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ARTICLE

Exploring resources for intrafamilial communication of cancer genetic risk: we still need to talk

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While the importance of intrafamilial communication of hereditary cancer risk has been acknowledged, the factors that promote and act as barriers to patients disclosing their information to their families are complex and emerging. This raises the question: How are patients guided in practice to contemplate intrafamilial communication? Focusing on breast cancer, we conducted an exploratory study examining current resources supporting patients and health-care professionals, and isolated the messages surrounding intrafamilial communication of cancer risk. We find the duty for health-care professionals to counsel patients regarding intrafamilial communication is acknowledged to varying degrees by multiple actors in the cancer care delivery landscape, including health-care professional associations, health service organizations, and patient groups. A range of medical, psychosocial, and other factors underlying intrafamilial communication are acknowledged in messages to patients. Patients, however, are often referred to a single group of health-care professionals to discuss their diverse and complex needs. At the same time, messages aimed at patients appear to place the emphasis on barriers that could exist for patients contemplating intrafamilial communication, while highlighting the benefits families derive from such communication. Taken together, this points to a lack of coherence within materials directed to patients and suggests the need to do coordinated research among stakeholders to address two related issues: (1) determining who are the actors best positioned to send messages surrounding intrafamilial communication to patients and (2) addressing the content of messages conveyed in patient materials.
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INTRODUCTION

Family history is an important element of a patient's risk profile for developing a number of medical conditions, including breast and ovarian cancer.[1] Knowledge of family history, however, requires reciprocal communication, from patients to family members. Ensuring that family members are made aware of the risk of their relatives is not straightforward as patients are not legally required to disclose their medical information to their relatives, and confidentiality requirements prohibit health-care professionals from disclosing information to third parties including family members.[2,3] Nevertheless, a moral duty for patients to disclose has been recognized and calls have been made to encourage patients to share their information within their families.[2–4] Guiding patients through the intrafamilial communication (IFC) process is not straightforward as it requires patients to receive complex information from their health-care provider, which they must then transmit to the family, while reconciling conflicting interests between patients and family members.[5–7]

Receiving and transmitting genetic information, by itself, is a complex task. Research suggests that patients' and families' abilities to understand genetic information can act as barriers to IFC.[8] Indeed, a patient's poor understanding of their own cancer risk has been cited as a factor influencing their decision to disclose, while patients with inconclusive results, or who are carriers, are less likely to disclose their information and report more difficulties explaining their results to relatives.[3,9,10]

In addition, not all family members are willing to communicate. In families with BRCA1/2 mutations, some members are effective at gathering and disseminating health information, whereas other members are blockers, reluctant to learn, and transmit health information.[7,11] Further, contextual factors, such as gender, relationship, and cultural background, have each been shown to influence decisions to communicate. For example, patients are more likely to share with female relatives over male, more likely to tell children or siblings than parents, and first-degree relatives over second- and third-degree relatives.[8,9,12] Individual relationships with family members and patients' own definitions of who is a family member have also been shown to influence the level of responsibility one feels to disclose.[2,13] Finally, expectations surrounding IFC vary by culture, whereby genetic testing for BRCA1 in the Netherlands presupposes active and harmonious involvement of relatives, in contrast to testing in the United States, which does not.[14]

The complexity and delicate nature of IFC raises the question of how patients are supported and counseled, at a practical level, to identify and reconcile these challenges and barriers when contemplating IFC? What are their needs with respect to communicating risk information with family members? Who among actors in the health-care delivery system can address their needs and how are they guided?

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To our knowledge, such questions have not been addressed, although the need to develop targeted interventions for patients to promote family communication has been recognized.[9,15,16] Indeed, some jurisdictions, such as Australia, have recently proposed legislation that would allow health-care professionals to inform their patients' relatives of their risk for genetic disease.[17] In other jurisdictions, for example in Canada, the question of whether a doctor is bound by professional responsibility to inform relatives of their patient of the risks of inherited disease has been recently litigated at the appeal level (V Watters, White, 2012 QCCA 257, Quebec Court of Appeal).

