Issues associated with a hereditary risk of cancer: Knowledge, attitudes and practices of nurses in oncology settings

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ABSTRACT

Documenting a patient's family history of cancer is useful in assessing their predisposition to some types of hereditary cancers. A group of nurses working with cancer patients were surveyed, by way of a questionnaire, to determine their level of knowledge about oncogenetics, describe various issues related to their capacity to identify, refer and support individuals with a hereditary risk of cancer, and explore their interest in continuing education on this topic. The findings show limited knowledge and a low sense of competence among the participating nurses, as well as a lack of access to university and continuing education programs in this field. Training focused on competency development would enhance their capacity to carry out an initial assessment of individuals who are potentially at risk for cancer and refer them to specialized resources.

Keywords: hereditary cancers, oncogenetics, family history, nursing competencies

There were an estimated 225,800 new cancer cases and 83,300 cancer deaths in Canada in 2020 (Brenner et al., 2020). Despite significant progress in reducing the mortality rate for several types of tumours (breast, prostate and lung) (Brenner et al., 2020), cancer continues to be the country's leading cause of death (Comité consultatif des statistiques canadiennes sur le cancer/Canadian Cancer Statistics Advisory Committee, 2019). Some forms of cancer can be qualified as "hereditary," i.e., caused by a genetic mutation inherited in an autosomal dominant form. A parent who is a carrier of a predisposition gene mutation has a 50% chance of passing on the mutated gene to their children (Garber & Offit, 2005; Lindor et al., 2008; Mucci et al., 2016). Some 5% to 10% of various types of cancer are associated with hereditary syndromes (Viassolo & Chappuis, 2016). These include colorectal, breast, ovarian, prostate and pancreatic cancers (Foulkes, 2008; Garber & Offit, 2005). In addition to hereditary cancers, roughly 15% to 20% of cancer cases are categorized as "familial" (Berliner & Fay, 2007; Eberl et al., 2005). They may be the result of genetic mutations that have yet to be identified, interactions between genetic and environmental factors, or exposure to a similar environment or shared lifestyle practices (Berliner & Fay, 2007). Familial cancers do not generally exhibit the classic characteristics of hereditary syndromes (Berliner & Fay, 2007), but they may be associated with an increased risk of cancer, which is at its greatest when a member of the family has a certain kind of cancer, such as breast or colorectal cancer (Mavaddat et al., 2013; Mucci et al., 2016).

Obtaining a family history can help in assessing the risk of developing cancer and, thereby, reducing the overall cancer burden at the initial assessment stage by identifying high-risk individuals and developing personalized prevention strategies (Brennan & Wild, 2015; Chen et al., 2021; Stadler et al., 2014). The data collected on a patient's personal medical history and family history of cancer can be used to determine the likelihood of their having a familial mutation predisposing them to certain types of cancers (Riley et al., 2012). Taking and analyzing a patient's family history is an integral part of good clinical practices and should be systematically incorporated into every cancer care scenario (Chen et al., 2021; Eberl et al., 2005), especially when it comes to identifying individuals likely to be at high risk for colorectal, breast, ovarian or prostate cancer (National Institute for Health and Clinical Excellence [NICE], 2013). Despite the important role of family history-taking in cancer prevention, it remains an underutilized technique in the cancer care trajectory, which limits its impact on prevention outcomes (Chen et al., 2021; Houwink et al., 2014; Valdez et al. 2010). Many studies report that family information is not always documented in patient files in cases where it would be called for. Furthermore, even when a family history is taken, it is often incomplete and, therefore, ineffective in assessing cancer risks (Powell et al., 2013; Wood et al., 2013). Individuals at risk of familial cancer are not always referred to oncogenetics, thus hindering an accurate assessment of their risk and

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preventing them from receiving personalized care and follow-up (Stuckey et al., 2016; Wood et al., 2013).

Many factors contribute to the underutilization of family history-taking by healthcare teams, including the lack of time to collect this information (Houwink et al., 2014), the lack of applicable guidelines (Wood et al., 2013), a limited grasp of the role played by heredity in the development of cancer (Chen et al., 2018), and negative attitudes in the public healthcare system toward genetics and genomics (Khoury et al., 2007). Studies also point to a lack of understanding with regard to the potential of family history information in screening (Chow-White et al., 2017; Wood et al., 2013) and insufficient overall training of healthcare professionals, including nurses (Carroll et al., 2009; Farndon & Bennett, 2008; Sussner et al., 2011; Talwar et al., 2017). Furthermore, although the Human Genome Project opened many doors in terms of preventing, diagnosing and managing of cancer and many other diseases, it also led to a considerable increase in the demand for oncogenetic services (Petersen et al., 2014). Due to a shortage of specialists in the field, non-specialists are often responsible for taking and evaluating family histories, interpreting the results of genetic testing, providing genetics/genomics education to patients and referring them to the appropriate oncogenetic resources (Houwink et al., 2014; Secretary's Advisory Committee on Genetics Health and Society [SACGHS], 2011). Nurses, as the most numerous group of professionals in the healthcare system, play a crucial role in cancer prevention (Chen et al., 2021; Wood et al., 2013). They have been specifically trained to listen and provide support to patients and have the distinctive knowledge, know-how and professional experience to deliver differentiated care, advice, support and information to individuals at high risk of cancer and their families (Murphy & Chappuis, 2006).

This paper presents the results of a pilot project for a research program designed to enhance the competencies of front-line healthcare professionals, so they can identify and attend to patients with a hereditary risk of cancer. The results will be incorporated into a broader research project currently underway (**C-MOnGene**), the goal of which is to improve the range of oncogenetic services available in Quebec (Lapointe et al., 2021). More specifically, this paper aims to document the knowledge, attitudes and practices of nurses working at a CISSS[1] in Quebec in several different healthcare settings. There are three main objectives: 1) assess nurses' knowledge with regard to oncology and oncogenetics; 2) describe various issues related to their capacity to identify, refer and support individuals with a hereditary risk of cancer; and 3) explore their interest in continuing education on this topic.

1 CISSSs (*centres intégré de santé et de services sociaux* or integrated health and social services centres) are facilities created as a result of the amalgamation of all public institutions in a given health and social services region, or part of a region, with the health and social services agency, as the case may be (sections 3 et 4 *Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies*) (Ministère de la Santé et des Services sociaux [MSSS], 2017).

METHODOLOGY

Research design and procedures

An exploratory descriptive research design (Gray, 2017) was selected for this study. A cross-sectional questionnaire-based survey was conducted among nurses working with cancer patients. A purposive sample was drawn with the support of targeted CISSS managers working in nursing care (NC), oncology/palliative and end-of-life care (PELC) and support for the autonomy of seniors (SAS), who helped identify key individuals within their respective teams. The individuals thus identified were asked to draw up lists of potentially eligible participants for the study for each of the healthcare settings involved. Inclusion criteria were as follows: a) be a nurse working with cancer patients; b) work in a hospital centre (CH), family medicine group (GMF), long-term care facility (CHSLD), local community service centre (CLSC) or palliative care facility (MSP); c) work in one of the five sectors of the CISSS. This study was approved by the research ethics committee of the CISSS (2018-490).

