A QUALITATIVE INVESTIGATION OF COMMUNICATION PRIVACY MANAGEMENT (CPM) WITHIN FAMILIES WITH HEREDITARY NON-POLYPOSIS COLORECTAL CANCER (HNPCC)

A Thesis

Presented to

The Faculty of the Department

of The Valenti School of Communication

University of Houston

In Partial Fulfillment

Of the Requirements for the Degree of

Master of Arts

By

Carmen M. Galvan

May, 2014

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ABSTRACT

This study examined communication privacy management (CPM) among persons with Lynch syndrome (LS), specifically seeking to understand (a) the prompts that motivate participants to share LS health information, (b) the relatives with whom they share the information, and (c) the mediums through which they communicate the information. Based on responses from 32 LS mutation carriers, the vast majority of participants demonstrated high permeability orientations with close and distant family members through in-person visits, phone, email, and social media. Participants characterized by moderate permeability shared what they considered important LS-related health information with close, distant, and conflict family groups through phone, email, social media, through other family members, and through email and postal mail attachments. Though there were very few instances of low permeability, participants in this category chose not to share any LS information with certain family groups due to level of health importance, maturity, appearing weak, not wanting to cause stress, or because they did not think their relatives would care or be interested in the information. The implications of this study could provide the basis for a more widespread approach by offering physicians, genetic counselors, and family members a new understanding of communication privacy and hesitancy in sharing, as well as new means of raising genetic risk awareness among all family groups.

ACKNOWLEDGEMENTS

This thesis began a year ago when I received an email from my University of Houston mentor, and now committee chair, Dr. Jill Yamasaki. Her research collaborators at The University of Texas M.D. Anderson Cancer Center were looking for a summer graduate research assistant, and Dr. Yamasaki offered to recommend me for the position. Her recommendation led me to interview with Dr. Susan K. Peterson, Dr. Allison Burton-Chase, and Dr. Shelly R. Hovick, and I began working with them almost immediately. I learned much while part of this team, and am beyond grateful to Allison and Susan for offering *A Social Network Approach to Improve Genetic Risk Communication* as secondary data. I am very thankful to these four very special women, because through their faith in me, what was supposed to be a short 3-month research assistantship has developed into a paper, a thesis, and an incredible new career.

I am blessed to have my parents' support in everything I do, but especially the past two years of graduate school. Thank you for listening to me, guiding me, and reminding me that through God all things are possible. My stress levels also were kept to a minimum through the help of my dog, Hershey. He's better than chocolate… and zero calories.

Finally, thank you to my thesis committee, Dr. Yamasaki, Dr. Peterson, and Dr. Jennifer Vardeman-Winter, for everything you've done to help make this project a success.

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Chapter 1

INTRODUCTION

"We didn't (talk about family health history) a lot until I was also diagnosed with Lynch syndrome. I called my sister and I said, 'What do you know about this?' ... And she said, 'Well, I told you 4 or 5 years ago about Lynch syndrome.' It didn't affect me at all because it's like, 'well, I don't have it, so I don't have to think about that,' kind of a thing. I'd stick my head in the sand. So it wasn't until 2 years ago when I was diagnosed with it that we then started talking about Lynch syndrome, living with it, living with all of the ramifications of it, and how it can affect your family history. As soon as I got the genetic testing back I sent it to my daughters so they could look at it and think about what they wanted to do, and then we could kind of go from there – compare notes on how it affects you physically, how it affects you psychologically, and so on."

In May 2013, I joined a research team at The University of Texas M.D. Anderson Cancer Center's (M.D. Anderson) Department of Behavioral Science as a graduate research assistant. The team's primary study centered on genetic risk communication among families with Lynch syndrome (LS). There I began to understand the potentially life-saving impact of what was being studied and tested at M.D. Anderson, particularly regarding family communication and privacy management.

Lynch syndrome, also referred to as hereditary nonpolyposis colorectal cancer syndrome (HNPCC), is caused by harmful germline mutations in genes MLH1, MSH2, MSH6, PMS2, and EPCAM (Bronner et al. 1994; Fishel et al., 1993; Nicolaides et al.,

1994; Palombo et al., 1995; Papadopoulos et al., 1995; Tutlewska et al., 2013). Lynch syndrome mutation carriers have a higher lifetime risk for many cancers compared with the general population. Colorectal cancer risk is estimated to be as high as 60% in male carriers, while female carriers are approximately at 30% risk for colorectal cancer and are up to 60% risk for endometrial cancer (Lindor et al., 2006; Lynch H., Lynch J. F., Lynch P. M., & Attard, 2008). There is also a 50% chance that a person with Lynch syndrome will pass the mutation to each of his/her children, since it does not skip generations or discriminate by gender (The University of Texas M.D. Anderson Cancer Center, 2008).

With genetic predisposition becoming a widely accepted measure of cancer risk, many physicians and genetic counselors are recommending genetic testing as a means to ensure families are aware of their susceptibility and can begin to implement cancer risk management recommendations, such as cancer testing and screening, to help manage their cancer risk (Robson et al., 2010). These recommendations reflect an enhanced aspect of health care regarding cancer prevention (Apker, 2012).

Preventing a disease such as cancer requires much more extensive and complex methods of communication in order to effectively reach the public (Apker, 2012). Though easy to place the majority of responsibility upon physicians, health professionals, and genetic counselors in communicating preventive messages and suggestions for behavioral change, my research with M.D. Anderson has led me to understand that cancer prevention also should start within the family. Consequently, it has become pertinent to study the communication between gene mutation carriers and their families so as to better influence preventive behaviors such as cancer screenings and testing.

Because of the increased inherited cancer risk, it is critical for LS gene mutation carriers and family members, including those who do not have LS, to communicate with other relatives about genetic testing, early prevention, and cancer screening. However, to effectively raise awareness of genetic risk, individuals must bridge the communication gap that often exists among family members who experience physical and/or emotional distance, disruption, reluctance to discuss, or who are unaware of family health history and information. Developing a new tool that would help faciliate family communication was the primary aim of M.D. Anderson's study, *A Social Network Approach to Improve Genetic Risk Communication*. I participated as a research assistant in that study, and the collected information has been generously made available to me as secondary data for this research.

The original study focused on three major areas related to overall family communication. First, participants were asked how frequently they use the Internet and social media, followed by how they communicate about and preserve family health information. Finally, participants were asked if they would like and use a private social media site designed for users to create and maintain a family health history tree. Once interviews for the project were complete, I began coding interview transcripts and watched several themes emerge around communication patterns, the increasing role of social media in family communication, and the need for family health history to be centrally available to all family members.

As I coded data for M.D. Anderson's study, I anticipated participants would express an unwillingness to share genetic risk information with their family members due to discomfort, emotional and/or physical distance, or even because of past conflict(s). I

quickly found my initial assumption was wrong; most participants showed a very high desire and willingness to share health information with all family members. This unexpected discovery sparked my interest and shifted my focus from studying the gaps in genetic risk family communication to what health information is shared and with whom.

Very little research examines how LS carriers select genetic risk information to share with specific family members or family groups, so this thesis aims to understand family communication patterns among LS carriers through the lens of the Communication Privacy Management (CPM) theory. Specifically, I focus on (a) the prompts that motivate participants to share LS-related health information, (b) the relatives with whom they share the information, and (c) the mediums through which they communicate the information.

