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Canadian Association of Nurses in Oncology
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EDITORIAL

We have embarked on a pilot initiative

You may have noticed in the April issue of the Canadian Oncology Nursing Journal (CONJ) that there has been a change in our approach to translation within the issue. We have embarked on a pilot initiative for one year regarding translation and the April issue marked the beginning. Let me share the rationale for this pilot approach and describe what it is.

The Canadian Association of Nurses in Oncology (CANO/ACIO) has been, and continues to be, committed to all members having access to resources in both French and English. In light of that commitment, and in the face of financial constraints, the association has been reviewing exactly what its approach regarding bilingual material ought to be in order to meet the needs of all of the members. We want to determine how best to allocate and spend our available budget for translation—and by translation we mean from English to French and French to English.

As part of our deliberations over this issue, we ran a survey in early January this year asking members about the importance of, and their preferences for, translating a range of association-related materials. These included business materials, educational resources, practice standards, newsletters, and the articles in the CONJ.

The feedback within the survey responses was very similar from both French-speaking and English-speaking members. The responses were well distributed across Canada with 28.75% of all responses coming from members in Quebec. In summary, the responses indicated:

- The highest priority area for translation is national practice resources (e.g., standards, position statements, the Pocket Guide, and survivorship modules), followed by the national policies and member renewal forms, and followed by peer reviewed articles in the CONJ.
- Half of those who responded did not know that the CANO/ACIO website has Google Translate capacity, and of those who knew about that function on the webpages, only 30% had tried it.

- Of all the options for CONJ translation, the respondents indicated the most acceptable change would be to translate the peer reviewed journal articles only; the second choice was to publish the articles in the language of submission, but have extended 750 word abstracts translated instead of the whole article.

The survey feedback and discussions with our Francophone colleagues in the Quebec Chapter of CANO/ACIO, the CANO/ACIO Board, and the CONJ Editorial Committee led to the decision to engage in a pilot approach for translation in the CONJ for one year. At the end of that time, we will evaluate the impact on the CANO/ACIO members and the CONJ readership. Currently that readership includes readers from more than 162 countries around the world. We have a growing number of readers from countries with large French-speaking populations (e.g., France, Belgium, Switzerland, Tunisia).

The pilot approach for translation in the CONJ is to translate the peer reviewed articles (English to French and French to English). The remainder of the issue content (i.e., editorial, features, columns, lectureships, president message) will remain in the language in which it was submitted. In this regard, we will continue to welcome manuscript submissions in English and in French and be able to submit them for peer review in the language of choice.

The pilot approach will allow a third of the current translation budget to be made available for the translation of the newly revised survivorship modules and the Pocket Guide (which have not been translated in the past).

I ask that you pay close attention to each issue in the coming year and be prepared to provide feedback when it is time to evaluate this pilot approach at the end of the year. Your feedback will be important in setting the future direction regarding translation for the CONJ, as well as other resources offered by CANO/ACIO.



Marg Fitch
Editor in Chief

Letter to the Editor

Dear Editor CONJ,

I am a Bachelor of Science candidate majoring in nursing with a strong interest in palliative care, (PC) and was delighted to come across a submission by Collins and Small entitled, "The nurse practitioner role is ideally suited for palliative care practice: A qualitative descriptive study", published January 1, 2019, in the *Canadian Oncology Nursing Journal*. Although I agree enthusiastically with the authors' points, I do feel as though one key concept merits some expansion.

The authors mention the fact that palliative care clinical training is lacking in the nursing curriculum, which may contribute to nurse emotional discomfort with end-of-life (EOL) care. They propose a solution in which healthcare institutions allot funding to their NPs to pursue clinical continuing education hours in PC. This solution is promising, but another education area that is important to address is practitioners' attitudes toward death and dying, and how it impacts their EOL patient care. Education on death itself may be an essential component to examining and improving attitudes on dying, and caring for dying patients (Peters et al., 2013). There is a tendency in healthcare to view death as a failure, when this is not always the case. A paradigm shift toward viewing death as a natural part of life, and acknowledging that there are perhaps worse outcomes than death, may be necessary to help nurses feel comfortable with providing PC (Peters et al., 2013). When healthcare providers harbour negative attitudes toward death, they are reticent to speak honestly with patients and families about dying. It is the patient who suffers, subjected to medical treatments that may add meagre quantity to the very end of

their lives, at the expense of quality. Treatments that they may not have agreed to if an open and compassionate discussion of EOL care had taken place. This concept is further underscored in Dr. Atul Gawande's seminal book on dying, *Being Mortal* (2014).

Clinical nursing experience in PC is essential, but it will fail to do the most good if deeply-held emotional and intellectual barriers to accepting death are not given their due diligence. Death is difficult to talk about. This fact, more so than just lack of experience with PC, makes it that much harder for the clinician to do right by patients' wishes and values. Death education potentiates nurse comfort with talking about death, which provides patients with support during this deeply frightening process. A fully-informed practitioner can make all the difference for a peaceful, dignified death.

Sincerely,

Victoria Stadolnik

Bachelor of Science Nursing Candidate 2019

Curry College School of Nursing, Milton, MA USA

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Response to Letter to the Editor

Dear Editor CONJ,

We thank Victoria Stadolnik for her insightful comments about nurses' negative attitudes toward death and the potential detrimental impact of such attitudes on quality of nursing care for palliative patients. As portrayed by Peters et al. (2013), personal attitude and emotional response toward death are complex phenomena. Stadolnik suggested that education specifically about death may be essential to improving nurses' attitudes about dying. In our study, nurse practitioners also emphasized the importance of palliative education (Collins & Small, 2019). They thought that nurse practitioners who work with palliative patients need specialty palliative knowledge, inclusive of knowledge about providing end-of-life care and discussing end-of-life care with patients and families. As well, they emphasized the importance of emotional comfort with dying and death. Interestingly, the NPs who were emotionally comfortable in providing palliative care thought their emotional comfort was influenced by their philosophy about dying and death and their clinical experience in working with palliative patients (note that perhaps the phenomena of emotional comfort and the conducive philosophy in our study are

the opposite of "death anxiety" and "negative attitudes towards end-of-life patient care," as described by Peters et al. [2013, p. 14]). More research needs to be carried out to fully understand nurses' attitudes and emotional responses to death and the relationship between the two phenomena and to determine how best to intervene with nurses such that they have the knowledge, skill, attitude, and value competencies and the emotional comfort to provide the best quality nursing care to patients who are at end of life.

Sandra Small, RN, PhD

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Toward equitably high-quality cancer survivorship care

by Tracy L. O. Truant, Colleen Varcoe, Carolyn C. Gotay, and Sally Thorne

ABSTRACT

Although models of cancer survivorship care are rapidly evolving, there is increasing evidence of health disparities among cancer survivors. In the current context, Canada's survivorship care systems privilege some and not others to receive high-quality care and optimize their health outcomes. The aim of this study was to improve survivorship care systems by helping clinicians and decision makers to a better understanding of how various psychosocial/political factors, survivors' health experiences and health management strategies might shape the development of and access to high-quality survivorship care for Canadians with cancer. Using a nursing epistemological approach informed by critical and intersectional perspectives, we conducted a three-phased Interpretive Description study. We engaged in critical textual analysis of documentary sources, a secondary analysis of interview transcripts from an existing database, and qualitative interviews with 34 survivors and 12 system stakeholders. On the basis of these data, we identified individual, group, and system factors that contributed to gaps between survivors' expected and actual survivorship care experiences. By understanding what shapes survivorship care systems and resources, we help illuminate and unravel the complex nature of the issue, supporting clinicians and decision makers to find multi-layered approaches for equitably high-quality survivorship care.

BACKGROUND

Over the past two decades, advances in the detection and treatment of cancer have enabled more people to live

longer with a cancer diagnosis than ever before (Canadian Cancer Statistics Advisory Committee, 2018). Rather than questioning, "Will I live?", at least two-thirds of people diagnosed with cancer in North America ask, "How well will I live?", often shifting the conversation about cancer from victim to survivor (Bell, 2010). Although technically cured or in long-term remission, many cancer survivors continue to face life-long physical, psychological, sexual, social, and financial challenges after treatment completion, including lingering cancer recurrence and secondary prevention concerns, negatively impacting quality of life (Canadian Partnership Against Cancer [CPAC], 2012; Jones & Grunfeld, 2011; Mehnert, de Boer, & Feuerstein, 2013; Ness et al., 2013). Rooted in a biomedical model of treating and managing disease (cancer care), and maintaining wellness (primary care), our existing formal structures demonstrate significant gaps in addressing the multitude of medical and supportive care needs of survivors (CPAC, 2018; Wittal, 2018).

There is a strong consensus that current models of cancer survivorship care are suboptimal across Canada, and most other jurisdictions (Canadian Cancer Research Alliance [CCRA], 2017; National Academies of Sciences, Engineering and Medicine, 2018). Coordination of care between specialty and primary care is disjointed, and the primary focus is on medical surveillance at the expense of psychosocial support and health promotion (Fitch et al., 2018 in press; Shaw & Jennings-Shaw, 2017). Rarely are the voices of survivors included in the planning conversation; in particular, the voices of those in marginalized groups—those known to experience marginalizing conditions within society—are typically absent (Ashing-Giwa et al., 2013; Boehmer, Glickman, Milton, & Winter, 2012; Brooks, 2010; CCRA, 2017; Gifford, Thomas, Barton, Grandpierre, & Graham, 2018; Skinner, 2012).

Further complicating the situation is an evolving public discourse on "survivorship" that is often uncritically positive, characterizing cancer recovery as a "transformative" experience, and highlighting the role of self-care, personal choice and autonomy (Bell, 2012; Kromm, Smith, & Singer, 2007). These kinds of discourses lead to unrealistic expectations and a diversion of accountability for those with difficult and lingering effects, including many who are inequitably affected by social determinants of health (Bell & Ristovski-Slijepcevic, 2013; Sinding, 2014).

The Canadian Partnership Against Cancer (CPAC) has set out a pan-Canadian strategy with the goal for all Canadians to have access to equitable, person-centred, safe and high-quality cancer care (2018). This kind of care optimally aligns timely, safe, effective, efficient and equitable resources with survivor needs to achieve desired outcomes such as improved survival,

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functional status, quality of life and personal cancer experience (Feuerstein & Ganz, 2011; Lotfi-Jam et al., 2009; Malin et al., 2011). However, without the structures and contexts necessary to enact person-centred care within the health and cancer care systems, health disparities may be inadvertently accentuated, especially among those who experience marginalizing conditions within society (Epstein, Fiscella, Lesser, & Stange, 2010; Hankivsky, 2011; Niu, Roche, Pawlish & Henry, 2013; Weaver, Geiger, Lu & Case, 2013).

With the goal of optimal health in view, equity means that peoples' needs, rather than their social privileges, ought to guide the distribution of opportunities for optimal health and well-being (Ahmed & Shahid, 2012). Nurses are ideally situated and morally obligated to include sociopolitical advocacy in their practice (Falk-Rafael, 2005), and oncology nurses recognize an ethical and social justice imperative to support and advocate for optimal health for both individuals and aggregates (Canadian Association of Nurses in Oncology [CANO/ACIO], 2006; Canadian Nurses Association, 2017).

PURPOSE

Models of care to date, if left unchecked, will continue to entrench the status quo in how survivorship resources are developed, enacted, and evaluated with little impact on rectifying inequities (Jones & Grunfeld, 2011; Smith & Hall, 2015). Contextual knowledge is required to inform our thinking about future survivorship models of care and resources, taking into consideration the complexities involved in the layering and intersection of factors that shape survivors' agency both at an individual and population level. Thus, the aim of this study was to move beyond describing the issues and challenges and to develop possibilities, recommendations and/or principles for action toward equitable cancer survivorship care that might recognize those complexities and help to foster models of care that reflect both comprehensiveness and equity.

RESEARCH QUESTION

The study was guided by the overarching question: How can cancer survivor and system stakeholder perspectives inform our understanding of what is needed to ensure both high quality and equity in cancer survivorship care systems in Canada? Within the umbrella of this question, we were interested in how diverse cancer survivors describe and explain their access to and experience with care, how they envision a system of care that might meet their needs, and what approaches might surface from both survivors and cancer care system stakeholders to promote the development of high-quality resources and models of care capable of meeting both individual and aggregate needs.

STUDY DESIGN

The theoretical scaffolding for this study was underpinned by a pragmatic approach that included a critical intersectional lens to explicate the complexity embedded within survivorship care. Interpretive Description, an applied qualitative method, allowed us to draw upon nursing's disciplinary epistemology to develop a series of sub-studies designed to collectively

generate new insights about clinically relevant phenomena for the purpose of translation into practice (Thorne, 2016; Thorne, Stephens, & Truant, 2016).

Within this context, we designed a three-phased approach to allow for perspectival diversity within a process of increasingly complex analysis: a critical textual analysis, a secondary analysis of transcripts from an existing survivor interview database, and finally a set of new interviews with cancer survivors and system stakeholders. The latter two phases involved ethical approval from our university's behavioural research board (UBC BREB # H09-0171 & H14-0382). The full detail of how the method was enacted and the findings arrived at in each of these three phases is beyond the scope of a single article; each deserves a more fulsome report, which we intend to generate in future publications. Our purpose in this rendering is to describe the overall design we used and to provide highlights of the kinds of findings that we generated. The system recommendations we ultimately generated arose from the combined analysis of these three distinct, but interrelated inquiry processes.

Study Process and Outcomes

Critical Review of Documents

We began with a critical textual analysis of more than 70 documentary sources, including survivorship guidelines, education programs, policies and resources. Most of the documents analyzed were Canadian in origin. Some American clinical practice guidelines were included in the analysis, as they often provide direction to survivorship care in Canada, in the absence of Canadian-developed guidelines (see for example, Resnick et al., 2015). We also targeted documents specific to cancer survivorship care in British Columbia such as British Columbia's Patient-Centred Care Framework (BC Ministry of Health, 2015), to align geographically with the survivors included in phase three of this study. The documentary sources provided a lens through which to view current challenges, gaps and inconsistencies, as well as opportunities to identify and strengthen aspects of survivorship care to move toward equity and high quality.

From this body of material, we became attuned to extensive variability in what the term survivorship signified in different contexts. Various national cancer control organizations and advocacy groups, for example, defined it as beginning at diagnosis and continuing for the remainder of one's life (see for example, Canadian Partnership Against Cancer [CPAC], 2012; Ristovski-Slijepcevic, 2008; University Health Network [UHN], n.d.). Mid-range definitions positioned it as beginning at the conclusion of primary treatment and lasting until recurrence or end of life (see for example, Howell et al., 2011; Sussman et al., 2016). The narrowest definitions targeted the transition between active treatment and primary care (see for example, Chomik, 2010; Ward, Doll, Ristovski-Slijepcevic, Kazanjian, & Golant, 2010). If "everyone is a survivor" then it becomes increasingly difficult to identify those with complex situations and needs, and may advantage those with the greatest capacity to advocate for their unmet needs, regardless of complexity or self-care resources. For example,

such definitional politics blur the distinction between those “cured” and living a relatively normal life and those living decades with stable, yet metastatic (i.e., non-curative) disease, or those whose survivorship care necessitated a palliative approach. Thus, the more politically correct broad definitions seem to reinforce the invisible and somewhat taken-for-granted privileging of individuals with curative cancers. In this way, they become part of the social metanarrative that equates victory with transformation as a result of having had or lived through cancer (Bell, 2013).

We also recognized that the available documents were far more oriented to matters at the population and system level than to the level of individual person-focused experience. We recognized a fluidity and interchangeability between terms such as patient- versus person-centred care, and were struck by the invisibility of equity concerns across most of the available material. Where equity language was explicitly used, it was often limited to a population focus on enhancing access to care (for example, rural populations), or in relation to collecting social determinants data (such as socioeconomic status or education) to describe inequities among groups rather than individuals. Thus, the documents were highly informative regarding how the system was “thinking” about this phenomenon and the social forces with an investment in its evolving direction.

Secondary Transcript Analysis

We then conducted a secondary analysis of transcript data, using a set of 61 interviews from 19 adults who identified as cancer survivors. The survivor interviews were drawn from a longitudinal study comprising more than 500 interviews with 125 cancer patients over a seven-year period (2005–2012); the focus of those interviews was on cancer care communication from the patient perspective (see Thorne & Stajduhar, 2012; Thorne et al., 2014). From these interviews, we accessed an in-depth perspective of the ambiguity of life after cancer treatment, when the safety net of being embraced by the cancer care system was (often suddenly) no longer accessible. Patients felt “abandoned” to the primary care system—relegated to oversight by the very same practitioners they felt they had been subliminally encouraged to distrust as inexperienced in matters of cancer relative to practitioners in the cancer specialty system. Not only did they find the anticipated “getting back to normal” completely elusive, but they also often experienced the loss of the social support networks that had arisen around them in such a meaningful manner throughout their active treatment phase. These networks typically began to withdraw now that the individuals were no longer legitimately ill; in some cases, friends and families expected them to immediately resume the full set of duties for which they had required coverage since their cancer diagnosis.

Another feature of the accounts of these survivors was the system and professional focus on the biological and physical aspects of what they were experiencing from a more holistic perspective. Many felt that their access to survivorship care was prioritized according to the presence/absence of disease, as well as severity of disease. Thus, when their cancer was in

remission or cured, and there was little or no disease to focus on, many felt shut out of a system focused on pathology. They also described system disinterest in late and long-term effects of treatment, and in the lingering post-traumatic psychological effects of the life-altering experiences they had undergone. In this context, they became increasingly aware of the wider healthcare system, with its hierarchical politics, its territorial tensions between jurisdictions, and its efficiency drivers. Many felt invisible within a system of care in which they still perceived themselves as highly vulnerable.

Survivor and Stakeholder Interviews

Informed by insights arising from these two initial aspects, the culminating phase of this study involved individual face-to-face interviews with 34 cancer survivors. These individuals were recruited using purposeful sampling to include a wide diversity in relation to both disease and social determinants variables, as well as 12 individuals recruited for their expertise and depth in the development and implementation of cancer survivorship care in Canada. Half of this group were physicians, and the remainder were registered nurses, nurse practitioners or psychosocial health practitioners. Each held roles within cancer care systems focused on administration, education, research or program development on cancer survivorship. Seven of the 12 were from British Columbia, and the remainder from Alberta or various cancer centres in Ontario. These interviews were conducted by the first author [TT] over an 18-month period (2016–2017) and yielded a data set consisting of transcripts, field notes and analytic notes, all coded and sorted using NVivo™ qualitative software. The survivor interviews were dominated by accounts of how their expectations for cancer survivorship care failed to match their anticipated and hoped for reality. Considering the nature and nuances of those gaps between perceived need and experienced reality, and the way the study participants made sense of them, became a key feature of our analytic reflections.

Most survivors had expected to receive person-centred, individualized, holistic care within an ongoing and reciprocal relationship with their healthcare providers. They often had some expectation for self-care, but also assumed that this would be supported by healthcare provider expertise to optimize their self-care activities. We found that a number of specific social determinants of health played a powerful role in setting these expectations. Those who lived in rural or remote areas, those who had “non-curable” or rare or complex cancers, those who had concurrent chronic conditions, those who were younger or very old adults, those who spoke a language other than English or represented other identifiable “equity groups,” had significantly lower expectations that their needs would be met relative to what they considered to be the “average” patient. Those who had tumour sites other than breast cancer also perceived themselves to be at a disadvantage relative to patients with breast cancer, for whom resources and supports were more ubiquitously visible. Those who had negative experiences with the cancer care system were less likely to trust that survivorship care would be forthcoming. Thus, we were able to see

how the initial conditions might perpetuate discrepancies in both expectations and engagement that might accentuate inequities for those already vulnerable.

We were struck by the “work” of survivorship described by many of the study participants, both the work of living a new life post-treatment and the work of securing survivorship care. From their accounts, we also learned how frequently they felt bypassed by communication about their survivorship care, in that information passed between various professionals without their awareness. For example, some were aware that a survivorship plan existed, but said they had never seen it. Overall, it seemed apparent that, while some patients fit well into existing survivorship supports and resources, many did not. The subgroup of cancer survivors we found most likely to report having their expectations needs optimally met tended to be 50 to 70-year-old women with curable breast cancer, urban living, with a high socio-economic status, including good extended health benefits and back to work supports, strong social supports, a high capacity for self-care and self-advocacy, few lingering side effects of treatment, and good relationships with their primary care provider. In some respects, it seemed that the majority of cancer survivorship systems were designed with this kind of patient in mind.

We found the stakeholders in the cancer survivorship system well prepared to explain from their perspective how and why these gaps existed. From their embedded perspective, it was possible to critically reflect on the structures, contexts, and factors within the system that might account for both barriers to high-quality survivorship care and strengths within the system with the potential to promote both equity and quality within that context. On a fundamental level, they were concerned about how our systems set up the “measuring stick” to assess potential inequities, using group comparisons against a standardized “norm” to determine inequities rather than to consider a diversity of individual circumstances from an intersectional lens. Thus, they cautioned that the serious degree of inequity experienced by some individuals was rendered invisible in “equity group” data. Further, they described entrenched attitudes within care delivery systems, including the influences of colonialism, a prioritization of the Western biomedical model, a scarcity ideology, prioritization of evidence-based practice, the invisibility of social determinants of health, and tumour group driven “norms,” resulting in survivorship guidelines that are not inclusive of diverse people and needs. These attitudinal barriers were further complicated by structural features of our care delivery system, including physician and (extended) health insurance reimbursement systems that tie resources for cancer care to the treatment component, and the siloing of specialty knowledge and services within care organizations with little or no community reach. Finally, they also acknowledged the role of the tension between system level decisions grounded in biomedical priorities and a person-centred empowerment ethos. Thus, their accounts surfaced a form of paternalism they characterized as “institutional arrogance” with respect to the challenge of increasing numbers of cancer survivors, and whose responsibility it was to support them.

DISCUSSION OF THE FINDINGS

Many of our findings confirm the relevance of the emerging equity critique that has been appearing in the cancer care literature in recent years (Truant, 2017). We believe that the intersectional and layered approach taken in this study has allowed us to illuminate the complexities inherent in trying to develop a high-quality, population-based approach to cancer survivorship in Canada. Specifically, this approach facilitates our awareness not only for the comparatively high levels of unmet need among what we consider “equity groups,” but also the many and diverse needs of individual persons who do not fit dominant norms for a wide variety of reasons. Among the most important outcomes of this work is the basis it creates for needed critically reflective research into what survivorship constitutes in the changing world of personalized medicine, who benefits, and who may be systematically disadvantaged by the ideas we hold, the systems within which we deliver survivorship care and the structures we develop within which to determine who deserves care and what kind of care they deserve.

We see great promise in the way the voice of cancer survivors is increasingly being attended to. Of particular importance is the recent national call to ensure that patient-reported outcomes on the experience of those living with and beyond cancer are informing clinician practices, health system administrative processes, and provincial and territorial government databases (CPAC, 2018).

On the basis of these findings, and informed by the increasingly persuasive advocacy work of both patients and professional stakeholders within our systems, we recognize that the cancer survivorship challenge in Canada will require thoughtful attention to the tensions between population-based service provision and care for unique and distinctive individuals in need. It will require rethinking of the organizational models within which we have traditionally organized and prioritized both cancer care and also healthcare in general. And, finally, it will require reconceptualization of the appropriate deployment of healthcare resources, including the roles of the different professions in planning, delivering and leading various aspects of the survivorship care challenge.

Recommendations for System Improvement

Although, as we have established, the barriers to equitable high-quality cancer survivorship care are many and complex, there is also much we can learn from building on the strengths of the system that are apparent in the documentation, as well as the accounts of both survivors and system stakeholders. We can also recognize that the traditional curative focus on cancer has led to systems oriented toward an acute, episodic illness, rather than a dimension that must be integrated into the everyday lives of so many Canadians. While we all appreciate the importance of treatment, our prioritization of disease management cannot be at the expense of psychological, emotional, spiritual and informational needs of the person if we have any commitment to the ideal of person-centredness (CPAC, 2018). And, although evidence-based guidelines make excellent sense at the level of treatment design and delivery,

they necessarily erase the relevance of individual difference (Thorne & Sawatzky, 2014). Thus, we design our systems of care around the “average person,” stripping diversity and context from approaches we design around population norms (Sulik, 2013). We need to learn not to take up organizational ideological commitments uncritically, such as evidence-based practice and person-centred care, without recognizing they will be in inherent tension with one another, and that patients may suffer if we don’t also make concerted efforts to prioritize grappling with the very real complexities of inequity.

We know that privileging Eurocentric norms to define standards in survivorship care is a colonialist practice with real impact on those who do not fit our theoretical norms (Anderson et al., 2009). There is considerable room for further action with respect to engaging equity groups in constructively informing us about the aspects of our assumptions around care that may systematically dis-serve various survivor groups. However, we also need to learn to tap the wisdom of our thoughtful insider populations—including system leaders and clinicians—with respect to questions such as who is least well served by our institutions and support services. If we envision prioritizing systems with the potential to provide excellent care for the most vulnerable minority client, we can go a long way toward being well prepared for the full spectrum of individual diversities our systems inevitably encounter.

From the accounts of cancer survivors, we know that effective communication with their healthcare professionals in the context of relational practice goes a long way toward flattening the hierarchies that patients perceive as barriers to care. By thinking of our systems as relational hubs, rather than depersonalized institutions that deliver units of service, we can focus attention on how best to fill gaps and meet needs. Nursing has long espoused an ideal of continuity of care, and stepping up to ensure the capacity for ongoing relationships and effective relational handovers will remain important. When system metrics and the quantification of complex quality of life phenomena render the relational aspect of care invisible, it is easy to understand why it shifts away from being a priority. So, we must find ways to recommit to communication across the cancer care trajectory, as a safety measure for all patients, and to enact our care delivery approaches with patient engagement support in mind.

As we continue to build models of care for cancer survivorship, we must consider stratified care models based on complexity of needs. This assumes that we know the needs of our patients and that we co-create care models in active collaboration between caregivers and survivors. We believe there is tremendous potential for nurse-led survivorship care, including placing specialized oncology nurses (RNs and NPs) in primary care settings, and including in those models an anticipation of both ongoing and urgent survivorship-related concerns. Clearly, such changes would require modifications to the prevailing structure and attitudinal culture with respect to

nursing roles in many cancer care organizations. Rather than organizing our care around tumour groups, which has been the traditional biomedical model, but is now being eroded by precision medicine and new ways of conceptualizing cancer management, we may find it necessary to advocate for survivorship care organized around survivor experiences and needs, integrating such services with chronic illness service delivery and also a palliative approach to care, which implies individualized goals of care. There will be a role for peer-led models of care, but these will differentially support some groups of survivors better than others, and cannot be a replacement for integrated survivorship care. In addition, our models must include return-to-work resources, family guidance, and accessible community-based supports.

In order to capitalize on the opportunity before us, we will clearly need to focus on cultural sensitivity (safety and humility) training and expectations for all healthcare professionals, across both specialized and primary care. And we will need to support communities of practice within which healthcare professionals can continue to optimize their understanding of the complexities of survivorship care, as well as fuel their ongoing commitment to it.