We conducted an exploratory qualitative study asking to what extent existing resources address the reported challenges and barriers to IFC. We focused our research on breast cancer as it is a cancer for which surveillance and risk reduction options are available to those at higher risk based on family history.[18] Further, as significant documentation and resources are available for breast cancer, our research represents a test case for IFC for other cancers or hereditary disease. As IFC involves two-way communication between health-care professionals and patients, and patient and family, we hypothesized that health professional associations, health service organizations, and patient associations each have a potential role in influencing IFC of genetic cancer risk between patients, their health-care professionals, and families. Guided by questions from our published studies,[2,6] we examined text and web-based documents, such as pamphlets, guidelines, and recommendations, aimed at patients and/or health-care providers in the cancer care delivery landscape and isolated the messages surrounding IFC.

METHODS

Document collection

Three groups were identified as significant actors: health-care professional associations, patient groups, and health service organizations (comprising government cancer agencies and cancer clinics). Organizations were identified from experts in our field, and internet searching using the following search terms: 'cancer*' [or] 'hereditary' [or] 'genetic' [and] 'group*' [or] 'organization'. Within each group, we sampled purposefully to ensure a range of perspectives were captured. Following qualitative tradition, we estimated the number of organizations required to achieve saturation, beyond which new organization would not provide fresh information, in this case approximately 20 organizations within each group.[19]

From each organization, we sought publically available guidelines, policy statements, brochures, pamphlets, and/or handouts that discussed the genetic or familial component of cancer or hereditary disease. Documents were obtained via (i) searching websites of identified organizations, and (ii) requesting copies of publically available printed materials over the timeframe from September 2010 to December 2011. Guideline and policy searches were performed by conducting a review of HUMGEN (www.humgen.org/int/_ressources/Method_en.pdf), a database of laws and policies related to human genetics), PubMed, and Google using the following search terms: 'famil*' [and] 'genetic' or 'communicat*' [and] 'genetic' or 'famil*' [and] 'cancer', and reinforced with searches of sections titled 'publications', 'guidelines', 'documents', 'prevention', and 'treatment'.

Documents were also obtained by request following a search for cancer centers on the National Cancer Institute (NCI) website and several other professional associations in different countries. Associations were contacted by email, fax, postal mail, and via announcement in the 49th issue of newsletter of *The International Multidisciplinary Community Genetics Network* (IMCGN).[20,21] Organizations examined were in Canada, the United States, Europe, the United Kingdom, and Australia.

Inclusion and exclusion criteria

Our primary interest was IFC of hereditary breast and ovarian cancer risk. However, as many organizations were silent altogether with respect to IFC, we expanded our scope beyond documents specific to hereditary breast and ovarian cancer, to include documents discussing IFC of genetic information broadly, so long as hereditary breast and ovarian cancer risk would be within the target audience. Two categories of documents met this criteria: (1) documents discussing IFC following genetic risk assessment for « Hereditary Cancer » (see pp 9–11), and (2) IFC following « genetic carrier » testing (eg HSO6).

Included were documents that explicitly addressed (1) genetic testing OR genetic risk assessment, OR hereditary cancer AND (2) familial interest in the information. Only documents written or translated into English or French were eligible for inclusion.

Excluded were documents not addressing IFC (eg technical, or organizational issues). Uncertainties regarding inclusion were discussed and agreed upon by two to three researchers.

Document analysis

For each stakeholder group, we used a two-step qualitative analysis following methods described in our previous studies.[22] First, documents acknowledging IFC were rated along three incremental levels: (1) 'Family Interest Acknowledged', where family interest in the individual's genetic information was acknowledged; (2) 'Role of Health-Care Professional Acknowledged', where family interest AND a role for the health-care professional in encouraging disclosure were each acknowledged; or (3) 'Resources Provided', where family interest AND the role of the health-care professional in facilitating disclosure were both acknowledged, AND resources to facilitate IFC were provided.

Second, text from documents was further classified using a combined inductive–deductive approach. Thematic analysis was performed on extracted text related to IFC using a list of key themes developed *a priori* by the research team.[6] Subthemes were continually developed according to the content by one member (KAM or EK) and verified by three members (KAM, DA, and EK) in total.

RESULTS

Actors involved in IFC

We examined 185 documents from the following three actors: health-care professional associations, patient groups, and health service organizations (comprising government cancer agencies and cancer clinics). In all, 59 documents satisfied the inclusion criteria from 60 organizations (see Table 1 and Supplementary Table 1 for a full list of included documents).

Degree of IFC of cancer risk

ACROSS actors in the cancer care delivery landscape. Degree of acknowledging IFC varied across all three actors. Three incremental levels were apparent from our analysis (Figure 1).

