

## Supportive Care of Cancer Survivors

DAUNA CROOKS, ROSEMARY COLUCCI,  
MARGARET FITCH, DANIEL GILLESPIE,  
LYNN HRYNIUK AND WILLIAM HRYNIUK

### Introduction

There is no agreement on exactly who is a cancer survivor; definitions range from anyone with a diagnosis of cancer<sup>1</sup> to only those reaching landmarks such as five year survival.<sup>2,3</sup> With the advent of newer and more effective treatments and screening, three per cent of Canadians (one million) are now cancer survivors, and cancer is considered a chronic disease. Attention has been recently focused on the range of psychological and physical problems cancer survivors face, that can be incapacitating or even life threatening.

Early literature discussed survivorship as dealing with negative psychological aspects of the cancer experience. Thus, survivorship was known to carry a price in terms of these sequelae, with issues related to psychological, social and spiritual aspects of well-being.<sup>4</sup>

Clarity around survivorship is beginning to unfold. In a concept analysis of survivorship, Peck<sup>5</sup> identified the following characteristics:

- confronting mortality and trust in life;
- dealing with alienation and isolation;
- searching for meaning and growth;
- needing to reprioritize life; and
- coming to terms and moving on within a continuing identity as a cancer patient.<sup>3</sup>

In order to address these needs a variety of supports are needed for survivors to accept past life altering events, assimilate an altered self image and adapt to a modified (uncertain) future.

In addition to constant anxiety of disease recurrence, more recent studies have recognized a plethora of physical problems in survivors, especially those who received more intensive treatment. Among these are prolonged or delayed side effects in specific organ systems, altered physiology resulting in increased risk for obesity, and some combination of heart disease, diabetes, hypertension, or osteoarthritis (collectively known as the metabolic syndrome), and debilitating fatigue.<sup>7</sup> Sexual dysfunction can also be particularly troublesome and is fre-

quently overlooked or inadequately treated. As a result of all of these residua, survivors have a higher than normal death rate from non-malignant disease, and are among the most frequent claimants for long term disability insurance based on physical causes.<sup>8</sup>

Common to all of these problems is some degree of distress, extending along a continuum ranging from feelings of vulnerability to disabling problems such as depression, and spiritual crises. Distress (or suffering) may interfere with the ability to cope effectively with the long term issues related to cancer survivorship.<sup>9</sup> Failure to achieve healthy resolution of distress may result in unhealthy behavior and many of the complications faced by survivors.<sup>10</sup>

Recognition and successful management of distress by psychosocial and other supports can have substantial benefits. There is now considerable evidence that diet changes and increased exercise can not only prevent cancer but can also prevent cancer recurrence.<sup>11,12</sup> Combinations of exercise and counseling can combat cancer-related fatigue,<sup>13,15</sup> and exercise can reduce depression.<sup>14,16</sup>

Interventions can enhance the quality of life and improve caregiver-patient communication resulting in better adherence to survivor recommendations geared to active treatment.

Given the threats to survivors' mental and physical well-being, the impact of survivors' disability on the workplace and society, and the effectiveness of interventions to circumvent a downward spiral to disability, clearly, more attention must be paid to supportive care for cancer survivors. This would encompass the range of activities that help survivors and families cope with the burden of illness, namely assistance with:

- adjustment to the physiological and psychosocial effects of having gone through treatment for cancer,
- alleviation or avoidance of the prolonged or delayed side effects of treatment, and
- education regarding the lifestyle changes required to reduce risk of recurrence of cancer and other chronic diseases sharing risk.

## **The Role of Nurses in Managing Survivorship Issues**

Oncology physicians are increasingly preoccupied with efficient and effective application of newer technologies, are not trained in the techniques required for supportive care interventions, and do not have the time or education to provide the support survivors require.<sup>17</sup> Given the predominant style of practice of cancer medicine in Canada (in institutionally-based nurse-doctor teams treating cancer patients in government-supported cancer centres and clinics), oncology nurses are strategically placed at the front line to deal with many of the issues facing cancer survivors. Secondly, their education amply qualifies them to take a leading role in both supportive care and screening, as well as successful delivery of the interventions listed earlier.<sup>18</sup>

In an earlier survey conducted by CACC, oncology nurses across Canada were interviewed to determine the extent to which they were providing supportive care to cancer patients receiving active systemic (drug) treatment. The results of the survey indicated nurses were providing a level of support that could be considerably enhanced through administrative and attitudinal change.<sup>19</sup> From that survey, improvements were recommended in physician control of clinics, attitudes of physicians and others in the instrumental role of nurses in supporting physician work and lack of understanding regarding the legislated scope of nursing practice. As a sequel, the present survey was conducted to determine in more detail the level of supportive care provided to survivors who had completed treatment for their cancer.

