ORIGINAL ARTICLE

Family Communication of Genetic Risk: What is it and Why does it Matter?

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ABSTRACT

Inherited conditions have implications not only for the individual affected but for the entire family. It is in this context that family communication of genetic risk information is important to understand. This paper aims to provide an overview of the construct of family communication of genetic risk and provide implications for healthcare providers. A search of relevant literature was done with electronic databases including PubMed, CINAHL, Embase, Scopus, and Web of Science. The findings from the literature were organized based on the Family Communication of Genetic Risk (FCGR) conceptual framework which highlights the attributes of the family communication of genetic risk process including influential factors, communication strategy, communication occurrence, and outcomes of communication. Healthcare providers need to understand how individuals share genetic risk with their family members so that appropriate support and interventions can be provided to them. This is especially important across countries, including the Philippines, as genetic services and testing move beyond the traditional medical genetics clinic to other medical specialties, a development where we would expect an increase in individuals and family members undergoing genetic evaluation and testing.

Keywords: communication, family, genetic predisposition to disease, genetic testing, genetic risk

INTRODUCTION

Inherited conditions seldom affect a single individual in a family. This is because the diagnosis of an inherited condition impacts family members as it informs them of their or their progeny's risk of developing the same (or an associated) condition resulting in a variety of health and reproductive concerns.[1-4] Individuals found to have a pathogenic variant in a particular gene are at increased risk of developing conditions associated with that gene. Since genetic material is shared, their offsprings and other first-degree relatives are also at increased risk of inheriting the same variant and developing the same or associated conditions.

Through cascade genetic testing, it is possible to identify relatives who have inherited the familial pathogenic variant. Cascade genetic testing is defined as a stepwise and systematic testing of at-risk relatives for pathogenic variants previously identified in a family.[5] In this way, cascade genetic testing allows for presymptomatic identification of individuals ensuring that prophylactic approaches, early detection of disease, and regular surveillance are made available to them. Likewise, individuals who are carriers of an X-linked or an autosomal recessive condition can be provided with adequate genetic counseling so they are able to make informed reproductive decisions. The uptake and benefits of cascade genetic testing and/or early detection and surveillance, however, may only be realized if risks and other

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information about the genetic aspects of inherited conditions are communicated within families.

Genetic counseling is the primary means by which affected individuals (usually the proband or the first person in the family that brings the concern of an inherited condition to healthcare professionals) or parents (also known as consultands in the case of affected children) are supported in informing their relatives about their genetic risks. Because healthcare providers often do not have established provider-patient relationships with the proband's relatives, it is presumed and considered a moral obligation of the proband (or consultands) to communicate genetic risk information to their relatives.[6] However, earlier studies have suggested that probands (or consultands) do not always communicate genetic risks to the rest of the family.[7] More recent studies corroborate this earlier finding. Shah et al.[8], for example, found that only about half (52.5%) of relatives at risk of hypertrophic cardiomyopathy (HCM) or Long QT Syndrome (LQTS) were informed about their risk. This is concerning because the failure to communicate genetic risk information is a lost opportunity for the at-risk relatives to know about their inherited risks, and subsequently to potentially explore their own risks and participate in any available early detection or management.

In a recent review, Srinivasan et al.[9] highlighted that the extent of family communication of genetic risk can be a barrier or facilitator in cascade genetic testing. Thus, a better understanding of the family communication of genetic risk process can inform strategies to improve the uptake of cascade genetic testing. Elucidating the experiences of families in communicating genetic risk may also inform practice guidelines and resources on how healthcare providers can better support families in the communication process.[6] Moreover, the development of innovative interventions to promote family communication of genetic risk can be informed by an understanding of the barriers, facilitators, and factors associated with the communication process.[10]

Guided by the Family Communication of Genetic Risk (FCGR) framework[10], this paper aims to provide an overview of the construct of family communication of genetic risk using data culled from the literature. This paper does not aim to provide a comprehensive literature review or a state-of-science review. Rather, it aims to create awareness about the importance of family communication of genetic risk and stir interest among scholars especially those involved in clinical genetics, genetic counseling, and social and behavioral research to conduct research on this topic. Further understanding the process and outcomes of family communication of genetic risk is especially more important given the mainstreaming of genetics technology where genetics services will be expected to be delivered not only in the traditional medical genetics clinic but also in other medical specialties.[11]