Looking to the Future

High-quality cancer survivorship care delivered with an equity perspective in mind will require ongoing study and advocacy. Among the key research questions that we will need to integrate into our consideration of evolving models of care are: a) how and where can we integrate the biomedical approach with attention to the psychological, sexual, social, and financial challenges that confront survivors and characterize many of their areas of greatest need? and b) how can we articulate population-based guidelines without obscuring the very real and immediate concerns of unique individuals and, in particular, those who are most vulnerable? The Canadian Partnership Against Cancer has set a clear challenge for our country:

From the moment people start wondering if they have cancer to post-treatment care, the cancer experience is a continuous one for everyone involved. Providing person-centred care during each stage of the journey will ensure that patients and families are seen as unique individuals, receive coordinated care that is considerate of their time and preferences, have access to useful information that promotes self-care, and have their various needs met as they arise (CPAC, 2018, p. 45)

To achieve the goal of providing equitably high-quality cancer survivorship care to all Canadians, we must align our ongoing research with the rich resource of experiential and clinical wisdom of those who are at the interface of everyday service delivery. We must also work together to provide those in planning and policy-making roles the critically reflective insights they will require to discern where we are making progress and where gaps may remain.

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Les soins aux survivants du cancer : vers une grande qualité, en toute équité

par Tracy L. O. Truant, Colleen Varcoe, Carolyn C. Gotay et Sally Thorne

RÉSUMÉ

Les modèles de soins aux survivants du cancer évoluent rapidement, mais des disparités en matière de santé sont néanmoins de plus en plus évidentes entre les survivants de la maladie. Le Canada n'y échappe pas, et on observe que certains survivants privilégiés reçoivent des soins de plus grande qualité et conservent donc une meilleure santé que d'autres. La présente étude a pour but d'améliorer les soins aux survivants en aidant les cliniciens et les décideurs à mieux comprendre comment le vécu des survivants, les stratégies de gestion des soins et différents facteurs psychologiques et politiques peuvent influencer l'offre de soins aux survivants de grande qualité développés au Canada, ainsi que l'accès à ces soins. La présente étude descriptive et interprétative en trois étapes se fonde sur une approche infirmière épistémologique adoptant une perspective tant critique que multidimensionnelle. Nous avons procédé à une analyse textuelle critique de sources documentaires, de même qu'à une analyse secondaire de transcriptions d'entrevues provenant d'une base de données déjà existante; nous avons également mené des entrevues qualitatives auprès de 34 survivants et de 12 intervenants du système de santé. Nous avons ensuite extrait de ces données les facteurs individuels, collectifs et systémiques qui contribuent à creuser le fossé entre l'expérience de soins attendue et le vécu réel des survivants. En comprenant ce qui fait varier les soins aux survivants et les ressources qui leur sont allouées, nous espérons contribuer à éclaircir cette question complexe et encourager les cliniciens et les décideurs à adopter des approches à plusieurs niveaux pour assurer l'équité des soins de grande qualité.

CONTEXTE

Au cours des vingt dernières années, plus de gens que jamais ont vu leur espérance de vie augmenter après un diagnostic de cancer grâce aux progrès réalisés dans le dépistage et le traitement (Comité consultatif des statistiques canadiennes sur le cancer, 2018). Pour au moins les deux tiers des Nord-Américains ayant reçu un diagnostic de cancer, la question n'est plus de savoir s'ils vont survivre à la maladie, mais plutôt s'ils auront une bonne qualité de vie, ce qui les amène à se voir davantage comme des survivants que des victimes. (Bell, 2010). Or, nombreux sont les survivants du cancer qui, bien que techniquement guéris ou en rémission prolongée après leurs traitements, vivent des difficultés physiques, psychologiques, sexuelles, sociales et financières; la crainte persistante d'une récurrence et les inquiétudes liées à la prévention secondaire, notamment, peuvent nuire à leur qualité de vie de manière permanente (Partenariat canadien contre le cancer [PCCC], 2012; Jones et Grunfeld, 2011; Mehnert, de Boer et Feuerstein, 2013; Ness et al., 2013). Les structures de soins officielles actuellement en place, ancrées dans un modèle biomédical axé sur le traitement et le contrôle de la maladie (soins du cancer) et sur le maintien du bien-être (soins de première ligne), présentent des lacunes importantes et ne permettent pas de répondre à la multitude de besoins des survivants en matière de soutien et de soins médicaux (PCCC, 2018; Wittal, 2018).

Il existe un large consensus selon lequel les modèles actuels de soins des survivants au cancer sont sous-optimaux partout au Canada, et ailleurs aussi (Alliance canadienne pour la recherche sur le cancer [ACRC], 2017; National Academies of Sciences, Engineering and Medicine, 2018). La coordination des soins spécialisés et des soins de première ligne manque de cohérence et les efforts se concentrent sur la surveillance médicale aux dépens du soutien psychologique et de la promotion de la santé (Fitch et al., 2018 sous presse; Shaw et Jennings-Shaw, 2017). Lorsqu'il est question de planification, on pense rarement à entendre l'opinion des survivants, et les groupes marginalisés, qui vivent des situations particulières en raison de leur marginalisation, sont communément absents du débat (Ashing-Giwa et al., 2013; Boehmer, Glickman, Milton et Winter, 2012; Brooks, 2010; ACRC, 2017; Gifford, Thomas, Barton, Grandpierre et Graham, 2018; Skinner, 2012).

La situation est rendue encore plus complexe par l'évolution du discours public sur la « survie », discours souvent positif et peu nuancé, qui associe la rémission du cancer à une expérience « transformatrice » et valorise l'autosoin, les choix personnels et l'autonomie (Bell, 2012; Kromm, Smith et Singer, 2007). Ce genre de discours suscite des attentes irréalistes, en plus de faire peser la responsabilité de la guérison sur des personnes qui subissent encore parfois les effets

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difficiles et persistants de la maladie, notamment les patients défavorisés par les déterminants sociaux de la santé (Bell et Ristovski-Slijepcevic, 2013; Sinding, 2014).

Le Partenariat canadien contre le cancer (PCCC) a établi une stratégie pancanadienne dont le but est de fournir à tous les Canadiens un accès à des soins du cancer équitables, axés sur la personne et de grande qualité (2018). Pour ce faire, les ressources doivent être sûres, efficaces et équitables, disponibles en temps opportun et alignées sur les besoins des survivants afin d'optimiser les résultats souhaités, notamment une amélioration du taux de survie, des capacités fonctionnelles, de la qualité de vie et de l'expérience personnelle par rapport au cancer (Feuerstein et Ganz, 2011; Lotfi-Jam et al., 2009; Malin et al., 2011). Toutefois, l'absence de structures ou de contextes encourageant la prestation de soins axés sur la personne au sein des systèmes de santé et de soins du cancer peut mener à un accroissement involontaire des disparités en matière de santé, au détriment, particulièrement, des personnes marginalisées (Epstein, Fiscella, Lesser et Stange, 2010; Hankivsky, 2011; Niu, Roche, Pawlish et Henry, 2013; Weaver, Geiger, Lu et Case, 2013).

Pour optimiser la santé et le bien-être et atteindre l'équité, il faut s'assurer de mettre les besoins des personnes, et non leur statut social, au centre du processus. (Ahmed et Shahid, 2012). Les infirmières sont les mieux placées pour défendre les droits sociopolitiques des patients dans leur pratique, sans compter qu'elles en ont aussi l'obligation morale (Falk-Rafael, 2005). Les infirmières en oncologie sont convaincues de la nécessité, pour des raisons d'éthique et de justice sociale, de promouvoir et favoriser une santé optimale, à la fois pour les individus et les collectivités (Association canadienne des infirmières en oncologie [CANO/ACIO], 2006; Association des infirmières et infirmiers du Canada, 2017).

Si rien n'est fait, les modèles de soins actuels continueront de renforcer le mode de création, de mise en place et d'évaluation des ressources destinées aux survivants en vigueur sans jamais rectifier les inégalités (Jones et Grunfeld, 2011; Smith et Hall, 2015). Pour orienter notre réflexion sur les futurs modèles et ressources de soins aux survivants, il faudra mieux comprendre le contexte et tenir compte de la complexité des relations et croisements entre les différents facteurs qui influencent la capacité d'agir des survivants, que ce soit à l'échelle individuelle ou collective. Par conséquent, la présente étude vise plus qu'une simple description des enjeux et des défis : son objectif est de proposer des voies à explorer, des recommandations ou des principes d'action qui embrassent toute cette complexité, afin d'aménager des soins et des modèles de soins à la fois équitables et complets pour tous les survivants.

QUESTION DE RECHERCHE

La question directrice fondamentale de l'étude est la suivante : Comment les différents points de vue des survivants du cancer et des intervenants du système de santé peuvent-ils éclairer une démarche visant à assurer aux survivants du cancer des soins de grande qualité en toute équité, partout au Canada? Pour répondre à cette question, nous avons cherché

à savoir comment différents survivants du cancer décrivaient et expliquaient leurs expériences, notamment leur accès aux soins, de même que leur vision d'un système de soins adapté à leurs besoins; nous avons tenté de dégager des approches à partir des témoignages des survivants et des intervenants du système de soins du cancer pour appuyer la création de ressources et de modèles de soins de grande qualité qui répondent aux besoins individuels et collectifs.

DEVIS DE L'ÉTUDE

Le raisonnement théorique de la présente étude repose sur une approche pragmatique adoptant un point de vue critique multidimensionnel pour expliquer la complexité inhérente aux soins des survivants. Grâce à la description interprétative (une méthode quantitative appliquée), nous avons pu puiser dans l'épistémologie de la discipline infirmière pour élaborer une série de sous-études visant à générer, une fois mises en commun, de nouvelles pistes de compréhension qui permettront de transposer les phénomènes pertinents à la pratique clinique (Thorne, 2016; Thorne, Stephens et Truant, 2016).

Dans ce contexte, nous avons conçu une approche en trois étapes afin de laisser place à une diversité de points de vue, en procédant à une analyse de plus en plus complexe : nous avons d'abord réalisé une analyse textuelle critique, puis une analyse secondaire des transcriptions d'une base de données d'entrevues déjà constituée, avant de mener de nouvelles entrevues auprès de survivants du cancer et d'intervenants du système de santé. Les deux dernières étapes nécessitaient l'approbation du comité d'éthique de la recherche comportementale de notre université (UBC BREB no H09-0171 et no H14-0382). Il va sans dire que le détail de la méthodologie et des résultats de chaque étape ne peut être couvert en un seul article; chacune mériterait à elle seule un rapport complet. D'autres publications sont d'ailleurs prévues. L'objectif du présent article est donc de décrire le devis général utilisé et de présenter les résultats obtenus dans leurs grandes lignes. Les recommandations formulées pour améliorer les soins découlent de l'analyse combinée de ces trois processus à la fois distincts et interdépendants.

Processus et résultats de l'étude

Revue critique de la documentation

Nous avons, dans un premier temps, effectué une analyse textuelle critique de plus de 70 sources documentaires, notamment de lignes directrices sur la survivance, de programmes d'éducation, de politiques et de ressources, publiées au Canada pour la plupart. Certaines lignes directrices cliniques américaines ont été incluses à l'analyse, étant donné qu'elles influencent souvent les soins aux survivants d'ici en l'absence de lignes directrices canadiennes (pour des exemples, voir Resnick et al., 2015). Nous avons également choisi des documents portant plus exactement sur le soin des survivants en Colombie-Britannique, comme le cadre de soins axés sur le patient (Patient-Centred Care Framework, ministère de la Santé de la Colombie-Britannique, 2015) pour prendre en compte la région géographique des survivants interrogés pendant la troisième étape. Nous avons pu, grâce aux sources documentaires, brosser le portrait des difficultés, lacunes et

incohérences actuelles, mais aussi relever des occasions de cerner et de renforcer des facteurs qui favoriseront l'équité et la qualité des soins aux survivants.

Ce corpus nous a permis de constater à quel point la définition du terme *survivant* varie selon les contextes. Par exemple, pour plusieurs groupes de défense des droits et organismes nationaux de lutte contre le cancer, la survivance s'étend du diagnostic à la fin de vie du patient (voir entre autres le PCCC, 2012; Ristovski-Slijepcevic, 2008; Réseau universitaire de santé, sans date). Des définitions intermédiaires la font commencer à la fin du traitement primaire, et se poursuivre jusqu'à la récurrence ou le décès (voir Howell et al., 2011; Sussman et al., 2016), alors que d'autres, plus restreintes, n'incluent que la période de transition entre le traitement actif et les soins de première ligne (voir par exemple Chomik, 2010; Ward, Doll, Ristovski-Slijepcevic, Kazanjian et Golant, 2010). Si « tout le monde est un survivant », il devient difficile d'identifier les personnes dont la situation ou les besoins sont complexes, ce qui peut avantager les patients mieux outillés pour trouver réponse à leurs besoins, peu importe la complexité de leur cas ou les ressources d'autosoins. En outre, ces définitions viennent brouiller la distinction entre les personnes « guéries » qui mènent une vie relativement normale et celles qui vivent pendant des décennies avec un cancer stable mais métastatique (c.-à-d. non traitable), ou encore les survivants dont les soins nécessitent une approche palliative. Ainsi, les définitions les plus larges et politiquement correctes, semblent renforcer, d'une manière implicite et qui semble toute naturelle, le statut privilégié des patients dont le cancer est guérissable. Ces derniers contribuent ainsi au métarécit social, qui véhicule l'idée que l'expérience du cancer et la victoire sur la maladie sont un vecteur de transformation (Bell, 2013).

De plus, force est d'admettre que les documents disponibles traitent davantage des aspects collectifs et systémiques que des expériences individuelles. Nous avons en outre constaté que les termes « soins axés sur le patient » et « soins axés sur la personne » étaient facilement interchangeables, et nous avons été frappées par l'absence quasi totale de références à l'équité. Lorsque la question de l'équité est textuellement abordée, elle se limite souvent à l'amélioration de l'accès aux soins à l'échelle de la population (par exemple, pour les collectivités rurales), ou à la cueillette de données sur les déterminants sociaux (comme le statut socioéconomique ou le niveau d'éducation) pour décrire les inégalités collectives plus qu'individuelles. Par conséquent, les documents nous ont beaucoup appris sur la « vision » du système par rapport au principe d'équité, de même que sur les forces sociales à l'œuvre pour faire évoluer cette perception.

Analyse secondaire de transcriptions d'entrevues

Nous avons ensuite procédé à une analyse secondaire des données de 61 entrevues réalisées auprès de 19 adultes se décrivant comme des survivants au cancer. Il s'agissait d'une étude longitudinale de 500 entrevues menées auprès de 125 patients atteints de cancer sur une période de 7 ans (de 2005 à 2012); les entretiens mettaient l'accent sur la perception qu'avaient les patients de la communication entourant les

soins du cancer (voir Thorne et Stajduhar, 2012; Thorne et al., 2014). Grâce à ces entrevues, nous avons pu mesurer la profondeur de l'incertitude qui habite les patients après la fin du traitement, lorsque le filet de sécurité du système de soins disparaît (souvent soudainement). Les patients se sentent « abandonnés » aux mains du système de soins de première ligne, leur cas relégué à des praticiens dont on les a inconsciemment encouragés à se méfier en leur disant qu'ils connaissaient mal le cancer, contrairement aux spécialistes. Non seulement le « retour à la normale » tant attendu leur échappe complètement, mais ils perdent souvent le précieux réseau de soutien social qui s'était constitué autour d'eux pendant la phase de traitements actifs. Lorsque les patients ne sont plus officiellement malades, il n'est pas rare que leur réseau de soutien s'effrite; dans certains cas, les amis et la famille s'attendent même à une reprise immédiate de toutes les responsabilités déléguées à d'autres depuis le diagnostic de cancer.

Les survivants rapportent aussi que le système et les professionnels de la santé insistent beaucoup sur les aspects biologiques et physiques de ce qui constitue, pour eux, une expérience holistique. De l'avis de nombreux patients, c'est l'absence ou la présence, voire la gravité de la maladie, de maladie, qui détermine la priorité d'accès aux soins pour les survivants. Par conséquent, lorsque les patients entrent en rémission ou qu'ils ne sont plus (ou presque plus) malades, ils se sentent exclus de ce système axé sur la pathologie. Selon eux, le système se désintéresse aussi des effets différés ou persistants du traitement, ainsi que des effets psychologiques post-traumatiques des expériences qui les ont transformés. Ce contexte leur a fait prendre conscience du fonctionnement général du système de santé, notamment de ses politiques hiérarchiques et des tensions qui existent entre les différentes sphères de compétence, mais aussi de ses moteurs d'efficacité. Cette constatation en a amené plusieurs à se sentir invisibles, eux qui se sentent encore très vulnérables par rapport au système de soins.

Entrevues avec les survivants et les intervenants

Une fois les résultats des deux premières étapes de l'étude obtenus, nous avons terminé cette étude en réalisant des entrevues en personne avec 34 survivants du cancer. Ces derniers ont été sélectionnés par échantillonnage intentionnel afin d'assurer une grande diversité de variables liées tant à la santé et qu'aux déterminants sociaux; 12 autres personnes ont aussi été recrutées pour leur expertise et leur expérience du développement et de la mise en œuvre des soins aux survivants du cancer au Canada. La moitié d'entre eux étaient des médecins, le reste du groupe étant constitué d'infirmières autorisées, d'infirmières praticiennes ou de professionnels de la santé psychosociale; chacun jouait un rôle dans le système de soins du cancer, que ce soit dans l'administration, l'éducation, la recherche ou la création de programmes sur la survivance. Sept de ces douze spécialistes provenaient de la Colombie-Britannique et les autres, de l'Alberta ou de différents centres de traitement du cancer de l'Ontario. Les entrevues ont été menées par l'auteure principale [TT] sur une période de 18 mois (2016-2017) et ont permis d'amasser une foule de

données sous forme de transcriptions, de notes d'observation et de notes d'analyse, toutes codées et classées à l'aide du logiciel d'analyse qualitative NVivoMC. En majorité, les entrevues des survivants ont révélé que leurs attentes avaient été déçues, les soins ne correspondant pas à la réalité qu'ils avaient imaginée et espérée. Nous avons donc orienté nos réflexions analytiques sur la nature et la variation des écarts séparant la perception des besoins et l'expérience réellement vécue, ainsi que sur la manière dont les participants à l'étude s'expliquaient ces écarts.

La plupart des survivants s'attendaient à recevoir des soins holistiques individualisés et axés sur la personne, dans le cadre d'une relation continue et réciproque avec les professionnels de la santé. La plupart s'attendaient à devoir prendre en charge une partie des soins, mais ils pensaient pouvoir compter sur le soutien et l'expertise des professionnels à cet égard. Nous avons constaté que certains déterminants sociaux de la santé bien précis jouaient un rôle de premier plan dans ces attentes. Par exemple, les gens des régions rurales ou isolées, les personnes souffrant d'un cancer « non traitable », rare ou complexe ou présentant des maladies chroniques concurrentes, les jeunes ou les adultes très âgés, de même que les patients parlant une langue autre que l'anglais ou appartenant à d'autres « groupes visés par l'équité » reconnaissables, s'attendaient beaucoup moins à ce qu'on réponde à leurs besoins particuliers comparativement à ce qu'ils pensaient qu'on ferait pour ce qu'ils percevaient comme un patient « typique ». En raison de la grande visibilité des ressources et du soutien destinés aux patientes atteintes de cancer du sein, les personnes souffrant d'un autre cancer avaient aussi l'impression d'être désavantagées. Quant aux personnes ayant déjà vécu une expérience négative dans le système de soins du cancer, elles étaient moins susceptibles de croire qu'elles auraient accès à des soins aux survivants répondant à leurs besoins. Ainsi, nous avons constaté à quel point les conditions initiales peuvent perpétuer les écarts en ce qui a trait aux attentes et à l'engagement des patients, ce qui peut accentuer les inégalités pour les personnes déjà vulnérables.

De nombreux participants à l'étude ont décrit tous les efforts déployés pour rebâtir leur vie après les traitements et pour obtenir des soins aux survivants; leurs récits nous ont surpris et nous ont aussi appris que les survivants se sentaient souvent tenus à l'écart des communications concernant leurs soins, l'information circulant d'un professionnel à l'autre sans qu'ils soient au courant. Par exemple, certains patients savaient qu'on leur avait fait un plan de survivance, mais ne l'avaient jamais vu. Dans l'ensemble, on comprend que si certains survivants trouvent leur compte dans les ressources et le soutien existants, ce n'est pas le cas de nombreux patients. Selon nos recherches, le sous-groupe de survivants du cancer le plus susceptible de voir ses attentes comblées de manière optimale était surtout constitué de femmes âgées de 50 à 70 ans au statut socioéconomique élevé souffrant d'un cancer du sein traitable et vivant en milieu urbain, qui disposaient notamment de bonnes prestations d'assurance-maladie et de soutien pour le retour au travail, d'un réseau social solide, d'une excellente capacité à pratiquer l'autosoin et à faire entendre leur voix, qui

ressentaient peu d'effets secondaires persistants et qui entretenaient de bonnes relations avec leur médecin traitant. À certains égards, il semble le système de soins aux survivants soit majoritairement conçu pour répondre aux besoins de ce patient type.

De leur côté, les intervenants du système de soins aux survivants du cancer ont été en mesure de fournir une perspective éclairée sur le pourquoi et le comment de ces écarts, leur connaissance intime du système leur permettant une réflexion critique sur les structures, contextes et facteurs susceptibles de nuire à la qualité des soins aux survivants, mais aussi de favoriser l'équité et la qualité des services. Essentiellement, ils ont dit s'inquiéter des « critères de mesure » utilisés pour évaluer les inégalités potentielles, critères qui consistent à comparer les groupes à une « norme » standardisée plutôt que d'examiner les différentes circonstances individuelles d'un point de vue multidisciplinaire. Ils ont aussi attiré notre attention sur le fait que les données du « groupe visé par l'équité » masquaient la grande iniquité vécue par certaines personnes. De plus, ils ont décrit des travers qui mènent à des lignes directrices sur la survivance qui ne tiennent pas compte de la diversité des patients et de leurs besoins : manque de flexibilité du système, influence du colonialisme, domination du modèle biomédical occidental, mentalité de pénurie, priorité donnée aux pratiques fondées sur les données probantes, invisibilité des déterminants sociaux de la santé, « normes » établies en fonction des groupes de tumeurs. Aux obstacles engendrés par ces travers s'ajoute des complexités structurelles, dont le fait que les ressources allouées pour les soins du cancer sont directement liées au traitement en raison de la façon dont fonctionne la rémunération des médecins les prestations (prolongées) d'assurance-maladie. Un autre problème se situe dans la concentration des connaissances et des services spécialisés dans les établissements de soins, qui se traduit par une absence (ou une pénurie) de services dans la communauté. Enfin, les intervenants mentionnent aussi les contradictions qui opposent les décisions systémiques, ancrées dans les priorités biomédicales, et la philosophie des soins axés sur la personne. De leurs propos se dégage une forme de paternalisme qu'ils qualifient « d'arrogance institutionnelle » par rapport au nombre croissant de survivants du cancer et à la responsabilité de les soutenir.

DISCUSSION

Plusieurs de nos résultats confirment la pertinence de critiquer l'équité, un sujet de plus en plus abordé dans la littérature sur les soins du cancer ces dernières années (Truant, 2017). Nous croyons que la méthodologie multidimensionnelle à plusieurs niveaux adoptée pour la présente étude nous a permis de mettre en lumière les difficultés inhérentes à l'adoption, au Canada, d'une approche de soins aux survivants du cancer de grande qualité axée sur la population. Plus particulièrement, cette méthodologie nous amène à reconnaître non seulement le niveau relativement élevé de besoins non satisfaits de ce que nous appelons des « groupes visés par l'équité », mais également les nombreux et divers besoins des individus qui, pour toutes sortes de raisons, ne cadrent pas dans les normes

dominantes. L'une des retombées les plus importantes de cette étude est sans contredit de jeter les bases d'une réflexion critique nécessaire sur la définition de la survivance dans le contexte de la médecine personnalisée, en pleine évolution, ainsi que sur les patients qui sont avantagés ou, au contraire, systématiquement désavantagés par les idées que nous entretenons ainsi que par les structures de soins aux survivants et les moyens actuellement mis en place pour déterminer qui doit recevoir des soins et quels types de soins sont appropriés.

Des voix s'élèvent toutefois pour faire entendre celles des survivants du cancer, ce qui nous semble très prometteur. À ce chapitre, soulignons l'importance toute particulière du récent appel national à se fonder sur l'expérience des patients qui vivent avec le cancer et qui survivent à la maladie pour guider les pratiques cliniques, les processus administratifs du système de santé, et les bases de données gouvernementales des provinces et des territoires (PCCC, 2018).

À la lumière de ces résultats, nous sommes conscients de la nécessité de porter une attention particulière aux discordances entre l'offre de services à l'échelle de la population et les soins nécessaires pour répondre aux besoins uniques et distinctifs des individus afin de relever les défis liés à la survivance au Canada, en écoutant notamment les patients et les professionnels, qui sont de plus en plus nombreux à revendiquer du changement. Pour ce faire, nous devons repenser les modèles organisationnels ayant traditionnellement structuré et hiérarchisé les soins du cancer, et les soins de santé en général. Enfin, il faudra revoir le déploiement des ressources de soins, notamment le rôle des différentes professions dans la planification, la prestation et la direction des soins, particulièrement complexes, dédiés aux survivants.

Recommandations pour l'amélioration du système

Bien que les obstacles à l'équité et à la qualité des soins aux survivants du cancer soient nombreux et complexes, nous pouvons aussi en apprendre beaucoup en misant sur les forces du système qui sont rapportées dans la documentation, ainsi que dans les propos des survivants et des intervenants. Il nous faut aussi reconnaître que l'approche traditionnelle, qui met l'accent sur l'aspect curatif des soins du cancer, a abouti à un système axé sur la pathologie aiguë et épisodique plutôt que sur l'intégration des soins à la vie quotidienne des patients et des survivants, qui sont fort nombreux. Nous comprenons tous l'importance des traitements, mais si nous sommes sincères dans notre idéal d'offrir des soins axés sur la personne, la gestion de la maladie ne doit pas se faire aux dépens des besoins psychologiques, émotionnels, spirituels et informationnels du patient (PCCC, 2018). Et bien que les lignes directrices fondées sur les données probantes soient extrêmement utiles au moment de concevoir et de dispenser les traitements, elles occultent nécessairement la pertinence des différences individuelles (Thorne et Sawatzky, 2014). Par conséquent, nous organisons nos systèmes de soins en fonction de la « personne moyenne » en mettant de côté la diversité et le contexte, car nos approches reposent uniquement sur des critères normatifs (Sulik, 2013). Nous devons éviter d'adhérer aveuglément à des idéologies organisationnelles, qu'il s'agisse de pratiques

fondées sur les données probantes ou de soins axés sur la personne, et tenir compte du fait que ces idéologies peuvent entrer en conflit les unes avec les autres, sachant que les patients en feront les frais si nous ne collaborons pas pour résoudre en priorité les enjeux complexes et très concrets de l'iniquité.

Nous savons que le fait de définir les standards des soins aux survivants du cancer en privilégiant les normes eurocentriques est une pratique colonialiste ayant des répercussions réelles sur les personnes qui n'entrent pas dans le moule théorique (Anderson et al., 2009). Nous aurions tout avantage à impliquer davantage les groupes visés par l'équité et à profiter de leurs commentaires constructifs pour déterminer quelles sont nos préconceptions des soins qui desservent systématiquement différents groupes de survivants. Nous devons aussi apprendre à écouter l'avis réfléchi des gens qui sont au cœur de l'action, notamment les décideurs du système de santé et les cliniciens, sur certains sujets tels que les groupes moins bien servis par nos établissements et services de soutien. Nous disposons déjà d'outils précieux pour bien nous préparer à accueillir toute la diversité individuelle avec laquelle nos systèmes doivent inévitablement composer si nous voulons favoriser l'émergence de systèmes qui pourront fournir des soins d'excellente qualité aux groupes minoritaires les plus vulnérables.

