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Toward equitably high-quality cancer survivorship care

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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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