Chapter 2

LITERATURE REVIEW

Family Communication and Genetic Risk

In a review of family communication studies involving LS carriers and their families, researchers found that individuals who do not share genetic risk with other family members often cite three specific communication deterrents: 1) perception of the recipient as lacking sufficient maturity, 2) estrangement and family disruption, and 3) hesitancy in conveying potentially painful information (Bleiker et al., 2013). Studies have also reported that the likelihood of individuals sharing genetic information is based upon emotional closeness and inter-family communication expectations, as gene mutation carriers are less likely to share their genetic test results with family they identify as distant (e.g., aunts, uncles, cousins, and relatives they do not know well) than close (e.g., children, siblings, and parents). This is often due to lack of contact between family members, emotional distance, and/or because the individual expected other family members or friends to inform/have informed distant relatives (Claes et al., 2003; d'Agincourt-Canning, 2001; Ormondroyd et al., 2008; McGivern et al., 2004; Mesters, Ausems, Eichhorn, & Vasen, 2005).

Stoffel et al. (2008) quantified the likelihood of individuals communicating LS genetic risk information among family members, finding 171 of 174 (98%) participants shared their genetic test result with at least one first-degree relative. The researchers discovered that 90% of the participants had informed their children while the remaining percentage said they would wait until their children were older before informing them. The study also reported that 109 of 162 (67%) participants shared the information with

one or more second-degree or third-degree relatives. Differing slightly from other studies, Stoffel et al. reported participants did not share information because they did not wish to worry relatives, there was a lack of contact or closeness, and the possibility relatives would not understand the meaning of the test results.

Trends have shown that, although some remain hesitant, individuals who choose to communicate genetic risk information do so in order to fulfill what they perceive as a moral obligation to other family members, and often feel guilty if they fail to share (McCann et al., 2009; McGivern et al., 2004; Mesters et al., 2005; Peterson et al., 2003; Seymour, Addington-Hall, Lucassen, & Foster, 2010). Other reasons for sharing genetic risk information are to inform relatives of their own risk, to encourage relatives to get tested, and to obtain emotional support (Stoffel et al., 2008). Interestingly, families desire and even expect the mutation carrier, or the relatives who know about the genetic risk, to inform the rest of the family if the information would impact others' health and lifestyle (Pentz et al., 2005).

Studies seem to consistently indicate that individuals who have had genetic testing feel it necessary to share their health information and test results with their family. However, these same studies also have reported a significant difference between sharing information with close and distant relatives, often naming emotional distance or lack of contact as primary culprits for this phenomenon. I did not find any studies within the past five years that more closely examine the reasons why genetic risk information is or is not disseminated among close and distant family members, e.g., understanding if knowledge is deliberately withheld because of an unwillingness to share private health information, or if it is simply because the individuals do not have their relatives' contact information.

Communication Privacy Management (CPM)

In its most basic definition, communication privacy management (CPM) describes private information as something a person owns (Petronio & Caughlin, 2006). The theory explains that the ways people handle or share private information are dependent upon the interaction of their boundary structure(s) and rule-based management system(s) (Pecchioni & Keeley, 2011; Petronio, 2010).

Privacy boundary structures and rule-based management systems are based on dialectical tensions among communicators, as the contrast between simultaneous desires for privacy and openness significantly affects how individuals choose to manage their private information (Petronio, 2010). The acknowledgement of these tensions is reflective of the theory's development, since it now allows for consideration of others (openness) in privacy management versus protecting just the individual (privacy) (Petronio, 2010). As Petronio (2006) explains, the dialectical relationship between the two ideas helps define the domain of the other, since if all information is open, privacy is moot. Similarly, if all information were to be withheld, disclosure, or openness, would not exist. The relationship between openness and privacy proves to be a crucial factor in this study, considering an individual's gene mutation is hereditary and could impact many more members of his/her family instead of only his/herself.

CPM is built around five primary constructs of how people manage the disclosure or suppression of perceived private information. First, individuals or groups view private information as something they own. Second, people believe they have the right to manage the sharing of private information since they own it, and third, people use privacy rules to decide whether to open or keep closed a privacy boundary for specific

information. Fourth, someone becomes a shareholder of information if a person discloses private information to him/her, and the discloser expects the shareholder to follow existing privacy rules or to negotiate new ones. Finally, information management issues can become turbulent, as privacy boundaries may be violated and can result in mistrust, anger, suspicion, or uncertainty about sharing other private information (Petronio, 2007).

Privacy boundaries determine how much or how little information is shared beyond the owner, and they vary in permeability based on the owner's level of control. Boundaries are considered impermeable when a "private" individual exercises a high amount of control and is more careful in disclosing private information (Bridge & Schrodt, 2013). Conversely, boundaries are considered permeable when an "open" individual is more likely to reveal private information because he/she chooses to exercise less control over the information (Bridge & Schrodt, 2013). There are three orientations of permeability boundaries in family communication: high permeability, moderate permeability, and low permeability (Petronio & Caughlin, 2006).

High permeability families are characterized as very open and willing to share information internally with other family members and externally with those outside the family, though they do not necessarily always share information externally. High permeability is also understood as all members believing information that belongs to one person is actually everyone's personal information. Petronio & Caughlin (2006) define moderate permeability as being more "judicious" in choosing whom to inform, and these individuals consider more rules and precautions when choosing to share private information. Low permeability often represents secret-keeping since the families have many rules that do not permit information dissemination (Petronio & Caughlin, 2006).

Once boundaries are crosssed and an individual's private information is disclosed to others, it is no longer considered personal. Instead, it becomes collective, and the new shareholders of the information become responsible for further disclosure to third parties because the original boundaries were reconfigured to include the new shareholders (Petronio & Caughlin, 2006). Essentially, when the original private information owner includes shareholders in the circle of knowledge, the now collective owners are given the responsibility to either supress or further disclose the information to third parties, based on the agreed-upon boundaries and privacy rules the family has in place.

The rules management system within CPM plays a role in determining privacy boundaries, since it sets rules as to who may have/has access to private information, how much is shared, what specific information is disclosed, and why the information is shared (Caughlin et al., 2000). The rules are referred to as linkage rules, permeability rules, and ownership rules, and respectively, they negotiate with whom the information is shared, how much information is shared, and the degree of control each party has over the information (Petronio & Gaff, 2010).

Linkage rules refer to who will be privy to an individual's private information, i.e., they determine which people will be linked into a new privacy boundary (Petronio & Caughlin, 2006). Permeability rules regulate the flow of private information that passes through the privacy boundaries, and ownership rules determine whether the shareholder of the information has full rights of ownership like the original owner or if he/she has only a limited partnership in the information (Petronio & Caughlin, 2006).

Rules can be made on an individual or group level, but there must be a collective agreement to use specific privacy rules in order to effectively manage privacy boundaries

(Petronio, 2010). In a family setting, this means that when an individual shares private information with others, including health information, they must collectively agree to use a set of privacy rules to prevent potential familial discord and turbulence.