Nous savons, grâce aux survivants du cancer, qu'une communication efficace et une bonne relation avec les professionnels de la santé sont la clé pour aplanir les relations hiérarchiques que les patients perçoivent comme un obstacle aux soins. En voyant nos systèmes comme des incubateurs de relations et non comme des établissements dépersonnalisés qui ne servent que d'unités de services, nous pourrions concentrer nos efforts à combler les lacunes et à satisfaire les besoins des patients. La continuité des soins fait depuis longtemps partie des idéaux de la pratique infirmière et nous devons continuer de défendre notre capacité à nouer des liens continus et à assurer un transfert des soins efficace du point de vue relationnel. Lorsque les critères de mesure et la quantification des facteurs complexes de la qualité de vie éclipsent l'aspect relationnel des soins, il va de soi que cet aspect cesse d'être considéré comme une priorité. Nous devons donc trouver des manières de remettre la communication au centre de la trajectoire des soins du cancer, non seulement pour assurer la sécurité des patients, mais aussi pour nous assurer de placer la participation des patients au cœur de nos approches de soins.

Pour faire évoluer les soins aux survivants, nous devons envisager l'adoption de modèles de soins stratifiés en fonction de la complexité des besoins. Cela présuppose que nous connaissions les besoins de nos patients et que nous créions ensemble des approches de soins, avec la collaboration active des intervenants et des survivants. Nous croyons que de confier aux infirmières la direction des soins aux survivants offre de grandes possibilités. Pour ce faire, il serait notamment possible d'embaucher des infirmières spécialisées en oncologie (inf. aut. ou IP) dans les milieux de soins de première ligne, en modifiant les modèles en place en fonction

des préoccupations actuellement criantes dans le domaine de la survivance, mais également de celles à venir. Évidemment, pour apporter de tels changements, il faudrait modifier la structure en place et la culture institutionnelle, notamment en ce qui a trait au rôle joué par les infirmières dans de nombreuses organisations de soins du cancer. Plutôt que d'organiser les soins en fonction des groupes de tumeurs, comme le préconise le modèle biomédical traditionnel, d'ailleurs mis à mal par la médecine de précision et les nouvelles philosophies de la prise en charge du cancer, nous devrions militer en faveur d'une organisation fondée sur les expériences et les besoins des patients intégrant des services comme le soutien en cas de maladies chroniques ainsi que l'approche palliative des soins, qui sous-tendent des objectifs de soins individualisés. Les modèles de soins menés par les pairs auront leur rôle à jouer, mais puisqu'ils fonctionnent mieux pour certains groupes de survivants que d'autres, ils ne peuvent remplacer une véritable intégration des soins. De plus, nos modèles doivent proposer des ressources facilement accessibles pour le retour au travail, le soutien familial et le soutien communautaire.

Pour tirer parti des possibilités qui s'offrent à nous, nous allons évidemment devoir miser sur la sensibilité culturelle (par un accueil respectueux et déférent de la culture de l'autre), un concept qui devra faire l'objet de formations et auquel tous les professionnels de la santé devront être sensibilisés, qu'ils soient du domaine des soins spécialisés ou des soins de première ligne. Nous allons aussi devoir soutenir les communautés de pratique grâce auxquelles les professionnels de la santé peuvent continuer d'enrichir leur compréhension de la complexité des soins aux survivants afin de maintenir leur engagement à cet égard.

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Vision d'avenir

Pour arriver à dispenser des soins de grande qualité aux survivants du cancer en toute équité, nous devons poursuivre les efforts de recherche et de sensibilisation. Voici deux des grandes questions qui devront orienter notre recherche de modèles de soins évolutifs : a) Comment et où intégrer les difficultés psychologiques, sexuelles, sociales et financières que vivent les survivants et qui caractérisent plusieurs de leurs besoins de première nécessité? et b) Comment articuler des lignes directrices pour l'ensemble de la population qui n'éviteront pas les préoccupations immédiates et très concrètes des individus, et particulièrement des personnes les plus vulnérables? Le Partenariat canadien contre le cancer a clairement décrit la voie que doit suivre le Canada :

Entre le moment où l'on commence à se demander si on est atteint d'un cancer et les soins de suivi après le traitement, il s'agit d'une expérience continue pour toutes les personnes concernées. L'offre de soins centrés sur la personne à chaque étape de cette expérience permet de considérer les patients et les membres de leur famille comme des personnes uniques, de leur prodiguer des soins coordonnés qui prennent en compte leur temps et leurs préférences, de leur donner accès à des renseignements utiles qui favorisent l'autonomie en matière de soins, et de combler leurs différents besoins à mesure qu'ils se présentent (PCCC, 2018, p. 45).

Pour arriver à offrir à l'ensemble de la population canadienne des soins aux survivants de grande qualité, nous devons aligner les recherches en cours avec la riche sagesse expérientielle et clinique des professionnels responsables de la prestation des services au quotidien. Nous devons aussi travailler de concert pour porter à l'attention des planificateurs et des décideurs les réflexions critiques qui leur permettront de suivre les progrès et diagnostiquer les lacunes.

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Supportive care experiences of rural women living with breast cancer: An interpretive descriptive qualitative study

by Joanne Loughery and Roberta L. Woodgate

ABSTRACT

Breast cancer is the leading cause of female cancer in Canada. However, there is limited research on the health and supportive needs of rural women living with this illness. The purpose of this qualitative study was to arrive at an increased understanding of the supportive care experiences of rural women requiring treatment for invasive breast cancer who reside in rural Manitoba. To explore this phenomenon, an interpretive descriptive qualitative study was completed. Twenty women from four regional health authorities participated in the study. Data were collected using face-to-face, semi-structured interviews and analyzed by content analysis through an interpretive qualitative lens. The findings presented emphasize a holistic overview of the experiences of women living with breast cancer that captured both the positive aspects of living rurally and the described rural challenges. Pragmatic recommendations have been generated from the study findings that have implications for nursing practice and service delivery.

Key words: breast cancer, supportive care, experiences, rural, qualitative, interpretive description

Cancer is a devastating illness regardless of where a person lives. Breast cancer is the leading cause of female cancer in Canada with approximately 26,300 Canadians diagnosed each year (Canadian Cancer Society [CCS], 2017). One in every five Canadians lives in a rural setting, accounting for 18.9% of the population (Statistics Canada, 2015). Canadian research on the rural breast cancer experience is limited, with only two previous studies noted in the literature (Gray, James, Manthorne, Gould, & Fitch, 2004; Fitch et al., 2003). With the rising incidence in breast cancer in our country, it remains an important healthcare topic. Moreover, access to oncology expertise and services is limited in rural settings, therefore extensive travel and relocation is inevitable. By utilizing qualitative

inquiry in this study, the voice of rural Manitoba women living with breast cancer has been captured and provides a theoretical foundation for intervention and opportunity for positive change that warrants consideration.

BACKGROUND

In Manitoba, approximately 860 women are diagnosed with breast cancer each year (CCS, 2017). Invasive, ductal carcinoma accounts for 80% of all breast cancer cases. As a result, multi-modality therapy that involves a combination of surgery, chemotherapy/biologic therapy, radiation, and long-term hormone treatment is required (Crane-Okada & Loney, 2007; National Comprehensive Cancer Network [NCCN], 2014). The complexity of the experience increases for rural women due to lack of access to oncology services and fragmentation of healthcare available in rural settings. Cancer services in Manitoba include the following: specialized cancer service in the province capital; Western Cancer Centre in second largest city in Manitoba including multidisciplinary oncology services, chemotherapy, radiation and limited surgical procedures; 15 rural community cancer programs (CCP) that deliver chemotherapy, symptom management and follow-up care; and navigation, psychosocial oncology, and primary care in oncology programs in each regional health authority (CancerCare Manitoba [CCMB], 2000; 2017). Despite this, the need to travel to the urban centre is inevitable because surgery, breast reconstruction and radiotherapy are not available in most rural settings.

The supportive care framework is a tool utilized by health professionals to conceptualize the needs of individuals living with cancer (Fitch, 2009). Cancer is an unanticipated life event. It can create feelings of anxiety and vulnerability when basic human needs are not met. Individuals have a wide range of needs including the physical, social, psychological, emotional, spiritual, informational and practical domains. As treatment complexity increases, so will needs in each of these domains (Fitch, 2009). The supportive care framework was used to guide the research process in this study.

A review of the literature was completed and provided a foundation to explore the phenomenon of supportive care and the experiences of rural women living with breast cancer. Initially, an overview of breast cancer care across the illness trajectory was completed. It was apparent from the literature that each phase of illness has unique challenges and treatment-related problems (Crane-Okada & Loney, 2007; Fitch, 2009; NCCN, 2014).

Next, the needs of all women living with breast cancer were explored. Needs exist in each domain of the supportive

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care framework and no two individuals have exactly the same response to cancer and its treatment. However, common patterns within the breast cancer and rural experience are apparent. Some challenges related to rural living that are featured in the literature include: physical symptoms exacerbated by travel; limited access to family doctors; isolation from oncology expertise; social disruptions related to relocation; lack of privacy in rural communities; additional out-of-pocket costs related to travel and relocation; and treatment decisions made based on inability to travel (Fitch et al., 2003; Gray et al., 2004; Loughery & Woodgate, 2015; Matthews, West & Buehler, 2009; Pesut, Robinson, Bottorff, Fyles, & Broughton, 2010). However, there are also many positive aspects to rural living noted in the literature including: extension of support and close community ties; hardiness and resilient characteristics that foster effective coping; physical beauty and peaceful living; and close access to religious affiliations (Compas & Luecken, 2002; Pesut et al., 2010; Rogers-Clark, 2002; Winter & Lee, 2010).

Lastly, other models of oncology care from a national and international perspective were explored. It became clear that decentralization of cancer services into rural setting would improve services for all people living with cancer, but there is still room for improvement (Adams et al., 2009; Carlow, 2000; Clinical Oncology Society of Australia, 2006; National Institute for Clinical Excellence, 2004). With this in mind, this research project was initiated.

PURPOSE

The primary purpose of this qualitative study was to arrive at an increased understanding of the supportive care experiences of adult women requiring treatment for invasive breast cancer who reside in rural Manitoba. Findings were described from detection to the end of the treatment phase of illness and recommendations were generated directly from the study findings.

METHODS

Interpretive description, a qualitative investigation of clinical phenomenon, was utilized for this study (Thorne, 2008). This methodology provided a basis to understand the illness experience and how nurses make a difference and, ultimately, impact the lives of people living with illness. Interpretive description is rooted in a naturalist orientation, which honours individual experiences and, at the same time, allows for shared realities. These shared realities were used to generate an interpretive description capable of informing practice (Thorne, 2008). Ethics approvals from the Nursing Research Ethics Board, four health authorities and CCMB were obtained.

Inclusive criteria included the following: 1) adult women who were able to speak, read and write in English with no cognitive impairment; 2) a diagnosis of invasive breast cancer following completion of multi-modality treatment within the last three years; and 3) women who reside in rural or northern areas of the Manitoba. Women were excluded from the study if they had stage IV, relapsed or progressive illness, which results in different treatment plans. Purposive sampling was utilized to capture the essence of the rural breast cancer

experience through the shared characteristics (Streubert & Carpenter, 2011). A naturalistic setting of the participant's choice was honoured, which required more than 10,000 km of travel across the province.

Data were collected through face-to-face interviews, demographic questionnaires, field notes and journaling. Twenty first interviews and 12 second interviews were completed. At this point, the authors determined that repetition of data was occurring and no new information was surfacing (Streubert & Carpenter, 2011). Therefore, the remaining eight second interviews were not completed.

The women participated in open-ended, semi-structured interviews, which were recorded and transcribed verbatim. All the interviews were coded and analyzed through directed content analysis. This approach was used to validate the theoretical framework by looking at relationships within the coded data (Zhang & Wildemuth, 2009). Both authors iteratively reviewed all the raw data until interpretive descriptions were developed and then deductively shaped the data into categories within the domains of the framework. At the conclusion of the study, each of the study participants was provided with a summary of the findings with an open invitation for clarification. Methodological rigor was addressed through prolonged engagement with the participants, returning to the participants by way of member checking, peer review and debriefing, and documenting a detailed audit trail (Streubert & Carpenter, 2011).

DEMOGRAPHIC AND QUALITATIVE FINDINGS

Demographic Findings

Demographic data include participant descriptions, treatment modality data, and regional and travel demographics. Demographic data were collected through questionnaires and analysis of each interview.

Participant Description. Five women from each health authority, representing four regions of the province, participated in the study. The age ranged from 34–85 years with the majority of women between the ages of 46–65 years. Eleven women were married while the remainder were single, widowed or separated. Six women lived alone and the remainder lived with their spouse, adult children, children or grandchildren. Ten women were employed at the time of their diagnosis and five women worked through various stages of their treatment. The women who were employed worked in a variety of settings including healthcare, retail, office or home-based business. Half the women had completed postsecondary education and the remainder obtained Grade 12 or less. The majority of the women were Caucasian.

Treatment Modality Demographics. Ten women received a lumpectomy and the remainder received a unilateral or bilateral mastectomy with or without reconstruction or implant. All women required 4–8 cycles of chemotherapy and seven women required an additional year of biologic therapy. All of the women completed involved-field radiotherapy and 16 had initiated hormone therapy.

Regional and Travel Demographics. Eleven women lived or were close to a city with a population of 7,500 people or greater, while the remainder lived or were close to a town with a population less than 7,500 people. Sixteen women had a rural CCP in their community and four women were required to travel to access chemotherapy services. The travel distance to Winnipeg by these women was between 62–1,100 km and to Brandon was from 15–182 km. The women from one region had access to additional services in Brandon including surgery, chemotherapy and radiation. The primary mode of travel was land, but four women from the northern region utilized air travel and had access to financial compensation through Northern Patient Transport Services. Seventeen women had surgery in Winnipeg and the remainder in Brandon. Eighteen women had chemotherapy in a rural CCP and the remainder in Winnipeg. Sixteen women had radiation in Winnipeg and the remainder in Brandon.

Supportive Care Qualitative Findings

The findings have been categorized according to the domains in the supportive care framework (Fitch, 2009). A summary of the most common experiences is featured, however, individual variations are not captured.

Physical Domain. The physical domain was very demanding for the women. The side effects varied based on the mode of therapy. Chemotherapy was the most challenging treatment modality. Additionally, physical challenges occurred in relation to living rurally. During initial diagnosis, challenges occurred related to the travelling mammogram program or obstacles posed delays in diagnosis related to variables such as winter driving. During treatment, travel continued to be a challenge related to worsening physical symptoms such as fatigue, pain or skin reactions. Additionally, travel safety concerns were apparent related to symptoms such as overwhelming fatigue, “chemo fog” or not being able to wear a seatbelt following surgery. One single woman who drove herself daily to her radiation treatments, talked about travel safety as a primary concern.

But you know, with the chemo fog and being tired from radiation, you don't think properly, I should not have been driving.

Access to experienced and qualified health professionals in non-cancer settings or limited rural emergency services to manage complex physical needs was also a worry for these women. As a result, additional burdens on family and friends for travel or care for complex physical needs resulted. However, the positive roles of the rural cancer program and home care services were described and helped many transition through the physical demands that were encountered.

Informational Domain. Information was retrieved from a variety of health providers including family doctors, oncology specialists, hospital staff, urban and rural nurses, nurse navigators and other interdisciplinary professionals. A number of factors impacted the ability to process the information including escalating fears, long travel days, condensed appointment schedules, complex information, or lack of a support person

available to attend the appointment. A 50-year-old woman, who lived a considerable distance from the urban centre, talked about enduring multiple appointments with specialists in a short period of time. She subsequently felt pressured to make a treatment decision she later regretted.

Everything just happened so fast, I started thinking like, oh, what happened if I feel like because I don't have breasts, like everything just happened so fast that I wouldn't have gotten reconstructed...I had to make up my mind right there when they were telling us and it's like uh, like it was all so fast.

Access to family doctors appeared to be fragmented across the province and communication between rural and urban sites also provided challenges. Additionally, it became apparent that rural providers or hospital staff with limited knowledge about cancer-related problems became an additional challenge. The role of the nurses and staff at the rural cancer centre was vitally important to meet the informational needs of the women, but there was a lack of physical space or privacy for personal discussions in the rural sites. The use of nurse navigators or access to other interdisciplinary health professionals was limited and would have proved to be very useful. Many informational resources or other supportive services were utilized and both positive and negative opinions on the usefulness were described.

Social Domain. A vast scope of social networks including immediate or extended family, friends or community members was described and utilized at different points in time during the experience. The scope of supportive networks also varied based on marital status or available family or friends in the communities. Living alone was viewed both positively and negatively, but did pose practical challenges. Additionally, health providers, especially nurses in the rural setting, were an important source of support for the women and viewed positively.

The love of rural life was apparent. A strong sense of community atmosphere and peaceful living was described by the women. However, it also posed specific obstacles such as lack of anonymity, invasion of privacy, or communication challenges with others and would often lead to feelings of isolation. One woman who lived in a small community her entire life felt her diagnosis was a very personal experience and, for this reason, isolated herself from others in the community for the duration of her treatment. At the time of the interview, a year following treatment, she was just starting to re-integrate into public life.

Yeah, 'cause everyone knows everyone's business. That's the way it is. If you are a private person and you want to keep things private, it's pretty tough... and usually it gets out and it goes like wildfire.

Furthermore, relocation for treatment, physical challenges of illness and avoidance of public places or other people were also found to be isolating. A number of women talked about being approached by either complete strangers or distant acquaintances asking them very personal questions

about their illness or making comments that were upsetting or made them feel very uncomfortable. Other unique obstacles to rural life included personal connections with caregivers or having treatment with known community members. Some women talked about feeling very comfortable in the close-knit supportive environment of the CCP, whereas others were very uncomfortable in that intimate, personal setting.

Practical Domain. Many practical challenges existed and complicated the experience for these women. Managing basic daily activities when faced with other chronic illness became challenging. Other daily household chores or provision for dependent family members also required additional support. Some women had the needed support to help them manage, but others were forced to hire additional help or had no choice but to manage independently. This would often include the care of large acreages or farmyards. The burden of extensive travel, relocation, employment challenges and financial losses were significant findings in this study. Multiple trips to an urban centre, hazardous driving conditions, highway construction or navigating an unfamiliar city added to the complexity of the experience. Accommodating appointment schedules around travel was highly appreciated. However, limited diagnostic services in rural settings increased their demanding schedules.

Additionally, the northern women had unique challenges related to air and bus travel and were forced to relocate for radiation because of where they lived. Some women had the option to commute or relocate for radiation, but the decision significantly added to either the cost of relocation or the burden of travel. Supportive and affordable accommodation or staying in other comfortable lodgings proved to enhance the experience for the relocated women. However, some were not provided with this opportunity. The financial burden of cancer was apparent. Employment challenges, lost income and out-of-pocket costs were the primary issues contributing to this burden. One single woman talked about financial challenges prior to her diagnosis and how not being able to work and the additional out-of-pocket costs associated with rural life were financially devastating for her. This ultimately led to her moving out of her current living space to a more affordable option.

It cost me a lot because of the fact that I had to leave work. I didn't have my income coming in anymore, so I, I went through pretty much everything I had in my savings.

Out-of-pocket costs would include fuel, accommodation, taxi rides, meals, household care, parking or purchasing additional medical supplies. Although financial support from friends, family and communities was appreciated, the out-of-pocket cost associated with living rurally remained noteworthy.

Emotional Domain. Many emotions were described during the course of the interviews. Shock, disbelief, denial, fear, uncertainty, anger, guilt and feelings of anxiety were discussed. These are very common feelings when presented with a diagnosis of cancer. However, many of these emotions

were heightened by the rural experience. Increased emotions around relocation, challenges with inexperienced or insensitive care providers, and additional costs were featured. Travel burden also added to the ongoing emotional stress the women were experiencing. One woman described an incident where she drove hours to receive her biopsy results, filled with anxiety. Following a lengthy wait to see the specialist to receive her results, she then had to drive back to her home town alone filled with emotions. Many similar stories were illustrated during the interviews.

They are going to tell me that I have cancer and I have to drive here and then wait for two hours. I was kind of angry about that.

There were many descriptions about ways to release and cope with the complex emotions the women endured. Crying, venting or spending time alone were often useful. Additionally, using distraction such as music, yoga, meditation or gardening was also described. Many found solace in family, friends, co-workers, congregation members, care providers and other cancer survivors to help them through the experience. Moreover, the impact of close-knit communities and highly personalized care in the rural cancer settings also helped facilitate their emotional needs. Family response to illness was not thoroughly explored in this study, but it was apparent that a cancer experience is a family affair and separation from family related to relocation or travel was emotionally difficult.

Psychological Domain. Unmet needs in the psychological domain were described such as loss of control over the illness experience, altered body image related to hair loss or loss of a breast, or decreased self-esteem. Finding ways to cope with all these additional unmet needs was necessary. Gaining personal control by changing perspective on the illness or looking for positive opportunities as a result of the illness proved to be helpful for some. Additionally, utilizing distractions or taking a step-by-step approach to the illness also helped lessen these overwhelming feelings. One woman described many emotions related to her cancer journey and the only way she felt in control was by focusing on the here and now. In this situation, she chose to travel for more than six hours per day over the course of her radiotherapy treatments with the support of her spouse.

I guess you just cope the best you can... Like you almost kind of get into this mode where, well I have to do this, this is what I'm focusing on right now, this is what I have to do, like going back and forth to the city every day, that was what you had to do.

Focusing on staying well and fit proved to be very important and would result in some women feeling more energized and in control. Several attributes were also apparent such as resilience, self-reliance and optimism, which also fostered effective coping and promoted a positive self-esteem.

Spiritual Domain. As difficult as the journey was, it was often described as a time for discovery. For some of the women, facing their own mortality remained a very fearful process,

but many found different ways to cope with this ongoing uncertainty. Some found solace and comfort in their spiritual practices or prayer, yet were challenged to attend services because of other physical or social demands. One woman described her sole strength was her faith in God. However, she did isolate herself from her congregation because she felt shame from her diagnosis and found it very difficult to talk to others.

I couldn't have done this without God and prayer. And that's where I get all my strength from, because on my own I was weak, and I had to really count on him, especially going into the chemo.

Some women described the journey as just another hurdle in their lives. Others were unable to explain why the diagnosis happened to them and, therefore, moved through a process of finding a deeper meaning to the illness. Meaning and gaining new perspectives, such as developing a new and deeper sense of self or family, feeling thankful for life and each new day, or developing new and existing connections with others were described. Some women talked about this as a life-changing journey.

DISCUSSION

Our study provided an in-depth picture of the supportive care experiences of women requiring treatment for invasive breast cancer who reside in rural Manitoba. Guided by Fitch's (2009) holistic supportive care framework, we detailed both the positive and negative aspects of living rurally when faced with illness. We anticipate these findings should be of interest to nurses who work with rural people living with cancer. The findings are strongly supported by the literature and, therefore, provide grounding to develop tailored interventions to improve cancer services for rural individuals living with cancer.

Nurses working in oncology are positioned to provide professional leadership at many levels of the health system and pave the way to improve services for rural people living with cancer (Canadian Association of Nurses in Oncology [CANO], 2001). The role of nursing in both urban and rural sites is highly valued and it is imperative that nurses are familiar with the rural implications when faced with an individual from a rural setting who is diagnosed with cancer.

Additionally, the women who used navigation services described that role as essential. However, navigational service was underutilized. Nurse navigators are positioned to provide patient and family-centred services, provide ongoing patient education, act as advocates, and serve as a liaison between oncology specialists, primary care physicians, rural cancer practitioners and treatment staff. They also facilitate the web of diagnostic procedures and multiple treatments while providing overall case management through each phase of the cancer journey (Farber, Deschamps, & Cameron, 2002). This coordination of care throughout the treatment trajectory is essential for people living with cancer and becomes more crucial for our rural cancer population because of fragmentation of services. Concepts such as ambulatory oncology, early

discharge from acute settings, complex treatment plans and early follow-up in primary care settings can make the cancer experience that much more confusing for patients and their families. Nurses practising in both cancer and non-cancer settings can provide a link to continuous and coordinated care while considering the complex rural issues that were presented in the findings of this research study.

Recommendations (Appendix A, Table 1) generated from this study could enhance service delivery in rural areas. These recommendations could provide the opportunity to prevent delay in diagnosis, improve wait times, decrease travel demands, promote family-centred care, enhance support and services, and facilitate positive adaptation to the cancer experience. Many challenges exist in rural healthcare, which are highlighted in a report mandated by the Government of Manitoba in 2017 (Peachey, Tait, Adams, & Croson, 2017). Recommendations from this report that could potentially improve services for people living in rural areas include increased interdisciplinary care in primary care settings, enhanced rural home care supports, increased use of telehealth services, and increased funding for travel for people living in geographically isolated areas. Alternatively, re-alignment and centralization of emergencies and paramedic services across the province could be problematic (Peachey, 2017).

Additionally, CCMB 2016–2021 Strategic objective #5 (CCMB, n.d.) highlights the need to improve care for underserved populations. Provision of new and enhanced access to services for residents of geographically-isolated areas was identified as a priority. The authors of this manuscript challenge nurses in Manitoba and across the country to become familiar with any recent policy documents from the government and to utilize this as leverage to initiate change. The recommendations presented in this study are not new ideas, but are still valid and should be considered as a priority.

There are study limitations that warrant discussion. First, the age differentiation of the women was not thoroughly explored. It did not become apparent during the interview process that there was a major difference in the experiences based on age. However, age and lived breast cancer experience certainly warrant further inquiry. Moreover, people who live in remote areas were not captured in the study and it could be assumed that the challenges they face would be increasingly complex. Additionally, populations such as men living with illness, different cultural ethnic backgrounds, long-term survivors, advanced or palliative diagnosis and family caregivers were not featured. These indications provide a path for future research to gain insight into the depth of the rural experience in other populations.

However, the findings generated from this research provide rich descriptions and insight into the rural experience and illuminate areas where change can and should happen. It will take a collaborative and collective effort to drive the vision to improve supports and service through the words of the women. Nurses in collaboration with other health professionals who work with rural cancer patients are positioned to provide leadership in this regard.

CONCLUSION

The study findings feature the supportive care needs of rural women living with breast cancer from diagnosis to the end of the treatment journey. The findings and recommendations should be considered from a national perspective, as similar models of cancer service and geographic isolation in cancer populations remain as challenges across the country. We cannot change the fact that people live in rural areas of the country and specialized oncology services are primarily located in large urban settings. However, nurses and other care providers need to consider the unique features and implications that people face with a diagnosis of cancer who live rurally. There is still more that can be done to improve supports and services and enhance the quality of life and care for people living with this difficult illness in rural areas. The findings from this study provide insight into an important healthcare topic and a starting point to create awareness and change.