Data collection

An initial email was sent to the nurses on these lists by the managers of the concerned programs, inviting them to take part in the study. It contained a SurveyMonkey link to a short questionnaire with 33 questions, most of which were closed-ended (Appendix I). Respondents were first asked to fill out a short sociodemographic profile. The themes addressed in the body of the questionnaire were 1) knowledge of heredity and cancer; 2) past experience in identifying people at high risk of hereditary cancer; 3) sense of competence in meeting the needs of cancer patients or their families with concerns about their family history or risk of hereditary cancer; 4) role of the nurse with regard to oncogenetics in their clinical practice; 5) perception of professional responsibility in identifying and managing cases where there is a hereditary risk of cancer; and 6) interest in continuing education regarding the issues related to family histories of cancer and suggestions for the development of information tools and materials about oncogenetics. Given the dearth of literature concerning the knowledge, competencies and professional practices of nurses in oncogenetics, the questions were specifically developed by the research team on the basis of previous research studies focusing on healthcare professionals (Cléophat et al., 2020; Gonthier et al., 2018). In an effort to ensure a maximum number of respondents, three email reminders were sent by managers over a six-week period. A total of 151 invitations were emailed to the five sectors of the CISSS in question. This corresponds to the population of nurses likely to be in contact with cancer patients. Data collection took place in April and May 2018.

Analysis of the data

Descriptive analyses (means and proportions) were carried out for the sociodemographic characteristics and respondents' answers to the various questions in the survey and documented in an Excel spreadsheet. These analyses revolved around the themes addressed in the questionnaire, namely the participating nurses' knowledge and sense of competence with regard to oncogenetics, issues related to identifying

individuals with a hereditary risk of cancer, and the development and improvement of respondents' competencies in oncogenetics. Given the limited size of the sample, no subgroup comparisons were performed.

RESULTS

Participants

The sample consisted of 40 participants (rate of participation = 26%): 36 female nurses and four male nurses ranging in age between 24 and 60 years, with a median age of 38. Most of the respondents worked in a CH or an GMF. More than half had less than five years of experience in their current job. The average time per week spent working with cancer patients was 16 hours. Table 1 presents a detailed description of the participants.

Table 1

Socioprofessional Characteristics of Participants

	Characteristics	Number (*n*)	Percentage (%)
Gender	Women	36	90
	Men	4	10
Age	20–30 years	5	13
	31–40 years	16	41
	41–50 years	13	33
	51+ years	5	13
Years of experience for current position	1–5 years	21	53
	6–10 years	7	17
	11+ years	12	30
Hours/week worked with cancer patients	0–10 hours	20	50
	11–20 hours	2	5
	21–30 hours	4	10
	31+ hours	12	30
	Don't know/varies	2	5
Healthcare facility	Hospital centre (CH)	15	36
	Local community service centre (CLSC)	7	17
	Family medicine group (GMF)	15	36
	Long-term care facility (CHSLD)	1	2
	Palliative care facility (MSP)	4	9

Four observations, which fall under three main themes, emerged from the analysis of the data: 1) nurses lack knowledge of and sense of competence in oncogenetics; 2) discussions concerning a family history of cancer are generally held at the patient's prompting; 3) nurses feel they have an important role to play in oncogenetics; and 4) not enough training in oncogenetics is being done.

Observation 1: Nurses lack knowledge of and sense of competence in oncogenetics

A total of 71% of the nurses who answered the survey said their understanding of the role of heredity in the development of cancer was fair to non-existent. None qualified their level of knowledge as very good or excellent. More than half (56%) overestimated the influence of heredity on cancer susceptibility, responding that more than 10% of all cancers are hereditary. Similarly, 45% erroneously believed that genetic testing could be used to identify a hereditary risk for developing cervical cancer. A greater number of respondents were aware of the existence of genetic testing for predisposition for breast cancer (89%) than those who knew testing was available for ovarian cancer (58%) and colorectal cancer (45%). A lower percentage were familiar with genetic testing for prostate cancer (24%) and pancreatic cancer (3%). A majority of the participating nurses were able to identify the important pieces of data to collect when taking a family history, with the exception of the age of death of family members with cancer (Figure 1).

Most of the nurses in the study (82%) deemed it essential to evaluate the family health history on the paternal side when cancer is diagnosed on the maternal side (or vice versa). Similarly, a majority (61%) felt it was relevant to go back three generations when investigating a family history. About half (53%) considered, and rightly so, that patients with a hereditary form of cancer tend to be at a higher risk of developing another type of cancer and that hereditary cancers often occur at a younger age (55%). Moreover, although they believed that a carrier of a genetic mutation will not necessarily develop cancer in their lifetime (74%), many were of the opinion that the mutation can skip a generation (61%).

The respondents (84%) did not feel qualified to sufficiently address the concerns of cancer patients and their families with respect to their family history of cancer and the associated risks. Many (79%) specifically mentioned not having the skill sets necessary to recognize significant aspects of a family's cancer history, i.e., those that would suggest an increased risk of cancer within the patient's family members. In addition, 40% said they did not have access to resources they could turn to for help, if needed, to discuss the risks of cancer related to the family history with patients or family members. Many tend to refer patients and families to other healthcare professionals who are better equipped to answer these questions (oncology nurse navigator, oncologist/hematologist, geneticist, family physician, pharmacist, etc.). However, the nurses felt it was essential when working with cancer patients to have the necessary knowledge and competencies to discuss the matter with patients and their families (Figure 2).

Observation 2: Discussions concerning a family history of cancer are generally held at the patient's prompting

Fewer than half of the survey respondents (42%) said they were the ones to initiate discussions about family history with cancer patients or their families. They generally do so after being asked about it by the patient (68%) or a family member (47%). Less frequently, it is in response to a referral from another professional (18%). The topics that tend to be asked about are listed in Figure 3.

Although the nurses were not generally the ones to initiate discussions about a history of cancer in the family, 58% felt it was essential for the topic to be brought up with cancer patients and their families. Some 63% of the respondents felt that addressing these questions with patients or their families could easily be incorporated into their routine follow-up.

Observation 3: Nurses feel they have an important role to play in oncogenetics

The majority of the nurses surveyed considered that their role in oncogenetics is essential in that they 1) are someone cancer patients can talk to (97%); 2) support patients in their thought process about their cancer and family history (86%); 3) help families by referring them to the appropriate resources (92%); 4) empower patients, specifically by discussing the possibility that their situation might help prevent other family members from developing the disease (81%); 5) help manage family disagreements that may arise, especially those concerning the desire to know or not know more about their family health history (65%); and 6) facilitate discussions between cancer patients and members of their family by serving as a go-between or by organizing family meetings (55%). Moreover, although the respondents indicated that they seldom bring up the possibility of genetic testing, many of them (77%) felt they should assume this role. Regarding their professional duties, although they said the questions concerning previous cases of cancer in the family can be brought up at any point in the care trajectory (89%), some (34%) raised the idea that these matters should not be discussed unless they might actually benefit cancer patients or their families (Figure 4).