Family CPM and Health Information

Privacy management plays a large role in family functioning and communication since it can serve as protection from the public view, offers a more flexible interpretation of social norms, and provides something of a barrier from social pressures (Petronio & Caughlin, 2006). Gaff & Bylund (2010) suggest additional privacy boundaries related to the family, which include external and internal boundaries. While an external boundary separates the family from its environment, an internal boundary divides individual family members or family subgroups from other members and/or subgroups (Gaff & Bylund, 2010). Subgrouping can take many forms, such as grouping by physical and/or emotional closeness (close and distant relatives), or even placing the maternal side of the family in one subgroup and the paternal in another. Wilson et al. (2004) suggests several barriers that could potentially form boundaries and prevent open communication, including divorce or separation, adoption, geographical distance, signficiant sibling age gaps, and pre-existing conflict among relatives.

Internal boundaries could be considered a form of selective communication, since Petronio & Caughlin (2006) note that the borders of "interior privacy cells" can alter to include some members in the ownership of private information while excluding others who may be within the same cell. With this reasoning, it may be understood that internal boundaries could potentially shift to include and exclude family members based on the content of the private information, and while there are no permanent interior/internal or

exterior/external groups or subgroups, the consistent use of certain boundaries and rules defines families' privacy orientations (Petronio & Caughlin, 2006). It is also important to consider the possible role of a "representative" within families' communication rules and boundaries, since these family members act as a mesenger between relatives and communicate whatever information is given (Wilson et al., 2004).

Gaff & Bylund's (2010) concept of boundaries also explains families' decisions to disclose information to one particular family subgroup while still withholding information from others. From a health information perspective, a family's desire to set and manage privacy rules and boundaries may be significantly affected by medical conditions, including gene mutations, visible manifestations of medical conditions, and developmental life changes (Gaff & Bylund, 2010). These conditions can cause an interdependence dilemma (Petronio & Caughlin, 2006).

Such a dilemma stems from when an individual must decide between what is best for his/herself versus what is best for another relative or his/her relationship with another relative. Because families are by nature interdependent, individuals must not only be concerned for the risks and benefits associated with self, but also those associated with family members and their relationships. One risk individuals consider is worry; not wanting to worry others is a common concern raised by individuals who have genetic health issues and can affect what and how much information is shared (Hovick, Yamasaki, Burton & Peterson, In Press). In the context of this study, a gene-mutation carrier would be faced with the dilemma of keeping the test results to his/herself versus sharing potentially life-saving information with family members who would benefit from the knowledge.

Additionally, Forrest et al. (2003) found that family communication about genetic risk is affected by the nature of pre-existing relationships, the current patterns of interaction, and tensions and rifts that act as promoters or hindrances to communication. Petronio & Gaff (2010) note four specific hindrances, or "warning signals," to communicating genetic risk, which are blocking, sudden rule change, appropriating control, and locking information away.

Blocking is the act of a family member blocking the knowledge of genetic test results from other family members, while sudden rule change describes when privacy rules are redefined because of family tensions and/or reactions to the genetic risk information, or because other family members have different privacy rules (Petronio & Gaff, 2010, p. 130). Appropriating control involves a family member taking total control over information and acting as though they have more rights to the genetic risk result than other rightful co-owners, which can lead to information restriction and blocking (Petronio & Gaff, 2010, p. 131). In locking information, the controller does not release the knowledge and denies others' access from it while under the constant threat of the information being released through another family member's diagnosis or other situations (Petronio & Gaff, 2010, pp. 132-133).

Based on previous studies and the findings reviewed above, the current study seeks to understand the ways in which Lynch syndrome carriers practice communication privacy management when communicating health information in a family setting. The following research question guided my inquiry:

RQ: What privacy orientations are typical of LS families at risk of hereditary cancer?

Chapter 3

METHODS

This thesis originated with M.D. Anderson's study, *A Social Network Approach to Improve Genetic Risk Communication*. Since I worked in-depth on the project as a trainee, the collected data was offered to me as secondary data. Due to these circumstances, my thesis was developed through two major processes: first through data analysis and writing for M.D. Anderson's original project, and then through a second, more narrowed analysis I conducted solely for this thesis. Before further elaborating on these design decisions, however, it is essential to understand the participants' backgrounds as well as how and why they were selected to participate in this project.

Data Collection

Because this is secondary data, the study was approved by the Institutional Review Board at The University of Texas M.D. Anderson Cancer Center. Thirty-two (32) LS mutation carriers were recruited through M.D. Anderson's clinical genetics program, the center's hereditary cancer registry, and social media sites frequented by LS patients and their families, such as the Lynch Syndrome International and the M.D. Anderson Facebook pages. Half of the participants were recruited from a list of individuals who had participated in previous M.D. Anderson studies and had expressed interest in taking part in future projects. A social media announcement was also posted to the Lynch Syndrome International's Facebook page, and the first 16 eligible people who directly contacted M.D. Anderson were recruited.

Eligibility required being at least 18 years of age, the ability to read and speak English, completion of genetic counseling and testing for a Lynch syndrome mutation,

and having either a positive (i.e., carrier of Lynch syndrome MMR mutation) or indeterminate genetic test results. The final sampling of participants included 24 females (75%) and 8 males (25%). Eight (25%) participants reported having or had an unspecified form of cancer, seven (22%) have or had colon cancer, and two have or had a gynecological cancer.

The primary coder (AB-C), who was a team member at M.D. Anderson Cancer Center, and a research coordinator in the Department of Behavioral Science interviewed participants via telephone. They used a scripted interview guide (Appendix) centered on family communication methods and patterns when discussing general health, Lynch syndrome, and family health history. Participants were asked open-ended questions, such as whom they perceived as close (first-degree) and distant (second-degree or greater) relatives, as well as whether they are in conflict with any family members. Participants were also asked how open they are about their genetic mutation diagnoses and family health histories, and to describe recent health conversations with a family member. The interviews ranged between 20-60 minutes; each exchange was audiotaped by the interviewer and transcribed by a third party (Adept Word Management, Inc.).

Data Analysis

The parent study, *A Social Network Approach to Improve Genetic Risk Communication*, was devised to develop and test a new social media tool, titled "My Family Garden," that would help promote family health history and genetic risk communication through an online family health history tree. Participants were asked their opinion of the "My Family Garden" concept in addition to their Internet and social media use, how they communicate about genetic risk – specifically LS – and family health

history information, as well as how family health information is documented and maintained. In analyzing the initial data, AB-C and I found that the interviews not only offered information about a new social media tool, but presented new, important data regarding individuals' willingness to share genetic risk information, and what communication methods they use to relay the information. The discovery prompted the first part of analysis and writing for that project.

Using randomly selected interviews placed in ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, Version 7, 2013), AB-C and I created codes based on common themes found within the data. As the codes began emerging, we were able to categorize them into "code families." The families represent major categories of codes, such as the frequency of social network and Internet use, family health history, family health history information seeking, and gene mutation information sharing, relatives, and LS.

The results that emerged using our preliminary codebook were straightforward. The participants either did or did not use Internet or social media; they did or did not share the risk of gene mutations with other relatives. Seeing the need to delve further, AB-C and I revised the codebook to identify correlations. Now participants were not just using social media, they were using social media to communicate with distant relatives or family members with whom they have conflict. Similarly, we began to notice participants sharing specific types of information with certain relatives through various means of communication.

The results of this analysis formed the foundation of the manuscript I wrote for M.D. Anderson. Correlations were apparent between the types of health information

shared (e.g., general, LS, new health information) with which relatives (close, distant, conflict) and through what means (e.g., phone, social media, in-person, etc.). The paper reports participants' open patterns of communication, and discusses the increasing role of social media in genetic risk communication among families.