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APPENDIX A

Table 1. Recommendations for Service Delivery

- Increase diagnostic procedures in rural settings.
- Encourage specialist site visits in rural communities.
- Record sessions with specialist.
- Increase awareness and utilization of navigation programs.
- Enhance rural primary care services and linkage to CCMB.
- Increase use of interdisciplinary healthcare team in rural areas.
- Increase use of telehealth services.
- Improve emergency care in rural settings.
- Encourage family escort during travel to enhance family-care giving.
- Consider discharge times and appointment schedules around travel.
- Promote socially directed supportive services such as meal service, driver programs or education or peer support programs in rural settings.
- Expand supportive relocation facilities and accommodations in urban settings.
- Improve aesthetics and private spaces in rural cancer settings.
- Expand oncology educational opportunities for practising generalist.

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Expériences des soins de soutien des femmes atteintes de cancer du sein vivant en milieu rural : étude qualitative et description interprétative

par Joanne Loughery et Roberta L. Woodgate

RÉSUMÉ

Au Canada, le cancer du sein est le type de cancer le plus fréquent chez les femmes. Malgré tout, la recherche s'est peu intéressée aux besoins en matière de soins de soutien des femmes des régions rurales prises avec cette maladie. L'objectif de la présente étude qualitative est donc de mieux comprendre les expériences de soins de soutien des Manitobaines qui vivent en milieu rural et qui doivent subir des traitements pour un cancer du sein invasif. Le phénomène a été exploré à l'aide d'un devis qualitatif, descriptif et interprétatif. Vingt femmes de quatre régions régionales de la santé ont participé à l'étude. Des entrevues semi-structurées conduites en personne ont permis de recueillir les données, qui ont par la suite été soumises à une analyse qualitative interprétative. Les résultats obtenus brossent un portrait holistique des expériences vécues par les femmes atteintes de cancer du sein qui reflète à la fois les aspects positifs et négatifs de la ruralité. Les recommandations pragmatiques, formulées à partir des résultats de l'étude, orienteront la pratique infirmière et la prestation des services.

Mots-clés : cancer du sein, soins de soutien, expériences, ruralité, étude qualitative, description interprétative

Le cancer est une maladie dévastatrice, quel que soit le lieu de résidence de la personne qui en est atteinte. Au Canada, le cancer du sein est prédominant chez les femmes; chaque année, elles sont environ 26 300 à en recevoir le diagnostic (Société canadienne du cancer [SCC], 2017). Un Canadien sur cinq vit par ailleurs en région rurale, ce qui correspond à 18,9 % de la population (Statistique Canada, 2015). Malgré tout, la recherche canadienne sur l'expérience d'avoir un cancer du sein en milieu rural est limitée : deux études seulement figurent dans la littérature à cet égard (Gray, James,

Manthorne, Gould et Fitch, 2004; Fitch et al., 2003). Avec l'incidence croissante du cancer du sein au pays, ce sujet demeure prépondérant. En outre, comme l'accès aux services et aux spécialistes en oncologie est restreint dans les régions rurales, les patients doivent inévitablement voyager beaucoup et se reloger. Nous avons choisi de réaliser une étude qualitative pour donner la parole aux Manitobaines des régions rurales atteintes de cancer du sein et jeter les fondements théoriques des possibilités d'intervention et de changement qui méritent considération.

CONTEXTE

Au Manitoba, environ 860 femmes reçoivent un diagnostic de cancer du sein chaque année (SCC, 2017); dans 80 % des cas, il s'agit de carcinomes canaux infiltrants. Le traitement recommandé est donc multimodal, combinant chirurgie, chimiothérapie et thérapie biologique, radiothérapie et hormonothérapie à long terme (Crane-Okada et Loney, 2007; National Comprehensive Cancer Network [NCCN], 2004). L'expérience est cependant plus complexe pour les femmes vivant en milieu rural, vu la difficulté d'accès aux services d'oncologie et la fragmentation des soins de santé en région. Au Manitoba, des soins du cancer spécialisés sont offerts dans la capitale provinciale; les patients peuvent aussi bénéficier de services d'oncologie multidisciplinaires, de chimiothérapie, de radiothérapie et de certaines interventions chirurgicales au Western Cancer Center, situé à Brandon, dans la deuxième ville en importance du Manitoba; quinze programmes communautaires de lutte contre le cancer en milieu rural s'occupent d'offrir de la chimiothérapie ainsi que la prise en charge des symptômes et des soins de suivi, et des programmes de navigation, d'oncologie psychosociale et de soins de première ligne en oncologie sont en place dans chaque région régionale de la santé (Action Cancer Manitoba [ACM], 2000; 2017). Malgré tout, les patientes n'ont pas le choix de se rendre dans un centre urbain, car la chirurgie, la reconstruction mammaire et la radiothérapie ne sont pas accessibles dans la plupart des régions rurales.

Le Cadre de soins de soutien est un outil utilisé par les professionnels de la santé pour conceptualiser les besoins des patients aux prises avec le cancer (Fitch, 2009). Le cancer est un événement imprévu de la vie qui peut entraîner des sentiments d'anxiété et de vulnérabilité lorsque les besoins de base de la personne ne sont pas comblés, qu'ils soient physiques, sociaux, psychologiques, émotionnels, spirituels, informationnels ou pratiques. Et chaque fois que le traitement gagne en complexité, ces sphères de la vie se compliquent elles aussi (Fitch, 2009). Le Cadre de soins de soutien a servi de guide au

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processus de recherche de la présente étude.

Une revue de littérature a servi de base pour explorer le phénomène des soins de soutien et les expériences des femmes vivant en milieu rural qui sont atteintes de cancer du sein. La première étape a été de faire un survol des soins de cancer pour toute la trajectoire de la maladie, ce qui a fait ressortir combien chaque étape présentait des problèmes associés au traitement et défis particuliers (Crane-Okada et Loney, 2007; Fitch, 2009; NCCN, 2004).

Ensuite, l'exploration s'est tournée vers les besoins de toutes les femmes atteintes de cancer du sein. Chaque domaine du Cadre de soins de soutien regroupe des besoins différents, sans compter que la réaction à la maladie et au traitement n'est jamais exactement la même d'une personne à l'autre. Toutefois, dans le cas du cancer du sein et de l'expérience des patientes vivant en milieu rural, certaines tendances se dégagent. La littérature aborde quelques-unes des difficultés liées à la ruralité : l'exacerbation des symptômes physiques à cause des déplacements; l'accès limité aux médecins de famille; l'éloignement des spécialistes en oncologie; les perturbations sociales liées au relogement; le manque d'intimité dans les collectivités rurales; les frais supplémentaires que les patients doivent payer de leur poche pour le transport et le logement; les décisions thérapeutiques prises en fonction de l'incapacité à voyager (Fitch et al., 2003; Gray et al., 2004; Loughery et Woodgate, 2015; Matthews, West et Buehler, 2009; Pesut, Robinson, Bottorff, Flyes et Broughton, 2010). Toutefois, la vie à la campagne présente aussi de nombreux aspects positifs, mentionnés dans la littérature, par exemple : l'extension du soutien et les liens étroits entre les membres de la communauté; la résilience et la force de caractère, gages d'une adaptation efficace; la beauté et la tranquillité de l'environnement; la proximité de la congrégation religieuse d'appartenance (Compas et Luecken, 2002; Pesut et al., 2010; Rogers-Clark, 2002; Winter et Lee, 2010).

Enfin, les autres modèles de soins oncologiques ont été explorés selon une perspective nationale et internationale. De toute évidence, la décentralisation des soins du cancer vers les régions rurales améliorerait les services pour tous les patients, mais il y a tout de même place à l'amélioration (Adam et al., 2009; Carlow, 2000; Clinical Oncology Society of Australia, 2006; National Institute for Health and Clinical Excellence, 2004). Le présent projet de recherche a donc été lancé en tenant compte de tous ces éléments.

BUT

Le principal objectif de l'étude qualitative était de mieux comprendre l'expérience des soins de soutien des femmes adultes des régions rurales du Manitoba qui devaient subir un traitement pour un cancer du sein invasif. Les résultats obtenus couvrent toutes les étapes de la maladie, du dépistage à la fin du traitement, et ont permis de générer différentes recommandations.

MÉTHODOLOGIE

La description interprétative, modèle choisi pour la présente étude, permet d'investiguer qualitativement un phénomène clinique (Thorne, 2008). Cette méthodologie a servi de cadre pour comprendre l'expérience découlant de la maladie, de même que le rôle des infirmières et leur influence sur la vie des patients cancéreux. La description interprétative est ancrée dans l'orientation naturaliste, qui respecte les expériences individuelles tout en laissant l'espace nécessaire aux réalités communes. Ces réalités communes servent de fondement pour générer une description interprétative apte à orienter la pratique (Thorne, 2008). L'étude a été approuvée par le comité d'éthique de la recherche en sciences infirmières, quatre régions de la santé et Action Cancer Manitoba.

Les critères d'inclusion étaient les suivants : 1) femmes adultes capables de parler, lire et écrire l'anglais et ne souffrant d'aucun trouble cognitif; 2) diagnostic de cancer du sein invasif suivi d'une ronde de traitement multimodal dans les trois dernières années; 3) femmes résidant dans les régions rurales ou nordiques du Manitoba. Étaient exclues de l'étude les femmes qui avaient un cancer de stade IV, qui avaient connu une récurrence du cancer ou qui souffraient d'une maladie évolutive, car les plans de traitement sont différents dans ces cas. Pour bien capturer l'essence de l'expérience vécue en cas de cancer du sein en milieu rural et en dégager les caractéristiques communes, nous avons employé un échantillonnage intentionnel (Streubert et Carpenter, 2011). Les patientes avaient le choix du milieu naturaliste où serait réalisée l'entrevue, ce qui a suscité des déplacements dans la province totalisant plus de 10 000 km.

Les données ont été recueillies par des entrevues en personne, l'administration de questionnaires démographiques, la prise de notes d'observation et la tenue de journaux. Vingt entretiens ont été réalisés pendant la première vague d'entrevues et douze dans la deuxième. Les auteures ont alors constaté que les données se répétaient et qu'aucune nouvelle information ne ressortait de la deuxième série d'entrevues (Streubert et Carpenter, 2011). Les huit derniers entretiens de la seconde vague n'ont donc pas eu lieu.

Les réponses à ces entrevues semi-structurées non directives ont été enregistrées et retranscrites textuellement. Toutes les entrevues ont été codées, puis examinées sous la loupe d'une analyse de contenu dirigée. Cette approche a permis de valider le cadre théorique en établissant des relations entre les données codées (Zhang et Wildemuth, 2009). Les deux auteures ont revu les données brutes à plusieurs reprises pour en extraire des descriptions interprétatives. Puis, par déduction, elles ont classé les données en fonction des catégories décrites dans le Cadre. À la fin de l'étude, chacune des participantes a reçu le sommaire des résultats, ainsi qu'une invitation à apporter toute clarification requise. L'engagement continu auprès des participantes, la vérification par les membres, la révision par les pairs, le débriefage et la consignation détaillée de la piste de vérification ont tous contribué à la rigueur méthodologique du travail (Streubert et Carpenter, 2011).

RÉSULTATS DÉMOGRAPHIQUES ET QUALITATIFS

Résultats démographiques

Les données démographiques comprennent les descriptions des participantes, l'information sur les modalités de traitement, ainsi que les renseignements sur la région de résidence et les déplacements. Les données démographiques ont été recueillies à l'aide de questionnaires et de l'analyse de chaque entrevue.

Description des participantes. Les quatre régions régionales de la santé de la province étaient représentées par cinq femmes chacune. L'âge des participantes variait entre 34 et 85 ans, la majorité étant âgée entre 46 et 65 ans. Onze d'entre elles étaient mariées; les autres étaient célibataires, veuves ou séparées. Six femmes vivaient seules, les autres avec leur conjoint, leurs enfants adultes, leurs enfants ou leurs petits-enfants. Dix femmes occupaient un emploi au moment du diagnostic et cinq ont travaillé à divers moments pendant leur traitement. Elles exerçaient leur métier dans différents secteurs, notamment dans le domaine de la santé, de la vente au détail, dans un bureau ou une entreprise à domicile. La moitié des femmes avaient obtenu un diplôme d'études postsecondaires et les autres avaient poursuivi leur scolarité jusqu'en 12^e année ou moins. Elles étaient majoritairement de race blanche.

Données démographiques des modalités de traitement. Dix femmes ont subi une lumpectomie et les autres une mastectomie unilatérale ou bilatérale avec, parfois, reconstruction mammaire ou pose d'implant. Toutes les femmes ont dû recevoir de 4 à 8 cycles de chimiothérapie, et sept d'entre elles ont été sous traitement biologique pendant une année supplémentaire. Toutes les femmes ont subi une radiothérapie du champ atteint et seize d'entre elles ont commencé l'hormonothérapie.

Données démographiques sur les régions et les déplacements. Onze femmes vivaient dans une ville de 7 500 habitants ou plus (ou à proximité), les autres dans une ville de moins de 7 500 habitants (ou à proximité). Six femmes avaient accès à un programme communautaire de lutte contre le cancer dans leur collectivité et quatre devaient se déplacer pour obtenir des services de chimiothérapie. Pour se rendre à Winnipeg, ces dernières parcouraient entre 62 et 1 100 km; celles qui allaient à Brandon faisaient entre 15 et 182 km. Dans l'une des régions, les patientes pouvaient se rendre à Brandon pour obtenir des services supplémentaires, notamment la chirurgie, la chimiothérapie et la radiothérapie. Elles voyageaient principalement par voie terrestre, mais quatre participantes du nord de la province prenaient l'avion et recevaient une indemnisation du Programme de transport des malades du Nord. Dix-sept femmes avaient été opérées à Winnipeg et les autres, à Brandon. Dix-huit participantes avaient reçu leur chimiothérapie grâce à un programme communautaire de lutte contre le cancer; les autres se rendaient à Winnipeg. Seize femmes avaient reçu de la radiothérapie à Winnipeg, et les autres, à Brandon.

Résultats qualitatifs sur les soins de soutien

Les résultats ont été catégorisés en fonction des domaines du Cadre sur les soins de soutien (Fitch, 2009). Les expériences les plus courantes sont décrites pour chaque domaine sans préciser les variations individuelles.

Domaine physique. Le domaine physique était très exigeant. Les effets secondaires variaient selon le mode de traitement, la chimiothérapie étant la plus éprouvante. De plus, la ruralité était associée à certaines difficultés physiques. À l'étape du diagnostic, certains éléments incontrôlables, liés au programme de mammographie mobile notamment, entraînaient des délais, par exemple les conditions de conduite hivernale. Pendant le traitement, les déplacements demeuraient pénibles, car ils aggravaient les symptômes physiques tels que la fatigue, la douleur ou les réactions cutanées. De plus, la sécurité pendant le trajet soulevait des inquiétudes, notamment à cause des symptômes comme la fatigue accablante, le « brouillard de la chimio » et l'impossibilité de porter la ceinture de sécurité après la chirurgie. L'une des participantes, qui conduisait tous les jours pour se rendre à ses traitements de radiothérapie, a mentionné la sécurité sur la route comme grande source d'inquiétude.

Mais vous savez, à cause du brouillard mental de la chimio et la fatigue causée par la radiothérapie, c'est difficile de réfléchir comme il faut. Je n'aurais pas dû conduire.

Pour les participantes, l'accès à des professionnels de la santé qualifiés expérimentés dans des établissements non voués aux soins du cancer ou dans les services d'urgence, limités dans les collectivités rurales, afin de trouver réponse à leurs besoins physiques complexes constituait également une préoccupation. Le fardeau du transport et des soins nécessaires pour satisfaire ces besoins physiques complexes en était d'autant plus lourd pour la famille ou les amis. Toutefois, les participantes ont mentionné le rôle positif des programmes de soins du cancer en milieu rural et des soins à domicile, qui avaient aidé bon nombre d'entre elles à supporter les difficultés physiques.

Domaine informationnel. L'information émanait de différents professionnels de la santé : médecins de famille, spécialistes en oncologie, personnel hospitalier, infirmières travaillant en milieu urbain et rural, infirmières pivots et autres professionnels interdisciplinaires. Plusieurs facteurs influençaient la capacité à assimiler l'information, notamment l'intensification des craintes, les longues journées de voyage, l'horaire de rendez-vous chargé, la complexité de l'information ou l'absence d'un accompagnateur disponible pour assister au rendez-vous. Une participante de cinquante ans, qui vivait loin d'un centre urbain, a mentionné les multiples rendez-vous avec des spécialistes auxquels elle devait assister en un court laps de temps. Elle s'est sentie obligée de prendre rapidement une décision par rapport à son traitement, qu'elle a fini par regretter.

Tout s'est passé si vite et je me suis mise à penser à ce qui pourrait arriver... si je n'ai pas de seins et que tout se passe si vite et que je n'ai pas de reconstruction... j'ai dû prendre une décision sur-le-champ pendant la discussion et tout allait juste trop vite...

L'accès aux médecins de famille semble être inégal dans la province et la communication entre les établissements urbains et ruraux comporte sa part de défi. En outre, il appert que les fournisseurs de soins ou le personnel hospitalier en milieu rural ne possèdent qu'une connaissance limitée des problèmes liés au cancer, ce qui constitue un casse-tête supplémentaire. Les infirmières et le personnel des établissements ruraux de soins du cancer jouaient un rôle capital pour répondre aux besoins informationnels des femmes, mais faute d'espace ou de lieux adéquats, il leur était difficile de discuter en toute confidentialité. L'accès aux infirmières pivots ou à des professionnels de la santé interdisciplinaires était limité, même s'il aurait été fort à propos. Beaucoup d'autres ressources informationnelles ou services de soutien ont été utilisés, chacun présentant des avantages et des inconvénients.

Domaine social. Les participantes ont mentionné différents types de réseaux de soutien social, notamment la famille immédiate ou élargie, les amis, les membres de la communauté, auxquels elles avaient eu recours à différents moments de l'expérience du cancer. L'importance des réseaux de soutien variait aussi selon la situation familiale ou la présence de membres de la famille ou d'amis vivant dans la collectivité. Le célibat avait ses bons et ses mauvais côtés, mais comportait son lot de défis sur le plan pratique. De plus, les fournisseurs de soins de santé, et particulièrement les infirmières en milieu rural, étaient une source de soutien importante pour les femmes, qui en parlaient en termes positifs.

Il était évident que les participantes aimaient vivre en région rurale. Elles décrivaient le fort sentiment d'appartenance à la communauté et la tranquillité. Mais la vie rurale créait aussi son lot d'obstacles, comme le manque d'intimité, les intrusions dans la vie privée ou les difficultés de communication, ce qui causait souvent un sentiment d'isolement. L'une des participantes, qui habitait depuis toujours dans un petit village, voyait son diagnostic comme une expérience très personnelle, ce qui l'a poussée à s'isoler des autres membres de la communauté pendant toute la durée de son traitement. Au moment de l'entrevue, un an après le traitement, elle venait tout juste de recommencer à sortir.

Oui, parce que tout le monde sait tout sur tout le monde. C'est comme ça. Lorsqu'on tient à sa vie privée, ce n'est franchement pas évident... et, généralement, tout finit par se savoir et la nouvelle se répand comme une traînée de poudre.

L'isolement pouvait aussi être causé par la nécessité de se reloger pour le traitement, les difficultés physiques inhérentes à la maladie et le fait d'éviter les endroits publics ou les interactions sociales. Plusieurs femmes ont dit que des gens qu'elles ne connaissaient pas ou qui n'étaient que de vagues connaissances leur avaient posé des questions très personnelles sur leur maladie ou avaient fait des commentaires déplacés ou gênants. Les participantes ont mentionné d'autres obstacles propres à la vie en milieu rural, comme le fait de connaître personnellement les fournisseurs de soins ou de suivre des traitements avec d'autres membres de la communauté. Certaines ont dit être très à l'aise dans l'environnement intime et personnel du programme communautaire de lutte contre le cancer, tandis que d'autres ne s'y sentaient pas très bien.

Domaine pratique. L'expérience des participantes était semée de nombreuses embûches pratiques. En effet, la gestion des activités du quotidien n'est pas simple lorsqu'on doit vivre avec des maladies chroniques. De l'aide supplémentaire était aussi requise pour effectuer certaines tâches domestiques ou encore s'occuper d'autres membres de la famille encore dépendants. Certaines femmes disposaient du soutien nécessaire pour y arriver, mais d'autres avaient dû embaucher de l'aide ou se débrouiller seules. Plusieurs devaient souvent s'occuper en plus d'un très grand terrain ou d'une ferme. Le poids des nombreux déplacements, du relogement, des problèmes liés à l'emploi et des pertes financières était des thèmes prédominants de l'étude. Les multiples allers-retours en ville, les conditions routières hasardeuses, les travaux routiers et l'orientation dans une ville inconnue compliquaient aussi l'expérience. Les participantes appréciaient beaucoup que les rendez-vous soient coordonnés avec leurs déplacements, mais les services diagnostiques limités dans les régions rurales venaient alourdir leur horaire.

De plus, les femmes du nord de la province rencontraient des difficultés particulières lorsqu'elles voyageaient en bus ou en avion et, vu leur lieu de résidence, elles étaient forcées de se reloger. Certaines femmes avaient le choix de faire la navette ou de se reloger pour recevoir de la radiothérapie, mais quelle que soit leur décision, elles devaient composer avec le coût du logement ou la fatigue des déplacements. En cas de relogement, l'expérience était plus positive lorsque les participantes trouvaient un logement abordable où elles avaient de l'aide ou, à tout le moins, un endroit confortable. Cependant, toutes n'avaient pas cette chance. Le fardeau financier du cancer était évident. Les difficultés liées à l'emploi, la perte de revenus et les frais à déboursier constituaient les principales sources d'inquiétude. L'une des participantes avait des soucis financiers avant le diagnostic et elle a décrit les conséquences dévastatrices de son incapacité à travailler et des coûts qu'entraînait la vie en milieu rural. Elle a fini par déménager pour trouver un logement plus abordable.

Ça m'a coûté cher parce que j'ai dû arrêter de travailler. Je n'avais donc plus de revenus, alors j'ai pas mal épuisé mes économies.

Les frais encourus comprenaient l'essence, le logement, les courses en taxi, les repas, le soutien aux tâches domestiques, le stationnement ou l'achat de fournitures médicales. Bien que les participantes aient apprécié le soutien financier de leurs amis, de leur famille et de leur communauté, les coûts associés à la vie en région demeuraient considérables.

Domaine émotionnel. Pendant les entrevues, les participantes ont évoqué une multitude d'émotions : état de choc, incrédulité, déni, peur, incertitude, colère, culpabilité, sentiments d'anxiété, etc. Ces émotions sont très fréquentes à l'annonce d'un diagnostic de cancer, mais elles sont souvent exacerbées par les conditions de vie en milieu rural à cause du relogement, de la difficulté de traiter avec des fournisseurs de soins inexpérimentés ou insensibles, et des frais supplémentaires à déboursier. Le fardeau des déplacements amplifiait aussi le stress émotionnel constant des participantes. L'une d'entre

elles a raconté avoir dû conduire plusieurs heures pour recevoir les résultats d'une biopsie, habitée pendant tout le trajet d'une grande anxiété. Après une longue attente pour voir le spécialiste, elle est rentrée chez elle, seule avec ses émotions et les nouvelles reçues. Plusieurs histoires semblables ont été rapportées pendant les entrevues.

Ils vont me dire que j'ai le cancer et je dois conduire jusqu'ici, puis attendre deux heures. Ça me mettait en colère.

Plusieurs participantes ont décrit leurs stratégies pour relâcher et gérer les émotions complexes qu'elles ressentaient. Elles trouvaient notamment utile de pleurer, de se défouler ou de s'offrir des moments de solitude. La musique, le yoga, la méditation ou le jardinage les apaisaient également. Plusieurs cherchaient du réconfort auprès de leur famille, leurs amis, leurs collègues, les membres de leur congrégation, les fournisseurs de soins et d'autres survivants du cancer pour les aider à traverser cette épreuve. De plus, les liens communautaires étroits et les soins hautement personnalisés des milieux ruraux de soins du cancer contribuaient aussi à satisfaire leurs besoins émotionnels. La présente étude n'a pas examiné en détail la réaction de la famille à la maladie, mais il semblait évident que l'expérience du cancer est une affaire de famille et que la séparation causée par le relogement ou les déplacements était astreignante sur le plan émotionnel.

Domaine psychologique. Dans ce domaine, les participantes ont rapporté certains besoins non satisfaits, comme la perte de contrôle sur leur vécu en raison de la maladie, la modification de l'image corporelle à cause de la perte de cheveux ou d'un sein, et la perte d'estime de soi. Les femmes devaient composer avec tous ces besoins insatisfaits. Pour certaines, il a été salutaire de reprendre le contrôle en changeant leur perspective sur la maladie ou en se concentrant sur ce que la vie leur apportait de positif. En outre, le fait de se distraire et de vivre la maladie au jour le jour aidait à moins se sentir dépassé. Pour l'une des participantes, le cancer suscitait de nombreuses émotions et la seule manière pour elle de se sentir en contrôle était de vivre dans le moment présent. Dans sa situation, elle avait donc choisi de faire six heures de route par jour pendant ses traitements de radiothérapie, avec le soutien de son conjoint.

J'imagine qu'on s'adapte du mieux qu'on peut. On entre presque dans un état d'esprit qui nous force à agir, à nous concentrer sur ce qu'il faut faire ici et maintenant. Dans mon cas, ce que je devais faire, c'était aller en ville tous les jours.

Il était très important pour les femmes de se sentir bien et de rester en forme; cela renforçait leur sentiment de contrôle et augmentait leur niveau d'énergie. Plusieurs autres caractéristiques, comme la résilience, l'autonomie et l'optimisme, facilitaient l'adaptation et soutenaient l'estime de soi.

Domaine spirituel. L'expérience du cancer, aussi difficile soit-elle, est souvent décrite comme un moment de découverte. Être confrontées à leur propre mortalité s'est révélé très éprouvant pour certaines femmes, mais elles ont, pour la plupart, trouvé des stratégies pour apprivoiser cette incertitude constante. Certaines cherchaient du réconfort dans leurs pratiques spirituelles ou dans la prière, mais elles

pouvaient difficilement assister aux offices religieux à cause de contraintes physiques ou sociales. L'une des participantes a dit qu'elle trouvait sa force dans sa foi en Dieu. Elle s'était malgré tout distancée de sa congrégation parce qu'elle avait honte de son diagnostic et qu'elle peinait à en parler.

Je n'aurais pas pu y arriver sans la prière et ma foi en Dieu. C'est là que je puise toute ma force parce que, seule, je suis faible et j'ai vraiment dû m'appuyer sur Lui, surtout pendant la chimio.

Certaines femmes ont décrit l'expérience simplement comme un obstacle de plus sur leur chemin. D'autres ne comprenaient pas pourquoi cette situation leur arrivait et ont cherché un sens profond à la maladie. Les participantes ont mentionné l'importance de donner un sens ou de poser un nouveau regard sur l'expérience, par exemple en approfondissant la connaissance de soi, en renforçant les liens familiaux, en étant reconnaissantes d'être en vie et de vivre un jour de plus, en nouant de nouvelles relations et en cultivant celles qui existent déjà. Pour certaines femmes, il s'agissait d'une expérience transformatrice.

DISCUSSION

La présente étude a permis de préciser l'expérience des soins de soutien pour les femmes des régions rurales du Manitoba qui ont reçu des traitements pour un cancer du sein invasif. Guidées par le cadre de soins de soutien holistique de Fitch (2009), nous avons détaillé tant les aspects positifs que négatifs de la maladie découlant de la vie en milieu rural. Les résultats de l'étude présenteront sans doute un intérêt pour les infirmières qui travaillent en région rurale auprès des patients atteints de cancer. Nos conclusions font écho à celles des autres recherches sur le sujet et peuvent donc servir de canevas à l'élaboration d'interventions personnalisées qui amélioreront les soins du cancer offerts aux patients des régions rurales.