Figure 1

Information to Collect When Taking a Family History

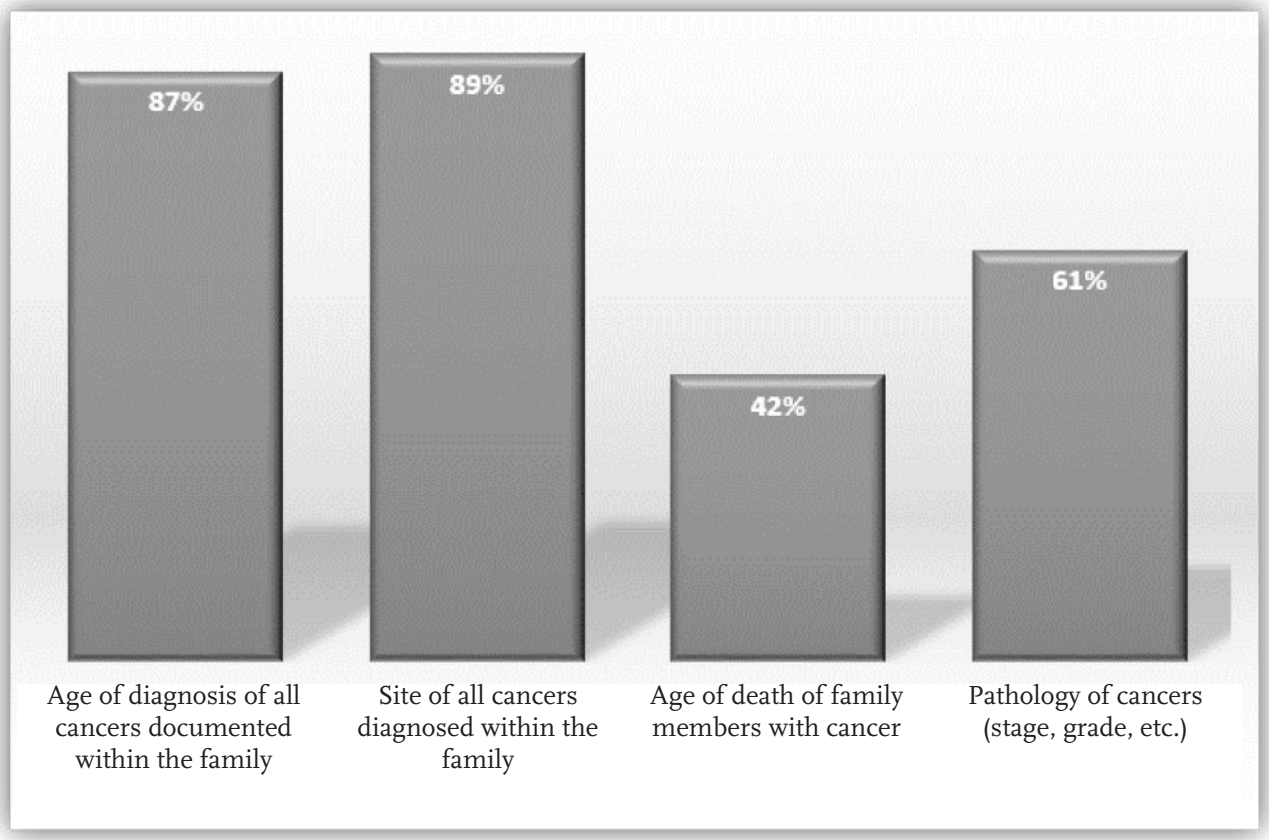


Figure 2

Knowledge and Competencies of Nurses in Oncology Settings

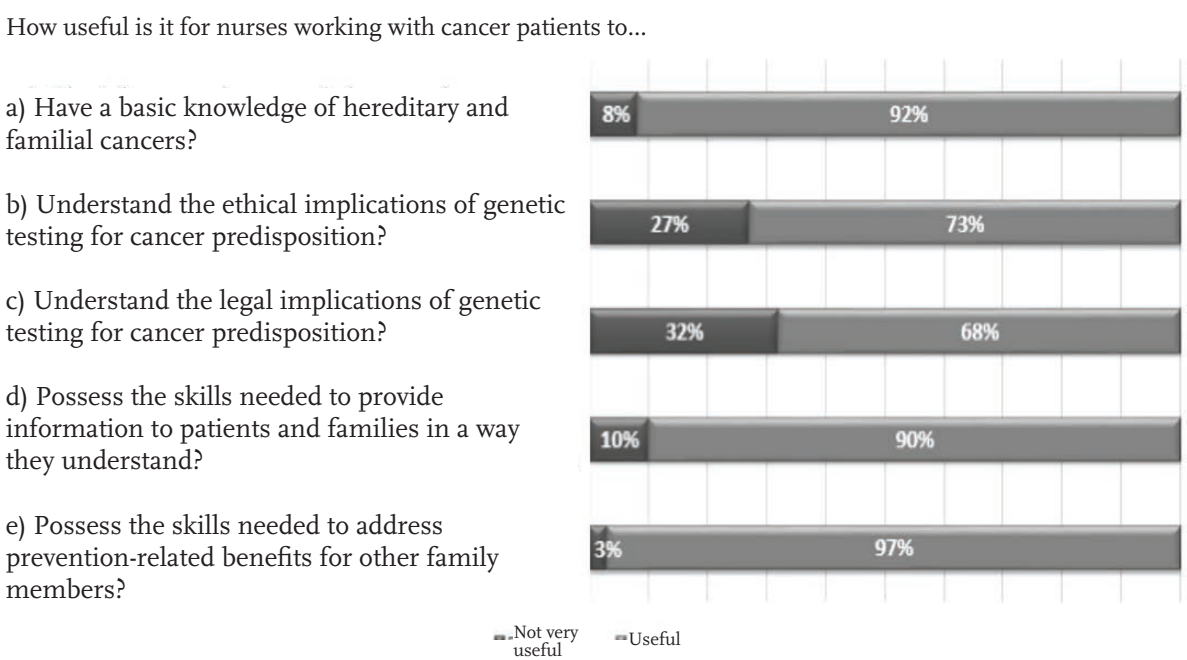


Figure 3

Topics of Discussion Related to Family History

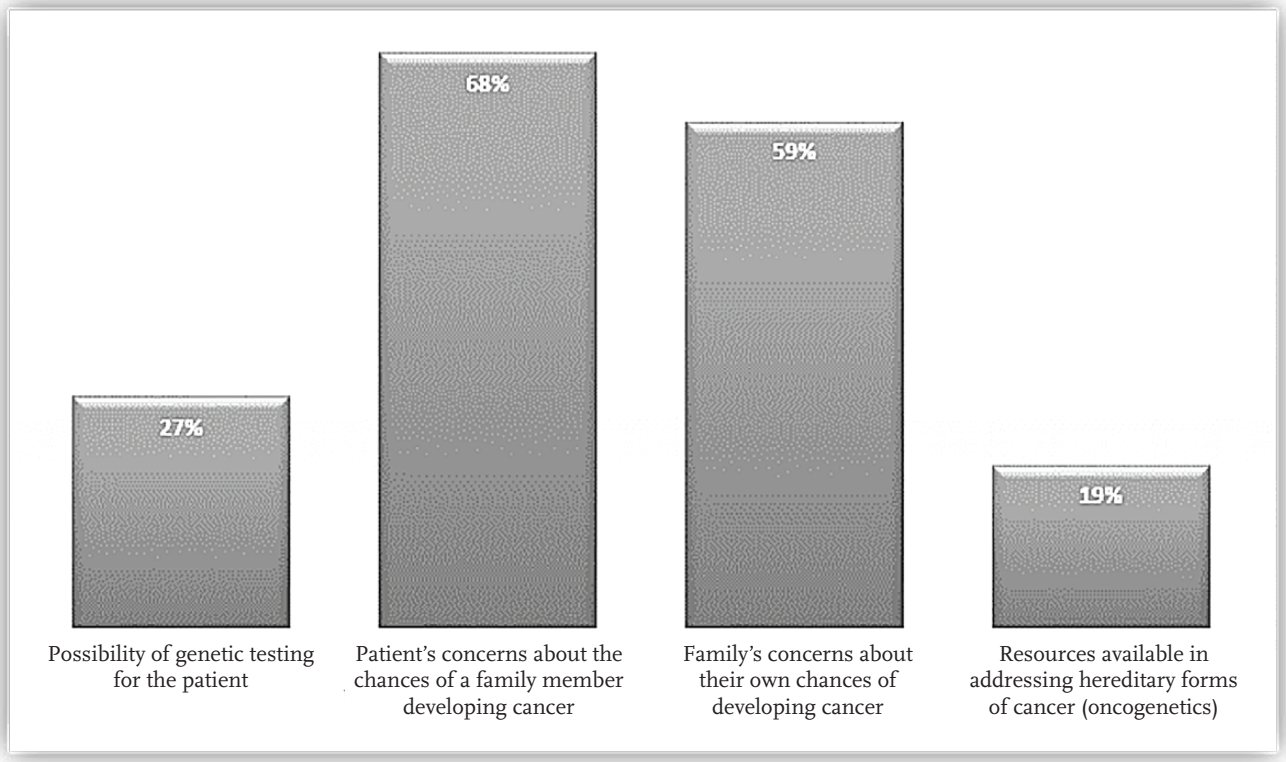
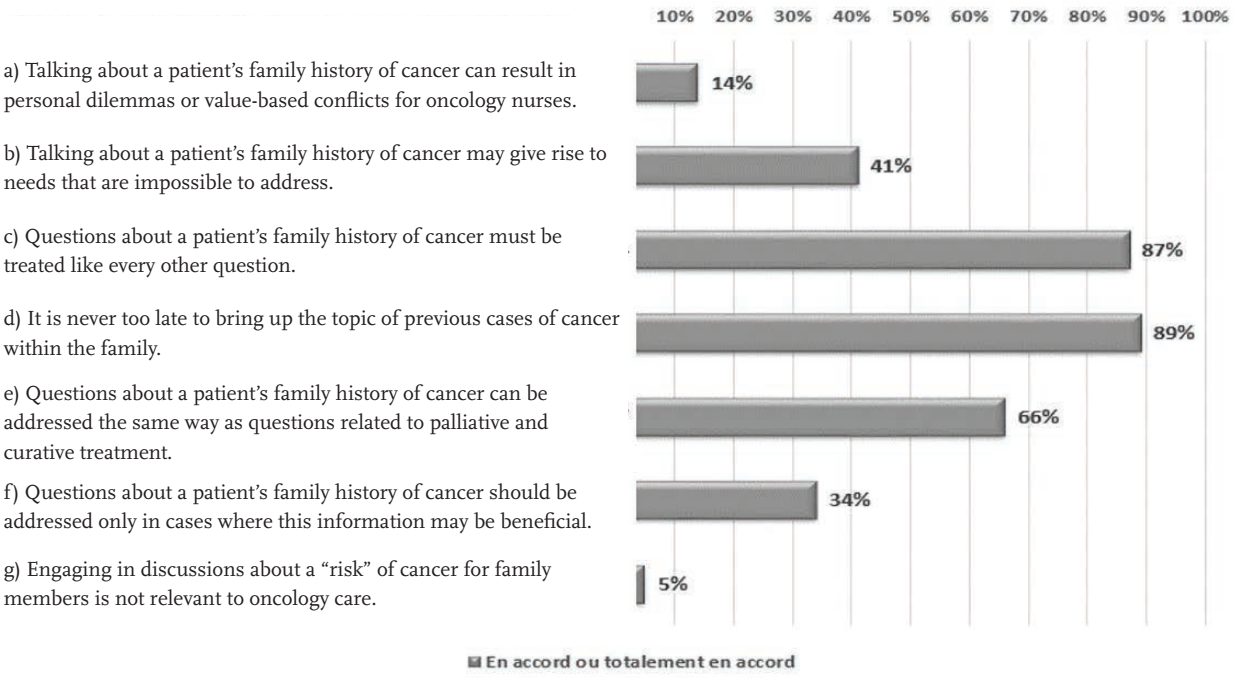


Figure 4

Professional Duties of Nurses Related to Oncogenetics



Observation 4: Not enough training in oncogenetics is being done

There are precious few continuing education programs, courses in university curricula and conferences on hereditary and familial cancers available to nurses who work with cancer patients. In all, 95% of the nurses surveyed indicated they had not been informed of the existence of activities of this nature or been given the opportunity to attend. Yet, 77% of them felt it was paramount to have access to this type of content in their academic studies and to be able to stay current on the latest information on familial and hereditary cancers. When asked about their areas of interest for ongoing training, more than 90% identified hereditary forms of cancer and family prevention. This was followed by techniques for conducting family histories and the ethical and legal issues of genetic testing for cancer predisposition, at 76% and 66% respectively. Some 61% of the nurses surveyed indicated that they would be interested in learning more about hereditary and familial cancers, although the results point to a preference for flexible formats that can be easily integrated into their schedule, namely videoconferences (55%), webinars (47%), and websites (45%). More traditional paper-based methods (brochures, booklets, etc.) were a less popular choice (34%).

DISCUSSION

The goals of this study were to assess how familiar the nurses working with cancer patients at a CISSS in Quebec were with oncogenetics, to describe the issues related to their capacity to identify, refer and support individuals with a hereditary risk of cancer and to explore their interest in continuing education in this regard.