MATERIALS AND METHODS

The articles used in this paper were from a search of electronic databases including PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Embase, Web of Science, and Scopus. A combination of the following search terms was used: "family communication", "disclosure", "sharing", "genetic information", "genetic risk", and "genetic predisposition to disease". The search was limited to original or review articles and those published in English. Date limiters were not included in the search since part of the interest in writing this paper is to determine how far along historically the investigation of communicating genetic risk in families is.

A total of 20 articles were deliberately chosen to be reviewed. These articles examined disease conditions with varied inheritance patterns and described studies done in varied contextual settings. Thirteen (13) studies examined autosomal dominant conditions – seven on cancer predisposition syndromes, three on cardiomyopathy and/or arrhythmia syndromes, two on neurocognitive conditions, and one study on muscular dystrophy. Four studies examined X-linked recessive conditions, one study on an autosomal recessive condition, and two studies involved several conditions with varied inheritance patterns. Ten (10) studies were conducted in the United States, two each in Australia and United Kingdom, and one study each in Finland, Netherlands, New Zealand, the Philippines, Singapore, and Sweden.

A deductive analytic approach was used to categorize findings from the literature according to the attributes of the FCGR framework.[12] The use of a matrix facilitated this analytic approach.

DISCUSSION

Description of the Construct

The construct of family communication of genetic risk is anchored on the idea that genetic information has familial implications and individuals affected have the moral obligation to inform their relatives about their risk.[6] During pre- and post-test genetic counseling sessions, probands (or consultands) are given information about the disease including the familial implications of the diagnosis and any genetic testing result. Consistent with several international, regional, and national guidelines, healthcare providers are obligated to duly inform their patients about the increased genetic risk of their patient's relatives and the importance of patients communicating this information with their relatives.[6,13] It is presumed that patients, given these information, will communicate the same to the rest of the family so their relatives can decide to participate in risk assessment, early detection, and/or management.[13] However, this is not always the case as has been highlighted by empirical studies on family communication of genetic risk.[8]

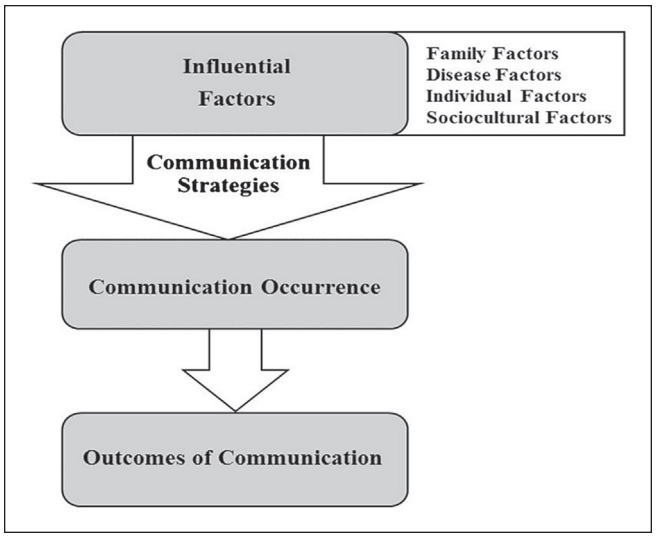

Figure 1. Family Communication of Genetic Risk (FCGR) conceptual framework.