However, after being immersed in data analysis and writing through the summer and fall, I began to see the data in a new way. First, I saw a correlation between participants' degrees of communication openness and sharing what they considered important health information with relatives whom they rarely have regular contact. The pattern surprised me, since I had not expected participants to express their willingness, even desire, to share their health information with relatives they do not speak to or get along with. Seeing the richness of data and the potential it held in predicting what health information is shared within families, I chose to examine the secondary data through the lens of communication privacy management (CPM) for this thesis.

Building from the initial coding AB-C and I had applied to the data, I added a new code family, or category, with three subcodes: high permeability, moderate permeability, and low permeability. To better understand the participants' permeability orientations, I collapsed the original codes under recurrent code themes and their subcategories (Figure 1). Doing so offered a more detailed idea of communication behaviors and patterns within each permeability orientation, including what specific health information is considered private.

Discussion headers refer to specific subjects, e.g., if the conversation between family members focuses on general health information, new health information, or LS. Family groups indicate specific relatives that participants classify as close, distant, or

conflict. These groups vary based on the individual participant's interpretation; while close family is most often defined as first-degree relatives and distant as second-degree or greater, some participants classified family as close and distant based on geographical distance. Conflict family members were universally considered family members with whom there is some form of emotional distance.

Patterns refer to CPM's linkage rules, since it identifies with whom information is shared, e.g., open, closed, selective communication, and under what circumstances the information is shared, e.g., only when it is important to the family, only if asked about the information, etc. Methods include the medium of information sharing, e.g., whether family members used a phone call, in-person visit, social media, etc. to share information or check on relatives with health conditions. Health communication prompts are comprised of recent or past doctor visits, genetic testing and/or results, cancer screening experiences and/or results, etc., and the context or subject matter is determined by one of the three discussion header subcategories.

Prompts are what actually initiated the conversation, e.g., a routine phone call to check on a relative's health or a regular conversation that morphed into a health topic, concern for family member that prompted some form of communication, and test results relatives felt compelled to share with others. Finally, private health information categorizes the health information participants would not share, from whom they would withhold the knowledge, and reasons for withholding it. For example, "too young to share" is when the individual thought the relative was too young to bear the information or to understand the risk, and "day-to-day issues" is considered personal information, such as high blood pressure or arthritis, that is not necessary for others to know.

Themes	Subcategories
Discussion Headers	Family health history
	General health information
	Lynch syndrome
	New family health information
Family Groups	Close
	Children
	Conflict
	Distant
	Nonspecific (unspecified)
Family Communication Patterns	One-way
	Open
	Selective
	Closed or no/very little communication
	More readily shares serious news
	Shares everything
	Shares/would share important information
Family Communication Methods	Email
	Family sharing website (e.g., CaringBridge)
	In person
	Nonspecific communication method
	Phone and/or text message
	Social network
	Through family members
Health Communication Prompts	Screening/medical management
	Doctor's visits/appointments
	Genetic test results
	New health information
	Relative keeps tabs/wants to stay in loop
Privacy Reasons	Too young to know information
	Don't want to seem whiny/weak
	Don't want to worry/stress relatives
	Relatives wouldn't care/be interested
	Day-to-day health issues

Table 1: Major themes and subcategories used to differentiate high, moderate, and low permeability orientations.

To further analyze how genetic risk affects an individual's typical permeability orientation, I first created "supercodes," which is a tool specific to Atlas.ti data analysis software. Supercodes are new codes that are formed by correlating pre-existing codes in the data, and I created a total of 20 supercodes for each family group and discussion header subcategory. These codes were important to my analysis because it allowed for a more complex correlation analysis. For example, in order to determine how LS information is shared with close family members, I would correlate the supercode *Close COOCCUR LS with each of the communication method subcategories. This system offered guidance in identifying high, moderate, and low permeability orientations as well as the behaviors and patterns within them.

For the purposes of this thesis, I am considering LS-carriers as their own demographic and am therefore specifically analyzing permeability orientations regarding LS information sharing as opposed to general family health history. The following results describe with whom and through what mediums LS information is shared, in addition to participants' reasons for not sharing.

Chapter 4

RESULTS

Using the correlation tests as a guide, my results can be divided into three main areas of permeability: high, moderate, and low. Additionally, I have narrowed my focus to examine permeability orientations when specifically sharing LS information. Variations primarily occur among communication patterns, methods, and prompts (Table 2). It is essential to note, however, that the results cannot be placed into finite categories. Because all of the participants had varying levels of permeability depending on the family group, there is some overlap in coding, and some quotes could have been placed in other categories based on themes and subcategories. Despite the overlap, the quotes used for this thesis melded into one overarching discussion header: LS information.

Permeability	Themes	Subcategories
High	Family groups	Close, distant
	Patterns	Open, shares everything
	Methods	In person, phone, email, social media
	Prompts	All
Moderate	Family groups	Close, distant, conflict
	Patterns	Selective, shares important information, more readily shares serious news
	Methods	Phone, email, social media
	Prompts	Screening/medical management, genetic test results, new health information
Low	Family groups	Close, distant, conflict, children
	Patterns	Closed or no/very little communication
	Privacy reasons	All

Table 2: High, moderate, and low permeability differentiations in sharing LS information.

High Permeability

High permeability was most often associated with open communication participants, meaning they were willing and highly likely to share LS information with their close and distant family members. They were also likely to "share everything" about their health with these same family members. Most often, participants with a high permeability orientation shared their health information through in-person visits, phone calls, emails, and social media outlets such as Facebook private messaging. Participants also reported being prompted into health conversation by topics such as screening and medical management, doctor's visits and appointments, genetic test results, new health information, and because relatives want to check on the participants' health.

Family communication patterns. Unsurprisingly, participants were very open with relatives they consider close, including parents, aunts or uncles, siblings, and children. Consider the following:

> **Interviewer:** I was asking you to describe a recent conversation you had with a family member about your health?
>
> **Participant:** Well that would be those close family members when they told me the other day that I had this little bitty stroke. I called them all to tell them.
>
> **Interviewer:** Okay. So you talked about the ministroke and the fact that it—it sort of happened and then you learned about it and then you got on the phone and started talking to those family members?
>
> **Participant:** Exactly. I just called them individually and shared with them everything that I knew. I shared with them my visit to the doctor. I left the doctor

on Friday and called each one of them on my way home and said, "Here's what's happened"—and visited with each of them about it. So that was it.

Interviewer: So why did you talk to these particular people?

Participant: Well first off was my husband for obvious reasons. He needs to know, and he was concerned. He is my caretaker if something happens to me. So he is my first line of sharing everything with. So that was first. I don't remember what order it was in—my daughter, my sister, my dad, my cousin. I wanted them all to have the same information because we are all very close. They want to know what is going on with me health-wise, and I want them to know what is going on with me health-wise.

Families with a high number of LS-related deaths seemed especially open about sharing their health information with close family members:

> We talk about it (health history) a lot. I don't know how much you want to know. We're very open and honest and forthcoming about everything mainly because we lost so many members – immediate family members – to the disease before we knew what it was. So when we knew what it was then it was important to get children on board. … to know about the disease, to know about prevention, to know about close surveillance – frequent testing and that kind of thing. So we are very open about it.