Les infirmières en oncologie sont bien placées pour jouer le rôle de chefs de file à différents niveaux du système de santé et pour ouvrir le chemin à l'amélioration des soins prodigués aux patients cancéreux qui vivent en région rurale (Association canadienne des infirmières en oncologie [ACIO], 2001). En ville ou à la campagne, le travail des infirmières est très apprécié; elles se doivent de bien maîtriser les spécificités du monde rural lorsqu'elles soignent des patients cancéreux vivant dans ce milieu.

De plus, les services de navigation étaient considérés comme essentiels pour les femmes qui y avaient recours; ils étaient toutefois sous-utilisés. Les infirmières pivots sont en excellente posture pour offrir des services axés sur les patients et les familles, pour donner de l'enseignement continu, pour défendre les droits des patients et pour servir de lien entre les spécialistes en oncologie, les médecins de première ligne, les fournisseurs de soins du cancer en milieu rural et le personnel en charge des traitements. Elles facilitent aussi la coordination des procédures diagnostiques et des multiples traitements tout en s'occupant de la gestion générale des cas à chaque étape de la trajectoire du cancer (Farber, Deschamps et Cameron, 2002). Cette coordination est déjà essentielle pour les patients atteints de cancer, mais elle est encore plus cruciale pour les

populations rurales, vu la fragmentation des services. Les concepts d'oncologie ambulatoire, les congés rapides des établissements de soins de courte durée, les plans de traitement complexes et le suivi précoce en milieu de soins de première ligne peuvent dérouter les patients et leur famille. Les infirmières, qu'elles pratiquent dans des établissements voués ou non aux patients cancéreux, peuvent jouer le rôle d'agent de liaison pour assurer la continuité et la coordination des soins tout en tenant compte des réalités complexes de la vie rurale décrites dans la présente étude.

Appliquer les recommandations de la présente étude (Annexe A, tableau 1) permettrait d'améliorer la prestation des services en région et pourrait notamment éviter des retards de diagnostic, raccourcir les délais d'attente, réduire les exigences de déplacement, promouvoir les soins axés sur la famille, améliorer le soutien et les services et faciliter l'adaptation à l'expérience du cancer. Les soins de santé en milieu rural présentent de nombreux défis, déjà abordés dans un rapport commandé par le gouvernement du Manitoba en 2017 (Peachey, Tait, Adams et Croson, 2017). Pour arriver à améliorer les services aux populations rurales, ce rapport recommande, entre autres, une augmentation de l'offre de soins interdisciplinaires dans les milieux de première ligne, la bonification de l'aide à domicile en milieu rural, l'utilisation accrue de la télésanté, et l'augmentation du remboursement des déplacements pour les gens vivant dans les régions géographiquement isolées. À l'opposé, on y souligne qu'une réorganisation et centralisation des services d'urgence et ambulanciers dans la province pourrait se révéler problématique (Peachey, 2017).

De plus, l'objectif stratégique n° 5 d'Action Cancer Manitoba pour 2016-2021 (ACM, sans date) souligne la nécessité d'améliorer les soins pour les populations mal desservies. La création de nouveaux services et l'amélioration de l'accès pour les résidents des régions isolées ont été désignées comme des priorités. Les auteures du présent article invitent les infirmières du Manitoba et du Canada à prendre connaissance des derniers documents stratégiques du gouvernement et à s'en servir pour provoquer le changement. Les recommandations formulées dans la présente étude ne sont pas nouvelles, mais elles demeurent valables et devraient être prioritaires.

L'étude présente certaines limites, qu'il importe de mentionner. D'abord, la différence d'âge entre les participantes n'a pas été examinée en profondeur. Pendant les entrevues, l'âge ne semblait pas avoir une si grande influence sur l'expérience du cancer. Néanmoins, la question du lien entre l'âge et l'expérience du cancer du sein mérite sans conteste d'être explorée davantage. De plus, les personnes vivant en région isolée n'étaient pas représentées dans l'étude. On peut toutefois présumer que cela exacerbe encore plus les défis à surmonter. En outre, plusieurs thèmes sont absents de l'étude, notamment les hommes vivant avec une maladie, le bagage ethnoculturel, les survivants à long terme, le diagnostic de maladie avancée ou de stade palliatif et les proches aidants. Ces éléments devraient faire l'objet de futures recherches afin de mieux comprendre toutes les nuances de l'expérience rurale chez différentes populations.

Les résultats de la présente recherche ont tout de même produit de riches descriptions et ouvert de nouvelles perspectives sur l'expérience de la ruralité tout en faisant la lumière

sur les domaines où un changement est souhaitable, voire nécessaire. Tous devront coopérer pour donner suite aux témoignages des femmes et concrétiser l'objectif d'amélioration du soutien et des services. Les infirmières, en collaboration avec les autres professionnels de la santé qui travaillent avec les patients cancéreux des régions rurales, sont bien placées pour être la figure de proue de ce mouvement.

CONCLUSION

L'étude décrit les besoins en soins de soutien des femmes des régions rurales atteintes de cancer du sein, du diagnostic à la fin du traitement. Les résultats et les recommandations de l'étude doivent être envisagés dans une perspective nationale, puisque l'application de modèles de services aux patients atteints de cancer vivant en région isolée constitue un défi partout au pays. Nous ne pouvons pas changer le fait qu'il y a des populations rurales au Canada et que les services spécialisés en oncologie sont principalement offerts dans les grandes villes. Toutefois, les infirmières et les autres fournisseurs de soins doivent tenir compte des caractéristiques et conditions particulières des patients des régions rurales qui reçoivent un diagnostic de cancer. Il reste beaucoup à faire pour améliorer le soutien et les services, de même que la qualité de vie et les soins des populations rurales aux prises avec cette terrible maladie. Les résultats de la présente étude explorent ce sujet si important et serviront de point de départ à la prise de conscience et au changement.

ANNEXE A

Tableau 1. Recommandations pour la prestation des services

- Augmenter le nombre de procédures diagnostiques dans les milieux ruraux.
- Encourager les spécialistes à se rendre dans les collectivités rurales.
- Enregistrer les séances avec les spécialistes.
- Améliorer la connaissance et l'utilisation des programmes de navigation.
- Améliorer les services de première ligne en milieu rural et les liens avec ACM.
- Accroître le recours à des équipes de soins interdisciplinaires dans les régions rurales.
- Recourir davantage à la télésanté.
- Améliorer les soins d'urgence en milieu rural.
- Encourager la présence d'un membre de la famille pour les déplacements afin de favoriser la proche aide.
- Prévoir le moment du congé et les rendez-vous en fonction des déplacements.
- Promouvoir des services de soutien à orientation sociale, comme les services de repas et de transport, ou alors les programmes d'éducation ou de soutien par les pairs en milieu rural.
- Augmenter le nombre d'installations d'aide au relogement et de logements en milieu urbain.
- Améliorer l'esthétique des établissements ruraux de soins du cancer et y aménager des espaces privés.
- Multiplier les occasions de formation en oncologie pour les généralistes en exercice.

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Knowledge regarding cervical cancer among undergraduate female students at a selected college of Lalitpur, Nepal

by Rachana K.C. and Rita Giri

ABSTRACT

Cervical cancer is the second most common cancer in women living in less developed regions. In Nepal, little is known regarding the knowledge of cervical cancer in female young adults. A descriptive cross-sectional study was conducted to find out the knowledge regarding cervical cancer among undergraduate female students. A self-administered questionnaire was used to collect information from a non-probability sample of 150 female students from Little Angels College of Management in Lalitpur, Nepal. The data were analyzed using descriptive and inferential statistics.

Among the respondents, the mean age was 19.3 ± 1.1 years. Almost all (95%) of the respondents had inadequate knowledge regarding cervical cancer. Fifty-six percent of the respondents knew the meaning of cervical cancer and 35% of the respondents had an average knowledge about risk factors. Almost two-thirds of the students knew that cervical cancer is preventable. Regarding the preventive measures, good hygiene was identified by 68.5% of respondents followed by HPV vaccine 38.3%, using condom 19.5%, and Pap smear test 8.7%. The knowledge about HPV vaccine was only told by 11.3% of respondents. There was no statistically significant association between knowledge with selected variables (age, religion, ethnicity, family income, smoking and sexual practice) in the study.

Based on the findings, it is concluded that female students had inadequate knowledge regarding cervical cancer. This result reflects the need for health awareness campaigns to the students and community regarding cervical cancer, including the symptoms, causes, risk factors and preventive measures.

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INTRODUCTION

Worldwide, cervical cancer is the fourth most frequent cancer in women with an estimated 530,000 new cases in 2012, representing 7.5% of all female cancer deaths. In less developed regions, cervical cancer is the second most common cancer with an estimated 44,500 new cases in 2012 (84% of the new cases worldwide). In 2012, approximately 270,000 women died from cervical cancer; more than 85% of these deaths occurred in low- and middle-income countries (WHO, 2016). The incidence and mortality related to cervical cancer has declined significantly over the past 40 years due to Pap tests in the United States (Centers for Disease Control [CDC], Cervical Cancer Statistics, 2016).

In Nepal, cervical cancer is thought to be the leading cause of cancer-related deaths, where a population of 10.16 million women ages 15 years and older are at risk of developing cervical cancer. The annual number of new cases of cervical cancer is 2,332 while deaths from cervical cancer account for 1,367 cases {(ICO) Information Centre on HPV and Cancer, 2016}. The most important cause of cervical cancer is infection with human papilloma virus. Other risk factors of cervical cancer include genetics, low socioeconomic status, early sexual activity (before 17 year of age), multiple sexual partners, immunosuppression, and smoking (Chintamani, 2011). Primary prevention of cervical cancer includes human papillomavirus (HPV) vaccination to girls aged 9 to 13 years, aiming to reach them before they become sexually active. Secondary prevention for women older than 30 years of age occurs through screening tools such as VIA (visual inspection of the cervix with acetic acid) (PAP TEST) or HPV testing for screening, followed by treatment of detected precancerous lesions that may develop into cervical cancer (WHO, 2014).

Though it's a completely preventable disease, Nepalese, unlike in the western countries, have not been able to prevent cervical cancer due to lack of knowledge regarding the vaccination, lack of availability, and high cost. Primary prevention, such as early detection through increased awareness, the use of HPV prophylactic vaccine among young adolescents (age 9-13) who have not been previously exposed to the infection, organized screening programs, diagnosis and treatment play a vital role in reducing morbidity and mortality related to cervical cancer (Sherpa et al., 2015; Dangal, 2012).

At present, little is known about the knowledge level of young females about cervical cancer and its risk factors. Yet, this is a group where the risk is high of acquiring

HPV infection. Therefore, in this study, undergraduate female students were chosen as a sample, as they fall in an age group eligible for the HPV vaccine and are a group where the risk of acquiring HPV infection is high. This study explored the knowledge about various aspects of cervical cancer. The results could play an important role in determining knowledge gaps that exist and, therefore, help in designing health education messages about cervical cancer.

METHODOLOGY

A descriptive cross-sectional study was carried out to identify the level of knowledge regarding cervical cancer among adolescent females at Little Angels College of Management located at Lalitpur, Nepal. The study population was 150 undergraduate female students who were selected using a non-probability sampling approach. Data were collected using a structured self-administered questionnaire that was developed from the literature. Twenty-one correct/incorrect questions were distributed to measure the knowledge level and one score was given to a correct answer. The 21-item questionnaire collected information on socio-demographic characteristics, knowledge of cervical cancer, and sexual practice. The following criteria were set for the scoring of the level of knowledge: Inadequate Knowledge – Below 50%; Moderate Knowledge – 50–74%; Adequate Knowledge – 75 % and above.

Data were collected over a period of 10 days in the month of October 2016. Questionnaires on paper were distributed individually in the classroom maintaining anonymity. Participation in the study was voluntary and written informed consent was obtained from respondents prior to their participation. Ethical approval was taken from Nepal Health Research Council.

The data collected were entered and analyzed using Statistical Package for Social Sciences (SPSS version 23). There were 10 knowledge-related questions for cervical cancer; one point was awarded for every correct response. ANOVA was used to test the associations between categorical variables. The level of significance was set at 0.05.

RESULTS

Table 1 shows that most (95.3%) of the respondents had inadequate knowledge regarding cervical cancer.

Among the respondents, 56% answered correctly the meaning of cervical cancer. Likewise, half (50.7%) of the respondents knew about the risk factor of cervical cancer as multiple sexual partners. On an average, 35% of the respondents had the knowledge regarding risk factors.

Respondents were asked to indicate which, out of five options, were the signs and symptoms of cervical cancer. Table 3 shows that 68.2% answered any unusual discharge

Variables	Frequency	Percentage
Inadequate	143	95.3
Moderate	7	4.7
Mean±SD	31.42±11.07	Range (9–72.7)

from vagina followed by excessive bleeding during periods (28.4%), and bleeding between menstruation (26.4%). A minority (14.9%) answered as bleeding after sexual intercourse.

Table 4 illustrates that more than half (63.3%) of the respondents stated that cervical cancer can be prevented. A majority (68.5%) knew about the preventive measures as good hygiene, while just above two-fifths of the respondents stated taking fluids and a sample from the cervix as the screening approach for cervical cancer. Thirty percent had average knowledge on preventive measures.

As shown in Table 5, most (88.7%) of the respondents didn't know about the HPV vaccine. Similarly, most of them (92.6%) thought only females were eligible for the vaccine. Likewise,

Table 2. Knowledge on Meaning and Risk Factor of Cervical Cancer (n=150)

Characteristics	Frequency	Percentage
Meaning		
Wound of cervix	40	26.7
Pain in the cervix	4	2.7
Abnormal growth of cells in the cervix	84	56
Swelling in the cervix	22	14.7
Risk factor*		
Smoking	40	27
HPV infection	57	38.5
Multiple sexual partners	75	50.7
Early marriage	72	48.6
Obesity	16	10.8
Mean knowledge of risk factors±SD	(35.1351±15.40768) range (20–100)	
*Multiple response		

Table 3. Knowledge on Sign and Symptoms of Cervical Cancer (n=150)

Characteristics	Frequency	Percentage
Sign & Symptoms*		
Fever	21	14.2
Bleeding between menstruation	39	26.4
Any unusual discharge from the vagina	101	68.2
Excessive bleeding during periods	42	28.4
Bleeding after sexual intercourse	22	14.9
*Multiple response		

Table 4. Knowledge on Prevention and Screening of Cervical Cancer (n=150)		
Characteristics	Frequency	Percentage
Possibility of cervical cancer prevention		
Yes	95	63.3
No	55	36.7
Preventive measures*		
Using condom	29	19.5
Good hygiene	102	68.5
HPV vaccine	57	38.3
Pap smear	13	8.7
Screening *		
By taking piece of cervical tissue	39	26.0
Blood test	76	50.7
By taking fluids/cells of the cervix	63	42.0
Urine test	42	28.0
Preventive measures Mean $\pm$ SD (30.0671 $\pm$ 12.65427)	(range= 20-80)	

34.8% of respondents thought that the HPV vaccine is available paying on private hospital, and the majority (44.7%) didn't know about the recommended age group for vaccine. Table 6 shows very few (4%) of the respondents were involved in a sexual relationship.

Table 7 reveals that there is no statistical significant relationship between knowledge regarding cervical cancer and the selected variables with 95 % confidence interval (CI).

DISCUSSION

This study is limited to female undergraduate students of Little Angels College of Management, Lalitpur, Nepal. Findings of this study revealed poor knowledge regarding cervical cancer among female undergraduate students even though cervical cancer is the leading cause of cancer deaths among women in Nepal. The findings were similar to the study conducted in Saudi Arabia and India where 98% and 95.7% of the participants respectively had a low level of knowledge regarding cervical cancer (Al-Sheikh et al., 2014; Saha et al., 2010).

Findings of this study showed that more than half of the respondents correctly answered the meaning of cervical cancer, which was similar to the finding seen in Australia (Rao, Heathcote, Jackson, & Rousseau, 2015).

Similarly, only a minority of the respondents identified PAP smear as the preventive measure in this study. This is similar to the study conducted in India, where only 11% knew about the PAP smear as a preventive measure. There is a need to increase health awareness programs in order to strengthen their knowledge (Al-Sheikh et al., 2014).

Table 5. Knowledge Regarding HPV Vaccine (n=150)		
Variables	Frequency	Percentage
HPV vaccine		
Yes	17	11.3
No	133	88.7
Eligibility for vaccine*		
Males	33	22.1
Females	138	92.6
Availability of vaccine*		
Paying on government hospital	10	15.2
Paying on private hospital	23	34.8
Free supply during government camp	22	33.3
Not available in Nepal	15	22.7
Recommended age group for vaccine		
Not answered	28	18.7
9–25 years	19	12.7
26–40 years	33	22.0
41–50 years	3	2.0
Don't Know	67	44.7

Table 6. Response Regarding Sexual Practice (n=150)		
Characteristics	Frequency	Percentage
Involvement in sexual relationship		
Yes	6	4.0
No	144	96.0

In this study, the majority of the students did not know about the HPV vaccine. The finding is supported by a similar study conducted in Johannesburg, South Africa and Kuala Lumpur where 88.2% and 73.7% of participants respectively did not know that there is a vaccine to prevent cervical cancer (Rashwan, Ishak & Sawalludin, 2013; Kalau, 2012).

In this study, there was no association seen between knowledge and age. In India, knowledge was associated with age, where high knowledge regarding cervical cancer was seen among the students above 20 years of age and low knowledge was seen among the students less than 20 years (Saha et al., 2010). Similarly, in the present study, there was no association between family income with knowledge. This is in contrast to a study carried out in Johannesburg, South Africa, where knowledge was found to be high among the students with high socioeconomic status and low among low economic status students (Rashwan, Ishak, & Sawalludin, 2013).

Table 7. Association of Knowledge of Cervical Cancer between Selected Variables (n=150)					
Variables	Frequency	Mean	Std. Deviation	F value	P value
Age					
Less than or equal to 20	130	31.1538	11.19303	0.58	0.44
21 and above	20	33.1818	10.33371		
Ethnicity					
Brahmin/Chhetri	54	30.3872	11.77469	1.02	0.39
Janajati	67	31.8860	11.20391		
Madhesi	23	30.4348	8.92775		
Muslim	2	36.3636	0.00000		
Dalit	4	40.9091	11.13404		
Religion					
Hindu	115	31.3834	10.80315	0.33	0.80
Buddhism	30	30.9091	12.76751		
Islam	2	38.6364	3.21412		
Christian	3	33.3333	6.94330		
Family Income					
<10,000	9	27.7778	10.27626	0.67	0.51
10,000–50,000	92	31.2747	9.85414		
>50,000	49	32.3748	13.24023		
Family history					
Yes	6	34.0909	14.86857	0.36	0.54
No	144	31.3131	10.93913		
Smoking					
Yes	11	33.0579	15.35945	0.25	0.61
No	139	31.2950	10.72416		
Sexual Practice(n=6)					
Yes	6	37.1212	12.66761	1.66	0.19
No	144	31.1869	10.98526		
Statistically Significant, ANOVA (P value <0.05)					

CONCLUSION

In this study, the majority of undergraduate female students had inadequate knowledge regarding cervical cancer. In particular, knowledge about preventive measures and the HPV vaccine is lacking among female students. Therefore, awareness regarding cervical cancer and its preventive measures, especially the PAP test and HPV vaccine, should be focused in Nepal for the prevention of cervical cancer.

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Cancer du col utérin : connaissances des étudiantes de premier cycle d'un collège sélectionné de Lalitpur, au Népal

par Rachana K.C. et Rita Giri

RÉSUMÉ

Le cancer du col utérin est le deuxième cancer en importance chez les femmes des pays en développement. Au Népal, on en sait peu sur l'état des connaissances des jeunes femmes adultes à propos de ce cancer. Une étude transversale descriptive a donc été réalisée auprès d'étudiantes de premier cycle afin de déterminer ce qu'elles savent. Un questionnaire autoadministré a permis de recueillir des données auprès d'un échantillon non probabiliste de 150 étudiantes du collège de gestion Little Angels à Lalitpur, au Népal. Ces données ont ensuite fait l'objet d'une analyse statistique descriptive et déductive.

L'âge moyen des répondantes était de $19,3 \pm 1,1$ an. Le niveau de connaissances sur le cancer du col utérin s'est révélé inadéquat chez presque toutes les participantes (95 %). Par ailleurs, 56 % d'entre elles savaient ce qu'est le cancer du col utérin, et 35 % en connaissaient moyennement les facteurs de risque. Près du deux tiers des étudiantes savaient qu'on peut prévenir ce cancer. Parmi les mesures préventives, 68,5 % des participantes ont parlé d'avoir une bonne hygiène, 38,3 % de recevoir un vaccin, 19,5 % d'utiliser le condom et 8,7 % de faire un test Pap. Seulement 11,3 % des répondantes ont indiqué déjà connaître le vaccin contre le VPH. Aucune association statistique significative entre les connaissances et les variables du groupe à l'étude (âge, religion, origine ethnique, revenu familial, statut tabagique et pratiques sexuelles) n'a pu être établie.

Les résultats permettent de conclure que les étudiantes ont un niveau de connaissances inadéquat à propos du cancer du col utérin. Ces résultats reflètent bien la nécessité des campagnes

destinées à sensibiliser les étudiants et le public en général au sujet de ce cancer (symptômes, causes, facteurs de risque, mesures de prévention, etc.).

INTRODUCTION

À l'échelle mondiale, le cancer du col utérin est le quatrième cancer le plus répandu chez les femmes. On estime à 530 000 le nombre de nouveaux cas en 2012, et ce cancer est responsable de 7,5 % de tous les décès dus au cancer, chez la femme. Dans les pays en développement, le cancer du col utérin est le deuxième cancer en importance : approximativement 44 500 nouveaux cas y ont été diagnostiqués en 2012, soit 84 % des nouveaux cas recensés partout dans le monde. En 2012, environ 270 000 femmes ont succombé au cancer du col utérin; plus de 85 % de ces décès sont survenus dans des pays à faible revenu ou à revenu intermédiaire (OMS, 2016). Aux États-Unis, l'incidence du cancer du col utérin et la mortalité qui y est associée ont diminué de façon importante au cours des 40 dernières années grâce aux tests Pap (Statistiques sur le cancer du col utérin, Centers for Disease Control and Prevention [CDC]).

Au Népal, le cancer du col utérin serait la principale cause de décès liés au cancer. Le risque de développer la maladie est donc grand pour les 10,16 millions de Népalaises âgées de 15 ans et plus. Le nombre annuel de nouveaux cas de cancer du col utérin est de 2 332, tandis que le nombre de décès attribuables chaque année à ce type de cancer s'élève à 1 367 (Information Centre on HPV and Cancer, 2016). L'infection par le virus du papillome humain est la principale cause de cancer du col utérin, les autres facteurs de risque étant les prédispositions génétiques, le faible statut socioéconomique, l'activité sexuelle précoce (avant 17 ans), les partenaires sexuels multiples, l'immunosuppression et le tabagisme (Chintamani, 2011). La prévention primaire du cancer du col utérin comprend la vaccination contre le virus du papillome humain (VPH) des filles âgées de 9 à 13 ans, afin de les protéger avant qu'elles ne deviennent actives sexuellement. La prévention secondaire se fait, chez les femmes de plus de 30 ans, au moyen d'outils de dépistage tels que l'IVA (inspection visuelle après application d'acide acétique), le test Pap ou le test de dépistage du VPH, suivi d'un traitement des lésions précancéreuses détectées pouvant entraîner un cancer du col utérin (OMS, 2014).

Même s'il s'agit d'une maladie tout à fait évitable, les

AU SUJET DES AUTEURES



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Népalaises, contrairement aux habitantes des pays occidentaux, ne sont pas en mesure de prévenir le cancer du col utérin en raison de leur manque de connaissances concernant la vaccination, laquelle n'est par ailleurs pas toujours offerte ou accessible à cause des coûts. La prévention primaire, comme la détection précoce par une sensibilisation accrue, l'utilisation de vaccins prophylactiques anti-VPH chez les jeunes adolescentes de 9 à 13 ans avant qu'elles soient exposées à l'infection, les programmes de dépistage structurés, le diagnostic et le traitement jouent un rôle majeur dans la diminution de la morbidité et de la mortalité liées au cancer du col utérin (Sherpa et al., 2015; Dangal, 2012).

À l'heure actuelle, on en sait très peu sur le niveau de connaissances des jeunes femmes au sujet du cancer du col utérin et de ses facteurs de risque. Pourtant, ces dernières courent un risque réel de contracter une infection au VPH. C'est dans cette optique qu'a été sélectionné l'échantillon de cette étude, composé d'étudiantes qui appartiennent à une tranche d'âge admissible au vaccin anti-VPH et constituent un groupe où le risque d'être infectée par le VPH est élevé. Les résultats de cette étude, qui explore leurs connaissances sur divers aspects du cancer du col utérin, pourraient réellement aider à identifier les lacunes et à concevoir des messages éducatifs ciblés et efficaces.

MÉTHODOLOGIE

Une étude transversale descriptive a été réalisée afin de mesurer l'étendue des connaissances sur le cancer du col utérin de jeunes femmes étudiant au collège de gestion Little Angels de Lalitpur, au Népal. L'échantillon, composé à l'aide d'une méthode non probabiliste, regroupait 150 étudiantes de premier cycle. Les données ont été recueillies grâce à un questionnaire autoadministré structuré fondé sur des études antérieures. En tout, 21 questions de type « correct/incorrect » ont été élaborées afin de mesurer le niveau de connaissances; des points étaient attribués pour chaque bonne réponse. Le questionnaire recueillait des renseignements sur les caractéristiques sociodémographiques, les connaissances sur le cancer du col utérin et les pratiques sexuelles. Le niveau de connaissances était établi selon le barème suivant : Inadéquat – Moins de 50 % de bonnes réponses; Moyen – 50 à 74 % de bonnes réponses; Adéquat – 75 % et plus de bonnes réponses.

Les données ont été recueillies au cours d'une période de 10 jours, au mois d'octobre 2016. Des questionnaires papier ont été distribués individuellement dans la salle de classe, en veillant à respecter l'anonymat. La participation à l'étude était volontaire et le consentement éclairé écrit des répondantes a été obtenu avant leur participation. Le Nepal Health Research Council a validé le caractère éthique de l'étude.

Les données ont été saisies et analysées au moyen de la version 23 du Statistical Package for Social Sciences (SPSS). Le questionnaire comptait 10 questions évaluant les connaissances sur le cancer du col utérin; un point étant accordé pour chaque bonne réponse. Une analyse de la variance (ANOVA) a été réalisée pour tester les associations entre les variables nominales. Le niveau de signification statistique était fixé à 0,05.

RÉSULTATS

Le tableau 1 montre que la plupart (95,3 %) des répondantes avaient un niveau de connaissances inadéquat sur le cancer du cancer du col utérin.

Parmi les participantes, 56 % ont répondu correctement aux questions portant sur la compréhension de la maladie. De même, la moitié (50,7 %) d'entre elles savaient que le fait d'avoir plusieurs partenaires sexuels augmente le risque de développer un cancer du col utérin. En moyenne, 35 % des répondantes présentaient un niveau de connaissances adéquat des facteurs de risque de la maladie.