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Previous reviews have suggested that family communication of genetic risk is a complex process rather than a single event.[7,14,15] Gaff et al.[7], in their review of the process and outcomes of family communication of genetic information, described it as a highly deliberative process that starts with the proband making sense of his/her personal risk. In coming up with a decision to communicate, Gaff et al.[7] found that individuals consider the effects of disclosure as well as their relatives' situational vulnerability and receptivity to the information. The individual also selects what information to disclose and when. Throughout this process, the proband (or consultand) struggles with conflicting options of whether to provide highly valuable information that could influence health care decisions or to withhold information to prevent any harm that may arise from this knowledge.[7]

Attributes of Family Communication of Genetic Risk

The Family Communication of Genetic Risk (FCGR) conceptual framework developed by Shah and Daack-Hirsch[10] is used as the organizing framework for this paper (Figure 1). The FCGR conceptual framework was originally developed to better understand how families communicate genetic risk in the context of hereditary cardiomyopathies and arrythmias. The model was based on previous systematic reviews examining family communication in non-cardiac conditions.[7,14-16] In the FCGR conceptual framework, four major attributes of family communication of genetic risks were identified: influential factors, communication strategies, communication occurrence, and outcomes of communication. These four attributes are used to organize the subsequent parts of this paper.

Influential Factors

Influential factors are defined as the motivators for deciding to communicate and it includes disease, individual, family, and sociocultural factors.[10]

Disease Factors

Understanding of information about the disease appears to be an important factor that may contribute to an individual's decision to communicate genetic risk to their relatives. In families affected with Lynch Syndrome, Bartuma et al.[17] reported the families' difficulty in understanding the information about the condition which resulted in several misconceptions. Similarly, Batte et al.[18] found in their study of families affected with HCM that comprehension of disease and associated risks is higher in families who communicated genetic risks.

Not only is the understanding of the disease important but also the understanding of associated reproductive implications and treatment. The lack of knowledge on reproductive options in case of X-linked muscular dystrophy has been reported as a barrier for mothers to communicate risks to their daughters.[19] Ashida et al.[20] also reported that among individuals who underwent susceptibility testing for Alzheimer's disease, greater optimism about disease treatment was associated with family communication.

Some studies reported the families' perception of familial risks inherent in the diseases studied. These perceptions appear to be important drivers of communication within families. Abad et al.[21], in their study about family communication in those affected with congenital adrenal hyperplasia (CAH), noted that families communicate about the disease because of their desire to seek further information on their family history of CAH. They do this because of their perceived susceptibility of others to also have a child with CAH. Similarly, in families affected with Duchenne Muscular Dystrophy (DMD), mothers sought carrier testing because of the risk of disease recurrence and to identify other individuals who may also be carriers.[2]

The expression (phenotype) of the disease within families is also an important factor that may be a barrier or motivator of family communication. Bartuma et al.[17] reported that in families affected with Lynch Syndrome, those with many affected relatives who are younger communicated more and opted to undergo genetic testing while those with fewer cases and older tended to postpone genetic testing. A similar pattern has been observed by Kam et al.[3] in their study examining family communication of risk in inherited cardiac conditions. They found that there are family members who do not communicate risks and are reluctant to initiate cardiac screening because their relatives seem to be 'healthy'.

Individual Factors

One important individual factor is the age of the person communicating and being communicated to. Studies have shown that younger parents who are carriers are less likely

to disclose their genetic status.[22] The age of the person being communicated to is also vital in deciding to communicate information about CAH[21] and Fragile X syndrome[23]. In this sense, the developmental maturity of the person receiving information is important.

An individual's perceived risk and perceived importance of genetic information have also been shown to impact the decision to communicate genetic risks. Ashida et al.[20] reported that individuals with a lower perceived risk of Alzheimer's disease (AD) and higher perceived importance of genetic risk tend to communicate more with their relatives about the AD susceptibility testing result. Similarly, Banerjee et al.[24] reported that the perceived risk of skin cancer is associated with greater communication about general cancer risk.

Several studies have highlighted how an individual's perceived responsibility to share genetic information motivated them to communicate with their family. In a study among Latina and non-Latina women on cancer risk communication, MacDonald et al.[25] found that 88% of respondents thought that it is their duty to inform their relatives about cancer risks. Parents have also been shown to perceive having the responsibility to share genetic risk information with their children and this has been reported in studies examining communication in families affected with Duchenne Muscular Dystrophy[19] and Huntington's Disease[26]. Some studies have also shown that perceived responsibility goes beyond sharing genetic risk and extends to informing about possible ways to act on the increased risk. In a study examining communication of inconclusive breast cancer genetic test results to daughters and sisters, Baars et al.[27] reported that the participants felt that when they share test results with their sisters, they also transmit information about breast cancer screening.