The results show that the nurses working in oncology settings did not feel they had the knowledge required to fully grasp the role of heredity in the development of certain types of cancer. This lack of knowledge stands to undermine their confidence and influence their sense of competence in assessing cancer risks based on family history and addressing the concerns of patients and their families. Some authors have suggested that the rapid expansion of knowledge about oncogenetics in recent years (Chen et al., 2018; Talwar et al., 2017), and the lack of training specifically related to this field of practice in nursing programs (Carroll et al., 2009; Farndon & Bennett, 2008; Sussner et al., 2011; Talwar et al., 2017) contribute to this knowledge deficit among nurses in oncology settings. As a result, they may feel ill-equipped to answer questions put to them by individuals who are concerned about a possible hereditary predisposition to cancer and, therefore, reluctant to initiate discussions in this regard. The results of this study indicate that questions involving family history and the associated cancer risks tend to come from cancer patients themselves. Although the nurses surveyed felt that addressing these questions is essential, our data suggest that their involvement in these discussions and in supporting patients and their families in this regard is underutilized. Yet, identifying people who could benefit from oncogenetic services constitutes a nursing competency (Gaff, 2005). A number of authors also posit that nurses are in the best position to identify high-risk families among those who are affected by a hereditary

predisposition, but who are categorized as low or moderate risk (Allen, et al., 2016; Calzone et al., 2010; Chen et al., 2018, 2021). Nurses can also raise awareness among cancer patients and their families about the importance of documenting family histories of cancer, identifying the appropriate genetic services and encouraging high-risk individuals to consult these resources. Cooley (2014) considers it essential for nurses to be involved in developing oncogenetic knowledge in order to improve their competencies in this field and strengthen their capacity to identify, assess and refer high-risk patients and families.