Les répondantes devaient indiquer, parmi les 5 options, quels étaient les signes et symptômes du cancer du col utérin. Le tableau 3 montre que la réponse la plus fréquente (68,2 %) a été « écoulements vaginaux inhabituels », suivi de « saignements très abondants pendant les menstruations » (28,4 %), puis de « saignements entre les menstruations » (26,4 %). Une minorité des répondantes (14,9 %) ont identifié les saignements après les relations sexuelles comme un symptôme de la maladie.

Tableau 1. Niveau de connaissances sur le cancer du col utérin

Variables	Fréquence	Pourcentage
Inadéquat	143	95,3
Moyen	7	4,7
Moyenne ± É.-T.	31,42 ± 11,07	Étendue (9–72,7)

Tableau 2. Compréhension de la maladie et des facteurs de risque du cancer du col utérin (n=150)

Caractéristiques	Fréquence	Pourcentage
Compréhension		
Lésion du col utérin	40	26,7
Douleur au col utérin	4	2,7
Croissance anormale des cellules au col utérin	84	56
Gonflement du col utérin	22	14,7
Facteurs de risque*		
Tabagisme	40	27
Infection au VPH	57	38,5
Partenaires sexuels multiples	75	50,7
Mariage précoce	72	48,6
Obésité	16	10,8
Connaissances moyennes des facteurs de risque ± É.-T.	(35,1351 ± 15,40768)	Étendue (20–100)
*Réponses multiples		

Le tableau 4 montre que plus de la moitié (63,3 %) des répondantes ont indiqué que le cancer du col utérin peut être évité. La majorité des jeunes femmes interrogées (68,5 %) savaient que la prévention repose sur une bonne hygiène, tandis que seulement un peu plus de 40 % d'entre elles connaissaient le dépistage par prélèvement de fluides et d'un échantillon de cellules au col utérin. Globalement, 30 % des répondantes avaient un niveau de connaissances moyen des mesures préventives.

Tableau 3. Connaissances des signes et symptômes du cancer du col utérin (n=150)

Caractéristiques	Fréquence	Pourcentage
Signes et symptômes*		
Fièvre	21	14,2
Saignements entre les menstruations	39	26,4
Écoulements vaginaux inhabituels	101	68,2
Saignements très abondants pendant les menstruations	42	28,4
Saignements après les rapports sexuels	22	14,9
*Réponses multiples		

Tableau 4. Connaissances sur la prévention et le dépistage du cancer du col utérin (n=150)

Caractéristiques	Fréquence	Pourcentage
Possibilité de prévention du cancer du col utérin		
Oui	95	63,3
Non	55	36,7
Mesures préventives*		
Utilisation du condom	29	19,5
Bonne hygiène	102	68,5
Vaccin anti-VPH	57	38,3
Test Pap	13	8,7
Dépistage*		
Biopsie du col utérin	39	26,0
Prélèvement sanguin	76	50,7
Prélèvement de fluides/ cellules au col utérin	63	42,0
Analyse d'urine	42	28,0
Mesures préventives Moyenne ± É.-T. (30,0671 ± 12,65427)	(étendue=20–80)	

Comme le montre le tableau 5, la majorité (88,7 %) des répondantes ne connaissaient pas le vaccin anti-VPH, et la majeure partie du groupe (92,6 %) pensait que le vaccin était réservé aux femmes. De plus, 34,8 % des répondantes pensaient que le vaccin n'était offert que moyennant des frais dans un hôpital privé, et bon nombre (44,7 %) des répondantes ont avoué ne pas savoir l'âge recommandé pour recevoir le vaccin. Le tableau 6 montre que très peu (4 %) des répondantes étaient actives sexuellement.

Le tableau 7 ne révèle aucune relation statistique significative entre les connaissances sur le cancer du col utérin et les variables déterminées (intervalle de confiance [IC] de 95 %).

Tableau 5. Connaissances sur le vaccin anti-VPH (n=150)

Variables	Fréquence	Pourcentage
Vaccin anti-VPH déjà connu		
Oui	17	11,3
Non	133	88,7
Admissibilité au vaccin*		
Sexe masculin	33	22,1
Sexe féminin	138	92,6
Disponibilité du vaccin*		
Moyennant des frais dans un hôpital public	10	15,2
Moyennant des frais dans un hôpital privé	23	34,8
Offert gratuitement dans le cadre d'une campagne gouvernementale	22	33,3
Non disponible au Népal	15	22,7
Âge recommandé pour le vaccin		
Aucune réponse	28	18,7
De 9 à 25 ans	19	12,7
De 26 à 40 ans	33	22,0
De 41 à 50 ans	3	2,0
Je ne sais pas	67	44,7

Tableau 6. Réponses concernant l'activité sexuelle (n=150)

Caractéristiques	Fréquence	Pourcentage
Pratique sexuelle active		
Oui	6	4,0
Non	144	96,0

Tableau 7. Association des connaissances sur le cancer du col utérin avec les variables choisies (n=150)					
Variables	Fréquence	Moyenne	Écart-type	Valeur de F	Valeur de P
Âge					
Inférieur ou égal à 20	130	31,1538	11,19303	0,58	0,44
21 et plus	20	33,1818	10,33371		
Origine ethnique					
Brahmane/Chhetri	54	30,3872	11,77469	1,02	0,39
Janajati	67	31,8860	11,20391		
Madhesi	23	30,4348	8,92775		
Musulman	2	36,3636	0,00000		
Dalit	4	40,9091	11,13404		
Religion					
Hindouisme	115	31,3834	10,80315	0,33	0,80
Bouddhisme	30	30,9091	12,76751		
Islam	2	38,6364	3,21412		
Christianisme	3	33,3333	6,94330		
Revenu familial					
< 10 000	9	27,7778	10,27626	0,67	0,51
De 10 000 à 50 000	92	31,2747	9,85414		
> 50 000	49	32,3748	13,24023		
Antécédents familiaux					
Oui	6	34,0909	14,86857	0,36	0,54
Non	144	31,3131	10,93913		
Tabagisme					
Oui	11	33,0579	15,35945	0,25	0,61
Non	139	31,2950	10,72416		
Pratique sexuelle (n=6)					
Oui	6	37,1212	12,66761	1,66	0,19
Non	144	31,1869	10,98526		
Statistiquement significatif, analyse de variance (valeur de P < 0,05)					

DISCUSSION

Cette étude se limite au cas des étudiantes de premier cycle du collège de gestion de Lalitpur, au Népal. Les conclusions de l'étude ont mis en lumière le faible niveau de connaissances des répondantes sur le cancer du col utérin, et cela malgré qu'il s'agisse du cancer le plus meurtrier chez les femmes vivant au Népal. Les résultats obtenus ici sont similaires à ceux des études menées en Arabie Saoudite et en Inde où, respectivement, 98 % et 95,7 % des participantes connaissaient peu le cancer du col utérin (Al-Sheikh et al., 2014; Saha et al., 2010).

On constate également que plus de la moitié des répondantes ont répondu correctement aux questions portant sur la compréhension de la maladie, un résultat similaire à celui obtenu en Australie (Rao, Heathcote, Jackson et Rousseau, 2015).

De même, seule une minorité de répondantes ont identifié le test Pap comme une mesure préventive. Ce résultat s'apparente à ceux d'une étude réalisée en Inde, où seulement 11 % des personnes interrogées connaissaient le test Pap. Cela prouve bien qu'il faut intensifier les programmes de sensibilisation à la santé (Al-Sheikh et al., 2014).

La majorité des répondantes de la présente étude ne connaissaient pas le vaccin anti-VPH. Ce constat est le même que ceux rapportés par deux études réalisées à Johannesburg (Afrique du Sud) et à Kuala Lumpur où, respectivement, 88,2 % et 73,7 % des personnes interrogées ne savaient pas qu'il existait un vaccin visant à prévenir le cancer du col utérin (Rashwan, Ishak et Sawalludin, 2013; Kalau, 2012).

La présente étude n'a révélé aucune relation entre les connaissances sur le cancer du col utérin et l'âge. En Inde, le niveau de connaissances était associé à l'âge : les étudiantes de plus de 20 ans avaient un niveau de connaissances supérieur à celles qui avaient moins de 20 ans (Saha et al., 2010). Dans le même ordre d'idées, la présente étude ne permet pas non plus de faire de lien entre le revenu familial et le niveau de connaissances, des résultats qui diffèrent de ceux de l'étude réalisée à Johannesburg, en Afrique du Sud, où le niveau de connaissances était plus élevé chez les étudiants jouissant d'un statut socio-économique élevé, et plus faible chez les étudiants dont le revenu était plus faible (Rashwan, Ishak et Sawalludin, 2013).

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CONCLUSION

Dans la présente étude, la plupart des étudiantes de premier cycle avaient un niveau de connaissances inadéquat sur le cancer du col utérin. Ce sont en fait les connaissances sur les mesures préventives et le vaccin anti-VPH qui se sont révélées le plus lacunaires chez les étudiantes. Par conséquent, des efforts devraient être faits au Népal pour sensibiliser davantage le public au cancer du col utérin et à ses mesures de prévention, particulièrement au test Pap et au vaccin contre le VPH, afin de prévenir la maladie.

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The legacy of lymphedema: Impact on nursing practice and vascular access

by Gail Larocque and Sheryl McDiarmid

ABSTRACT

Breast cancer is the most common cancer in women. Breast cancer related lymphedema (BCRL) is a chronic condition characterized by an abnormal accumulation of protein-rich fluid in tissues resulting in swelling of the upper limb or trunk after treatment. Lack of consensus on definition, classification and grading of BCRL has led to subjective and objective parameters estimating incidence and severity. Prospective studies estimate the risk of BCRL to be approximately 21.4% (14.9–29.8). In patients with axillary lymph node dissection (ALND), the estimated risk of 19% (13.5–28.2) was about four times higher than those patients who had sentinel lymph node biopsy (5.6%, 6.1–7.9). Seventy percent of these patients will experience BCRL within two years of surgery, 90% within three years, and a 1% rate per year thereafter. Many patients who have no high-risk variables such as mastectomy, ALND and radiation therapy develop BCRL. Patients fear this complication, which has no cure and no proven prevention strategies. Risk reduction strategies, primarily focused on reducing trauma to the surgical arm, are based on anecdotal information and effectively restrict the use of the at-risk limb for the patient's lifetime.

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Although broad risk reduction strategies have been recommended, the avoidance of needle sticks has become the most common strategy practised, enforced through institutional policies and procedures and reinforced through patient education initiatives and breast cancer support groups. Large cohort studies have found no significant association between blood draws and intravenous infusions in the surgical arm and the development of BCRL. Current literature supports that approximately 21% of patients will develop BCRL, leaving 79% free of the complication. Due to increased survival, breast cancer survivors go on to develop other healthcare issues that may require vascular access. Therefore, long-held beliefs with regards to risk factors and preventative measures need to be challenged. Education of healthcare providers, patients and support groups through the dissemination of evidence-based information on the diagnosis, prevention and treatment of BCRL is necessary to ensure that patients receive the best care possible with the least risk.

INTRODUCTION

Breast cancer is the most common invasive cancer in women. In 2017, approximately 26,000 women were diagnosed with breast cancer, 80% of whom are diagnosed with Stage I or II disease. Thirty-one percent of patients are diagnosed after the cancer has spread to regional nodes or directly beyond the primary site, and subsequent treatment relies upon the pathologic information from the sentinel node biopsy or axillary node dissection. Although breast cancer incidence continues to rise, secondary to early detection strategies, the overall breast cancer mortality rate in Canada is the lowest it has been for 70 years and has fallen 44% since 1986. The five-year net survival for breast cancer patients in Canada is 87%. Even in patients with metastatic disease, 15% will survive

longer than five years. The median age of diagnosis is 61 years and these breast cancer survivors go on to develop other healthcare issues (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017).

Breast cancer related lymphedema (BCRL) is a chronic condition characterized by an abnormal accumulation of protein-rich interstitial fluid, resulting in swelling of the upper limb or trunk after treatment for breast cancer, and is a feared complication for patients (Cheng, Deitch, Haines, Porter & Kilbreath, 2013). Although clinical risk factors are increasingly well defined, cellular and molecular mechanisms are poorly understood and fail to explain why patients with similar characteristics, treated identically, develop secondary lymphedema (LE) and others do not (Cemal, Pusic & Babak, 2011). A study by Newman et al. (2012) reported that approximately 40% of women who developed BCRL had no high-risk variables, suggesting these factors were partial causes at best. Despite this lack of scientific knowledge, national guidelines and standards have been developed and contain a wide range of strongly stated recommendations based on pathophysiology and expert opinion, but not supported by evidence. Strategies recommended by healthcare providers and breast cancer support organizations to decrease the risk of BCRL effectively eliminate the use of the at-risk limb (surgical side) for the patient's lifetime.

PURPOSE OF PAPER

The primary objective of this paper is to provide an update on current literature and recommendations on the risk factors regarding BCRL and their management. The secondary objective is to discuss vascular access options for patients at risk for developing BCRL.

There is an abundance of evidence documenting the influence of mastectomy, axillary lymph node dissection (ALND), and radiation therapy on a patient's risk of developing BCRL. Mastectomy and, in particular, bilateral mastectomies, has been identified as increasing the risk for the development of BCRL (DiSipio, Rye, Newman, & Hayes, 2013). In a review of mastectomy patients over a 13-year period, Basta et al. (2016) demonstrated that BCRL occurred in 10% of mastectomy patients, with or without reconstruction. Similarly, the differences in occurrence of BCRL in patients undergoing ALND compared to sentinel lymph node biopsy (SLNB) demonstrates the impact more extensive surgery has on patient outcomes. BCRL is three to four times higher (13–19.9% versus 3–5.6%) when comparing these surgical interventions (DiSipio et al., 2013; Bromham, Schmidt-Hansen, Astin, Hasler, & Reed, 2017). Patients with positive nodal disease, require additional radiation to the regional lymph nodes, and often the surgical bed, as well. Reviews in breast cancer, as well as for other disease sites (including melanoma, head and neck, and gynecology), have confirmed that patients who require regional radiation have an increased risk of LE (Cormier et al., 2010; DiSipio et al., 2013; Tsai et al., 2009; Vieira et al., 2016).

DIAGNOSIS OF LYMPHEDEMA

Historically, there has been no international consensus on the definition of LE, and over the years there have been a variety of subjective and objective parameters used to classify and grade its severity (Bernas, 2013; International Society of Lymphology, 2016; Levenhagen, Davies, Perdomo, Ryans & Gilchrist, 2017). In 2016, The International Society of Lymphology (ISL) published its latest revision of a 1995 document on the evaluation and management of peripheral LE that provides both a clinical classification and staging severity for LE based on objective physical findings (Table 1; Figure 1). More recently, the American Physiotherapy Association (Levenhagen et al., 2017) published its clinical

practice guidelines on the diagnosis and management of upper quadrant LE in cancer patients.

The diagnosis of LE begins with a clinical history and physical examination (Armer et al., 2013, Bernas, 2013; Levenhagen et al., 2017; Paskett, Dean, Oliveri, & Harrop, 2012). In unilateral extremity LE, a key part of the differential diagnosis is to determine the possibility of other pathologies known to cause swelling, such as a new solid tumour, thrombosis or recurrent disease (Bernas, 2013; ISL, 2016; Levenhagen et al., 2017; Paskett et al., 2012).

Measurement in Lymphedema

Quantification of limb measurement involves assessing limb volume and/or circumference. In the studies reviewed, where objective measurements were utilized, baseline data were obtained pre-operatively on both limbs for future comparison. This is of importance, as studies have demonstrated

that 20% to 30% of patients have anatomic limb asymmetry of between 5% and 10% unrelated to hand dominance (Brunelle et al., 2015; Sun et al. 2016). These data suggest that early studies on the number of patients reported to develop BCRL may have been overestimated, given most diagnoses were made without baseline measurements. Challenges in clinical practice include: what degree of change in the unilateral limb measurement constitutes BCRL; what method of measurement should be used; and when should intervention be undertaken.

There are four objective measures of LE reported in the literature: water displacement; circumferential measurement; perometry; and bioimpedance spectrometry (BIS). Armer et al. (2013) state that the exact method used for measurement is not as important as using a standard, reproducible method, practised consistently over time. Some

Table 1: Stages of Lymphedema

Stage	Signs and Symptoms
Stage 0: Latent (subclinical) Lymphedema	- No visible edema or swelling - Subjective symptoms such as heaviness, tightness or tingling may occur - Symptoms may present for months/years before swelling occurs
Stage 1: Early Lymphedema	- Visible edema with or without pitting - Swelling subsides with limb elevation
Stage 2: Moderate Lymphedema	- Visible edema, usually with pitting - Limb elevation alone rarely reduces swelling - Increase in subcutaneous fat and fibrosis
Stage 3: Severe Lymphedema	- Visible edema - Pitting is absent - Enlargement of the affected area - Thickening of the skin (acanthosis) - Changes in skin character: thickening, fibrosis, overgrowth
Adapted from: International Society of Lymphology Executive Committee, 2016 p. 173.	



Figure 1: Stages of Lymphedema

Retrieved from: "Early intervention to prevent lymphedema" n.d.

methods, though useful in clinical studies, are both cumbersome and expensive in the general clinical setting (Sayegh et al., 2017).

The gold standard for measurement of limb volume is water displacement. Measurements are done by placing the limb in a cylinder of water and measuring, by weight, the water displaced from the vessel giving an almost exact volume of the limb (Bernas, 2013). This method is rarely used now given its inconvenience, time-intensive cleaning of equipment between patients, patient mobility, and the associated time required for this technique.

Circumferential tape measurement is an inexpensive, reliable, and highly accessible way to measure patients' limbs in a variety of settings. Serial measurements, using this method, have become the most commonly used technique in clinical practice (Bernas, Askew, Armer, & Cormier, 2010). Measurements are made at designated landmarks, using a non-stretch tape measure to assess limb volume changes, and are reproducible when using a standardized protocol (Armer et al., 2013; Bernas et al., 2010; Campanholi, Neto, Pedreira, & Fregnani, 2015; Czerniec et al., 2010). The most frequently reported measurements are taken starting at the ulnar styloid then measured every 10 cm along the arm to a point 40 cm from the styloid. Limb volume can be calculated from these measures by summing the values of the calculated volume of the truncated cone. Online calculators are available for ease of clinical use (e.g. www.armvolume.com). Manual calculations of volume show excellent correlation with other methods, and have validity in the diagnosis of LE. Lymphedema is defined as a ≥ 2 cm difference in limb girth from baseline, or volume difference of $>10\%$ in the at-risk arm (Armer et al., 2013; Campanholi et al., 2015; Cormier et al., 2010; Fu, Ridner, & Armer, 2009; Paskett et al., 2012; Specht et al., 2013). Tape measurements are not limited by a patient's mobility, limb size, or skin condition.

There are newer measurement devices, such as the perometer, which calculates total limb volume using infrared sensors. These measurements are highly reproducible and can

be completed within two to three minutes bilaterally. Though a valid, reliable, sensitive measure of limb volume, it is both expensive and cumbersome for use in the clinical setting. Perometric measurements of >200 mls or volume increase of 5–10% over baseline are used to define LE (Specht et al., 2013).

Bioimpedance spectroscopy (BIS) is another measurement technique reported in clinical studies. The machine passes low-level electrical current through the tissues to measure resistance (impedance) to current, thereby determining the extracellular fluid volume. This measurement is then expressed as an impedance ratio (Bernas et al. 2010). BIS is quick to complete. However, it is limited to patients who have undergone only unilateral breast surgery. This method has good inter- and intra-reader reliability and studies suggest that it can detect 'sub-clinical' (asymptomatic) BCRL.

Clinical Examination

Though measurement of the affected limb has been the most commonly used method to determine the presence of swelling, measurement alone is insufficient for patients with pain and heaviness in their limb (Paskett et al., 2012). Clinical examination, along with subjective information, should always be included in screening and diagnosis. For example, the Stemmer sign can be easily assessed and is a more sensitive than specific sign in determining whether a patient may have LE. If the examiner is unable to pinch skin on the dorsum of the hand (or foot), this is considered a positive Stemmer sign and LE is likely (Green & Goss, 2018).

Ideally, preoperative baseline measurements serve as the best comparison for future evaluation. However, many centres do not include these measurements as part of their routine pre-operative assessment. The importance of these measures is highlighted in the work by Kilbreath et al. (2016) and Lee et al. (2015) showing that many patients have transient swelling in the first post-operative year. The median time to development of BCRL has been demonstrated to range from 18 to 36 months, and it is suggested that classifying

swelling as BCRL in the first year may not be appropriate unless swelling has been present for at least six months (Kilbreath et al., 2013).

THE ISSUES: AN UPDATE ON RISKS FOR BCRL

Risk reduction for BCRL has been directed, historically, at minimizing stress on the at-risk arm, the premise being the reduction of load on the lymphatic system (Asdourian et al., 2016). The following sections explore some of the most frequently discussed issues around the risk of BCRL and some of the more current data addressing these issues. It is important to remember a statement by Bernas (2013), who emphasizes that all preventative measures for BCRL need to be tempered by the realization that the majority of patients will never develop BCRL.

Air Travel and Compression Garments

Long haul flights have been associated with edema in individuals with or without LE. It is suggested that low cabin pressure, limitation of movement, dehydration and the hypobaric environment in air travel might be sufficient enough to create BCRL, particularly in people where their lymphatic system may be compromised (Asdourian et al., 2016).

Patients with a history of lymph node dissection have often been advised to avoid air travel or wear compression garments even without a history of LE (Cemal et al., 2011). Early work postulated there was a relationship between LE development and air travel, but the evidence was poor and often based on case studies or patient self-report (Asdourian et al., 2016; Cemal et al., 2011). These reports suggested that women who had an axillary lymph node dissection (ALND) and travelled were at a 2.5 times greater risk of developing BCRL than those who did not travel (Hayes, 2005, in Asdourian et al., 2016). Graham's (2002) prospective study surveyed a group of women who had undergone ALND and assessed their exposure to a variety of BCRL risk factors. None of the women in this study reported the development or worsening of BCRL after air travel, and only nine

women (3%), reported cases of 'transient' swelling. There was evidence that the women who used precautionary measures (compression) had an increased risk of BCRL.

More recently, studies have demonstrated no association between air travel and the risk of developing BCRL. Kilbreath et al. (2010) examined the effect of air travel and BCRL risk by measuring fluid volume in the at-risk arms of women with breast cancer. Data were collected pre-flight, on arrival, and six weeks' post-flight. Air travel did not cause any significant change in the bioimpedance ratio in the at-risk arms in the majority of these women. Subsequently, this same group undertook a prospective study to identify women at increased risk of BCRL based on having had axillary surgery. The study demonstrated that air travel did not increase the risk of BCRL regardless of the number of nodes removed (Kilbreath et al., 2016). These data were supported by Ferguson et al. (2016) who demonstrated there were no significant arm volume changes in women based on number or duration of flights taken.

Exercise

A major concern of patients is the use of their at-risk arm after LN surgery. For years, patients were advised to avoid exercise, as it was thought that the increase in blood flow increased lymphatic fluid in the affected limb. Sports such as rowing, golf, tennis, soccer, weight lifting, and running were ill advised (Cemal et al., 2011).

Systematic reviews examined studies directly addressing the effect of exercise on the risk of BCRL, and the data support the notion that strength exercises, particularly when done progressively, does not increase risk (Keilani, Hasenoehrl, Neubauer, & Crevenna, 2016; Stuiver et al., 2015). These reviews emphasize that monitoring for signs and symptoms of BCRL is important and treatment should be undertaken should these occur. Several studies have demonstrated that exercise, including progressive weight training, improves strength, enhances quality of life (QOL), and decreases fatigue without increasing the risk of BCRL (De Groef et al.,

2016; Schmidt et al., 2017; Schmitz, Speck, Rye, DiSipio & Hayes, 2012; Winters-Stone, Lauder milk, Woo, Brown, & Schmitz, 2014). The NCI recognizes the importance of exercise for the increase in QOL and function, but also states that controlled exercise is SAFE in patients with LE (Cemal et al., 2011).

Body Weight/BMI

The evidence regarding weight and body mass index (BMI) and the relationship to BCRL has been well studied, and there is good evidence to support recommendations. Early data demonstrated that BCRL was more than two times higher in obese patients than those at "normal" weight. This continues to hold true with the more conservative axillary surgery used today.

Prospective studies have consistently demonstrated that a BMI ≥ 30 at diagnosis increases the risk of BCRL approximately three-fold (Dominick, Madlensky, Natarajan, & Pierce, 2013; Ridner, 2011; Basta et al., 2016). Basta et al. (2016) also demonstrated that a normal BMI at diagnosis appears to confer a protective effect against BCRL. Some authors suggest that patients with a high BMI preoperatively undergo nutrition counselling, and should be closely monitored for detection and early treatment of BCRL (Hua-Ping, Jian-Rong, & Zeng, 2012; Togawa et al., 2014).

Additionally, there has been concern around weight gain after surgery and its impact on the development of BCRL. Though it appears there may be a slight increase in the risk of BCRL, these studies show a non-significant difference when analyzing the change in weight from pre-operative to subsequent follow-up measurements (Petrek, Senie, Peters, & Rosen, 2001; McLaughlin et al., 2008).

Trauma

Medical procedures in the at-risk arm demonstrate the potential impact of trauma on the ipsilateral limb. An early publication by Dawson (1995) followed 315 breast cancer patients who underwent carpal tunnel surgery (CTS) on the ipsilateral side. In this series, there were no new cases of BCRL or infection. Since then, several reviews and

prospective studies have examined outcomes for patients undergoing elective hand surgery who had ALND for breast cancer and/or melanoma. These studies showed no new cases and no exacerbation of existing LE (Baltzer, Harvey, Fox, & Moran 2017; Gunnoo, Ebelin, Arrault, & Vignes, 2015; Lee et al., 2015).

Reconstruction/Seroma

Women with mastectomies often opt for immediate or delayed reconstructive surgery, done with autologous tissue or breast implants. Given the surgery is done on the ipsilateral side, studies have been undertaken to assess the impact of reconstruction on the risk of BCRL. These studies compared the risk for women with or without reconstruction and analyses based on known confounding variables. Results have consistently demonstrated no increase in the risk of BCRL for women undergoing reconstructive surgery (Basta et al., 2015; Crosby, Card, Liu, Lindstrom, & Chang, 2012; Lopez Penha et al., 2014; Miller et al., 2016; Menezes et al., 2016).

Interestingly, in the surgical studies, seromas have been identified as an independent risk factor for the development of BCRL in the order of a two- to three-fold increase (Soares et al., 2014; Toyserkani, Jorgensen, Haugaard, & Sorensen, 2017).

Temperature Extremes

Patients at risk of, and those with BCRL have been advised to be cautious with sudden, prolonged temperature changes, and to avoid sunburns and exposure to extremes in temperature. In particular, avoid submersion of the at-risk limb in water above 38.9°C, including the avoidance of thermal-based heat and cold therapy (Asdourian et al., 2016). This was based on the assumption that inflammation and increased blood flow could result in increased lymphatic fluid production.