In level 1, family interest in a patient's genetic information was simply acknowledged in some way (Figure 1). For example, 'each of your children would have a 50/50 chance of having inherited that altered gene from you' (HSO17). At this level, no further message was made inviting patients to consider the choice they have in deciding whether to disclose the information to their relatives or where patients could turn for guidance in deciding whether to disclose or deliver the message.

In level 2, in addition to acknowledging familial interest, a role for health-care professionals in guiding IFC was also acknowledged (Figure 1). The role ranged from a simple mention that health-care professionals can provide information about the consequences for families: 'The genetic counselor will also discuss how genetic testing for cancer will affect you and your family' (PG9), to detailed description of topics patients could ask health-care professionals, such as: 'What about children? Should they be told? Can they be tested? Do I need to tell everyone? How do I approach the subject?'

Table 1 Document characteristics

Actors	*Number of groups examined*	*Number of documents examined*	*Number of documents included*[a]
Health-care professional association	20	56	10
Genetic counselors			
Medical geneticists			
Physicians			
Oncologists			
Health service organization	20	43	26
Individual hereditary cancer clinics			
Hospital-based cancer centers			
Government cancer agencies			
Patient group	20	86	23
Breast cancer patient support, fundraising, and advocacy groups			
General cancer patient support, fundraising, and advocacy groups			
Total	60	185	59

[a]The complete list of documents examined is provided in Supplementary Table 1.

(PG11). No mention was made directing patients to resources for IFC beyond consulting health-care professionals.

In level 3, in addition to acknowledging family interest and the role for health-care professionals, resources for facilitating IFC were also provided (Figure 1). Resources included: information documents, worksheets, and sample letters, with information of three varieties: (1) *Suggestions and tips* for the patient, such as planning logistics of message delivery; (2) *Tools*, such as sample letters that patients could modify or educational pamphlets for family members; and (3) *Direction to other resources*, including referrals to other supporting organizations, health-care professionals, or websites for patients and families.

WITHIN actors in the cancer care delivery landscape. Acknowledging IFC also varied according to three sets of actors: health professionals, health service organizations, and patient associations (Figure 1).

Health professional organizations. Among health professional organizations examined, documents fell mainly under level 1 or level 2 (Figure 1). Where a role for health-care professionals was acknowledged, it was often accompanied with affirmations that health-care professionals could not disclose information to the family. For example: 'Although the provider cannot contact family members directly, the individual should be encouraged to discuss the findings with his or her family if possible and appropriate'. While statements encouraging health-care professionals to discuss IFC with patients were noted, documents rarely contained content as to where health-care professionals themselves could turn for further guidance.

Health service organizations. Among health service organizations, documents acknowledged IFC across all three levels (Figure 1). Familial interest in the information was often associated with statements that relatives may be similarly at risk and qualify for testing. For example: 'if genetic testing identifies the specific mutation causing [hereditary breast and ovarian cancer] in a family, then other family members can be tested' (HSO13). Where a role for health-care professionals in guiding IFC was acknowledged, a range of topics for which professionals could be consulted was observed, from education about transmission 'genetic counseling usually involves […] discussions about […] the risk of passing a mutation to children' (HSO15), to acknowledging that health-care professionals can assist in planning message delivery 'Your genetics specialist can help you decide how best to share the information within your family' (HSO22). Some health service organizations also offered tools, such as letters, to inform family members.

Patient groups. Similarly, among patient groups we observed all three levels of acknowledging IFC (Figure 1). Regarding the role for health-care professionals, patients were invited to consult health-care professionals on a diverse range of topics, not only the medical aspects but also in some cases the psychosocial and economic consequences:

> The counselor will also outline the implications of genetic testing with respect to family relationships, insurance issues as well as the emotional and psychological impact of receiving positive or negative test results (PG8).

Notably, patient groups provided extensive resources directly to patients, such as pamphlets and web-based information discussing (1) how to identify potential at-risk family members to whom to disclose, (2) factors to consider in the content and method of disclosing information, (3) suggestions for how to handle immediate and long-term consequences of communicating, and (4) referral to other organizations for patients and families seeking further assistance (PG20). Further, sample letters for patients to disclose information to family members were provided (PG23).