Participants also shared health information with "distant" relatives, such as nieces and nephews, as well as nonspecific family members (i.e., the family in general). According to one participant, "We're an open book in our family. Everybody knows everything. . .We are a really close-knit family." Indeed, participants with high

permeability appeared to share all health information with close, and in some instances distant, family members, as exemplified below:

Interviewer: What health information would you share with your close relatives?

Participant: Everything.

Interviewer: What health information would you share with your distant relatives?

Participant: Everything.

According to another participant:

Interviewer: So with your close relatives, what information would you share with them?

Participant: I've shared everything. I'm really open with them, because I would hate to have somebody get ill and have me not talk to them about it.

Interviewer: What health information would you share with your distant relatives?

Participant: I've shared that I have cancer and that I have Lynch syndrome, but I haven't really talked about the implications of that, because they don't have it.

Family communication methods. Knowing that participants who communicate openly and share everything with their family members are characteristic of high permeability, it follows that they would use a variety of methods to communicate with relatives. These participants often used phone calls and in-person visits to share health information with close and distant relatives. As one participant explained:

Well if it's my immediate family – my husband, my daughter, my sister – I have a cousin that I'm very close with – a cousin on my mother's side of the family – we

> communicate by phone. If I had a health issue or there's something we needed to talk about health-wise, we do it over the phone. … Extended family – if there's something that – I usually talk about health information over the phone. I usually don't put stuff like that in an email.

Some participants, however, preferred email and Internet (i.e., social media) as ways to disseminate information to many people. Consider the following:

> **Participant:** Usually one person sends out (health information) to everyone on a list, the big family list, at least on my grandmother's side of the family. Most of the time I just get responses, like when I sent out information, I'm pretty much the one that, for the most part, has been sharing information more than others. I have definitely gotten responses from probably 70% of the family. Some of them have reached out to me by phone call after the email or through Facebook after the email or just directly by email. So people have reached out in all different ways when we first started discussing what was going on, just because my father was the first one diagnosed. And he answered the question about why is the family cursed.
>
> **Interviewer:** When they respond do they respond to everyone? So if there are 60 people who got the email—
>
> **Participant:** Yeah. There's a "reply all" almost all the time. It's a reply all. When they ask me questions, everybody's getting a copy.

Another participant similarly found that email was one of the best ways to share files and documents with a large group of family members:

> Once my father and I were both diagnosed with it, it was the easiest way to tell 30 people what was going on. And then they were all able to individually respond, asking questions. I was able to send attachments. I photocopied all of my results. I scanned my forms so that everyone would have it. My aunt would have it, my brother and cousins. Anybody who had any questions about what mutation they would be testing for. Everyone had a copy.

Facebook offers similar advantages. According to one participant, "Whatever research I can find I will either add to their (relatives') Facebook page or like it through LSI (Lynch Syndrome International). LSI is one of my favorite sites that I will use, and I will favorite or like a page and then send it to them via Facebook. If they are not Facebook users I can copy and paste and then email them directly."

Health communication prompts. Participants with high permeability openly shared health information with a variety of relatives in a number of ways for a variety of reasons. Visits to the doctor, for example, often prompted health information sharing:

> Usually we are constantly calling each other after doctor's appointments – discussing things that we found out. In my particular case I had – there's three children. My grandmother was the first person with Lynch syndrome, so my dad passed it on to all three of us. So because we all had it, we did a lot of talking about our – you know – every time we'd have a doctor's appointment, what the doctor said we should be doing, shouldn't be doing – things like that.

Similarly, another participant said, "My mother has trained me after going to M.D. Anderson for three years. I have learned that I am conditioned now that as soon as I leave

Dr. (name omitted) office and get in the car, I have to call my mother. You know my age because you have my records, but some things never change."

Other participants mentioned genetic testing, screening, or medical management as a prompt to communicate health information with relatives. According to one participant, "They (the family) all know. I've made them all aware, and I will make them all aware again in March when it's Lynch Syndrome Awareness Day. Another family-friendly reminder to please get tested or please think about it." Another participant described an attempt to alert family members after receiving new test results:

> When I found out that I had Lynch syndrome with Muir-Torre variants I felt the necessity to try to locate all of my family members that could be affected by this. And I either did that by telephone or by email. And I would basically find out if they were interested in knowing more about this, which almost every one of them did. And then I sent them quite a bit of information and several of my files—my personal files. And that way they could make the decision whether they or anybody in their family wanted to be genetically tested. Now I did have family members that basically turned their nose up and said, "No, this will never happen to me because I eat correctly unlike you." … Because I don't eat their way this is what has caused my problem. And so when I try to show them, "Look, this is a genetic thing that was passed down to me," they refused to believe it. So—and therefore they have not been tested, and therefore their children have not been tested which concerns me a lot because their children don't have the choice.

For other participants, health information is just part of many open conversations within their high permeability families. "I talk to them all the time, and if I didn't tell

them something like that, I would be in big trouble," said one participant. "We are very close, and we tell everything in our lives." Similarly, another participant explained:

> We update every day by e-mail. We just e-mail everybody and say, "This is what our day was like"—and actually have a copy of our schedule before we go so they'll know if we don't call in during the day that we're probably under the influence of some wonderful sedative or something, so—. No, we usually give them our schedule ahead of time. We'll call, you know, if anything occurs during the visit and usually give e-mail updates.

Indeed, these participants were comfortable sharing any and everything with their family members. As one participant noted, "I'll tell you how open it is. I've been with my son and my daughter and my nephews with their colonoscopies. I had to go for their initial colonoscopy. I was in the room with them. Yeah. We're real open about it."

Moderate Permeability

The moderate permeability orientation describes participants who use more caution in deciding whom to tell among close, distant, and conflict family groups, making their communication patterns selective. However, participants with a moderate permeability orientation also shared or would share health information they consider hereditary or important for family to know, as well as what they consider to be serious news. Similar to participants with high permeability orientation, moderate participants reported using the phone, email, and social media to communicate with relatives, but they also introduced two new methods: communicating through other family members, and sending documents to family members through email or postal mail. Health conversation

prompts included screening and medical management, genetic test results, and new health information.

Family communication patterns. Even though the majority of close family communication exchanges are characterized as high permeability, some participants expressed moderate permeability communication with close family depending on the relevance of the information to the relative. Consider the following:

> **Interviewer:** So when you make the hard copies of the information you mail them to your daughters? That's who you send them to?
>
> **Participant:** Yes. And my sister.
>
> **Interviewer:** Is there anyone else?
>
> **Participant:** Just my sister. The one with Lynch.

The reluctance of the relative to receive the information also determined whether or not some participants would share health information. According to one participant:

> One of my brothers is a little more reluctant to talk about it (LS), because I think he wants to avoid talking about it because he's a little bit afraid of it, plus he doesn't want to think that anything's wrong, I guess. Not to say that anything is wrong. He just wants to kind of—he's a little more reluctant, but he will talk about it with me, and he'll talk about it with my other brother as well. He just doesn't like to talk about it in a big group.

Participants also weighed disclosure based on the importance of the health information to the relative. These participants explained that distant relatives, in particular, only receive health information that "would maybe be life threatening" or includes "things that I think they need to know":

> I would say I think my whole family is in a similar situation. I mean, people who don't have Lynch but have other health issues. We usually let the distant relatives know if somebody has a cancer or has a heart condition or has a stomach condition. If there's a diagnosis in the family, I think all of us seem to get that email from the distant cousin, just letting us know if somebody has got something, just because we're all very aware that some things are hereditary, and people should be screened.