Showalter et al. (2013) examined the exposure of breast cancer survivors to 30 different lifestyle behaviours. Surveys were completed every three months for a year and temperature related risk factors were included in the analysis (e.g., vigorous exercise in the heat, travel to hot or humid climates, use of hot tubs and saunas, and the development of

sun or skin burns). Despite the small number of patients, only the sauna was associated with arm swelling. These patients also reported concurrent skin abrasions on the affected arm as a complicating factor not further assessed. In a review by Cemal et al. (2011) there is documentation of randomized studies using heat and microwave treatment for patients with LE that showed positive effects in lower extremity LE; 75% of the patients in one large study had at least a 50% reduction in the measured LE symptoms.

HISTORICAL PERSPECTIVES ON VASCULAR ACCESS AND THE RISK OF BCRL

The first reported case linking BCRL with needle-stick injury was published in 1992. Brennan & Weitz (1992) noted that a patient developed LE 30 years post mastectomy after initiating finger sticks to monitor blood sugars. Brennan (1992) subsequently published an article building on this theme and reported strategies to reduce the risk of BCRL focused on reducing the risk of limb injury, including needle puncture. Although there were several recommendations, the avoidance of needle sticks became the most common preventative strategy enforced through institutional policies and procedures and reinforced through patient education initiatives and breast cancer support groups.

Historical data from seven studies conducted between 1970 and 1998, prior to the wide adoption of venipuncture avoidance in the surgical arm reported a 24% (6–30%) incidence of BCRL (Petrek et al., 1998). Current studies where avoidance of the surgical side is widely practised, the estimated risk of BCRL is in the range of 14.9–29.8%. Therefore, as healthcare professionals, we have performed a single arm study where the vast majority of patients do not have venipuncture in the surgical arm, yet the rate of BCRL remains approximately 21%.

There are no known clinical trials demonstrating a causal association between venipuncture and BCRL. Studies, primarily retrospective and subjective, rarely include sufficient information regarding patient and treatment characteristics that allow

for multivariate analysis. Clark (2005), in a prospective study where 20.7% of patients developed BCRL, identified hospital skin puncture (versus none) as a risk factor. However, there were no data regarding the time to development of BCRL or multivariate analysis that could identify other factors that may have contributed (e.g., finger prick for glucose testing for diabetes may be a surrogate).

Current perspectives on venipuncture and BCRL

Current literature supports that up to 15–20% of breast cancer survivors are at a clinical risk of developing BCRL. Conversely 80–85% of patients remain free of BCRL occurrence. Seventy percent of these patients will experience BCRL within two years of surgery, 90% within three years and a 1% rate per year onwards (Cheng et al., 2013). Yet, 100% of patients are instructed to avoid venipuncture in the surgical arm for the rest of their lives. A recent publication from our centre reported that when patients were asked about specific factors that would increase the chance of BCRL, the most frequently identified risk factor was blood draws on the surgical arm (117/156; 75%). Chemotherapy administration in the surgical arm was identified as a risk factor by 52/156 patients (33%), the same number that identified the use of hot tubs or saunas as a risk (LeVasseur, et al., 2018). The perception that venipuncture in the surgical arm increases the risk for BCRL continues despite published data suggesting otherwise. Other publications found no association between blood draws and injections in the surgical arm and the development of BCRL and acknowledge that current guidelines are burdensome to both patients and clinicians without any consideration to other factors that occur when the at-risk arm is always protected from venipuncture (Asdourian et al., 2016; Ferguson et al., 2016; Kilbreath et al., 2016). In summary, what are supported by evidence as risk factors for the development of BCRL are: axillary node dissection; mastectomy; administration of chemotherapy and/or radiotherapy; obesity; and the presence of arm swelling.

Approaches to address vascular access in patients with lymphedema

The following sections provide practical approaches for addressing the vascular access needs of patients presenting with a diagnosis of BCRL, those at risk of BCRL during the first three years' post-surgery (where 90% of BCRL will occur), and those greater than three years' post-surgery (where the incidence is remarkably reduced, but continues for the patients' life time). As practice patterns change, vascular access specialists can lead the collaborative effort necessary to ensure information is available to patients and practitioners to promote understanding of the risk and benefits of each vascular access decision.

Reduction in the number and frequency of venipuncture should be a planning priority. When venipuncture is necessary, employ strategies to facilitate vessel dilation such as hydration, topical heat and arm positioning (Canadian Vascular Access Association, 2019; Infusion Nurses Society, 2016). The use of vein visualization technology such as ultrasound and near infrared light may also be helpful in locating peripheral veins, reducing the number of attempts and associated trauma.

Phlebotomy

The Clinical and Laboratory Standards Institute (2017) states that a phlebotomist requires a physician order before performing venipuncture on the at-risk arm. However, they acknowledge that studies are scant and inconclusive. There is no time limitation and the restriction applies whether there is arm swelling or not. Registered nurses have a broader knowledge base and the ability to undertake a thorough assessment and risk/benefit analysis. It is recommended to use the non-surgical side if veins are adequate. However, if venipuncture becomes problematic, perform a risk/benefit analysis and discuss with the patient and healthcare team, as use of an adequate vein on the surgical side may be the best option.

Peripheral intravenous (IV) access

When emergent vascular access is required, establishing prompt IV access in the most readily available vein in either arm should be considered the

appropriate approach with the least risk and most benefit. Use a systematic approach to plan for subsequent and ongoing access.

As the body of evidence grows, perhaps the most appropriate timeframe to introduce change is in patients without BCRL who are three years post-surgery where the risk of experiencing BCRL has markedly decreased to a rate of 1% per year (Cheng et al., 2013). When the need for IV therapy arises, the decision to choose the optimal vein and site in either arm is the appropriate clinical decision. Choose the best upper extremity vein for cannulation, limit the number of attempts and use sterile technique to reduce the risk of infusion-associated complications such as infiltration, extravasation, phlebitis and infection (Helm et al., 2015). When LE is present, avoid the limb for IV access, as LE contributes to poor tissue perfusion, impairs immune function and increases the risk, frequency and severity of infections (Cemal et al., 2011). Use of veins in the lower extremities has the potential for medical complications

(e.g. phlebitis, thrombosis, tissue necrosis) and should not be performed as a substitute for the use of adequate veins in the at-risk arm (Infusion Nurses Society, 2016). When veins are inadequate in the non-surgical arm, initiate a vascular access specialist referral for assessment and recommendations. Figure 2 provides a decision tree to assist in decision making when performing vascular access procedures in patients greater than three years post-surgery.

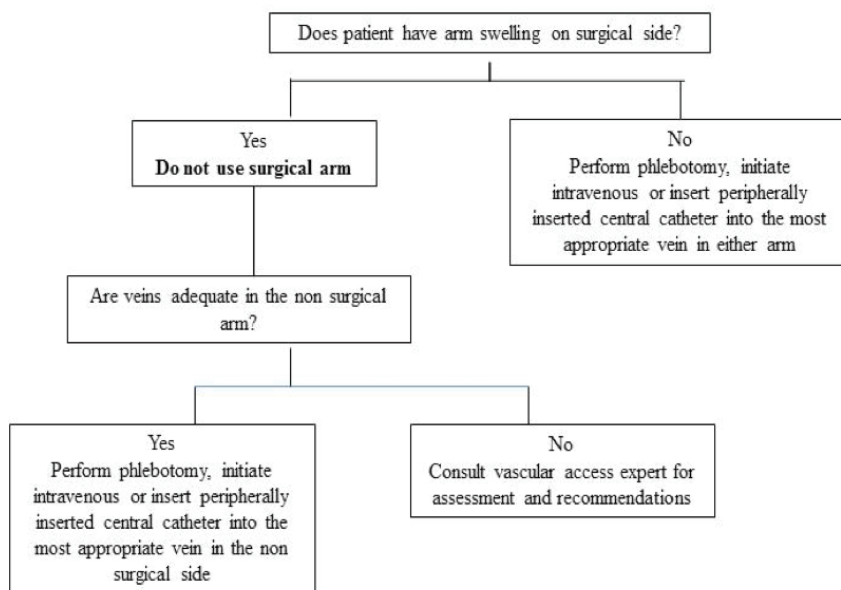
Bilateral breast cancer poses unique challenges. In this clinical scenario patients should be given additional post-operative information that describes what procedure was performed on each side. It is important for the vascular access clinician to understand the impact of therapeutic and prophylactic mastectomies. The use of contralateral prophylactic mastectomy has increased over the past two decades among women diagnosed with early-stage unilateral breast cancer (Asdourian et al., 2017; Yao, Stewart, Winchester, & Winchester, 2010).

However, unlike the surgical side in patients with bilateral breast cancer, the surgical side of a prophylactic mastectomy where no ALND was performed does not appear to increase the risk of developing BCRL (Miller, Colwell, Horick, Skolny, Jammallo, O'Toole, et al., 2012).

Central Vascular Access

Every vascular access device option is associated with its own risks and benefits, which are often higher than those associated with peripheral catheters (Piran, et al., 2014; McDiarmid, et al., 2017). Peripherally inserted central catheters (PICCs) placed in the upper extremity and implanted vascular access devices (IVADs), placed directly in the central veins, are the most common central venous catheters placed in patients receiving breast cancer therapy (LeVasseur et al., 2018). Ghandi et al. (2003) reported that the placement of IVADs on the surgical side did not increase the incidence of LE. However, if radiation therapy is planned on the ipsilateral side, the radiation oncologist

Vascular Access* Algorithm for Breast Cancer Patients > 3 years Post-Surgery**

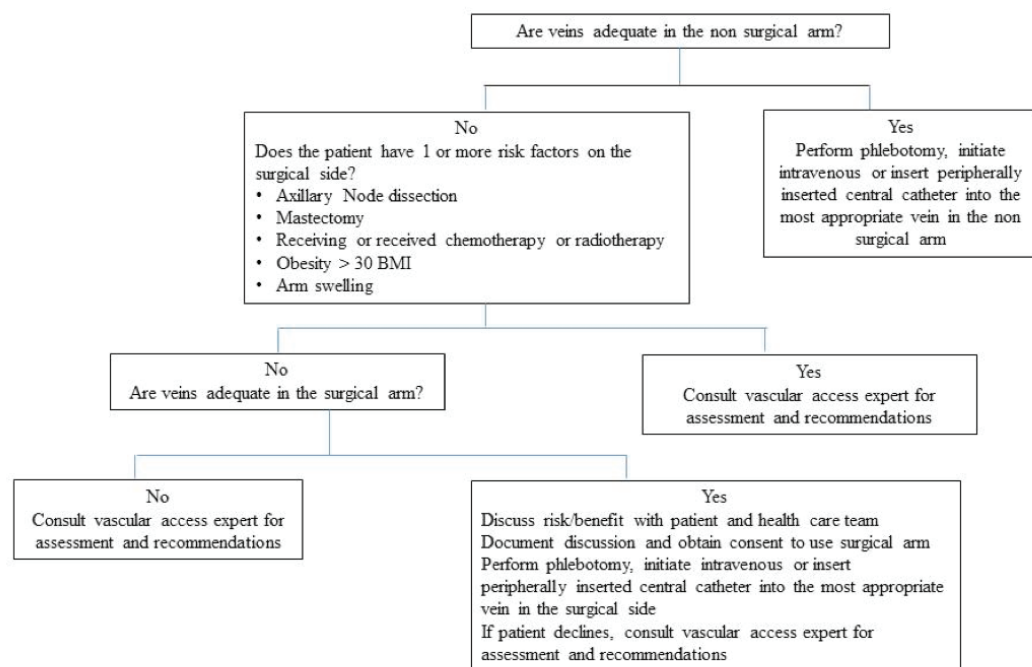


* Assumes appropriateness of device has been determined

**90% of initial LE diagnosis occurs < 3 years post surgery (Cheng et al., 2013)

Figure 2

Vascular Access* Algorithm for Breast Cancer Patients < 3 Years Post Surgery **



* Assumes appropriateness of device has been determined

**90% of initial LE diagnosis occurs < 3 years post surgery (Cheng et al., 2013)

Figure 3

will need to consider the composite material of the device and the impact on radiation treatment dosimetry and may request the device be placed on the contralateral side (Gossman, et al., 2009).

The algorithms provided in Figures 2 & 3 are applicable to PICCs. Although the use of ultrasound guidance has reduced the complication rate with PICCs, upper extremity thrombosis reportedly occurs in approximately 1.4% to 3.3% of patients with breast cancer (Kang, 2016; Ellis & Satomi, 2017). Adhering to recommendations maintaining a minimum catheter to vein ratio of < 45% may decrease catheter-related upper extremity deep vein thrombosis (Sharp, Cummings Fielder, Mikocka-Walus, Grech, & Esterman, 2015).

CONCLUSIONS

There is a growing body of evidence on the risks and management of BCRL and many areas in which we can make strides. Firstly, given the issues with transient swelling post-operatively,

and with some chemotherapy regimens, it is important to ensure we accurately identify the patients who are at risk or affected. We need to establish a routine technique to diagnose BCRL that could be used at individual centres with standardized documentation and interpretation. Additionally, given the large proportion of patients who have asymmetry in their limbs unrelated to hand dominance, thought should be given to establishing baseline measurements prior to treatment and medical management.

Long-held beliefs with regard to the risks factors and preventative measures need to be challenged. Education of healthcare providers, patients and support groups through the dissemination of evidence-based information on prevention and treatment of BCRL is necessary to ensure that patients receive the best care possible with the least risk to their health.

Less invasive diagnostic strategies such as sentinel lymph node biopsy, shorter course therapy with HER2/neu

receptor antagonist use, increased interval dosing of bone modifying agents, and fewer anthracycline based chemotherapies are factors to consider when developing a plan for vascular access therapy in breast cancer patients. This, combined with the increasing evidence base that fails to support a cause-effect relationship between skin puncture and the impracticality of complete avoidance of the surgical arm for the rest of the patient's life, provides the opportunity to improve recommendations given to patients. Patients at different risks for BCRL should be given appropriate precautionary guidelines.

Finally, developing a designated specialty service for vascular access and infusion therapy, with staff members educated in theory and skilled in practice, can serve as a resource for best practice, clinical guidance, policy and procedure development, and staff training. Ultimately, it could improve the overall experience for breast cancer patients.

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The role of the internet in the cancer experience: Synthesizing patient and provider views to forge new directions for care

by Kristen R. Haase

ABSTRACT

The CANO/ACIO Clinical Lectureship highlights an innovative nursing intervention or nursing-led study that aims to improve the quality of life for individuals on the cancer journey. People with cancer have high information and supportive care needs, and despite the best efforts of cancer care clinicians, these needs are sometimes left unmet. The advent of the internet has allowed for the democratization of cancer knowledge and the development of online cancer resources, applications, and communities. To date, little research explores the role of cancer-related internet information (CRII) in the cancer experience, particularly the role it plays in the healthcare professional relationships and the selection and use of healthcare services. In this lectureship, I present key findings from a mixed methods study exploring how the use of CRII informs the patient experience, with an emphasis on how oncology nurses, as integral members of the cancer care team, can incorporate these findings into their practice.

INTRODUCTION

A diagnosis of cancer is a life-changing experience that half of all Canadians are expected to experience in their lifetime (Canadian Cancer Society, 2018). Cancer is a multifaceted experience that brings both physical and psychosocial stress (Bultz & Carlson, 2006). When diagnosed with cancer, patients enter a complicated healthcare system:

treatment choices, multiple new healthcare providers, and managing symptoms take their toll. Many people also face functional challenges—such as finances—during a period of unemployment, coping with altered levels of physical ability, and frequent travel related to health appointments. The burden of a cancer diagnosis is distressing, and patients and their families manage much of this burden on their own (McCorkle et al., 2011).

The use of internet information and support, as well as mobile-health (mHealth) applications, has become a lifeline for many individuals with cancer (Nasi, Cucciniello, & Guerrazzi, 2015). Patients can access information and support at their own choosing and on their own schedule without the input or mediation of their cancer care team (Ziebland et al., 2004). There has been growing awareness of the role of cancer-related internet information (CRII) in the cancer patient experience (Leykin et al., 2012; Ventura, Öhlén, & Koinberg, 2013), but less attention has been paid

to how clinicians and patients interact when discussing CRII, and how nurses, in particular, can support patients' online information-seeking efforts.

The purpose of this paper is to synthesize results from a mixed methods study exploring how people diagnosed with cancer use CRII to manage their cancer experiences and their interactions with the healthcare system. I present a practical model for oncology nurses to engage patients about their internet use, generated from a synthesis of study findings.

METHODS

This study was guided by an interpretive descriptive mixed methods approach (Cresswell, 2014; Thorne, 2016). The main findings of this study have been published elsewhere (Haase, Thomas, Gifford, & Holtslander, 2018a, 2018b, 2018c). Thus, I will provide only a brief overview of methods with summaries provided within the adjacent table (Table 1) and integrated into the findings section.

Table 1: Data sources and methods	
Data source	Methods
Websites	- Guided by an interpretive descriptive approach. - A review of 20 websites was conducted using a two-step approach: websites selected using a consensus search strategy and by asking patients (n=19) which websites they most commonly used. - Data were analyzed using inductive and deductive thematic analysis.
People diagnosed with cancer	- Guided by an embedded mixed design, - Interpretive description was the overarching methodology. - Nineteen people with cancer were interviewed twice (n=38). Each participant also completed a survey about CRII use. - Qualitative data were analyzed using thematic analysis. - Quantitative findings were analyzed using descriptive statistics.
Healthcare professionals	- Twenty-one healthcare professionals engaged in interviews (n=4) and focus groups (n=3) guided by an interpretive descriptive approach. - Data were analyzed via thematic analysis.

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We chose an embedded concurrent design, where the dominant qualitative research methodology was complemented by a supplementary quantitative approach (QUAL+quan) (Cresswell & Plano Clark, 2011). We used several data sources to ensure we addressed the research objectives robustly. These data sources included: (1) a sample of commonly-searched cancer websites (n=20); (2) people newly diagnosed with cancer (n=19); and (3) health professionals (n=21) in cancer care. The study was conducted within the Saskatchewan Cancer Agency, a university-affiliated cancer treatment centre in Western Canada, approved by the relevant research ethics board, and by the cancer agency. To ensure trustworthiness, we followed the guidelines for rigour presented by Thorne (2016). These steps included (1) ensuring epistemological integrity by choosing a design congruent with the research question, methods, and approach; (2) demonstrating credibility and believability of the findings by using multiple data sources and triangulating said data and member checking; (3) ensuring analytic logic by keeping audit trails and memoing throughout the study; and (4) enabling interpretive authority through the use of exemplary quotes.

FINDINGS

We triangulated data from commonly searched cancer websites, conducted interviews and surveys with people newly diagnosed with cancer, and conducted interviews and focus groups with healthcare professionals. Together the study findings contribute to a better overall understanding of how people with cancer use CRII, what types of information are accessible on the most commonly searched websites, and how CRII informs their interactions with healthcare professionals and healthcare services. The findings start to build a framework for understanding where and how patients use the internet in the cancer experience. Specifically, these results provide an understanding of: which patients are looking for information; what information they look at online; what they are looking for, which might be different than what they are

looking at; and how CRII fits into the patient-nurse relationship.

Website analysis

In the qualitative review of websites, we explored the online milieu in an effort to understand the types of cancer information and content available, and what patients find when seeking information on the internet. I used Barbara Carper's fundamental patterns of knowing as a guiding framework for the website review (Carper, 1978). Carper's approach is consistent with my worldview as a nurse, and encompasses a holistic conceptualization of knowledge. I used deductive and inductive thematic data analysis, first analyzing the website content inductively and applying codes, and then grouping these into the overarching themes that reflected the multiple types of knowledge laid out by Carper.

Findings from this review enable an understanding of the types of cancer content and information that an individual can expect to find when they search online. The most abundant is biomedical and empirical information about diagnosis, treatment, and medical management of cancer. This is vital information, and very important during diagnosis, as patients make sense of their illness, make decisions, and/or enter treatment. However, the dominance of biomedical information overshadowed other types of information. For example, information about death and dying was very difficult to locate (even when specifically searching these terms within websites), as was information to support self-management, or information accounting for diverse sociopolitical backgrounds. These findings are significant, as they raise questions and concerns about the information that people with cancer find when searching independently, as well as the information that is deemed important enough to be easily accessible. They also have implications in numerous domains of nursing and provide insight for future research. Furthermore, these findings raise questions about how nurses may address the limits of CRII in their nursing practice.

Patients

In the qualitative study with patients, I sought to understand CRII use by people newly diagnosed with cancer, how it shapes their cancer experience, and how it informs interactions with healthcare professionals and healthcare services. I used an embedded mixed methods design (Cresswell, 2014), guided by an interpretive descriptive approach (Thorne, 2016). I conducted two in-depth individual interviews and a short survey of CRII use with 19 people newly diagnosed with cancer (n= 38 interviews), over a period of 10 months. Qualitative data were analyzed using thematic analysis, and quantitative data were analyzed using SPSS.

The findings from this study demonstrate that patients feel CRII is an important resource during their cancer experience. From the time of diagnosis, patients describe CRII as their most important source of information, next to their healthcare professional. Patients felt that CRII complemented the information provided by their healthcare professional, and allowed them to have a better understanding of complex cancer and medical information. Many patients described a staged approach to CRII use. First, they would consult with their healthcare professional, next they would gather the information from their healthcare professional and consult the internet. Using both data sources they would triangulate the information to gain a better understanding of their diagnosis. Patients also described using CRII to manage their symptoms and to assist them, as they navigated the complexities of the healthcare system. Patients felt that the internet could be very useful to guide decision-making, especially when they were weighing two options. Clearly, CRII played a crucial role in multiple facets of patients' understanding of their diagnosis and the cancer experience.

Perhaps the most notable finding from this study was the diversity of the sample. The average participant age was 62, within a range from 43 to 87. Older adults described using CRII in much the same way as the younger adults in the study, although several

older adults relied on family members to instruct them about which websites to use. Furthermore, many participants did not have advanced education, but this was not seen as a barrier to using the internet and navigating health information. Individuals from rural and remote communities described using CRII to manage the intricacies of accessing healthcare services in urban areas. The rural participants also felt that they relied on CRII more, because they did not always have local access to healthcare services and could not readily access their doctor or emergency services. Thus, rural participants' use of CRII seemed to be based more on necessity compared to those living in urban areas. Together, the participant findings point to interesting opportunities for future research and present implications for nursing practice and cancer care.

Healthcare professionals

In the qualitative study with healthcare professionals, I explored healthcare professional views of patient use of CRII, and how healthcare professionals see CRII use informing patient interactions with the healthcare system. I conducted three focus groups with members of the multi-disciplinary team at the cancer centre including nurses, physicians, dietitians, social workers and a pharmacist (n=17) and four individual in-depth interviews (n=4).

Healthcare professional participants acknowledged that many of their patients rely upon CRII to understand and process their diagnosis. Most healthcare professionals found that their patients would go to the internet to learn about their illness and to help them understand the information provided by their healthcare professional. Healthcare professionals also felt that there were key transition points in the cancer trajectory where people were more likely to feel heightened uncertainty, and, therefore, look for more information on the internet. Those two points were: at the time of diagnosis before they had received their consult at the cancer agency, and when discharged from cancer care back to their primary care provider. Healthcare professionals

felt that these times were especially stressful and anxiety-provoking for patients, and that CRII could help them to process their concerns in the absence of actual (or perceived) healthcare professional support.

Healthcare professionals acknowledged and supported patient use of CRII, but they also expressed hesitations. Some of these hesitations related to the concerns that patients would access information they were unable to understand or that was wholly inaccurate. Healthcare professionals felt that even if patients could find 'good quality' information, they were skeptical that most patients (i.e., with no prior medical knowledge) would be able to understand and apply what was applicable to their specific diagnosis. Information about complementary and alternative approaches/medicines was also commonly cited as topics of concern.

DISCUSSION

Together, the findings from this mixed methods study begin to clarify the role of CRII in the cancer experience and patient interactions with healthcare professionals and services. We have drawn upon multiple data sources, including the perspectives of both patients and healthcare professionals. Patient and healthcare professional perspectives highlight the numerous ways that CRII is mobilized at diagnosis and throughout the cancer trajectory. The use of CRII supports patients as they interact with key healthcare professionals and informs decisions around treatment and service use. These findings present a robust picture of the role of CRII in many aspects of the cancer experience. The discussion will focus on the practice implications of this study, and how oncology nurses can integrate an awareness of CRII into practice.

Nursing practice encompasses practical care for the whole person, their family, and their environment (Bottorff, 1991; Carper, 1978; Fawcett, Watson, Neuman, Walker, & Fitzpatrick, 2001; Thorne, 2019). As a practical profession with a holistic focus that goes beyond care of the physical body,

the findings from this study have multi-faceted implications for nursing. Cancer nurses face a particular challenge as they support patients during existential crises and the associated fatalistic stigma of cancer (Powe & Finnie, 2003). Cancer nurses also provide information and support for the physical demands of illness (Marbach & Griffie, 2011). Thus, these study findings should motivate nurses to reflect on the information patients require to manage their diagnosis. Insights about where patients are finding information and how both patients and healthcare professionals (including nurses) view the role of CRII in the patient-professional relationship warrant further discussion.

Oncology nurses and other healthcare professionals identified key points on the cancer trajectory when patients require more information: at diagnosis, when entering cancer care, and at discharge from cancer care. Following a nurse-led model of patient navigation may proactively address patients' priority concerns during the transition into cancer care (Fillion et al., 2006; Pedersen & Hack, 2010). An oncology nurse navigator is well situated to assess what information patients want and address the gap with the acknowledgement that CRII may be an important source of cancer information.

People with cancer used CRII to manage their symptoms, including anxiety related to the numerous unknowns of their diagnosis. This is relevant to nurses, as our professional role includes significant support for symptom and self-management (Dodd et al., 2001; McCorkle et al., 2011). Information needs are present across the trajectory of cancer, especially at diagnosis (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013). Furthermore, past research on chronic disease management has found that the design of the care system is more important than the specialty training of healthcare professionals (Rothman & Wagner, 2003). Therefore, translating these findings into practice may include raising nurses' awareness of how and where patients are finding information

and what they feel is missing. Nurses can tailor care to encourage patients to bring CRII into the nurse-patient relationship so it is complementary rather than supplementary. The findings from this study suggest that the relationship would be strengthened if patients and healthcare professionals discussed CRII openly, an approach that does not necessitate more technology.

Strategies for practice implementation.

The findings from this study have implications for oncology nurses in practice and suggest that nurses could interact more with patients about their use of CRII. Patient teaching, patient education, or information exchange between nurse and patient by any other name has shifted over time from a top-down approach to a collaborative partnership model (Gottlieb, Feeley, & Dalton, 2006). The growing accessibility of information on the internet, alongside the current focus on patient-centred care (which advocates for patients taking part in their own healthcare), has jointly shifted power dynamics (Wald, Dube, & Anthony, 2007). Whereas, in the past, patients typically learned about cancer from their healthcare professional, the landscape has evolved to include patients finding their own information and engaging in independent learning about their illness (Lustria, Smith, & Hinnant, 2011). The desire for more exchange about CRII between patients and healthcare professionals has relevant repercussions for nurses.

In interviews with patients, we found that they used CRII to learn about their illness and to engage in self-management. Furthermore, patients reported that sometimes they did not mention CRII because they were concerned about judgment from their healthcare professional; healthcare professionals agreed that fear of being judged could be a reason for patients not to disclose their CRII. Thus, these results highlight a need to develop capacity amongst nurses and healthcare professionals to discuss patient use of CRII. Developing capacity might include interventions focused on increasing awareness of patient CRII use and presenting

tangible strategies to do so. As nurses are the healthcare professionals who spend the most time with patients, and for whom patient education is a key responsibility (Smith & Zsohar, 2013), these implications should resonate and be a call to action.