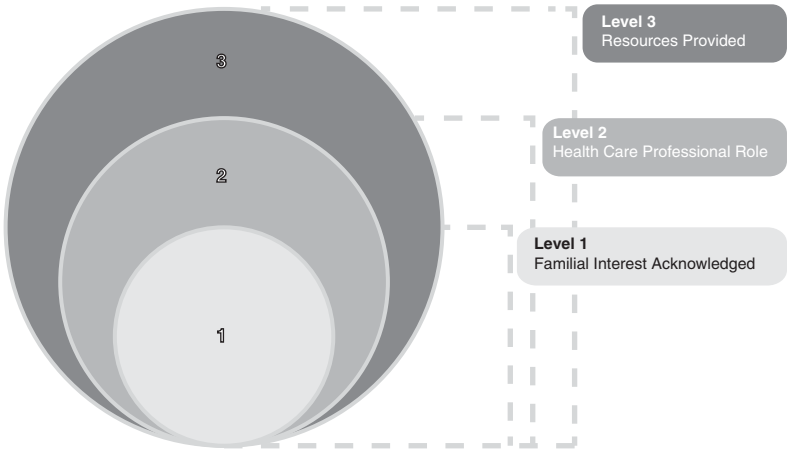
By comparing actors along the continuum of three levels we identified (Figure 1), it appears that acknowledgment of IFC is lower among health professional associations. Patient groups and health service organizations acknowledge diverse roles for health-care providers in providing guidance on medical, psychosocial, and economic considerations. Overall, among all three groups, relatively few resources are offered for patients and families in support of IFC.

Where are patients referred for assistance for IFC and what topics can be addressed?

The complexity of barriers that patients can face regarding IFC raises two questions: (1) Who are patients referred to for assistance, and (2) For what topics? We examined our materials for responses to these questions.

A diverse group of professionals and topics were identified (Table 2). Genetic counselors were often the health-care professionals where patients were referred for questions or guidance. However, patients were also referred to other health-care professionals, including 'doctors', 'nurses', 'oncogeneticists' or 'cancer geneticists', 'psychologists', or simply 'other health professionals'. Finally, some documents acknowledged a role for non-professionals, such as fellow patients referred through patient groups (Table 2).

Patients were encouraged to consult health-care professionals for (1) general guidance without specifying topics or issues that would be covered. For example, 'The genetic counselor will discuss how genetic testing for cancer may affect you and your family' (PG9), and (2) specific topics addressing the following themes: (1) *educational* – inviting questions about transmission and inheritance of genetic risk for other family members, (2) *medical* – encouraging awareness of



Number of documents

Actors	Continuum		
	Familial Interest Acknowledged	Role for Health Care Providers in IFC Acknowledged	Resources
Health Care Professional Association	3	7	0
Patient Group	1	17	5
Health Service Organisation	8	13	5
TOTAL	**12**	**37**	**10**

Figure 1 Levels of acknowledging IFC among actors. Acknowledgment of IFC can be understood as levels that build upon each other. In Level 1, familial interest in a patient's genetic information is simply acknowledged. In Level 2, not only is familial interest acknowledged but also a role for health-care professionals in guiding IFC is also acknowledged. In Level 3, in addition to acknowledging familial interest and the role for health-care professionals, resources are provided for patients and families to facilitate IFC. Acknowledgment of IFC among actors in the cancer care delivery can be understood as a continuum, where acknowledgment of IFC is less among health professional associations. Overall, among each of the actors, relatively few resources are offered for patients and families in support of IFC.

Table 2 Summary of topics of consultation for intrafamilial communication by health professional type

Topics	*Genetic counselor*	*Doctor, nurse, or other health-care professional*	*Psychologist*	*Patient*
General	✓	✓		
Educational	✓	✓		
Medical	✓	✓		
Psychosocial	✓	✓	✓	✓
Decision-making assistance	✓	✓		✓

genetic testing, screening, and other health services that would be made available to at-risk family members, (3) *psychosocial* – informing patients of assistance options for dealing with emotions, including guilt experienced by patients or blame from other family members, and (4) *decision-making assistance* – informing patients that health-care professionals can put into perspective the issues surrounding genetic testing, including non-medical issues, such as employment or insurance consequences (Table 2).

We next evaluated the topics on which each group of professionals are called to provide guidance. Table 2 demonstrates the interprofessional differences regarding specific topics. Genetic counselors as well as health-care professionals, including 'doctors', 'nurses', 'oncogeneticists', and 'other health professionals', were all called upon to provide guidance on all topics. However, many documents targeted primarily genetic counselors as being able to consult patients on issues in greater depth. For example, for educational information, genetic counselors were able to:

> Talk to you about the differences between cancer that occurs by chance alone (sporadic) and cancer that runs in families (hereditary). Explain what hereditary breast and ovarian cancer is and how it is passed down in families. Determine whether the cancers in your family may be related to hereditary breast and ovarian cancer (PG21).