Although discussions on genetic testing make it easier to identify and assess individuals at high risk for cancer (Brennan & Wild, 2015; Chen et al., 2021; Stadler et al., 2014), the results of this study show that the participating nurses seldom addressed this issue with cancer patients and their families. They, nevertheless, tended to believe it was their role to initiate discussions about family history and refer patients to the appropriate resources when required. In reality, it would seem the nurses were more likely to immediately refer patients and their families to other healthcare professionals who they deemed better qualified to tackle the issue of a family history of cancer. It is important to point out that documenting a patient's family history is the first step in assessing cancer risk and determining whether testing for genetic predisposition is warranted. Other authors have argued that the lack of knowledge about hereditary cancers, the downplaying of the potential of family histories and the uncertainty concerning the usefulness and clinical validity of genetic information can deter some healthcare professionals, nurses chief among them, from incorporating these elements into their practice (Chow-White et al., 2017; Wood et al., 2013). In a study by Cléophat et al. (2020), nurses showed a strong interest in adding a genetic counsellor to their team and having access to clear guidelines to make the family history-taking process easier and facilitate discussions concerning the hereditary component of cancer. That being said, these discussions can often be a source of anxiety and family conflict, making it necessary for nurses to make time and support available to patients and their families (Lapointe et al., 2013; Wood et al., 2013). In this sense, although some studies have shown that sharing genetic information can have positive effects, especially from a prevention standpoint (Lafrenière et al., 2013), others reveal that it can lead to increased family tensions, particularly in cases where a tested individual refuses to disclose their genetic results to other family members or when there is a lack of consensus among family members about whether or not this genetic information should be disclosed or followed up on with hereditary cancer predisposition testing (Lafrenière et al., 2013; Lapointe et al., 2013).

Even though a majority of the respondents felt that the questions concerning family histories of cancer can be brought up at any point during the cancer care trajectory, some said they were worried that doing so might create needs among cancer patients and their families that they, as nurses, would not be able to meet, especially needs of a psychological nature. In this regard, several authors note the limited capacity of some professionals to adequately convey the implications of hereditary risks (Cléophat et al., 2020; Hallowell et al., 2005; Sperber et al., 2017; Talwar et al., 2017), their worry about the potential psychological impacts on patients (guilt, concern, fear, sadness, anger) (Allen et al., 2016; Cléophat et al., 2020; Tercyak et al., 2010), and their lack of time to meet patients' needs in terms of support (Eberl et al., 2005; Lu et al., 2014) as factors that may deter them from evaluating a family history. The nurses who participated in this study felt that these questions should not be addressed unless there was a possibility of a tangible benefit for cancer patients and their families. This is consistent with NICE recommendations (2013) on appropriate treatment and care, which stipulate that discussions about family history should take place only when the benefits outweigh the risks. These discussions are more welcome when preventive and therapeutic options are readily available (Green et al., 2013; Valdez, et al., 2010). The nurses in this study also mentioned that being knowledgeable about existing specialized resources in oncogenetics and having access to these resources were essential to incorporating discussions about family histories of cancer into their clinical practices. This corroborates the findings of the study conducted by Cléophat et al. (2020), which assert that this knowledge is an important lever in initiating discussions about previous cases of cancer within the family. However, the cancer risk assessment should be optimized by an interdisciplinary team, comprised of oncology professionals and genetics experts, including genetic counsellors, medical geneticists, surgeons, oncologists, social workers, oncology nurses and psychologists (Berliner & Fay, 2007; Murphy & Chappuis, 2006; NICE, 2013).

Although oncology nurses consider genetics to be an important part of their practice (Calzone et al., 2010), the results of this study contend that their access to academic and continuing education in this topic is limited. Because genetics is a rapidly changing field, it is essential that healthcare professionals working with cancer patients be able to refresh their knowledge and skills on an ongoing basis (Talwar et al., 2017). Accordingly, several studies show that having access to continuing education with a focus on skills development helps improve assessments and referrals for patients at a high risk of developing cancer (Chen et al., 2018, 2021; Gaff, 2005; Talwar et al., 2017). For example, the study conducted by Chen et al. (2018) on healthcare professionals who were not specialized in genetics, revealed that, within three months of taking a course on family cancer histories, participants were more inclined to evaluate family histories and make recommendations for genetic predisposition testing. Similarly, a study by Gaff (2005) reported that oncology nurses who had attended a workshop on cancer genetics indicated that it was very useful and applicable to their work, specifically because it made them feel more confident in identifying individuals potentially at risk for a hereditary form of cancer. However, to be able to address family concerns and manage issues related to a family history of cancer, nurses should have access to training in cancer genetics as well as the ethical, legal and psychosocial impacts of hereditary cancers (Cléophat et al., 2020). The results of this study suggest that nurses are interested

in continuing education on hereditary and familial cancers, especially those with a flexible delivery format that can be easily worked into their schedule. These findings are consistent with those of Chen et al. (2018), which demonstrated that condensed, intensive training programs with a learning approach adapted to participants' professional realities make them easier to access and enjoy higher attendance.

Strengths and limitations

This study provides preliminary data on the knowledge, attitudes and practices in oncogenetics of nurses working with cancer patients in a CISSS in Quebec. Despite the innovative focus of the research (in that, to date, there have been very few studies documenting the issues related to nurses' capacity to discuss family histories and to identify, refer and support patients with a hereditary risk of cancer), there are certain limitations that should be considered. First and foremost, the study was undertaken with the goal of exploring a topic for which there are no pre-existing validated measures. The validity and reliability of the questionnaire used in this study are uncertain. Adjustments made based on the comments and recommendations compiled during the pre-test nevertheless provided an acceptable level of face validity. Statistical analyses aimed at comparing certain subgroups had initially been planned, but in the end, these were not feasible given the small sample size. It was, therefore, impossible to compare nurses' knowledge, experiences, perceptions and interests based on their sociodemographic and professional characteristics. Finally, although the data collected allow for a better representation of the competencies and knowledge of oncology nurses, the generalizability and transferability of the results remain limited, even though consistency with the scientific literature suggests a certain plausibility.

CONCLUSION

This study shows that many nurses working with cancer patients have to deal with patients' and family members' concerns about previous cases of cancer in their family. Although a number of the respondents considered these conversations to be essential, they were generally reluctant to initiate them, which can be explained by a lack of knowledge, competency, confidence and support with regard to broaching the topic of family history with patients and their loved ones. Yet, nurses, being at the front line of health promotion and disease prevention and having specialized care and support skills, play a predominant role in the initial assessments of individuals at risk of cancer. Not only is family history-taking necessary in conducting these assessments, but the information provided to cancer patients can also be extremely helpful to other family members and have a direct impact on them. However, these discussions must be supported by solid oncogenetic knowledge and competencies, which are currently lacking among nursing staff. Continued education about hereditary cancers (including the related psychological aspects) and the development of specific tools, guidelines and information materials related to oncogenetics would strengthen nurses' capacity to assess individuals and families who are at risk. This would also allow nurses to address concerns about family histories more efficiently and refer patients and families to specialized resources. Incorporating these considerations into the **C-MOnGene** project could help optimize the delivery of oncogenetic services in Quebec, especially in non-specialized healthcare facilities and in remote communities.

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CONFLICTS OF INTEREST

The authors report no potential conflicts of interest in the research, writing and/or publication of this paper and declare that they are the sole owners of all rights to this original work, entitled "Issues associated with a hereditary risk of cancer: Knowledge, attitudes and practices of nurses in oncology settings." The authors agree to assign all rights to CANO/ACIO for publication in the Canadian Oncology Nursing Journal.

