Cancer survivorship: Creating a national agenda

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Introduction

The cadre of individuals who are living after a diagnosis of cancer is growing steadily. In developed countries, as many as 78% of pediatric patients are alive five years following diagnosis, as are 60% of adult patients (Curtiss & Haylock, 2006). At present in Canada,

about one million individuals are living as cancer survivors (Canadian Cancer Society, 2008). With the anticipated increase in the incidence of cancer around the world and the success of treatment approaches, it is anticipated this cadre will continue to grow.

Unfortunately, cancer survivorship does not come without cost. It is becoming increasingly evident there are late and long-term effects cancer survivors experience, both physical and psychosocial, that can compromise quality of life and increase the burden of suffering. Compared to matched population controls, cancer survivors have significantly lower outcomes on many burden of illness measures and experience difficulties accessing appropriate health care for a broad range of chronic medical conditions (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004; Earle & Neville, 2004). A history of cancer may shift attention from important health problems unrelated to cancer and the roles of primary care providers and specialists in cancer care of survivors are not yet clear.

As well, quality of life issues are different for survivors than for individuals at the point of diagnosis and treatment. Cancer survivors face a range of physical and psychosocial challenges. Up to 75% of survivors have health deficits related to their treatments (Aziz & Rowland, 2003), more than 50% live with chronic pain (Lance Armstrong Foundation, 2004), 70% have experienced depression (Lance Armstrong Foundation, 2004), and between 18% and 43% have reported emotional distress (Vachon, 2006). Regardless of tumour type, there are commonly reported challenges: living with fear and uncertainty; changes in family roles; alterations in self image and self esteem; changes in comfort, physiological functioning and mobility; alterations in cognitive functioning; changes in employment and recreation; altered fertility and sexuality (Aziz & Rowland, 2003; Denmark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Ganz, 2001; Lance Armstrong Foundation, 2005). Clearly, cancer survivors are a vulnerable population. New approaches are needed to overcome the barriers cancer survivors experience and ensure they receive appropriate care.

Progress in cancer survivorship policy

The most significant work to date in the arena of survivorship has occurred in the United States, although other countries (including Finland, Australia, and New Zealand) have been working toward national strategies for cancer survivorship. Recognition of the emerging issues related to cancer survivorship led to the creation of the Office of Cancer Survivorship in 1996 in the United States. The organization's mandate is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship. The Office of Cancer Survivorship conducts and supports research that both examines and addresses the long- and short-term physical, psychological, social, and economic effects of cancer and its treatment among pediatric and adult survivors of cancer and their families. Over the years, several significant publications have appeared documenting the current knowledge about cancer survivorship and encouraging action at the policy and program level (Institute of Medicine [IOM], 2003, 2004, 2005). These documents provide an excellent summary of the current knowledge about cancer survivorship.

Survie au cancer : la création d'un programme national

Abrégé

La communauté des personnes survivant à un diagnostic de cancer s'accroît régulièrement. Dans les pays industrialisés, jusqu'à 78 % des patients de pédiatrie sont encore en vie 5 ans après leur diagnostic tandis que ce chiffre se monte à 60 % chez les patients adultes (Curtiss et Haylock, 2006). Le Canada compte actuellement environ un million de survivants du cancer (Société canadienne du cancer, 2008). Du fait de la hausse anticipée de l'incidence du cancer à l'échelle mondiale et du succès des approches thérapeutiques, il est prévu que cette communauté ne cesse de grandir.