In case of a lethal genetic condition such as X-linked severe combined immunodeficiency, personal reactions to the disease such as parental and survivor guilt (on the part of the siblings) have been reported to hinder open communication about the condition in the family.[28] Self-efficacy in communicating genetic information and the presence of family and/or personal history of the condition, on the other hand, are associated with greater communication. In a study exploring family health history (FHH) communication about cancer, those with greater self-efficacy are more likely to gather, share, and communicate FHH more frequently.[29] Likewise, the presence of a family history or personal history of skin cancer is associated with greater communication about cancer risk.[24]

Family Factors

Important family factors include physical proximity and the degree of biological and emotional relationships between relatives. In general, first-degree relatives and relatives living in close physical proximity to the proband are informed about the diagnosis and genetic risks first.[21] There are instances, however, when physical proximity (such as living in the same household) does not ensure genetic risk communication and emotional relationship was primarily considered. This is illustrated in the study of Hayes et al.[2] where they found that more than physical proximity, personal relationships between mothers and daughters influenced the extent mothers communicated DMD carrier risks to their daughters. This is consistent with other studies which found relatives who were not emotionally close tended to communicate less.[3,17,18]

The families' openness to communicate has also been studied previously.[3,29,30] Communication openness is measured as the extent to which families communicate about their health and their willingness to accept information.[29] In general, openness to communicate is a facilitator in communicating risks and this was reported in studies examining family communication about risks for inherited cardiac conditions[3] and about family health history in general.[29]

An associated variable to communication openness is family cohesion and flexibility. Family cohesion and flexibility reflect perceived functional or dysfunctional relationships within families.[29] Bartuma et al.[17] found that among families affected with Lynch Syndrome, those with dysfunctional relationships tend to have restricted communication. On the other hand, families reporting higher family cohesion have increased intention to communicate colorectal cancer risk[30] and they are also more likely to share information about their family health history in general.[29]

Sociocultural Factors

Many studies have highlighted how genetic risk communication in families is a 'gendered' responsibility. Ashida et al.[20], in their study about family disclosure of Alzheimer's Disease susceptibility testing results, found that women participants are twice as likely as men to communicate results. While men also participate in the communication process, usually a female relative is supporting them as they share information.[22] This happens even if the male spouse is the one at risk or affected by the condition.[26] The finding that women are more involved in the communication process has also been reported in studies examining family communication in HCM[18], Lynch Syndrome[22], Huntington's Disease and Hereditary Breast and Ovarian Cancer[26], myotonic dystrophy[31], family history of cancer[29], and CAH[21].

Previous studies have also highlighted how the intra-familial culture may influence family communication patterns, including communication about genetic risks. In a study about communication of inconclusive breast cancer genetic test results to their sisters and daughters, Baars et al.[27] reported that some families deliberately do not talk about breast cancer. This, the authors suggest, reflects the way the family copes with the disease. Similarly, in families affected with X-linked severe combined immunodeficiency, a lethal condition, participants reported that the poor communication patterns in their families resulted in the creation of a culture of having family secrets.[28] On the other hand, some families openly discuss about the diagnosis because they see it as a

family concern, and this has been documented by Abad et al.[21] in their study about Filipino families' communication about CAH.

Cultural notions of kinship and family structure may also impact family communication patterns.[15] In a study on communication in families with late-onset inherited conditions, Keenan et al.[26] found that participants have a differing definition of who is part of the family, and this influences their perceived responsibility to communicate genetic risks. According to Keenan et al.[26], the participants' notion of 'who is family' is attributed to their personal and familial experiences which may be related to the extent of emotional relationships within the family. Geographical proximity also tends to influence this notion such that relatives who are geographically distant may not be considered as part of the immediate family and thus, participants do not see an obligation to inform these relatives.