Similarly, another participant said, "Obviously there's mixed emotions in that (sharing health information with family s/he does not see). But, at the same time, I feel like if I am to save lives that it's my responsibility to share, even if it's uncomfortable for me."

Some participants, however, said they do not make an effort to share health information with distant relatives but would not mind if those relatives asked or learned the information through other sources. "I don't share it with them now," said one participant, "so unless it's something that directly affects them, I wouldn't see any point to inform them about it. . .If it's something that has to do with Lynch syndrome, do I mind if they're informed? No. I don't mind. But do I pick up the phone and do it or send an email and do it? No." According to another participant:

> I'm going to try to attend (a family reunion) this year, but none of them have any knowledge of me or my physical condition or Lynch syndrome. I don't have any communication with any of that side of the family. Not intentionally. It's just they're just not part of my life. But on my father's side, I have a couple of cousins that I keep up with and will from time to time—I still go to funerals on that side,

and I have a few cousins, and they are aware of my health issue, but I don't have regular contact with them.

Participants cited family conflict as another reason for lack of communication, although they said they still would be willing to "set the conflict aside" and share health information they consider important for family to know. "Oh, I'm just open to it if it'll help them. No problem at all," said one participant. "They can just take one more pin and put it in that voodoo doll (laughs). It doesn't matter to me as long as it helps them." Indeed, these participants often considered the sharing of genetic risk information as a life-saving act. "I would share with them anyway," said one participant. "I think, regardless of whether we've had a conflict or not, somebody's life is in danger in some respect." Echoing this idea, another participant said:

> I just feel like it's my responsibility to let them (distant relatives) know they need to be looking for it (i.e., cancer) perhaps earlier than they had anticipated. … They need that knowledge, and what they do with it, that's their decision, but they need to know. I guess it's mainly that kind (i.e., LS information). You know, it's the general, "Hi. How are you doing? Hope things are okay. This is what's going on right now," so we feel like that's really important to share that information.

Family communication methods. Participants characterized by moderate permeability cited phone calls as a common method of communication, particularly when sharing with close relatives. However, more often than not, these participants said they use email and social media to communicate important family health information to distant and conflict relatives. "For genetic type things – like I said – we have cousins and second cousins that we keep posted on any cancer diagnoses – things like that or keep

them – we email articles that we find about things for screening processes and changes in screening frequencies – things like that," said one participant. Another participant explained:

> Obviously, there are family members that we don't see on a regular basis. So that information—on my mother's side which is where the Lynch comes from, there's some distant cousins that I have never seen, but it was actually her father—she's like my second cousin—it was her father that had the original genetic testing done allowing all of us—I wouldn't have known that except through emails. Yes, it's very interesting, and she keeps me abreast of what's going on in her family through emails.

Some participants also regularly disseminate information through other family members, adding a new method of communication not seen in the high permeability orientation. "My brother and I don't speak anymore," said one participant. "So I talk to my other brother and tell him what's going on to relay the information to them so they can know what is going on as well. And he does that. He talks to—my middle brother talks to my youngest brother and tells him what is going on with my testing and everything."

Communicating through family members was also seen as an alternative method if other methods fail. For instance, another participant said, "I would call them and—you know—try—just say, 'Hey, I know we don't speak, but I need to tell you this new information. Please listen for a moment.' And if they refuse—if they didn't want to hear me, then I would just talk to my other brother and let him give them the information. Or I would email his wife."

Participants used multiple communication methods to share genetic risk information with family members. According to one participant, "I was the first one diagnosed, and I tried to verbally tell the other members of my family, but it didn't really do anything. But other people, it could have been a phone call, but it didn't do any good. Maybe if it's in writing they'll look at it." Similarly, another participant explained, "I have found that through email it requires quite a bit of back and forth to get the message across. Social networking sites are similar because you're basically sending an email anyway. But I have communicated information that way to family members that I can't reach and that I've never met through social networking sites."

Health communication prompts. Participants characterized as moderate permeability discuss genetic testing and results, screening, and medical management, and are prompted by new family health information they think others should know. This mainly consists of hereditary genetic risk information, since participants do not seem willing to discuss general health information at length. For example, one participant said, "They would have to ask, because I feel like if they wanted to know, they would ask about it. Initially I might bring it up, but then after they would have to ask me." Other participants expressed their desire to retain as much normality as possible with family:

> It's like one of those things that I don't want to drag out forever. I don't want that to define my life. We talk about other things in general, what your kid's doing, what's happening here and there, what kind of trips are they going on, what did you make for dinner? Just simple things, daily living. And I try to focus on that more than necessarily on health issues.

Low Permeability

There were not many instances of low permeability throughout the data, but the pattern most associated with low permeability is closed or none to very little communication. Because of this impermeability, communication methods will not be discussed. Though there was a small number of participants with a low permeability orientation, these participants reported having little to no communication with children, close, distant, and conflict family groups. Because there was no communication reported, prompts cannot be discussed. However, participants claimed to withhold health information for several reasons, including that the relatives were too young to know, the participants did not want to seem whiny or weak, they did not want to worry or stress other relatives, participants did not think relatives would care or be interested in the information, and because the participants were experiencing day-to-day issues they did not consider important for others to know.

Family communication patterns. Many instances of low permeability concerned LS, and the decision to withhold information was often determined by the recipient's real or perceived reaction. According to one participant:

> My children will not discuss it whatsoever. It's like me when my sister said it. "No, it doesn't affect me. I'm not going to listen to this." My kids—their reaction is strictly fear based. It's like they don't want to know. And it's the same way with my sister's other two sons. They don't want to know. If they get it, then they'll deal with it and get the testing done. But for the most part, it's definitely a fear-based reaction.

Similarly, another participant said, “Well, I think that it’s my opinion that they (distant relatives) don’t really need to know that nor want to know it, and that may not be true, but I wouldn’t want to impose that information on them if they didn’t want to know or weren’t interested. So since I don’t know if they would want to know or are interested, it’s best I just don’t tell them.” Still another participant noted, “My parents don’t even talk about it (LS) at all because I don’t even think they really realize what it is.”

Participants also determined whether relatives needed to know the information before choosing to share it. According to one participant:

> I mean, cancer scares—I mean, it scares us. But I’m saying, it scares people, and it makes them tongue-tied. They don’t know what to say. So it’s not—you know, I was at a 50th wedding anniversary for my aunt and uncle last fall, and it was the largest gathering of relatives – now that was on my dad’s side, not my mom’s side – that I’ve been to that I can remember, really. And it never came up because I’m not going to just jump in there and be like,“Hey, what’s going on?” And none of those people, to my knowledge, are at risk for it, right? It’s on the other side of my family, so it might be different if I thought I had a bunch of relatives who needed to do something, but I don’t.

However, once family members were perceived as willing or ready to listen, participants willingly shared LS information. “Well, it (communication) used to be pretty – I would have to say – pretty bad,” said one participant. “There was reluctance to acknowledge things. But lately, in the last few years, there has been more willingness to accept things and to look into things.”

Private health information. Distinct from closed communication, private health information encompasses the specific topics high, moderate, and low permeability participants will not share with family. Most participants said there was little health information they would withhold, or keep private, from their relatives. However, age and maturity was a reason for keeping information private from the children family group. "We don't talk much with my kids about it yet because they are too young," said one participant. Another agreed, saying, "I share very little with my sons because they are young. Everybody else – it's pretty much an open book."