Malheureusement, la survie au cancer s'accompagne d'un lourd fardeau. Il est de plus en plus évident que les survivants du cancer éprouvent des séquelles à court et à long terme, à la fois physiques et psychosociales, lesquels nuisent à la qualité de vie et rehaussent la souffrance globale. En comparaison avec des groupes témoins appariés, les survivants du cancer obtiennent des scores sensiblement plus bas pour de nombreuses mesures du fardeau de la maladie et éprouvent de la difficulté à accéder à des soins de santé adéquats pour une vaste gamme de conditions médicales chroniques (Yabroff, Lawrence, Clauser, Davis et Brown, 2004; Earle et Neville, 2004). Il est possible que des antécédents de cancer détournent l'attention de problèmes de santé importants non associés au cancer et les rôles des fournisseurs de soins primaires et des spécialistes n'ont pas encore été clarifiés relativement aux soins de cancérologie à dispenser aux survivants.

De plus, les enjeux de qualité de vie ne sont pas les mêmes pour les survivants que pour les individus en phase de diagnostic et de traitement. Les survivants du cancer font face à un large éventail de défis physiques et psychosociaux. Jusqu'à 75 % des survivants ont des problèmes de santé associés à leurs traitements (Aziz et Rowland, 2003), plus de 50 % éprouvent une douleur chronique (Lance Armstrong Foundation, 2004), 70 % ont souffert de dépression (Lance Armstrong Foundation, 2004) et entre 18 et 43 % d'entre eux ont signalé de la détresse émotionnelle (Vachon, 2006). Quelque soit le type de tumeur, les survivants signalent fréquemment les défis suivants : vivre dans la peur et l'incertitude; changements au niveau des rôles familiaux; altérations de l'image et de l'estime de soi; changements en matière de bien-être, de fonctionnement physiologique et de mobilité; altérations du fonctionnement cognitif; changements relatifs à l'emploi et aux loisirs; atteintes à la fertilité et à la sexualité (Aziz et Rowland, 2003; Denmark-Wahnefried, Aziz, Rowland et Pinto, 2005; Ganz, 2001; Lance Armstrong Foundation, 2005). Il est évident que les survivants du cancer constituent une population vulnérable. Il est nécessaire d'élaborer de nouvelles approches afin de permettre aux survivants du cancer de franchir les obstacles qu'ils rencontrent et de recevoir les soins adéquats dont ils ont besoin.

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Another significant leadership role for cancer survivorship emerged in United States from the survivor community itself. The Lance Armstrong Foundation (www.livestrong.org) has drawn attention to survivorship issues, raising public knowledge and mobilizing both research and practice initiatives. Their platform for a national survivorship agenda, developed in collaboration with the Centers for Disease Control and Prevention, contains four planks: surveillance and applied research; communication, education and training; programs, policies and infrastructure; and access to quality care and services (www.cdc.gov/cancer). Their work is supported by other organizations such as the Coalition for Cancer Survivorship (www.canceradvocacy.org) and C-Change (www.c-change.together.org). Recently, this work on cancer survivorship has become a priority for action under the leadership of the Surgeon General of the United States. It is one of the four planks embodied in their National Call for Action on Cancer Prevention and Survivorship (www.NCTAcancer.org).

Cancer nurses have also been providing leadership for cancer survivorship in the United States. Under the auspices of the American Nurses Association and the Oncology Nursing Society, workshops have been held to draw together experts in the field and gather the evidence that is a foundation for survivorship care (Curtiss & Haylock, 2006). Given the roles nurses hold, the various settings in which they work, and the relationships they have with their patients, they are in an ideal position to learn firsthand about the challenges cancer survivors face and see ways to resolve these issues. More recently, a workshop was held with nurse representatives from organizations across the United States and representatives from the International Society of Nurses in Cancer Care to develop the Prescription for Survivorship (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007). This document is an excellent resource and guide for cancer nurses who want to be leaders in cancer survivorship.

Purpose of article

Until recently, cancer survivorship has had very little attention in Canada. However, that situation is now changing. This article will describe the approaches taken in our country with the aim of improving interdisciplinary care for cancer survivors. Working at a country-wide level, we have been able to create and advance a national agenda for cancer survivorship. Awareness of the issues has been increased and survivorship has become a priority to action in policy and research arenas.