Communication Strategies

Communication strategies refer to the methods used to deliver information about genetic risk.[10] Often, disclosure of genetic risk information was done by a parent, mostly the mothers, or the proband themselves.[22,27] There are instances, however, when these individuals were accompanied by another person, usually their spouse, during the disclosure of genetic information. Aktan-Collan et al.[22], for example, found that almost 70% of parents with a Lynch Syndrome pathogenic variant disclosed the genetic testing result on their own while only about 30% disclosed it with someone else by their side.

The most common strategy used in disclosing genetic risk information is through in-person communication either through phone or by email.[27,32] The family letters that were provided by genetics health professionals to facilitate family communication have also been used although not as common as expected.[27] Social media was also reported to be used. Among families with an X-linked condition and those with hereditary cancer, one study found that almost 25% of respondents have used social media to communicate as this facilitated easier communication, especially with relatives who are geographically inaccessible.[32]

Communication Occurrence

Communication occurrence refers to the number of family members informed about their genetic risk.[10] Studies have shown that the majority of the communication happens within the proband's (or consultand's) first-degree relatives.[22,27] These studies have also reported a relatively high proportion of probands informing their relatives. One study, for example, reported that as many as 92% of women with breast cancer who had inconclusive genetic testing result informed their daughters and 88% informed at least one of their sister.[27] Among those who are affected with Lynch Syndrome, as high as 83% reported sharing their genetic testing result with their offspring.[22] A similar pattern of having a high proportion of probands informing their first-degree relatives has been observed in families affected with hypertrophic cardiomyopathy[3,18] and in those who are carriers of an X-linked condition[32]. While many studies reported a high proportion of probands (or parents) sharing risk information with relatives, there is scarce data on the proportion of relatives who are informed of their risk. A proband may only disclose information to a select number of relatives and not to all relatives who may otherwise be at risk. One such study that documented the proportion of at-risk relatives who are informed of their risk is by Shah et al.[8] Based on their study of families affected with hypertrophic cardiomyopathy and Long QT syndrome, only about 50% of at-risk relatives were informed.

Communication with non-relatives also occurs. In a study examining factors associated with family communication of skin cancer risk, Banerjee et al.[24] reported that participants also shared cancer risk information with their healthcare providers, friends, and co-workers. A similar finding has been reported by Abad et al.[21] in families affected with CAH. They found that families communicate with their friends and neighbors primarily to share about their family situation and gain emotional support.

In the process of genetic risk information communication, there seemed to be what Keenan et al.[26] referred to as a 'pivotal' person who initiates and leads the disclosure within the family. Most often, this pivotal person is the proband and they initiate the discussion as what has been reported in studies examining family communication in Lynch Syndrome[22], breast cancer[27], and hypertrophic cardiomyopathy[3,18]. In families where the proband is a child, it is the parents, usually the mothers, who serve as the primary communicators.[1,21,33] In those affected with X-linked conditions, the carrier, also usually the mother, initiates the disclosure.[32]

It is apparent from the literature that the communication of genetic risk is a process that occurs over time. While this is so, the time it takes for communication to happen differs across studies and this may be related to the content of information communicated. In a study examining the process and outcome of family communication in non-cancer conditions, Forrest et al.[1] noted how communication about the condition occurred immediately to inform family members about the diagnosis. A similar finding has been reported by Abad et al.[21] in their study about communication on CAH among Filipino families. In both studies, the focus of the communication was initially on the health implications of the condition rather than on the genetics. In contrast, Hayes et al.[2] reported that mothers who are carriers of Duchenne Muscular Dystrophy used a 'gradual style of communication' in communicating carrier testing results to their daughters. This style of communication was deemed important to give time for the daughters to assimilate the information received.[19]

Outcomes of Communication

Outcomes of communication refer to the emotions, behaviors, and actions that result from the communication

of information.[10] In general, families affected by inherited conditions reported strong emotional responses upon learning the diagnosis but the occurrence of open communication within the family generated the necessary support during the traumatic event.[1,21] While the diagnosis of an inherited condition influenced family relationships, Bartuma et al.[17] found that the effect is not necessarily negative. In their study, they found that families affected with Lynch Syndrome had improved family relationships because of altered priorities that centered around the 'family'.[17]