In contrast, other health-care professionals were called upon to consult at a more general level. For example, with respect to education, explaining 'How does my having breast cancer affect the risk of my family members' (PG19). A similar pattern between genetic counselors and other health-care providers was evident for the other topics: general guidance, medical, psychosocial, and assistance with decision-making.

In addition, some professionals were differentiated to address specific topics. Psychologists were identified as being capable of providing guidance on a single topic, psychosocial support related to IFC. Non-professionals such as fellow patients were identified as

resource persons capable of providing guidance on two topics, namely psychosocial support and assistance in decision-making.

From this analysis, it appears that genetic counselors are called upon to have a significant role in assisting patients with IFC. They are framed in the materials we examined as the primary professionals where patients are referred to discuss a diverse range of topics, at an in-depth level.

Neutral information, barriers, and benefits of IFC for patients and their families

As IFC involves the delivery of complex information combined with conflicting interests between patients and relatives,[6] we asked to what extent do existing resources acknowledge this complexity in their messages? We observed two main categories of messages in our data: (1) neutral information and (2) potential barriers and benefits to communicating information.

Neutral information. Neutral information educated the patient of the factual basis for the family's interest in a patient's genetic information. The information was broad, acknowledging that families share genes and environments, thus an individual's genetic or medical information has implications for family members. For example, for patients learning they have an altered copy of BRCA1 or BRCA2:

> Each of your children would have a 50/50 chance of having inherited the altered gene from you (HSO18).

Messages in this category were not accompanied with a mention of the possible barriers or benefits for patients or families related to IFC.

Barriers and benefits to IFC. Another category of messages apparent in the documents were barriers to and benefits of IFC. In this category, three themes emerged, namely: (i) psychosocial, (ii) medical, and (iii) lifestyle. Messages under these themes varied substantially between barriers and benefits and between patients and family members (Table 3).

Barriers. Barriers to IFC encompassed one theme, psychosocial factors (Table 3).

(i) *Psychosocial*: Some statements discussed concern for the patient's own emotional well-being following communication. For example, concerning positive test results:

> Be prepared for different emotions. When discussing your genetic test results with family members, you or others may experience several emotions such as guilt, anxiety, relief, sadness, anger, resentment, frustration or empowerment (PG20).

Concern for a patient's own emotional well-being was equally a barrier, even when it related to communicating negative test results:

> Some find it difficult to communicate the 'good news' to their siblings and other relatives who may themselves be carriers or have an affected child. They wonder why they 'escaped' when other family members did not. Sometimes it is difficult to accept that you have been fortunate when others have not (HSO6).

Other statements addressed the family dynamic surrounding message delivery:

> Some family members may appreciate being advised of your test results, while others may not. Some may even be angry that you had the testing in the first place and shared your results since it forces them to confront a difficult issue (PG20).

Finally, other statements raised long-term consequences for family relationships, for example: 'feeling distanced from relatives who have cancer or are at increased risk' (HSO3).

Of note, concerns differed by familial relationship. For example, in messages surrounding guilt, there was guilt for passing along a genetic variant to a child, or guilt that a partner feels for bringing a genetic variant into an otherwise healthy family. In summary, the barriers to IFC we observed focused on psychosocial barriers patients could face in disclosing their genetic risk information to their families.

Benefits. In contrast, benefits of communicating genetic information generally focused on family members and encompassed several themes: (i) psychosocial, (ii) medical, and (iii) lifestyle (Table 3).

(i) *Psychosocial*: Within psychosocial benefits, two components were apparent: benefits to the patients' own emotional well-being and long-term consequences for family relationships, as a result of disclosure. Some messages highlighted that disclosure to family members could also result in additional support and benefit to a patient's own emotional well-being: 'the genetic testing process brings families closer together and the family can be a good source of support' (HSO7). Other messages acknowledged the possibility that disclosure could have long-term consequences advantageous for family relationships, listing it as a 'pro' in the pros and cons of genetic testing (PG17).

(ii) *Medical*: Messages raised the medical opportunities available to family members following IFC. Some medical benefits involved identifying family members who would benefit, such as those at risk, or seeking a diagnosis:

> if you find out that you are a carrier you may wish to discuss this with other family members. This gives other family members the opportunity to have a blood test to see if they are also carriers, if they wish. This information may also be useful in helping diagnose other family members (HSO7).