Recognizing the emerging challenge

In Canada, the need to pay attention to the emerging cancer survivorship challenge was recognized within the ReBalance Focus Action Group of the Canadian Strategy for Cancer Control. This group was created in 2002 to provide national leadership for changing the cancer system in such a way that patient and family needs would be better served. During the deliberations within the ReBalance Focus Group, it was recognized there is a growing cadre of survivors in Canada, these individuals continue to struggle with unresolved issues, and relatively little attention had been paid to designing programs or interventions for this population. With the estimated increase in the number of individuals who would be diagnosed with cancer over the next decade and the improvements in treatment, this population is expected to grow considerably. Clearly, new approaches are needed.

In 2006, with the creation of the Canadian Partnership Against Cancer, an independent organization funded by the federal government to accelerate action on cancer control for all Canadians, the ReBalance Focus Group became the Cancer Journey Action Group and championed the cause of cancer survivorship. A plan was enacted to create a national agenda. The steps in the plan included: 1) conducting an environmental scan (and literature review) regarding cancer survivorship; 2) holding a national stakeholder workshop, and

3) gathering data about the needs of cancer survivors. Each of these initiatives will be highlighted below while **full reports** for all of these aspects of the work can be found at www.partnershipagainstcancer.ca.

Environmental scan of cancer survivorship in Canada

Aims and objectives:

The initial step in setting the agenda for cancer survivorship was to establish a clear understanding of care delivery for cancer survivors across the country. An environmental scan was crafted to accomplish this goal with the following specific objectives:

1. to explore the nature of and extent to which cancer survivorship conceptualization, research and practice are underway in Canada,
2. to identify some key Canadian contributions to cancer survivorship initiatives, and
3. to identify resources from the literature that may prove useful in future cancer survivorship efforts in Canada.

Methods

A literature review and series of key informant interviews were conducted for this environmental scan. The literature review was not exhaustive given the background literature that has emerged regarding this topic (Ganz, 2007). The focus of this review was on publications related to program development in Canada. The key informants were identified through a network or "snowball" approach, as well as contacting individuals who were designing or offering survivorship programs across this country. The focus of the interviews was on understanding conceptualizations of survivorship and the nature of the programs that were being offered. In total, 47 individuals were interviewed including professional experts, community members and/or survivors. For many, their roles cut across practice, education and research.

Key findings

The interview data revealed that there are different definitions of cancer survivorship operating across the country. Some definitions conceptualize survivorship starting at the point of diagnosis, while others pinpoint survivorship following the end of primary tumour treatment or at the five-year post-treatment point. Some stated that they embraced the idea of survivorship starting at the point of diagnosis, but realized that for program planning there would be merit in selecting a point at the end of and following primary treatment. Even with this focus, there is concern about what is done and said during treatment that would set the stage for survivorship. Clearly, this is an area for further investigation.

Overall, interviewees believed that cancer survivorship care in Canada is "patchy" and, overall, not of high quality. Participants recognized that cancer survivors are not a homogeneous group with respect to needs or risks and much more effort is needed to understand these variations. Work is also needed regarding prevention, surveillance, intervention, and coordination of care.

Significantly, there is a need for development and implementation of appropriate models of care, guidelines, and follow-up care plans. Increased collaboration between the cancer care systems and broader health care systems, including the community, was seen as imperative for future improvements in care.

Research was also identified as an important and required activity. The field of cancer survivorship is becoming more recognized as a valuable topic and Canada has researchers with a reputation in this field. Because of the availability of population data and a somewhat lower dependency upon politics and advocacy than other countries for funding and the identification of research priorities, Canada is well placed to provide leadership in cancer survivorship research. However, to make this happen, we would need to raise awareness about the need for this research, identify and agree upon priorities and topics, develop stronger collaboration across organizations, and develop stronger mechanisms for funding (Table One).

