmth (Cold to Warm)

- Warm: Family interaction is characterized by warm interaction including laughter, smiles, verbal attentiveness and encouragement and affection both verbally and nonverbally.
- Relatively Warm: The family interaction is mostly warm with some instances of family members disassociating themselves from the interaction and/or the story is often, but not always characterized by warmth and affection. If they are in conflict, they do so with positive nonverbal cues.
- Neutral: The storytelling interaction is balanced between warm attentiveness and distance or is neither warm nor cold, but relatively neutral.
- Relatively Cold: Family members are most distant than they are warm. There may be one or two instances of laughter, attentiveness, or affection, but, in general, the family is distant and does not express warm attentiveness. Expressions of negative affect are also possible.

- Cold: Family members appear distant and cold. There is very little or not warmth and affection. Family members do not appear associated with one another. May express negatively and engage in negatively valenced conflict.

Turn – Taking

Dynamic (Structured to Fluid)

- Fluid: Family members interact in a fluid, dynamic, and free manner. The interaction is marked by interruptions, overlaps, and energy. Little attention is paid to structured/polite turn-taking. Family members add without asking.
- Relatively Fluid: The interaction is fluid and flowing, but somewhat more reserved. Family members may still interrupt and build off one another freely, but they ask more frequently (e.g., "I just have to add something here").
- Neutral: Family members occasionally interrupt each other and build dynamically upon each other's comments, but they tend to also listen politely and wait their turn to talk. Or part of the story may be one family member telling the story and then the other half is marked by interruptions, overlaps, and energy.
- Relatively Structured: Family members rarely jump in to add to another's comments. Aside from a few additions or interruptions, family members wait their turn to talk.
- Structured: Turn-taking is extremely structured. The telling is characterized by one person talking/telling their version of the story, followed by the next person, followed by the next person. Each person has a turn and they rarely deviate from that format.

Distribution of Turns (Uneven distribution of turns to Even distribution of turns)

- Even distribution of turns: Each family member contributes equally to the telling of the story. There is an even distribution of who gets to talk; how many turns each person takes.
- Relatively even distribution of turns: The telling is fairly evenly distributed across the family. One member may dominated the telling, but the other contributes a fair/almost equal amount.
- Neutral: Every family members get a turn, but there is a sense that one family member takes more turns than the other. There is some uneven distribution.
- Relatively uneven distribution of turns: One family member has more room to tell the story than the other. Turns are more unevenly than they are evenly distributed.
- Uneven distribution of turns: One person dominates the telling of the story while the other takes very few to no turns.

Perspective – Taking

Attentiveness to Others' Perspectives (Ignored to Integrated)

- Integrated: During the telling of the story, family members demonstrate an understanding that others may have a different perspective, listen to the others' views, and incorporate the others' perspectives into the telling (e.g., acknowledge others' comments and make it part of their subsequent comments).

- Relatively Integrated: Family members sometimes acknowledge each other's perspectives and include them in their subsequent comments and/or one member is particularly attentive to the others' perspectives throughout the storytelling.
- Neutral: Family members sometimes acknowledge each other's perspectives and sometimes ignore them (e.g., do not acknowledge the other person had a different experience/something to add and do not incorporate this perspective into their subsequent comments). There is a balance in perspective taking. It may be that family members do so minimally. Family members acknowledge others' perspectives, but do not integrate them into their own comments.
- Relatively Ignored: Family members rarely take each other's perspective into account. Family members may occasionally verbally or nonverbally acknowledge the other person(s)' comments, but generally do not integrate these comments into their own and do not explicitly seek out others' perspectives. May be that a family member engages in moderate perspective-taking behavior and one ignores the others' perspectives.
- Ignored: Family members seem to ignore the perspectives of others in the family. There is a sense that the stories are separate and distinct for each family member and members only recognize their own experience of the story.

<u>Confirming of Perspectives (Disconfirming to Confirming)</u>

- Confirming: Others' perspectives are always or almost always acknowledged and confirmed (e.g. "Oh that's a good point;" "Yes I can see where you would feel that way"; nodding, smiling at another's perspective).

- Relatively Confirming: Family members confirm each other's perspective some of the time and do not engage in any disconfirming behaviors.
- Neutral: Family members sometimes confirm and sometimes disconfirm (e.g., "that's not what happened;" no, you're wrong, I was there") each other's perspectives or they are neither particularly confirming nor particularly disconfirming, but relatively neutral.
- Relatively Disconfirming: Family members tend to disagree with each other's telling more than agree. There is more of a disconfirming tone in response to others' contributions than confirming comments. More disagreement.
- Disconfirming: Family members consistently disconfirm each other's experience of the story. They continually disagree with the other person(s)' comments. Disagreements are frequently and potentially negative.

Coherence

Organization (Disorganized to Organized)

- Very Well-Organized: The story follows logical sequence throughout with a clear beginning, middle and end. Very little to no backing up and jumping around.
- Relatively Well-Organized: The story has an overall structure that generally gets followed with only some places where the telling gets messy and disorganized.
- Moderately between the two: Parts of the story are well organized and parts are quite disorganized or it is moderately organized throughout with a moderately discernable underlying structure guiding plot development.

- Relatively Disorganized: Much of the story does not follow a logical sequential development of the plot very well but there is some minimal discernable underlying structure.
- Very Disorganized: The story doesn't have a discernable overall structure and lacks sequential development.

Integration (Parallel to Collaborative)

- Collaborative: Family members consistently add on to each other's comments to build the story. There is one overall story being told and the various contributions "hang together"; A high degree of "jointness" to the story.
- Relatively Collaborative: Family members often build on each other's comments, integrating their stories, although occasionally one member tells portions of the story without much collaboration from the other member. Generally, with some exceptions, the parts of the overall story being told fit together.
- Neutral: Family members balance between adding to each other's stories and telling more separate individual versions. Family members sometimes collaborate and sometimes provide parallel comments. Overall, moderately coherent story with parts that fit together well and other parts that don't.
- Relatively Parallel: Family members generally tell separate versions of the story, with rare additions from other members. Family members occasionally add onto one another's comments, but it is rare.
- Parallel: Family members tell parallel stories, with little to no integration. They seem to be separate stories that don't hang together well at all.