In nursing, there has been some discussion of how to involve patient-sought CRII into the nurse-patient relationship, but guidelines and strategies vary in their patient-centredness. For example, a health education fact sheet from the Registered Nurses Association of Ontario (RNAO) entitled, 'Nurses and the use of computer technology: from nurses for you' (Registered Nurses Association of Ontario, 2008), refers to several ways technology functions in healthcare. The fact sheet suggests that patients may use internet health information to learn about their illness, that there are many websites of varying quality of which patients should be skeptical, and that patients should ask their nurse or healthcare professional for help in interpreting their internet information. Furthermore, the RNAO best practice guidelines on facilitating client-centred learning (Registered Nurses Association of Ontario, 2012) cite the need to create a safe space, assess patient learning needs, tailor education to patient needs, and use a combination of approaches (e.g., citing print, telephone, computer, etc.). Combined, these two approaches—encouraging patients to discuss CRII with their healthcare professional and encouraging nurses to create a safe space to talk about CRII—generate a pathway to integrate these findings into practice through patient education.

Based on the findings of our research, we would elaborate these guidelines by encouraging nurses to

be catalysts to start conversations about CRII rather than waiting for patients to broach the subject. The RNAO best practice guidelines emphasize the LEARNS Model, which draws on the nursing process by encouraging nurses to Listen, Establish, Adopt, Reinforce, Name, and Strengthen (Registered Nurses Association of Ontario, 2012). We believe this model poses several attributes for generating discussions about CRII, but can be tailored based on findings from this study.

Drawing on the study findings, we propose the following approach to begin conversations about CRII: Ask, Listen, Engage, Reflect/Reorient, and Time (ALERT) (Figure 1). This approach and the requisite nursing strategies are within the scope of practice of an oncology nurse, and are relevant to multiple other areas of nursing where patients use online information for self-management and to guide their use of health services.

(1) Ask patients and their families about their use of CRII and whether this is a source of information on which they rely. Although the RNAO fact sheet encourages patients to start this conversation, patient participants in this study clearly felt they wanted healthcare professionals to broach the topic first. Healthcare professionals emphasized that asking patients about what information they were looking for was an important way to understand what patients were interested in knowing. Starting from this simple question, nurses can then assess their patient's information needs, and make a plan to address them. This process mirrors the first step in the nursing process—assessment—which is the foundation of clinical reasoning in nursing (Alfaro-LeFevre, 2014).

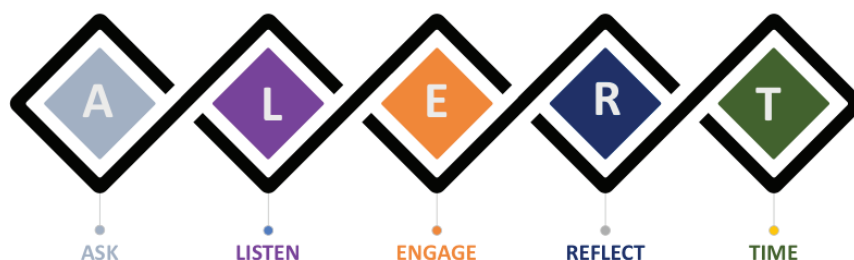


Figure 1: The ALERT model

(2) Listen to what your patient tells you. Listening and the accompanying non-verbal skills are an essential component of the patient-nurse relationship (McCabe & Timmins, 2013). Listening includes effectively using empathy, acceptance, silence, verbal and non-verbal communication (Shipley, 2010). Listening allows nurses an opportunity to understand their patients' information needs and creates an environment where they can share their needs or what they have already found on the internet.

(3) Engage with your patient. As laid out by the RNAO Best Practice Guidelines, engage your patient to establish a therapeutic partnership, ensure that they feel comfortable sharing, and ensure they understand your desire for them to have the best possible information (Registered Nurses Association of Ontario, 2012). Developing rapport and dialogue with the patient, rather than viewing these exchanges as a simple linear transaction creates opportunities for patients to feel like empowered partners rather than passive subjects (Sanford, 2000).

(4) Reflect upon and/or reorient what patients share with you. The idea of reflection was discussed amongst nurses as a means of essentially paraphrasing for patients their concerns, or simply repeating it back, using words you like: Here is what I think I hear you say. Nurses felt this was the first step to really understand if they knew what patients were looking for, or finding. By reflecting, nurses can also provide context for the information the patient has found, and apply it to their patient's specific needs.

The idea of reorienting goes one step further than reflection. Nurses discussed the idea of reorienting patients when they share information that might be partially but not completely factual or applicable. The nurse, having heard what information the patient has found, identifies any concerns and, if necessary, redirects the person to different or better CRII. This intervention positions

nurses to acknowledge patient resourcefulness as a strength, thereby validating their information-seeking efforts (Feeley & Gottlieb, 2000).

(5) Time and timing relates to the importance of incorporating discussions of CRII throughout the cancer trajectory. Many healthcare professional participants identified a reluctance to engage in discussions about CRII at the first meeting with a client, as they may not have developed a rapport at that time, whereas others expressed that there is no perfect time. However, patients may pass through the care of a medical oncology nurse and a radiation therapy nurse in a matter of one or two visits. Thus, we need to capitalize on the opportunity to address patient concerns at every visit and in every interaction (Thomas-MacLean et al., 2008). The notion of 'time' can be a reminder that each time we interact is an opportunity to use ALERT, and engage on this topic. Nurses in this study also mentioned that many patients used their phone or iPad to pass the time between or during chemotherapy, which can also serve as a prompt to have discussions about patient information needs and CRII questions.

The ALERT approach draws directly from the findings of this research, and is unique from LEARNS in several ways. First, we believe it is the role of the nurse to initiate discussions about CRII, and should not be the sole responsibility of the patient. Thus, the ALERT model starts with the nurse asking the patient about their use of CRII. Second, the website analysis indicated that CRII is predominantly empirical. And, from the patients and healthcare professionals, we know that patients do not always understand the CRII they find. Thus, nurses can reflect and reorient the concerns of the patient by listening to the information they have uncovered and putting it into a holistic context that applies to the patient. Finally, given the nature of cancer, nurses in all domains working with people with cancer can ask these questions in interactions at

all stages of the cancer trajectory, even in primary care. To summarize, the ALERT model is a practically derived model that can guide oncology nurses' discussions with patients about their use of CRII.

CONCLUSION

The study findings generate an understanding of how people mobilize CRII to support their needs, and how this influences and shapes interactions with healthcare professionals and the healthcare system. This paper presents a blueprint for nurses to proactively engage in conversations about CRII with their patients. Oncology nurses can be catalysts for change by demonstrating an open and non-judgmental approach to CRII in interactions with patients, healthcare professionals, and decision makers. Using the ALERT approach, nurses are especially well situated to ask patients about their CRII use and provide appropriate direction, particularly as these actions further support patient self-management. Intervening early to support CRII use might mitigate later concerns related to ill-suited information and allow nurses the opportunity to provide holistic cancer information. Nurses also embody the multifaceted knowledge described by Carper (1978) and bring this holistic approach to their patient care in ways that CRII cannot.

Through research, we should continue to explore the implications of CRII, be critical about its implications in practice, and cautious about over-investment in unnecessary technology. This study also generates many new questions about older adult engagement with technology to manage their cancer diagnosis, patient and family use of CRII, and the direct effects on healthcare systems and services. Patients described using CRII to support their self-management, thereby potentially using healthcare services or efficiently or effectively, and thus future research must explore whether this has direct effects on healthcare costs.

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CANO/ACIO International Symposium: Working in partnership within and beyond our Canadian borders to enhance oncology care

by Linda Watson, Margaret Fitch, Tayreez Mushani, Pamela Savage, Fay J. Strohschein, Martine T.E. Puts, Cindy Kenis, Lorelei Newton, and Maurene McQuestion

INTRODUCTION—LINDA WATSON

Globally, cancer is increasingly affecting our societies, families and healthcare systems. It is estimated more than 14 million people are diagnosed annually, greater than 8 million people die of cancer each year, and there are more than 32 million people living with and beyond cancer around the world. Complicating these overwhelming statistics is the reality that many countries in the world do not have well developed

cancer treatment programs; nor is it consistently recognized that specialized knowledge about cancer and caring for those with cancer is required by nurses.

CANO/ACIO has long held the vision of being a driving force nationally; but, importantly, we have also committed to being an influencing force internationally. To this end, a small working group of CANO/ACIO board members was created in 2014 to explore the potential role for the association within the international arena.

Our international interest led CANO/ACIO to host an International Symposium at the 2018 Annual Conference to highlight the work to date, discuss the guiding principles for our international work going forward, and explore how CANO/ACIO is currently engaging in the international arena. The symposium included two experiential cases that demonstrate how CANO/ACIO is actively influencing and advancing oncology nursing excellence internationally. In the first example, we heard from a CANO/ACIO member who, in collaboration with the Princess Margaret Hospital and the Aga Khan University School of Nursing and Midwifery in Kenya, developed the first African-based oncology nursing diploma program. This program was built on the CANO/ACIO Standards for Oncology Nursing. The second case explored the mutually beneficial partnership between CANO/ACIO and the International Society for Geriatric Oncology (SIOG) to collaborate on filling the knowledge gap about how to best support older adults with cancer.

In this article, we will recap CANO/ACIO's work to date on developing an international strategy, and explore how CANO/ACIO is actively influencing oncology nursing knowledge and expertise internationally. Although CANO/ACIO's prime priority is still meeting the needs of its members in Canada, the organization believes it can improve the quality of cancer nursing at home and abroad by leveraging the existing CANO/ACIO work in a broader context.

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DEVELOPING THE CANO/ACIO INTERNATIONAL STRATEGY—MARGARET FITCH

In 2014, CANO/ACIO established a work group to identify and define CANO/CIO's role and framework for engaging in the international arena. This group developed a discussion paper, conducted an environmental scan of other international nursing organizations regarding their international strategies, and proceeded to draft an action-oriented framework. Two subsequent Roundtable Focus Group Discussions with CANO/ACIO members helped to shape and finalize the International Strategy and Framework, titled "Engagement, Exchange, Influence and Partnerships".

In essence, CANO/ACIO sees that work is required both within and across borders in culturally sensitive ways to support the growth and development of oncology nursing. CANO/ACIO recognizes that nurses caring for cancer patients in many parts of the world do not have the benefit of access to specialized cancer nursing education nor specialty-related associations for support and, yet, they are facing an ever-growing population of cancer patients. In middle- and low-resource countries, almost three-quarters of the cancer population is diagnosed at an advanced stage and access to cancer treatment is very limited. In other words, the largest cancer burden is being felt by countries that are least prepared to respond to it effectively (Galassi, Challinor, et al., 2016a, 2016b).

Nurses have the potential to contribute in significant ways to cancer control. There are roles for nurses in prevention and public education, screening for disease, diagnosis, treatment and follow-up care. In particular, symptom management and patient/family education are roles nurses can undertake that will make a difference in the lives of cancer patients/survivors and their families around the world. However, to be effective, nurses need access to education and resources (So, Cummings, et al., 2016).

Not only are there important ways we can contribute beyond our borders, but there is also an opportunity for us to learn from those beyond our borders. Expertise in certain areas of cancer care has developed to a great extent in other nations. International collaborations provide the opportunity for us to incorporate that expertise into our work in Canada, and contribute to the further development of that expertise.

In thinking about CANO/ACIO's international role, it is important to also think about the multicultural population within our Canadian borders. As a country, we have many ethnic and cultural communities, as well as populations facing disparities due to social determinants of health. Our efforts need to balance what is done beyond our borders with what is done within our borders.

The principles for engagement articulated within CANO/ACIO's International Strategy include:

- Mutually negotiated process of exchange
- Social responsibility to articulate and build capacity
- Actively understanding and identifying what other countries seek from CANO/ACIO
- Forming partnerships
- Building on opportunities that present themselves to strategically engage
- Action-oriented framework applied in a phased-in approach.

The framework is depicted in Figure 1 and highlights the activities that are to be enacted with each phase of the work. The symposium at the 2018 conference was the first large-scale membership engagement in this work. Although the framework appears sequential and linear, the work outlined in the framework may not be, but will need to respond to the type/nature of opportunities that arise.

CANO/ACIO is most likely to be successful and effective within the international arena if it partners with other organizations such as the International Society of Nurses in Cancer Care, the Oncology Nursing Society, the European Oncology Nursing Society, and other national oncology nursing organizations (i.e., Australia) that are also actively engaged in international oncology nursing activities. Additionally, there may be opportunities to work collaboratively with organizations such as the Multinational Association of Supportive Care in Cancer (MASCC) and the International Psychosocial Oncology Society (through the Canadian Psychosocial Oncology Society) given we share similar goals for quality patient care. Such work can be synergistic and assist in initiatives within and beyond the borders of our country.

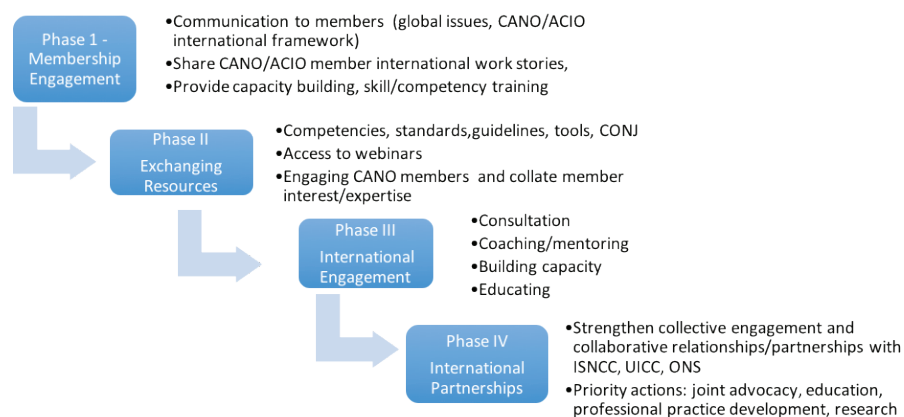


Figure 1: CANO/ACIO Framework for a phased approach to international engagement, exchange, influence and partnerships

CASE STUDY: ONCOLOGY HIGHER DIPLOMA PROGRAM, KENYA—TAYREEZ MUSHANI, PAMELA SAVAGE

Kenya, an East African country, is home to approximately 46.05 million people of which 45 percent are under the age of 15. Currently, the Kenyan health system is struggling to manage the rising burden of non-communicable diseases (African Health Observatory/World Health Organization, 2016) in the face of an underdeveloped healthcare system and a suboptimal health workforce. In 2013, Kenya reported two physicians and nine nurses per 10,000 individuals, far below the WHO recommendation of 44.5 physicians, nurses and midwives per 10,000 (2016). Additional challenges include the need to attract and retain nurses in specialized clinical areas, such as cancer care.

In response to this need, in 2013, Dr. Barry Rosen, a gynecologic oncologist, following a medical mission to Kenya, approached the nursing leadership at the Princess Margaret Cancer Centre (PM) to begin conversations on a philanthropic initiative to enhance oncology nursing capacity in Kenya through education. This conversation eventually led to a tri-institutional partnership between the PM, Moi Training and Referral Hospital (MTRH) and the Aga Khan University School of Nursing and Midwifery (AKUSONAM). MTRH, a public entity in Western Kenya which is funded by the Ministry of Health, runs a training school for various nursing specializations. AKUSONAM, a private entity, is part of the Aga Khan Development Network, a global non-governmental organization. The Aga Khan University has a School of Nursing and Midwifery in Nairobi. The PM and AKUSONAM jointly funded the partnership to collaboratively establish the oncology nursing diploma program.

The program mandate was based on the core principles of being standards based, meeting requirements

set by the Nursing Council of Kenya, adapted to the East African context, and achievable within a realistic time-frame. Program outcomes had to be achievable, applicable with theoretical and clinical components, and sustainable in the long term.

Initial work on program development, framed on the medical model, commenced in 2013 under the MTRH oncology team. The tri-institutional partnership formulated in 2014 resulted in a program shift to a nursing model. In August 2014, development work on the Oncology Nursing Diploma progressed on the foundational components of the PM Nursing Orientation grounded in the CANO/ACIO Standards. A Canadian Oncology Nurse Educator based in Kenya was recruited to develop a joint curriculum for the two sites.

The final curriculum consisted of 16 modules, encompassing the cancer trajectory from diagnosis to rehabilitation. The module contents included, but were not limited to cancer biology, treatment, side effect management, adult and pediatric cancers, symptom management, community care, leadership, research, teaching and learning and palliative care. The program consisted of 50% theory and 50% clinical hours. Additionally, the curriculum covered all CANO/ACIO Standards, met the Nursing Council of Kenya requirements and identified specific graduate attributes aligned to those of AKUSONAM. Each site delivered the program over a period suited to local nursing population needs. The MTRH course, delivered over one year full-time, graduated seven students from the first class. The AKUSONAM course, a work-study program delivered over 18 months, two days per week, graduated 16 students from the first class.

The Canadian Oncology Nurse Educator divided her time between both sites. Content was developed, faculty were mentored in oncology practice, teaching and learning strategies, and exams were established. The Educator also worked with the

Nursing Council of Kenya to develop an Oncology Syllabus, a template for other institutions aiming to develop an oncology nursing diploma program. The PM nursing leadership continually provided guidance and resource materials from abroad to support the Educator.

Key international partners further collectively supported the Diploma Program. The PM nursing leadership portfolio shared educational materials, and donated books and teaching mannequins. The Oncology Nursing Society donated books and the Oman Cancer Center sponsored faculty training in Muscat.

The CANO International Strategy identified roles in education, professional practice and research, and these were actualized through the development of the Kenya Oncology Nursing Diploma Program. The Program curriculum, founded on CANO/ACIO Standards, led to the recognition of oncology nursing as a specialization in Kenya. This work led to the development of an East African regional specific model of oncology nursing education for adaption in neighbouring countries. Finally, the Oncology Nurse Educator participated in grant-funded research to explore the beliefs of Kenyan women with particular cancers.

Reflecting on this experience, the authors shared prerequisites for international program development in oncology nursing education. Firstly, a standards-based customized nursing curriculum is crucial to ensure evidence-based nursing knowledge. The local presence of an oncology nurse expert or team of experts supported by an oncology centre such as PM ensures access to quality educational materials, updated relevant clinical content and peer support. Strong relationships with local and regional cancer care providers and nursing governing bodies ensures alignment of curriculum goals to the regional needs and context. Finally, mentorship of local and regional faculty for capacity building ensures long-term program sustainability.

CASE STUDY: STRENGTHENING THE NURSING CARE OF OLDER ADULTS WITH CANCER: AN INTERNATIONAL COLLABORATION—FAY J. STROHSCHN, MARTINE T.E. PUTS, CINDY KENIS, LORELEI NEWTON

In Canada, almost half of new cancer cases, and two-thirds of cancer deaths, occur among those aged 70 years and older (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017). Given that the number of older Canadians has doubled in the last 20 years, and is expected to double again within the next 20 (Statistics Canada, 2017), an increase of at least 40% in the number of new cancer cases over the next 15 years is expected (Canadian Partnership Against Cancer, 2017). Most of these will occur in older Canadians (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015).

Canada is not alone in these concerns. Population aging is mirrored in developed and developing nations worldwide (He, Goodkind, Kowal, & United States Census Bureau, 2016), with a corresponding impact on global patterns of cancer incidence (Global Burden of Disease Cancer, 2018). Internationally, researchers have identified important age-related disparities in survival (Coleman et al., 2011; Zeng et al., 2015) and treatment (Bojer & Roikjær, 2015; Fang et al., 2017; National Cancer Equality Initiative/Pharmaceutical Oncology Initiative, 2012). The Canadian Partnership Against Cancer is recognizing these concerns and has highlighted the importance of addressing the needs of older people with cancer in its strategy for Cancer Control for the next five years (Canadian Partnership Against Cancer, 2016).

Oncology nurses are uniquely positioned to identify and address the age-related concerns of older adults with cancer and their families. In 2015, a workshop was held at the Canadian Association of Nurses in

Oncology/Association canadiennes des infirmières en oncologie (CANO/ACIO) Conference to explore the need and relevance of starting an Oncology and Aging Special Interest Group. Within this workshop, members discussed the age-related concerns that they saw in their practice, identifying issues related to ageism, suboptimal treatment outcomes, and ethical issues concerning treatment and care decisions (Strohschein & Newton, 2018). The concerns that participants expressed related to the age-related needs of their older patients, and the lack of resources to appropriately address these needs supported the development of this group.

Geriatric oncology is a small and growing, specialty in Canada, but is much further developed in Europe and the United States (Puts et al., 2017). The International Society of Geriatric Oncology (SIOG) is the foremost network of healthcare professionals and researchers striving to integrate understanding of geriatrics into oncology care. In 2017, Dr. Martine Puts, a member of the CANO/ACIO Oncology and Aging Special Interest Group and co-chair of the SIOG Nursing and Allied Health Interest Group, suggested collaboration between these two groups. There was an important fit between the mission and goals of the organizations, and of the special interest groups themselves). Both organizations focus on the development and advancement of healthcare professions and both interest groups strive to mobilize nurses to strengthening the care of older adults with cancer in clinical practice, research, education and policy. These shared objectives provided the opportunity to develop a partnership that assists each organization to meet its goals. In February 2018, a formal memorandum of understanding was signed.

The purpose of this international memorandum of understanding between CANO/ACIO and SIOG is to "increase collaboration, mutual recognition, and shared, culturally sensitive approaches to the work of both organizations" (CANO/ACIO & SIOG, 2018, p. 2). The partnership focuses on "educational, resource development, advocacy and research activities, as well as

communication between the two organizations about strategies to develop and to promote optimal care of older people with cancer and those close to them" (CANO/ACIO & SIOG, 2018, p. 2). It also offers the opportunity for interdisciplinary and interprofessional collaboration and mentorship. To this end, CANO/ACIO and SIOG made the following commitments:

1. To work together to advocate for high quality care for older people at risk for/living with/or surviving cancer.
2. To work together to develop and promote geriatric oncology nursing as a sub-specialty.
3. To collaborate on the development of programs and/or resources for nurses, as well as for older people with cancer and those close to them. Programs/resources may include, for example, joint conference presentations or symposiums, joint position statements, clinical guidelines and practice tools, educational learning modules, or patient and caregiver information materials.
4. To exchange materials developed by both organizations. Materials may include, but are not limited to, position papers, educational resources, or other materials as agreed between the organizations. All publications and products developed as a result of this MoU [memorandum of understanding] will be co-branded and subject to relevant policies within CANO/ACIO and SIOG (e.g. Intellectual property policy). (CANO/ACIO & SIOG, 2018, p. 2)

This collaboration facilitated several joint projects in 2018, including a webinar, conference workshops and presentations, and a learning needs survey (Table 1). We are currently working to develop a joint international position statement concerning the role of nurses in optimizing the care of older adults with cancer and those close to them.

In this collaboration, the mutual benefits have far outweighed any challenges (Table 2). Important facilitators of this collaboration have included common goals and objectives; ongoing support from the CANO/ACIO and SIOG boards, executives, and head offices;

and members with joint involvement in both organizations. Collaboration at the level of special interest groups, a first for CANO/ACIO, has created a valuable synergy in the collaboration. Overall, this work has allowed us to draw on international resources to support CANO/ACIO members, while at the same time strengthening CANO/ACIO's international voice.

DISCUSSION/CONCLUDING REMARKS—MAURENE MCQUESTION

Following the two presentations that profiled different approaches to conducting international work, including 1) collaboration within a developing country using the CANO standards (i.e., Kenya), and 2) leveraging collaboration between CANO and an international association to develop resources that could be utilized both by CANO nurses and nurses working internationally (i.e., SIOG), input was sought from the symposium attendees. Feedback focused on the presentations and CANO's current work related to improving the quality of cancer nursing at home and abroad through leveraging the existing CANO/ACIO work in a broader context. It was important to see if the work to date resonated with members and participants, and to garner input about the directions that CANO/ACIO should move within its involvement in international work. Questions to the audience included 1), what level of involvement should CANO/ACIO have regarding international activity (now, in future), and 2) what are the next steps for the organization regarding international efforts?

Participants supported that CANO/ACIO is moving in the right direction with the International strategy, but indicated there needs to be ongoing discussion. While there is a need to think within and beyond our borders, there is a different level of thoughtfulness and work required for these two diverse environments, as well as different levels of collaboration and sophistication. Different drivers and strategies would be required for each.

Ongoing work will focus on identifying the structures and supports that would enable CANO/ACIO to enact the

Table 1. Overview of Organizations and Special Interest Groups

Canadian Association of Nurses in Oncology/Association Canadienne des Infirmières en Oncologie (CANO/ACIO) (SIOG) Established in 1985 ~1100 members* "Mission to <u>advance oncology nursing</u> excellence through practice, education, research, and leadership for the benefit of all Canadians, and a <u>vision of being an international nursing leader in cancer control</u>." (CANO/ACIO, 2017, 'About Us' section) Oncology and Aging Special Interest Group Established in 2015 ~100 members* Purpose is "to bring together <u>nurses with a common interest in the care of older adults with cancer</u>, engaging in activities to promote innovation in practice, research, education and policy development." (CANO/ACIO & SIOG, 2018, p. 1)	International Society of Geriatric Oncology Established in 2000 ~5000 members in 75 countries* Goal is to "foster the <u>development of health professionals</u> in the field of geriatric oncology, in order to optimize treatment of older adults with cancer." (SIOG, 2015, 'Mission & Vision' section) Nursing and Allied Health Interest Group Established in 2014 ~50 members* Aims to promote "<u>excellence in geriatric oncology nursing</u> and allied health-related activities through the SIOG strategic directions: education and clinical practice, communication and advocacy, and research." (CANO/ACIO & SIOG, 2018, p. 1)
*As of October 2018	

Table 2. Joint Projects

Webinar • Oncology & Aging 101: Understanding the Needs and Concerns of Older Adults with Cancer
Canadian Association of Nurses in Oncology/Association Canadienne des Infirmières en Oncologie (CANO/ACIO) Annual Conference 2018 • Pre-conference Educational Workshop: Integrating Geriatric Assessment into Oncology Nursing Care • Board-sponsored Workshop & Roundtable Discussion: A National Conversation about Oncology Nurses' Role in Optimizing Care of Older Adults with cancer
International Society of Geriatric Oncology (SIOG) Annual Conference 2018 • SIOG/CANO/ACIO/European Oncology Nursing Society Education Session: Comprehensive Geriatric Assessment Program Implementation and Nurse Role in Program from Netherlands, Belgium, Canada, and United Kingdom • SIOG Roundtable Discussion: Nurses' role in Optimizing Care of Older Adults with Cancer
Online Learning Needs Survey • Canadian Network on Aging and Cancer and CANO/ACIO Survey: Geriatric Oncology Learning Needs Survey https://surveys.nursing.utoronto.ca/267377?lang=en

international strategy. CANO/ACIO is committed to developing opportunities for members to be involved in international oncology nursing efforts, but further member input from those with an interest in this area is required. An

important enabler to explore in this conversation is CANO/ACIO's partnership with the International Society for Nurses in Cancer Care (ISNCC). This partnership may provide CANO/ACIO with direct opportunities to collaborate

on international issues and to provide impactful solutions that do not duplicate the efforts of other oncology nursing associations.

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Association canadienne des infirmières en oncologie

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