Others focused on the advantages that timing of disclosure could have for family members 'A positive result may lead to finding disease earlier and preventing deaths' (PG1).

(iii) *Lifestyle*: Some messages revealed that families could use the information to make informed lifestyle choices: 'Telling them might help them decide if they should [...] adopt some of the approaches to try to lower their risk' (PG1). Other lifestyle opportunities included taking advantage of future improvements in disease prevention

> through genetics research we are continually improving methods of cancer prevention, detection and treatment, and this will benefit our children in the future. Knowing about an inherited increased risk for developing cancer can help our children become more aware of the importance of preventive and/or early detection measures (PG9).

Sometimes lifestyle benefits included the opportunity for family members to fully consider reproductive options following IFC: 'It might also be particularly important to family members who are likely to have children in the future' (HSO7).

Barriers and benefits for patients and families. From our analysis, it appeared that messages surrounding IFC are framed differently for families and patients (Table 3). Patient-centered messages focused on

Table 3 Barriers and benefits to intrafamilial communication

Themes	*Barriers to communication*	*Benefits to communication*
Psychosocial	*Concern for individual emotional well-being*	*Benefits for individual emotional well-being:*
	Range of emotions about impact information may have on family: anxiety, fear, and anger	Relieves uncertainty in the family
	Guilt for	Family members can become a source of support
	passing mutation to child or other family members	Altruism
	bringing a mutation into the family	
	being negative where other family members are positive	
	Family dynamic surrounding message delivery	
	No close relationship, uncomfortable	
	Uncertainty about relatives wishes to know or not know	
	Family may react negatively, unpredictably, doubt the veracity of the information, or ask that information may be kept secret	
	Concern about how and when to communicate to children	
	Long-term consequences for family relationships	*Long-term consequences for family relationships*
	Stress on family relationships, for example	Positive impact on familial relationships
	where family members have different feelings about whether to get tested	Encourages openness and awareness in family
	if they receive different results	Relationships and family ties can become stronger
	Spouse or partner may feel left out	
	Upsetting for relationship with spouse or partner for planning future children	
	Potential to reveal family secrets such as adoption or paternity	
	Children may not be old enough to get tested, there may be no treatment or preventative measures	
Medical		*Improved access to medical care for family members*
		WHO
		Facilitates access to identification, screening, and treatment of at-risk family members
		WHEN
		Earlier diagnosis and improved prognosis, for relatives with cancer
		Prevent misdiagnosis
Lifestyle		*Opportunity to make informed choices for family members*
		Allows family members to make lifestyle changes and risk reduction measures
		Provides family members the opportunity to take advantage of future improvements in cancer detection, treatment, and prevention
		Assists in family planning

barriers they may face in disclosing, namely psychosocial barriers, which were framed as offset by few psychosocial benefits. Further, we observed few messages surrounding medical or lifestyle benefits experienced by patients themselves as a result of IFC. In contrast, family-centered messages focused on potential benefits derived by family members following IFC, namely medical and lifestyle benefits, with fewer psychosocial barriers reported.

DISCUSSION

IFC of hereditary cancer risk requires patients volunteer to share complex information obtained from their health-care professionals with their families, amidst a host of contextual factors. Responding to a need to develop strategies targeting family communication,[9,15,16] the purpose of our study was to first identify existing messages surrounding IFC for hereditary breast cancer risk in information aimed at patients and health-care professionals. To the best of our knowledge, our approach focusing on existing resources for IFC is unique. Our results are exploratory, intended to bridge a gap by providing those researching IFC with observations about the materials and guidance available to patients and the groups providing it.

We found that multiple actors in the cancer care delivery landscape acknowledged to varying degrees the duty for health-care professionals to counsel patients regarding IFC. Although a range of medical, psychosocial, and other factors underlying IFC are acknowledged, patients are often referred to a single group of health-care professionals (ie genetic counselors) to discuss diverse issues surrounding IFC. At the same time, messages aimed at patients appear to place emphasis on challenges that could exist for patients contemplating IFC, while highlighting the benefits families derive from such communication. Taken together, this points to a lack of coherence within patient-directed materials and we suggest that it identifies a need for coordinated research among stakeholders to address two related issues: (1) determining the actors best positioned to send messages surrounding IFC and (2) addressing the content of messages to be conveyed in patient materials.