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Appendix 1

QUESTIONNAIRE POUR LES INFIRMIÈRES ET INFIRMIERS EN ONCOLOGIE

EXPERIENCES D'INFIRMIERES TRAVAILLANT AUPRES DE PERSONNES ATTEINTES DE CANCER

MISE EN CONTEXTE ET CONSENTEMENT

Avant de donner votre consentement pour participer à cette étude, veuillez prendre le temps de lire, comprendre et considérer attentivement les renseignements suivants. Nous vous invitons à poser toutes les questions que vous jugerez utiles aux responsables de ce projet. Tout mot ou renseignement qui n'est pas clair vous sera expliqué.

1. **Chercheur responsable**
   Dr Michel Dorval : chercheur, Centre de recherche du CISSS de Chaudière-Appalaches; professeur titulaire, Faculté de pharmacie, Université Laval, Michel.Dorval@pha.ulaval.ca, 418-682-8047
2. **Organisme subventionnaire** : Fondation de l'Hôtel-Dieu de Lévis (CISSS de Chaudière-Appalaches)
3. **Contexte de l'étude et objectifs**
   Cette étude vise deux objectifs : 1) évaluer les connaissances des infirmières en oncologie du CISSS-CA concernant les cancers héréditaires, et 2) décrire les enjeux reliés à la capacité d'identifier et de référer des patients présentant un risque héréditaire de cancer dans la région de Chaudière-Appalaches.
4. **Nature et durée de votre participation**
   Votre participation consiste à compléter ce questionnaire, à une seule reprise, ce qui vous prendra environ 20 minutes.
5. **Risques et bénéfices**
   L'étude ne comporte aucun risque physique pour vous, ni aucun coût. Toutefois, il est possible que certains thèmes puissent susciter un malaise ou un inconfort chez vous. Le cas échéant, vous êtes tout à fait libre de ne pas répondre à certaines questions. Votre participation à cette étude contribuera à la mise en place d'une formation visant l'amélioration des compétences des infirmières de première ligne à identifier et à prendre en charge la clientèle présentant un risque héréditaire de cancer.
6. **Confidentialité**
   Ce questionnaire ne recueille aucune donnée nominale ni renseignement personnel qui pourrait permettre de vous identifier. L'accès à l'identité des participants est impossible pour qui que ce soit, même pour les membres de l'équipe de recherche. Afin de préserver votre anonymat, aucune rétroaction avec les gestionnaires du CISSS-CA sera réalisée à propos du taux de participation par secteur ou service.
   Ce questionnaire vous est soumis par l'intermédiaire d'une entreprise basée aux États-Unis qui gère un outil internet de sondage en ligne, Survey Monkey. Veuillez noter que l'accès aux données est assujetti aux lois d'accès à l'information du pays où se situe l'entreprise mentionnée. Une copie des données sera conservée sur les serveurs de cette entreprise. Les garanties de confidentialité sont expliquées à cette adresse : http://fr.surveymonkey.com/mp/policy/privacy-policy

Projet Hérédité-Cancer *: Évaluation des connaissances des infirmières en oncologie du CISSS-CA en matière d'oncogénétique et enjeux reliés à l'identification des patients présentant un risque héréditaire de cancer dans la région de Chaudière-Appalaches.*

7. **Conservation des données**
   Les données seront conservées sur les serveurs de Survey Monkey pour une durée d'un an. Par la suite, l'équipe de recherche s'assurera de les effacer en procédant à la fermeture du compte associé à cette étude. Pour fins d'analyse, les données seront alors copiées sur un disque externe et conservées sous clé dans un classeur appartenant au chercheur principal du projet au Centre de recherche du CISSS-CA. Les données seront ainsi conservées pour une durée de cinq ans, après la fin du recrutement des participants, et seront détruites par la suite dans le respect des règles en vigueur. Les résultats du questionnaire ne seront accessibles qu'à la coordonnatrice de l'étude et au chercheur principal. Advenant le cas d'utilisation ultérieure des renseignements recueillis dans le cadre de cette étude, les analyses seraient réalisées à partir de la base de données anonyme.
8. **Compensation**
   À titre de compensation pour votre participation à cette étude, le Réseau ROSE offrira aux milieux qui le désirent une formation de 90 minutes sur les cancers héréditaires et familiaux donnant droit à 0,15 unité de formation continue aux infirmières qui y assisteront.
9. **Participation volontaire et droit de retrait**
   Votre participation à cette étude est volontaire. Vous êtes libre de refuser d'y participer, en ne répondant pas à ce questionnaire. Il n'y a pas de possibilité de se retirer de l'étude une fois que vos réponses ont été soumises car il est impossible de retracer vos réponses puisqu'aucune donnée nominative n'est demandée sur le questionnaire. En aucun cas, le consentement de participer à la recherche implique que vous renoncez à vos droits légaux ni ne décharge les chercheurs, les promoteurs ou les institutions impliquées de leurs responsabilités légales et professionnelles.
10. **Personne ressource**
    Si vous avez des questions concernant cette étude, vous pouvez communiquer avec la coordonnatrice de recherche, Mme Anne-Marie_Veillette@ugar.ca, 481-833-8800 poste 3315.
11. **Comité d'éthique de la recherche**
    Le comité d'éthique de la recherche du CISSS de Chaudière-Appalaches a approuvé ce projet de recherche et en assurera le suivi (#2018-490). Pour toute information, vous pouvez joindre Jenny Keading, coordonnatrice du Comité d'éthique de la recherche, ou son représentant, au 418-835-7121 poste 1256.
12. **Consentement**
    J'ai pris connaissance des informations ci-dessus et j'en comprends le contenu. De ce fait, ma participation à ce questionnaire est volontaire et je consens à ce que mes réponses soient utilisées pour les fins de ce projet de recherche.

    J'accepte de participer :

    ☐ Oui (donne accès au questionnaire)
    ☐ Non (une fenêtre apparaît pour remercier de l'attention portée)

PARTIE 1 : VOTRE SITUATION PERSONNELLE

1. **Dans quel(s) secteur(s) du CISSS de Chaudière-Appalaches travaillez-vous :**
   (Cochez toutes les réponses qui s'appliquent)
   ☐ Alphonse-Desjardins
   ☐ Beauce
   ☐ Etchemins
   ☐ Montmagny-L'Islet
   ☐ Thetford Mines
2. **Vous êtes…**
   ☐ Un homme ☐ Une femme
3. **Veuillez indiquer votre âge : _____ ans**
4. **Veuillez indiquer le nombre d'années d'expérience dans votre poste actuel : _____ ans**
5. **Présentement, dans quel(s) milieu(x) de soins exercez-vous?**
   (Cochez toutes les réponses qui s'appliquent)
   ☐ Hôpital (clinique externe, oncologie ambulatoire)
   ☐ Hôpital (unités de soins)
   ☐ Hôpital (unité de soins palliatifs)
   ☐ CHSLD
   ☐ CLSC (soutien à domicile)
   ☐ GMF
   ☐ Maison de soins palliatifs
   ☐ Autre (veuillez préciser) _____
6. **Combien d'heures par semaine travaillez-vous en moyenne, auprès de personnes atteintes de cancer : _____ heures**

QUESTIONNAIRE PROJET HÉRÉDITÉ-CANCER

PARTIE 2 : VOS CONNAISSANCES EN MATIÈRE D'HÉRÉDITÉ ET DE CANCER

7. **Comment qualifieriez-vous votre niveau de connaissance en lien avec le rôle de l'hérédité dans le développement des cancers?**
   ☐ Nul
   ☐ Passable
   ☐ Bon
   ☐ Très bon
   ☐ Excellent
   ☐ Je ne sais pas
8. **Selon vous, quel est le pourcentage des cancers qui sont héréditaires?**
   ☐ Moins de 5%
   ☐ 5% à 10%
   ☐ 11% à 30%
   ☐ 31% à 50%
   ☐ Plus de 50%
   ☐ Je ne sais pas
9. **Selon vous, parmi ces cancers, pour lesquels est-il possible d'offrir un test génétique afin de déterminer s'il est héréditaire ou non? *(Cochez toutes les réponses qui s'appliquent)***