National stakeholder workshop on cancer survivorship

Aim and Objectives

The second step in the process of setting a national agenda for cancer survivorship was to hold a consultation with the broad cancer community. A national invitational workshop was organized to bring a range of stakeholders in cancer survivorship together. This was the first cancer survivorship meeting in Canada in which health professionals, cancer survivors, and advocacy groups could focus on what the country needed by way of an agenda for action in cancer survivorship. At the onset, the participants indicated their agreement with the vision for the work:

All Canadians experiencing cancer (and their family members/significant others) will receive the necessary support, education, and navigation (or referral) to utilize accessible, acceptable, affordable, comprehensive, and coordinated services to empower them to promote their health and well-being with, through, and beyond cancer.

A small planning group provided the overall direction for the workshop and its organization. The invitees to the workshop included a cross-section of professionals, volunteers/peers, and survivors. A total of 84 individuals attended the workshop, including 34 cancer survivors. Participants attended from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and Newfoundland/Labrador, as well as the United States and Australia.

The workshop began with a series of plenary presentations to share current knowledge about cancer survivorship in Canada, United States and Australia, and to review the findings from the Canadian Environmental Scan. The participants then engaged in a series of small group discussions over a day-long period. The groups had pre-set questions and both a group facilitator and a note-taker were assigned to each table for each conversation. The groups discussed the following questions:

1. What are the key issues facing cancer survivors in Canada?
2. What are the priorities for action concerning these key issues?
3. What are the implications for clinical care, education, and research flowing from the priorities identified?

The overall priorities were selected following the presentation of the discussion group reports to the whole group. The selection of the overall priorities was based on the items that were commonly identified across all the discussion groups. The seven priorities were not rank ordered, as participants thought they were all important. The priorities identified form the basic planks for the national cancer survivorship agenda (i.e., action plan).

Findings

The dialogue regarding key issues during the group discussions emphasized how varied the notions about cancer survivorship are across the country. As a result, there was much confusion about where the emphasis for action needed to be placed. Repeatedly participants emphasized the diversity of experiences and the variation in survivor needs. Living with cancer clearly continues after treatment is finished, but the exact pathways may vary dependent upon the type of cancer, treatment that was given, and stage of the disease. No one approach is

going to be effective for everyone. Participants emphasized the need for strong leadership and for clarity in use of language. There was debate about using the words “survivor” and “survivorship” with some participants suggesting “thrivor” would be more appropriate.

The group discussions also emphasized the need for care to be holistic—to be provided in a comprehensive manner that attended to the full range of survivor needs. Clearly, there are physical effects, but there are also psychosocial issues that continue to plague survivors. Better access to information and resources is needed and attention must be paid to the economics and cost burdens survivors incur. Guidelines, standards of care, care plans for follow-up, and transitions coordinators were all named as tools that would be useful if they were implemented.

Finally, research was highlighted as being critically important. Research evidence is needed to develop guidelines, follow-up protocols, and programs of support. In particular, this evidence needs to be generated in the Canadian environment. Many participants emphasized the need for collaboration amongst researchers and organizations, increased funding for survivorship research, and knowledge exchange models to guide the work. Closer ties between research and practice were recommended to accomplish widespread dissemination of cancer survivorship knowledge into practice settings. Additionally, collaboration within and beyond the cancer care community is imperative.

In the final analysis, seven priorities were identified, but not rank ordered. The priorities that will form the national agenda for cancer survivorship include the following:

- establishing national standards and guidelines for survivorship care
- identifying appropriate models of care delivery to meet the long-term needs of cancer survivors
- developing and implementing of survivorship care plans
- promoting survivorship research
- ensuring effective knowledge translation
- facilitating a comprehensive communications plan
- promoting a consortium of national cancer advocacy groups.

Gathering survivor perspectives in two provinces

Aim and objectives

Significant effort is needed to develop a comprehensive understanding of the needs of cancer survivors across Canada. In an effort to start this process and begin to gain some insight regarding how to access this community, the Cancer Journey Action Group was able to participate in two provincial symposia organized for cancer survivors in 2008. (One provincial symposium had already occurred in Nova Scotia prior to this step being undertaken. The Nova Scotia report is available on www.cancercare.ns.ca.)