Other reasons included day-to-day or non-life-threatening issues participants do not consider important for others to know. According to one participant:

> I am probably 95% open. I think the only things that I would keep private is I'm a little bit self-conscious about sounding weak, so complaining about how I feel on a daily basis mostly because I have had some major surgery and I don't want to sound like I'm whining or complaining about something. So if my stomach is bothering me I might just suck it up but as far as anything else there are no hidden secrets. Everything is open.

Not wanting pity and sounding weak both seemed to be motivators of keeping information private.

> I don't know. I think I just—I don't know. It's not that they wouldn't care, but I don't want anybody's pity, you know? I don't want people to feel sorry for me. It is what it is, and I probably don't share with my children how stressed I am about having the Lynch syndrome just because they haven't been tested yet, and I don't want them to start getting stressed out.

Still others keep the information private so as not to worry close or distant relatives. “I won’t call my sister now because she doesn’t know that I’m re-dealing with this,” said one participant. “She doesn’t know that the—because she has a tendency to get real worried. So I’ve just decided I’m going to spare her this until I get through—until I find out what’s going on.”

Chapter 5

DISCUSSION

The goal of this thesis was to ascertain the privacy orientations of LS families at risk of hereditary cancer, and to further delve into their reasons for sharing or withholding information. In doing so, I found similarities that support earlier research as well as a few new, important factors to consider when determining the likelihood of genetic risk information sharing. Three of the most prominent influencers are the importance of the genetic risk information, the level of comfort in contacting relatives, and the anticipated reaction of the information recipient.

Corresponding with Stoffel et al.'s (2008) findings that individuals share genetic risk information to inform relatives of their own risk and to encourage them to get tested, my analysis shows that the majority of participants desired to share their genetic risk if they believed it was important for their families to know. They saw it as a potentially life-saving act, and were willing to overcome personal differences with family members because of their "responsibility," as one participant said, to share the information. This is also similar to earlier findings that individuals are more likely to communicate genetic risk in order to fulfill a "moral obligation" to their relatives, and it offers some insight into the motives for health communication sharing (see, for example, Yamasaki & Hovick, 2014).

Relating this to CPM, it is clear that participants did not view their positive genetic test results as private; they immediately considered it as collective information that everyone in their family has a right to know. In all the interviews, there was not one instance in which the participant said he or she would not share their genetic risk

information if asked. Instead, the mutation carriers often informed as many close, distant, and conflict relatives as they could, while also expecting these relatives to act as "representatives" and further spread the reach of health information. The behaviors and perceptions exhibited by the participants fall within the realm of high permeability, which is defined as members believing that one person's information actually belongs to all.

While participants most often demonstrated having high permeability orientations, their levels of comfort in contacting relatives did somewhat affect their decision to communicate. Studies have shown a reluctance to disclose genetic risk information due to lack of contact or emotional distance (Claes et al., 2003; d'Agincourt-Canning, 2001; Ormondroyd et al., 2008; McGivern et al., 2004; Mesters, Ausems, Eichhorn, & Vasen, 2005), and the findings were reaffirmed in my study. CPM can be applied to people's reluctance through the concept of interdependence dilemma, which is caused when a person must choose between what the seems best for his/herself and what is best for another relative or relationship with a relative (Petronio & Caughlin, 2006). Lack of contact or emotional distance with a relative can place an individual in a potentially awkward and uncomfortable position, and in choosing not to share information, these individuals have chosen self. In overcoming barriers and setting aside conflict, as many participants said they were willing to do, they choose what they consider best for the relative.

Though prior research has reported that individuals share health information more often with close relatives, with the advent of social media, there appears to be more of a balance in distributing information among all family members. Along with traditional communication methods of phone calls and visits, this study has shown that the Internet,

specifically email and social media, is becoming an effective and convenient method of sharing genetic risk within families, particularly among distant relatives. This is especially true of sharing health information regarding genetic risk, as many of the participants in this study were willing to make an effort in communicating and be responsive to inquiries from relatives about genetic cancer risk.

In addition to communication patterns and privacy management, this research notes the use of social media, e.g., Facebook, online forums, blogs, etc., in communicating genetic risk among families. Considering Facebook is celebrating its 10th anniversary in 2014, social media cannot necessarily be labeled a new concept. It is, however, a new variable to consider when studying privacy management and genetic risk communication since social media offers its users a way to share health information to raise awareness and promote behavioral change (Scanfeld D., Scanfeld V., & Larson, 2010). Similar to research about LS families and privacy management, there are very few studies designed to understand the role of social media in family communication and genetic risk, specifically LS, information.

The increased use of social media and Internet is an encouraging development. It holds the potential to be used as a more detached communication tool to overcome some gene mutation carriers' reluctance to disclose genetic risk information due to lack of contact or emotional distance. Providing a tool that would reconcile people's discomfort in contacting relatives and their sense of responsibility to share, there is a strong chance of increasing permeability and promoting more engaged communication. It would prove beneficial to further research in this area in order to better understand the appeal of using social media to share health information.

In contrast with previous research that indicate LS carriers are disinclined to share health information due to a lack of maturity, estrangement and/or family disruption, and hesitancy in sharing unpleasant information (Bleiker, Esplen, Meiser, Petersen, & Patenaude, 2013), this study revealed that most gene mutation carriers have high permeability orientations since they are willing to reveal their health information if they perceive it can significantly affect the health and wellness of others. What has not been considered in prior studies is how the information recipient's response affects the mutation carrier's decision to share. One genetic risk communication hindrance mentioned by Petronio & Gaff (2010) is blocking, which is when a family member blocks the knowledge of genetic test results from others and is a characteristic of low permeability.

Thought blocking itself is not applicable, considering how willing participants were to share information, a reverse blocking did occur on several occassions when the family members were resistant to the health knowledge. The resistance caused the participants to refrain from sharing their knowledge about LS and sometimes general health. However, once the relatives came to terms with the importance of knowing, or realized it affected them, they removed the block and were more open to listening.

"Reverse blocking" was not the only culprit of low permeability. Some LS carriers did utilize communication privacy management in the form of permeability rules, since they were unwilling to share what they consider day-to-day or irrelevant health information with other family. More importantly, though, this research shows that a genetic mutation can significantly affect an individual's motivation and willingness to release private information. Since many individuals consider genetic risk important to

disclose because of its potential impact on a family's overall health and wellness, the information controller becomes willing to redefine or loosen, established health information privacy rules even with physically and emotionally distant relatives.

No family has one set privacy orientation. Rules, boundaries, and subgroupings tend to shift depending on the type of information and its relevance to other family members, and while the carriers holds the ultimate responsibility to share, relatives may affect information dissemination by blocking new health information that may be considered undesirable and frightening. Nevertheless, CPM as a theoretical framework offers basics that can still be used for the future, and is an important theory for prevention. The results demonstrate an overall high permeability across all families, sharing information ranging from genetic risk to overall wellbeing with close, distant, and even conflict relatives.

Limitations and Suggestions for Future Research

Limitations of the study include the sample population's characteristics. Participants were recruited from a single institution, are predominately of one race, are primarily female, and have higher levels of health literacy, which may not reflect the viewpoints of a diverse population. This sample population was limited to one representative member of a family, who may have expressed a perspective that may not be shared by other family members. Additionally, since this population was recruited primarily through social media, these types of personalities are more likely to be engaged with the Internet and social networking communication tools.