☐ Sein	☐ Prostate	☐ Vessie
☐ Ovaire	☐ Mélanome	☐ Lymphome
☐ Col de l'utérus	☐ Foie	☐ Os
☐ Cancers ORL (bouche, larynx)	☐ Estomac	☐ Aucun
☐ Poumon	☐ Pancréas	
	☐ Colorectal	

10. **Selon vous, quels sont les éléments importants à recueillir lors de la compilation de l'histoire familiale afin d'évaluer le risque de cancer héréditaire?**
    (Cochez toutes les réponses qui s'appliquent)
    ☐ Âge au diagnostic de tous les cancers répertoriés dans la famille
    ☐ Site de tous les cancers diagnostiqués dans la famille
    ☐ Âge au décès des personnes atteintes de cancer dans la famille
    ☐ Pathologie des cancers diagnostiqués (stade, grade, etc.)
    ☐ Autre(s), veuillez spécifier : _____ ☐ Je ne sais pas

11. Veuillez indiquer si ces affirmations sont « vraies » ou « fausses » selon vous :

	Vrai	Faux	Je ne sais pas
a) Lors de la compilation de l'histoire familiale de cancer, il est inutile d'évaluer l'histoire familiale du côté paternel lorsque le cancer est diagnostiqué du côté maternel (ou vice-versa).	☐	☐	☐
b) Lors de la compilation de l'histoire familiale de cancer, il est pertinent d'investiguer les antécédents familiaux sur trois générations.	☐	☐	☐
c) Les individus qui ont un cancer héréditaire sont généralement plus à risque de développer un autre type de cancer.	☐	☐	☐
d) Dans une famille où une mutation génétique est identifiée, une personne porteuse de la mutation développera nécessairement un cancer au cours de sa vie.	☐	☐	☐
e) Une mutation génétique peut sauter une génération.	☐	☐	☐
f) Les cancers héréditaires surviennent généralement à un plus jeune âge.	☐	☐	☐

PARTIE 3 : VOS EXPÉRIENCES ANTÉRIEURES

12. Au cours de la dernière année, à quelle fréquence avez-vous eu à discuter des préoccupations de patients ou de la famille concernant les antécédents familiaux de cancer…

	Jamais	1-2 fois	3-5 fois	6-10 fois	Plus de 10 fois	Je ne sais pas
a) …à la demande d'un patient?	☐	☐	☐	☐	☐	☐
b) …à la demande d'un membre de la famille?	☐	☐	☐	☐	☐	☐
c) …de votre propre initiative?	☐	☐	☐	☐	☐	☐
d) …sur recommandation d'un autre intervenant?	☐	☐	☐	☐	☐	☐

13. Quel était l'objet des discussions? (*Cochez toutes les réponses qui s'appliquent*)

- ☐ Possibilité de procéder à un test génétique chez le patient
- ☐ Préoccupations du patient face au risque de cancer des membres de sa famille
- ☐ Préoccupations des membres de la famille face à leur propre risque de cancer
- ☐ Ressources disponibles concernant les cancers héréditaires (oncogénétique)
- ☐ Autre, veuillez spécifier : _____
- ☐ Non applicable

14. Selon vous, dans quelle mesure est-il <u>pertinent</u> d'aborder des questions concernant les antécédents familiaux de cancer avec vos patients ou les membres de leur famille?

Pas du tout pertinent	Peu pertinent	Moyennement pertinent	Pertinent	Très pertinent	Je ne sais pas
☐	☐	☐	☐	☐	☐

15. Selon vous, dans quelle mesure est-il <u>réalisable</u> d'aborder des questions concernant les antécédents familiaux de cancer avec vos patients ou les membres de leur famille?

Pas du tout réalisable	Peu réalisable	Moyennement réalisable	Réalisable	Très réalisable	Je ne sais pas
☐	☐	☐	☐	☐	☐

PARTIE 4 : VOTRE SENTIMENT DE COMPÉTENCE

16. Vous vous sentez <u>confiante</u> pour répondre correctement aux préoccupations des patients ou de leur famille à propos de leur histoire familiale de cancer et des risques associés…

Pas du tout confiante	Peu confiante	Moyennement confiante	Confiante	Très confiante	Non applicable
☐	☐	☐	☐	☐	☐

17. Vous vous sentez <u>compétente</u> pour reconnaître les signes d'une histoire familiale de cancer significative, c'est-à-dire pouvant suggérer un risque accru de cancer chez les membres de la famille.

Pas du tout compétente	Peu compétente	Moyennement compétente	Compétente	Très compétente	Non applicable
☐	☐	☐	☐	☐	☐

18. Avez-vous accès à des ressources qui pourraient vous aider, si besoin, à discuter de risque de cancer lié à l'histoire familiale avec un patient ou un membre de sa famille?

- ☐ Non
- ☐ Je ne sais pas
- ☐ Oui, veuillez préciser lesquelles : _____

19. Vers quelle(s) ressource(s) dirigeriez-vous un membre de la famille qui s'interroge sur son risque de cancer en lien avec son histoire familiale?

_____

_____

_____

20. Dans quelle mesure trouvez-vous <u>pertinent</u> que les infirmières travaillant auprès de patients atteints du cancer…

	Pas du tout pertinent	Peu pertinent	Moyenne-ment pertinent	Pertinent	Très pertinent
a) …aient des connaissances de base sur les cancers héréditaires et familiaux?	☐	☐	☐	☐	☐
b) …aient des connaissances sur les implications éthiques des tests génétiques de prédisposition au cancer?	☐	☐	☐	☐	☐
c) …aient des connaissances sur les implications légales des tests génétiques de prédisposition au cancer?	☐	☐	☐	☐	☐
d) …aient les compétences pour informer les patients et les familles de façon adaptée?	☐	☐	☐	☐	☐
e) …aient les compétences pour parler des avantages en matière de prévention pour les proches?	☐	☐	☐	☐	☐

21. Parmi ces connaissances ou compétences, quelles seraient à votre avis les deux plus importantes à développer chez les infirmières travaillant auprès de patients atteints de cancer?
(Veuillez les indiquer par ordre d'importance, le premier choix étant le plus important)

1 = Connaissances de base sur les cancers héréditaires et familiaux

2 = Connaissances sur les implications éthiques

3 = Connaissances sur les implications légales

4 = Être capable d'informer les patients et les familles de façon adaptée

5 = Être capable de parler des avantages en matière de prévention pour les proches

99 = Je ne sais pas

Premier choix : _____

Deuxième choix : _____

22. Voyez-vous d'autres connaissances ou compétences pertinentes à développer chez les infirmières travaillant auprès de patients atteints de cancer?