Methods

Participation in the provincial symposia provided an opportunity to gather perspectives on issues and challenges for survivors from their perspectives. This opportunity allowed us to begin to understand the needs of cancer survivors within the Canadian context.

In St. John's, Newfoundland, in May, the 9th Annual Breast Cancer Survivors Network hosted more than 200 women for a three-and-a-half-day conference. Individual surveys designed to elicit needs and concerns were distributed to all participants as they entered the plenary session. A total of 95 completed surveys were returned at the end of the session (response rate 41%). Following the plenary presentation about the work of the Canadian Partnership Against Cancer, small group discussions allowed the women to talk about their perspectives with one another and identify priorities for action. The discussion group time lasted about 60 minutes. Each group was given a page with instructions for the discussion and for documenting their responses. Each group was asked to identify issues facing survivors, select the top three or four, and make recommendations

Table One. Topics identified for survivorship research in Canada (from scan and workshop)

1. needs assessments to identify and measure the proportion of those survivors who are in need (who is in need, what are the needs, how to address the needs)
2. identification of late effects and interventions for management
3. focus on lifestyle, wellness, and the chronic nature of cancer
4. potential of technology /support web-based information
5. evaluating models of care

about what could be done to improve each of the top three items. The discussion sessions included all women divided into 32 small groups. Each group selected its own leader and person to take notes.

In Toronto, Ontario, in November 2008, the first province-wide survivorship conference was hosted by the Ontario Division of the Canadian Cancer Society. Each of the 200 attendees was alerted to copies of an individual survey at their tables as they joined into a plenary session. The attendees were invited to complete the survey and leave it at the conference registration desk or return it by mail. A total of 55 surveys were submitted (response rate 27.5%).

Findings

Of the 95 individual responses from the Newfoundland conference, 36 women had been diagnosed in the past five years while 31 had been diagnosed between five and 10 years and the remainder had been diagnosed more than 10 years ago. Sixty-five reported living in a rural setting. Responses were categorized as positive comments when respondents indicated there was “no issue” or “no concern” in a need area or actually wrote a description about a positive event (i.e., “I feel a lot better now than I did”). Responses were categorized as negative comments when respondents indicated there was an issue or a problem or lack of necessary assistance.

Table Two highlights the seven supportive care need areas and the nature of the responses described by the survivors at both provincial

conferences. Clearly, many individuals were continuing to struggle with challenges in some areas following the cancer treatment. Women emphasized the value of information, communication, support, navigation and access to supportive services as key aspects for coping successfully as survivors. The summary from the group discussions at the Newfoundland conference is presented in Table Four. The most frequently identified issues for survivors concerned 1) lack of follow-up care and support, 2) having to travel to treatment, and 3) lack of information/poor communication.

These issues were also identified as priorities for action in addition to the issue of lack of continuity and consistency in professional care. Repeatedly, the comments described uncertainty regarding who was in charge of their follow-up care and to whom they ought to go for specific issues. The interface between cancer care and primary care was often missing. Access to relevant and consistent information was seen as key to being able to cope and knowing where to go for assistance. Acknowledgment by health care professionals about the legitimacy of the ongoing concerns survivors were experiencing was also emphasized. Education about survivorship was cited as important for both health care providers and the public.