The uptake of cascade genetic testing is one of the clinically relevant outcomes of family communication of genetic risk. Aktan-Collan et al.[22] investigated whether parents who are carriers of a Lynch Syndrome mutation communicated risk information to their offspring and what the outcome of the communication is. They found that only 69% of first-born adult children of the respondents who were informed of their risks underwent cascade testing. The results mirror the results of the study of Shah et al.[8] in which they found that only about 50% of the family members informed of their risk underwent cascade genetic testing. In both studies, however, the data on the proportion of relatives informed of their risk who eventually underwent cascade genetic testing was based on reports by their study respondents and not directly from the relatives themselves. This is important to note because the data reported may be an over or underestimation. Regardless, it is also important to point out the possibility that the intention of the relatives to undergo cascade genetic testing may not be solely predicted by family communication of genetic risk as other factors may also be at play. Given this, it is important to also understand other factors that may influence at-risk relatives' decision to undergo cascade genetic testing. Srinivasan et al.[9] recently published a comprehensive review highlighting the barriers and facilitators of cascade genetic testing.

Research on Family Communication of Genetic Risk

The earliest literature that examined communication of genetic information with relatives is by Ashery.[34] She examined the openness of couples to discuss genetic conditions diagnosed through amniocentesis with their friends and relatives. She found that while the couples were open to sharing about the procedure of amniocentesis, they were not as open in telling their children about the procedure and the implications of a positive diagnosis.

Since the publication of the study of Ashery[34], there has been an increasing published literature on the topic of family communication of genetic risk. In the Philippine context, however, only two articles reporting the findings of one study were published on the topic.[21,33] This study by Abad et al. examined the communication of genetic information among families living with CAH.[21,33] Varied methods were used by studies in examining family communication of genetic risk. Many published studies used qualitative methods to explore the process and outcomes of genetic risk family communication.[1,3,17,19,21,26,28,31,35] Studies have also used survey methods to examine factors associated with family communication of genetic risk.[2,18,22,24,25,29,30,32] There is also an increasing number of studies utilizing social network methods to understand the family network factors that influence family communication.[8,18,29,36]

In general, the aims of previous research on family communication of genetic risk revolved around: a.) determining the extent of communication of genetic risk or genetic test result with relatives[20,22]; b.) examining the individual and family-level factors that are associated with family communication[8,24,36]; c.) exploring the experiences of families in communicating genetic information[1,21]; d.) examining patterns of family functioning in those affected by a genetic condition[28]; and e.) identifying the outcomes of family communication of genetic risk[8]. More recently, there has been an interest in understanding the factors associated with the intention of individuals to invite at-risk relatives to undergo cascade genetic testing.[37] Several interventions, mostly technology-aided, have also been developed to facilitate family communication of genetic risk including results from genetic tests. Some of these interventions include a web-based app[38], a smartphone app[39], and a chatbot[40].

Currently, there are two instruments developed to measure family communication of genetic risk.[41] The first is the Family Communication Questionnaire (FCQ) which is a seven-item tool that assesses four dimensions of family communication including communication of genetic test results to specific family members, length of time lapsed before communication took place, motivations for disclosure, and the specific topics discussed with relatives. This tool, however, has limited psychometric validation and is not widely used. The second tool is the Openness to Discuss Hereditary Cancer in the Family (ODCF) Scale which was developed to assess individuals' communication about hereditary cancer with their nuclear family. It consists of 8-items in a four-point scale and like the FCQ, it is also not widely used.