_____

_____

_____

PARTIE 5 : RÔLE DE L'INFIRMIÈRE EN LIEN AVEC L'ONCOGÉNÉTIQUE

23. Dans quelle mesure trouvez-vous pertinent que les infirmières travaillant auprès de patients atteints de cancer…

	Pas du tout pertinent	Peu pertinent	Moyenne-ment pertinent	Pertinent	Très pertinent
a) … soient à l'écoute du patient qui soulève des questions relatives à ses antécédents familiaux de cancer?	☐	☐	☐	☐	☐
b) … accompagnent le patient dans sa réflexion à ce sujet?	☐	☐	☐	☐	☐
c) … favorisent un certain sentiment « d'utilité » chez le patient? (ex. en lui parlant de la possibilité qu'il puisse aider à prévenir la maladie chez ses proches)	☐	☐	☐	☐	☐
d) … gèrent les divergences familiales qui peuvent surgir dans ce type de situations? (ex. certaines personnes pourraient vouloir connaître certaines informations, mais d'autres pas)	☐	☐	☐	☐	☐

23. Dans quelle mesure trouvez-vous pertinent que les infirmières travaillant auprès de patients atteints de cancer…

	Pas du tout pertinent	Peu pertinent	Moyenne-ment pertinent	Pertinent	Très pertinent
e) … facilitent les échanges entre le patient et sa famille? (ex. en servant d'intermédiaire entre eux ou en organisant des rencontres familiales)	☐	☐	☐	☐	☐
f) … soutiennent les familles en les orientant au besoin vers des ressources spécialisées?	☐	☐	☐	☐	☐

24. Parmi ces rôles, quels sont à votre avis les deux plus importants à développer chez les infirmières travaillant auprès de patients atteints de cancer?
(Veuillez les indiquer par ordre d'importance, le premier choix étant le plus important)

1 = Être à l'écoute du patient qui soulève des questions relatives à ses antécédents de cancer

2 = Accompagner le patient dans sa réflexion à ce sujet

3 = Favoriser un certain sentiment d'« utilité » chez le patient

4 = Gérer les divergences familiales qui peuvent surgir dans ce type de situations

5 = Faciliter les échanges entre le patient et sa famille

6 = Soutenir les familles en les orientant au besoin vers des ressources spécialisées

99 = Je ne sais pas

Premier choix : _____

Deuxième choix : _____

25. Voyez-vous d'autres rôles qu'il serait pertinent de développer chez les infirmières travaillant auprès de patients atteints de cancer?

_____

_____

_____

PARTIE 6 : PERCEPTION DE RESPONSABILITÉ PROFESSIONNELLE

26. Selon vous, serait-il approprié qu'une infirmière en oncologie discute de la possibilité de passer un test génétique avec un patient ou un membre de sa famille?

☐ Oui

☐ Non

☐ Je ne sais pas

27. Dans quelle mesure êtes-vous en accord avec les énoncés suivants :

	Pas du tout en accord	Peu en accord	Moyenne-ment en accord	En accord	Totalement en accord
a) Parler des antécédents familiaux de cancer peut entraîner des dilemmes personnels ou des conflits de valeur chez les infirmières en oncologie	☐	☐	☐	☐	☐
b) Parler des antécédents familiaux de cancer risque de susciter des besoins auxquels on ne peut donner suite. (ex. la prise en charge médicale éventuelle des membres de la famille)	☐	☐	☐	☐	☐
c) Les questions concernant les antécédents familiaux de cancer doivent être prises en compte comme n'importe quelle autre demande	☐	☐	☐	☐	☐

27. Dans quelle mesure êtes-vous en accord avec les énoncés suivants :

	Pas du tout en accord	Peu en accord	Moyenne-ment en accord	En accord	Totalement en accord
d) Il n'est jamais trop tard pour aborder le sujet des antécédents familiaux de cancer	☐	☐	☐	☐	☐
e) Les questions concernant les antécédents familiaux de cancer peuvent être abordées de la même façon en soins palliatifs qu'en soins curatifs	☐	☐	☐	☐	☐
f) Les questions concernant les antécédents familiaux de cancer ne devraient être abordées que dans les cas où cela peut avoir des conséquences bénéfiques (ex. il est possible pour les proches de prendre des mesures préventives; il existe un traitement)	☐	☐	☐	☐	☐
g) Soulever des discussions qui concernent un « risque » de cancer pour les proches n'est pas pertinent en oncologie	☐	☐	☐	☐	☐

28. Dans quelle mesure trouvez-vous réaliste d'aborder les questions concernant les antécédents familiaux de cancer avec vos patients ou les membres de leur famille:

	Pas du tout réaliste	Peu réaliste	Moyenne-ment réaliste	Réaliste	Totalement réaliste
a) À l'hôpital (clinique externe, oncologie ambulatoire)	☐	☐	☐	☐	☐
b) À l'hôpital (unité de soins)	☐	☐	☐	☐	☐
c) À l'hôpital (unité de soins palliatifs)	☐	☐	☐	☐	☐
d) En CHSLD	☐	☐	☐	☐	☐
e) Au CLSC (soutien à domicile)	☐	☐	☐	☐	☐
f) En GMF	☐	☐	☐	☐	☐
g) En maison de soins palliatifs	☐	☐	☐	☐	☐

PARTIE 7 : INTÉRÊT POUR LA FORMATION CONTINUE

29. Avez-vous déjà reçu une formation, suivi un cours ou assisté à un congrès sur les cancers familiaux et héréditaires?

☐ Oui ☐ Non

Si oui, veuillez préciser :

Année de la formation : _____

Thèmes de la formation : _____

30. Indiquez dans quelle mesure une mise à jour de vos connaissances sur les cancers familiaux et héréditaires vous serait-elle utile dans votre pratique clinique.

	Pas du tout utile	Peu utile	Moyenne-ment utile	Utile	Très utile
	☐	☐	☐	☐	☐

31. Seriez-vous intéressée par de la formation sur…

	Pas du tout intéressée	Peu intéressée	Moyenne-ment intéressée	Intéressée	Très intéressée
a) Les cancers héréditaires	☐	☐	☐	☐	☐
b) La réalisation de l'histoire familiale	☐	☐	☐	☐	☐
c) Les enjeux éthiques liés aux tests génétiques de prédisposition au cancer	☐	☐	☐	☐	☐
d) Les aspects légaux liés aux tests génétiques de prédisposition au cancer	☐	☐	☐	☐	☐
e) Les possibilités de prévention pour les proches	☐	☐	☐	☐	☐

32. Voyez-vous d'autres sujets sur lesquels vous aimeriez avoir de la formation en lien avec les cancers familiaux et héréditaires?

☐ Oui
☐ Non

Si oui, veuillez préciser lesquels :

_____
_____
_____

33. Quel(s) type(s) de moyens de formation ou d'information préférez-vous?
(Cochez toutes les réponses qui s'appliquent)

☐ Imprimés : dépliants, brochures, etc.
☐ Ligne téléphonique d'information
☐ Site Internet
☐ Application pour appareil mobile
☐ Visioconférence
☐ Webinaire
☐ Formation continue
☐ Autre(s), veuillez préciser : _____

PARTIE 8 : REMERCIEMENTS

Merci de l'attention portée à cette étude!

Les résultats de l'enquête feront l'objet d'un rapport qui sera présenté au CISSS-CA. Des constats sur l'état actuel des connaissances des infirmières en oncologie en matière d'oncogénétique y seront formulés et, le cas échéant, des pistes d'amélioration des compétences dans ce domaine seront proposées.

Qui plus est, le Réseau ROSE offrira aux milieux qui le désirent une formation de 90 minutes sur les cancers héréditaires et familiaux donnant droit à 0,15 unité de formation continue aux infirmières en oncologie qui y assisteront. https://reseaurose.ca/