Next steps

To implement the national agenda for cancer survivorship, the next step is to formalize a leadership group. This group will utilize a co-chair

Table Two. Needs of cancer survivors reported by individual respondents

	Newfoundland Breast Cancer Survivors (n=95)			Ontario Mixed Cancer Survivors (n=55)				
	Positive comments examples	#	Negative comments examples	#	Positive comments examples	#	Negative comments examples	#
Physical	No complaints. I feel fit.	40	Lymphedema in my arm. I am so tired.	45	None (no concerns)	3	Sexual dysfunction due to side effects of hormone treatment. Some weakness in left arm due to surgery.	47
Social	My social and family life has improved. My family is very supportive.	62	Family is very stressed. I am uncertain.	15	Social contacts with family and a few friends mostly by phone. Have more contact with volunteer work and get satisfaction.	13	Because treatment is over everyone thinks it's 'cured', but mentally and physically I still have a long road to travel.	26
Emotional	I feel I am a better person. I got over the crying.	36	I feel up and down a lot. I am still scared.	39	I feel wonderful. Life is wonderful. Cancer made all the good things in life better.	10	Depression—tired of treatment that never ends.	34
Psychological	I have come to accept this all and move on. I feel good about my body.	66	I am not really confident about my body I find it hard to let my husband see my body.	16	I had good assistance/help with this through really good nursing and social work care.	13	Hate my body.	19
Spiritual	It strengthened my faith. I pray a lot and depend on God.	74	Not much faith right now.	3	I believe that taking care of the temple (my body) will benefit me and help me deal with the illness.	32	I lost my spiritual beliefs.	2
Informational	I feel well-informed. I get the info I need.	18	Need to know more. So many questions.	40	Got all information that I had from medical people and support groups.	6	More about late effects (childhood). Why such poor care from late effects clinics?	40
Practical	I am lucky—I have insurance. Everything's okay—I am still working.	54	The budget is strained. I have not been back to work yet.	19	Not as important anymore. I would rather spend my time having fun and experiencing life.	14	Finance is still huge and also because my insurability is greatly affected.	24

model where one of the co-chairs is a survivor. At the time of writing this paper, the process was underway to recruit the co-chairs and then populate the working group. It is anticipated this group will mobilize efforts around the agenda, especially for those topic areas where no activity is currently unfolding.

Additionally, activity is underway amongst the national cancer research funders to consider this topic area for future funding allocation. Several groups have indicated cancer survivorship is a priority for them (e.g., Canadian Cancer Society Research Institute—Leadership Fund; Canadian Health Institutes of Research—Cancer Advisory Board; Breast Cancer Research Alliance). A national research workshop focused entirely on survivorship was held in British Columbia in November 2008, and the report will be ready soon. It is expected this report will describe priorities for moving a research agenda forward for cancer survivorship.

Discussion and conclusion

There is no doubt about the need for research and program activity in the area of cancer survivorship. The needs of cancer survivors and the experienced quality of life are different from those individuals

who are receiving treatment. We have an obligation, after treating these individuals, to assist them in achieving the optimal level of well-being they can achieve and not leave them to bear the suffering of dealing with late and longer-term effects from that treatment alone. It is imperative we take action, as a nation, to implement a national action agenda for cancer survivorship.

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Table Four. Topics identified as gaps in care for survivors by 32 groups

What do you see as the Gaps in Care or Service to cancer survivors today?		What are the 3 or 4 most important gaps or barriers to overcome?	
Lack of follow-up care and support	34	Communication and information; help sorting through information	21
Gaps in information	22	Lack of continuity and consistency in professional care	14
Lack of communication	12	Providing follow-up care and support	13
Travelling for treatment	15	Wait times	9
Lack of continuity and consistency in care by professionals	11	Travel to care in order to get it	6
Wait times	11	To be treated as a person	6
Access to services	5	Financial issues	5
Screening	4	Advocacy	3

Table Three. Specific negative physical issues from women at Newfoundland workshop (N=95)	
Lymphedema	9
Fatigue	8
Memory loss/Confusion/Cognitive Changes	7
Frozen shoulder/Joint stiffness/↓ ROM	7
Side effects medication (i.e. Tamoxifen)	7
Skin changes/Scar	7
Pain	5
Other (1 or 2 responses): not feeling well, hair loss, hot flashes, tingling hands and feet, sleeping problems, loss of taste, get cold easily, low immune response)	22

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