Though this is not an exhaustive list, several gaps in literature can be the subject of future research. First, many studies on family communication of genetic risk were on hereditary cancer and other autosomal dominant conditions such as inherited cardiac conditions. Limited studies have focused on conditions inherited in another pattern (i.e., autosomal recessive and X-linked dominant). This trend is understandable and can be attributed to existing early screening recommendation protocols for hereditary cancer and other autosomal dominant conditions such as cardiomyopathies.[42,43] Nevertheless, it is still important to understand family communication of genetic risk in those affected with autosomal recessive and X-linked recessive conditions because of the personal utility of the information such as in reproductive decision-making. In the Philippines, for example, many locally important inherited conditions (e.g., X-linked Dystonia Parkinsonism, Maple Syrup Urine

Disease, and thalassemia) are inherited in X-linked and autosomal recessive patterns; family communication within the context of these conditions could be examined in future studies. Second, many studies have focused only on the perspectives of an individual member of the family and their perspective may be different from other members (both affected and unaffected). Third, family communication is also socially and culturally influenced as highlighted by the findings of Keenan et al.[26] that the notion of 'who is family' influences the disclosure process. Since the definition of 'family' is culturally determined, it is important to consider examining family communication in populations other than those currently represented in the published literature usually from Western countries. This highlights the importance of understanding the nuances of family context (including familial relationships and dynamics) by which the process of family communication of genetic risk is embedded. Finally, one of the clinically relevant outcomes of family communication of genetic risk is the cascade screening or genetic testing of at-risk relatives. However, current studies in family communication only focused on identifying the experiences of families and factors associated with communication of genetic risk. There is limited literature that examines the reasons at-risk relatives do not get screened or undergo genetic testing even if they were informed about their risk.[10]

Implications for Healthcare Providers

Healthcare providers need to understand family communication of genetic risk because it is their responsibility to provide support as the family undergoes the genetic risk communication process.[6] Healthcare providers, both genetics and non-genetic specialists, will be expected to support families as they navigate through the genetic risk communication process because of the mainstreaming of genetic technology in all medical specialties and the increasing use of next-generation genomic sequencing for clinical diagnosis.[11] This support is important because of consistent data from studies showing that individuals do not always disclose genetic risk information to their relatives.[8,30] Even if individuals may disclose, they may only do so to a select number of relatives with whom they are emotionally close and have established relationships.[8] Some individuals are not knowledgeable in identifying at-risk relatives to whom the genetic risk information is relevant.[21] Other individuals also reported personal difficulty in initiating discussion with their relatives as they reported a sense of inauthority and a perceived lack of knowledge to explain the familial implications of the genetic risk information.[5] It is for these reasons that several studies have highlighted the advantage of healthcare provider-mediated communication with relatives rather than individual or proband-mediated communication since the former can simplify the communication process and may reduce the burden from the probands.[5,44]

However, instituting a mechanism for healthcare provider-mediated communication with at-risk relatives is not a straightforward solution. Studies have shown that while healthcare providers feel a responsibility to inform relatives directly, they are constrained with an ethical dilemma to either fulfill their duty to warn relatives versus protecting their privacy and confidentiality.[45] Indeed, data privacy policies and laws are important to consider, and healthcare providers should be aware of nuances in privacy policies in their countries or work settings.[46] There should also be guidelines that would guide in resolving such dilemmas.[46] Future research should also focus on determining ways on how healthcare providers can share information with relatives and how competing interests in family communication can be resolved.[47]

CONCLUSION

This paper provided an overview of the construct of family communication of genetic risk. The studies reviewed in this paper support the notion that family communication of genetic risk is a process that unfolds over time. Some pivotal people, often the probands or consultands, play key roles in communication. In deciding to communicate or withhold information, several influential factors are considered by the individual. These factors may be inherent in the disease affecting the family, individual characteristics of the messenger and receiver of information, family characteristics, or sociocultural context in which communication happens. In communicating genetic risk, several methods have been used but it usually involves in-person communication or through the aid of technology such as telephone, email, or social media. Studies have also shown that most of the communication happens within the immediate family with some communication happening with distant relatives and even with non-relatives such as friends, co-workers, and neighbors. The outcomes of family communication involve changes in family relationships or a decision to participate in cascade screening or testing.

The increasing use of genetic technology across medical specialties necessitates that healthcare providers are informed about the familial implications of genetic testing results. They should also be prepared to support individuals as the latter communicate genetic risk information to their relatives. To better guide healthcare providers in providing support, further studies may examine family communication of genetic risk across locally significant inherited conditions.

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