Despite the limitations, this research provides a foundation for future research concerning privacy management among gene mutation carriers' family health

communication. Because Lynch syndrome carriers do not appear to claim ownership of their private genetic risk information and even encourage their relatives to spread the knowledge in order to reach as many people as possible, it would be advantageous to focus future research on CPM among families without a hereditary gene mutation in order to better understand if high permeability can be directly attributed to genetic risk.

The implications of this study could provide the basis for a more widespread approach by offering physicians, genetic counselors, and family members a new understanding of communication privacy and hesitancy in sharing, as well as new means of raising genetic risk awareness among all family groups. Based on this thesis, it is clear that LS gene mutation carriers do not withhold information because they are unwilling to share their private health information. In fact, it is often the communication recipient who is unwilling to listen to the information due to their own personal reasons. Therefore, another distinction could be added to CPM: intent to share versus actual behavior in health information communication.

Though additional research is necessary, the concept is significant because it would refocus the need for communication from mutation carriers to the carriers' family members. Consequently, it would be imperative for genetic counselors and physicians to teach mutation carriers how best to approach family members so that they will be more accepting of the new information instead of being dismisive or closing communication due to fear. This study offers implications that could encourage a continued discussion at M.D. Anderson and beyond regarding how best to design and implement a successful genetic risk awareness and cancer prevention campaign.

Conclusion

The vast majority of participants demonstrated high permeability orientations with close and distant family members, while participants characterized by moderate permeability shared what they considered important LS-related health information with close, distant, and conflict family groups through phone, email, social media, other family members, and through email and postal mail attachments. Though there were very few instances of low permeability, participants in this category chose not to share any LS information with certain family groups due to, maturity, appearing weak, not wanting to cause stress, or because they did not think their relatives would care or be interested in the information. These implications offer a basis to better communication among families with LS, and eventually, gene mutation carriers as a whole.

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APPENDIX

My Family Garden

Individual Interview Question Guide

Hello, Mr./Ms./Mrs. (insert name here). How are you today?

Thank you again for your interest in taking part in this study. Before we get started with the interview, I would like to tell you a little bit about the study and ask you to verbally consent to participate.

The purpose of this study is to create an internet-based program designed to improve the communication of health and health history information among family members affected by Lynch syndrome. In order to ensure that this website is useful to Lynch syndrome families, we would like to get information from people like you about how your family communicates about family health history. We also would like to get your opinions on website features. We will be recruiting 16 adults with Lynch syndrome to participate in this phone interview. We estimate that the phone interview will take between 45 and 60 minutes to complete, but that will vary by participant. Upon completion of the interview, you will receive a $40 gift card to thank you for your time.

I have been read the description of the study, and I have decided to participate in the research project described here. I understand that I may refuse to answer any (or all) of the questions at this or any other time. I understand that there is a possibility that I might be contacted in the future about this, but that I am free to refuse any further participation if I wish.

During the course of this study, the research team at The University of Texas MD Anderson Cancer Center (MD Anderson) will be collecting information about me that they may share with health authorities, study monitors who check the accuracy of the information, and individuals who put all the study information together in report form. By answering the questions, I am providing authorization for the research team to use and share my information at any time. If I do not want to authorize the use and disclosure of my information, I may choose not to answer these questions. There is no expiration date for the use of this information as stated in this authorization.

I may withdraw my authorization at any time, in writing, if my information can be used to identify me. For information on the Notice of Privacy Practices, please call.

Do you consent to participating in this tape-recorded interview?

Great. Now that you have been consented, I am going to start out by asking a few general questions about your Internet usage. Your ideas and comments are important and there are no right or wrong answers. Let's begin.

1. How often do you use the Internet for social networking (Facebook, twitter, etc.)?
    a. What do you like about those sites? What don't you like?
    b. If you don't use the Internet for social networking, why?
2. How often do you use the Internet to keep in touch with your family?
    a. Do you use the Internet to keep in touch with relatives that you don't see very often?
    b. Do you use the Internet to keep in touch with relatives that you have had conflicts with in the past?
3. Have you ever worked on a family tree?

4. Have you ever used the Internet to research or document your family tree?
    a. Which sites have you used?
    b. What did you like about those sites? What didn't you like?

Next I would like to ask you a few questions about how you use the Internet to look for health information.

5. Tell me how use the Internet to search for health information.
    a. Which sites do you use?
    b. What do you like about those sites? What do you think can be improved?
    c. What health information do you wish you could find on the Internet but haven't been able to?
6. How useful is health information that you find on the Internet?
7. How much do you trust health information that you get from the Internet?

Now I would like to talk to you specifically about your family and how your family communicates about Lynch syndrome and family health history.

8. How does your family communicate about family health history?
9. When there is new family health information, for example a recent cancer diagnosis or genetic test results, how is that talked about in your family?
10. If you have questions about your health history information, how would you go about getting those questions answered?
11. Who do you consider your close relatives?
    a. What health information would you share with your close relatives?
    b. How would you share this information?
12. Who do you consider your distant relatives?

a. What health information would you share with your distant relatives?
b. How would you share this information?

13. Describe a recent conversation you had with a family member about your health.
    a. What did you talk about? What prompted the conversation?
    b. Who in your family did you talk to about your health? Why did you talk to this person/these people about your health?
    c. Are you open with your family about your health? Do you keep some things private? If you keep some things private, why?
    d. Do you freely tell your family details about your health? Or does your family have to ask about your health? Why?
14. How do you keep track of all of this family health information? For example, is the information written down somewhere?
15. Who in your family is in charge of keeping this information?
16. How is Lynch syndrome talked about in your family?
    a. How does your family talk about things like screening recommendations, test results, and doctor's visits?
17. Family members aren't always close, so keeping that in mind, how would you feel about sharing your health information with family members that you do not regularly see?
    a. How would you feel about sharing information with family members that you have had conflicts with in the past?

18. If there were an important piece of family health information, for example a new cancer diagnosis or positive genetic test result, that impacted your relatives that you do not frequently talk to, how would you share this information with them?
    a. How would you share this information with family members that you have had conflicts with in the past?
    b. *For people who would not share this information with those family members*: are there any circumstances that might change your mind?

For my last set of questions, I would like to ask you some questions about what features you would want in a website that is used to store and share personal and family health history.

19. What do you think of the idea of a secure website, accessible only to your family, that you could use to store your personal and family health history?
20. Under what circumstances would you be willing to share a site like this with your family members?
21. Under what circumstances would you be willing to share a site like this with your health care providers?
22. Under what circumstances would you be willing to share health information with a close family members via such a site? How about a distant family member?
23. What concerns might prevent you from using such a site?
24. What benefits do you see to using such a site?
25. If you could print out a family tree that included your family health history to bring to your provider, would you find that useful?

Are there any other things that you would like to talk about? Did I miss anything?

Thank you very much for participating. I really appreciate you taking the time to share your thoughts and experiences with me. If you have any questions, please feel free to call me or to e-mail me.

I will be mailing a $40 gift card to you, so can you please verify your mailing address. The one I have for you is *read participant's mailing address*. Is that correct?

If yes: Great, thank you again for your time. Have a good day!

If no: Oh, okay. Can you please give me the correct address? *(enter into tracking database and verbally verify)* Great, thank you again for your time. Have a good day!