Who are the actors that can support patients in IFC?

Although a variety of topics surrounding IFC were apparent, topics were often accompanied with messages directing patients to a single health-care professional for guidance. This implies that a single group of health-care professionals is capable of addressing all topics. Given the complexity of information to be delivered surrounding IFC, and multiple actors in the cancer care delivery landscape are providing information to patients, the question that follows is whether guiding patients through IFC could be improved by adjusting how these topics are addressed among professionals and actors. For example, we noted that patients are often referred to genetic counselors with the message that genetic counselors can provide guidance on all their informational needs and psychosocial concerns. However, the increased number of conditions requiring counseling, and complexity of genetic information has increased demand for genetic counseling services.[23,24] Meeting this demand is a challenge facing the profession.[23,24] Thus, considering whether roles related to IFC can, or should, be shared among other health-care professionals is timely. Indeed, psychologists and oncology nurses have been suggested as capable of playing an increased role in counseling patients in IFC.[25,26] Further, as some patient groups and health service organizations already offer tools to patients for family conversations, or are sources of psychosocial support, other actors may be capable of supporting patient needs. Additional research could explore the ways in which different stakeholders frame IFC, consider how best to raise awareness across stakeholders of IFC, and address how patient needs in IFC could be met by multiple actors.

Shaping the content of messages to patients regarding IFC

Our work also identifies the need to consider the message patients take away when counseled on IFC regarding (1) the decision to disclose and (2) the content of disclosure.

Patients have the choice to communicate their information to their families. From research on families with breast cancer, not all individuals disclose their results to families or are open to communication.[7,9,11,12] Our research exposes that messages to patients highlight both the benefits that exist for family members and the challenges patients may face in communicating. Yet within materials we examined, we observed few messages addressing (1) how patients can overcome the challenges, and (2) the possible benefits patients could derive themselves by disclosing. In highlighting the benefits for families, while minimizing the benefits patients may derive, or how they can overcome the challenges, we observed an imbalanced message. For patients facing challenges, an absence of messages addressing the challenges, or mentioning individual benefits could contribute to their decision not to disclose. Thus, research considering what a balanced message to patients would be, identifying individual patient benefits and strategies to address communication challenges, is needed. Such research would ultimately assist patients in making informed decisions.

One approach to improving the balance could be to reframe the concept of IFC, as part of an expanded concept of family medical history. Knowledge of family medical history requires a reciprocal cycle of giving and receiving medical information among family members. By framing IFC as part of family history, a patient's disclosure to their relatives becomes part of the cycle of giving and receiving. Under this light, disclosure is necessary to the cycle, and the benefit to patients is the indirect benefit of receiving or having received information from their relatives.

Equally important, patients require guidance about what to disclose to their relatives. Effective IFC requires that patients receive and understand complex information to transmit to multiple family members. At the same time, knowledge and ability to understand are barriers.[8–10] We observe that some messages directed at patients provide the factual basis for disease, whereas other messages discuss the need to take distinct family concerns into consideration. However, messages designed to educate the patient on how to meet the diverse information needs of individual family members were lacking. Thus, research is needed to consider what the reasonable expectation is for conversations from health-care professionals counseling patients. In other words, to what degree are patients expected to inform and educate their family members on the nature of their risk and the medical options available. Or are patients expected to simply raise the issue with their families and direct them to additional resources or actors, who will in turn educate family members directly? Addressing these questions would lead to the development of coherent guidance for patients and health-care professionals on these issues.

Research examining who counsels patients, and what the take-home message is of such counseling will also assist in the development of pertinent materials that address patient needs, and contribute to optimizing health and psychosocial outcomes for patients and families. Involving stakeholders in the research process will contribute to the development of materials that balance patient and family needs with available resources across the cancer care delivery landscape. Indeed, following recent proposed legislation allowing health-care professionals to disclose genetic test results to family members, and litigation over health-care professionals' responsibilities to inform family members of their genetic risk,[17] (V Watters, White, 2012 QCCA 257, Quebec Court of Appeal) a greater understanding how IFC can be effectively encouraged at a practical level is needed.

Limitations

As an exploratory qualitative study, our sample was limited to volunteers who submitted information and what was available on public websites, thus conclusions cannot be generalized as applicable to the entire landscape of resources available for IFC. Further, we acknowledge documents discussing IFC to health-care professionals may be addressed in a broader scope of materials from what we examined.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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