## **Methods**

Staff nurses and nursing supervisors in medical oncology clinics across the country were interviewed or re-interviewed (90 per cent). Staff nurses were asked whether they personally provided supportive care to cancer survivors. Nursing supervisors were asked about both their clinic nursing policy with respect to support for survivors, and the extent to which they perceived staff were delivering such care. As part of the interview, both staff and supervisors were encouraged to voice their personal opinions regarding issues related to providing care for cancer survivors.

Emphasis was placed on interviewing nurses and supervisors in larger centres only to gauge the priority placed on supportive care within the formal cancer treatment system. The number interviewed is smaller than in the 2007 survey.

A standard set of questions was designed to probe the characteristics of the respondents' practice, details of what they provided to survivors attending follow-up clinics, and the degree of responsibility they had in doing so.

They were also asked if patients completing treatment were being provided with a written survivorship

care plan detailing: 1) the treatments they had received; 2) the toxicity they had experienced from those treatments; 3) schedules and tests for follow-up; 4) which caregiver would be responsible for what aspects of continuing care; and 5) advice on how to reduce risks of: (i) recurrence of the original cancer; (ii) occurrence of another cancer; (iii) development of delayed treatment complications; and (iv) development of chronic diseases (metabolic syndrome) sharing risk factors with cancer.

They were questioned whether patients and survivors were being screened for distress. A positive reply required that the screen used was a comprehensive standardized instrument eliciting details of the type and extent of distress such as the Basic Symptom Inventory (BSI) or the Centre for Epidemiologic Studies Depression Scale (CES-D) questionnaires. A simple question asking if the survivor felt distressed was not deemed sufficient to qualify as a screen.

The survey questions can be accessed on-line in the appendix to this paper at [www.canceradvocacy.ca](http://www.canceradvocacy.ca).

Telephone Interviews were conducted by an oncology research nurse with extensive administrative and personal experience delivering supportive care and primary nursing during and after a patient's active treatment.

Respondents were assured their identity and the identity of their clinic would be kept confidential.

No statistical tests were conducted; the results are presented in descriptive form.

No attempt was made to determine the extent to which supportive care services were being provided to survivors by other categories of health care personnel in each centre.

## **RESULTS**

### **Characteristics of the Nurses Interviewed**

Twenty-two nurses (12 nursing supervisors and 10 staff nurses) were interviewed from 20 clinics across Canada. With two exceptions, the staff nurses interviewed were from different clinics than the nursing supervisors. Twenty of the nurses were practicing in multidisciplinary centres that also provided radiotherapy, and two were in clinics where radiotherapy was not provided.

Primary nursing was the predominant practice model (68 per cent), where nurses were partnered with a doctor or team and the team provided care to a particular group of patients on a continuing basis.

Staff nurses stated they spent on average 80 per cent of their time performing nursing duties; for administrators it was 25 per cent or less of their time in direct care.

All were full-time with one exception, and all were involved in the care of patients receiving systemic treatment, predominantly drug therapy (data not shown).

### Screening for Distress

Only 59 per cent of nurses indicated their practice was to screen for distress all patients about to undergo treatment. Even fewer (18 per cent) reported routinely screening survivors for distress.

### Nursing Time Spent Providing Supportive Care to Survivors

Table 2 shows the percentage of survivors reported as receiving supportive care from nurses and the associated time involved, with a further breakdown of those survivors who received care from the same nurse during active treatment. In each case the staff nurses estimated a lesser degree of coverage and a relatively smaller fraction of their time on these aspects than did the supervisors: 15-41 per cent vs. 33 to 47 per cent respectively. However, it must be pointed out that the supervisors interviewed were from different centres than the staff nurses in all but two instances.

### Per Cent of Centres in Which Nurses Reported Providing Supportive Care to Survivors

Table 3 depicts the provision of a specified range of support and advice to survivors. In a large proportion of centres they reported activities focused on alleviating the persistent symptoms from side effects of treatment, although they did not develop a planned approach in most instances. A lower proportion said they directed their attention to reducing the risks of delayed side effects of treatment or risk of cancer recurrence in survivors. The least amount of attention seemed to be paid to reducing the risk of those chronic diseases that share risk factors with cancer. In 70 per cent of centres, nurses reported they provide sexual counseling to survivors attending their clinics.

In 85 per cent of centres, responding nurses reported that survivors were able to contact clinic nurses by telephone for advice after treatment was completed. Survivors usually received this form of support from triage nurses tending the phones on a rotating basis, rather than the particular nurse who had cared for them during active treatment.

### Provision of a Survivorship Care Plan

Only one centre (five per cent of the total) reported that a survivorship care plan was provided to patients after treatment was completed.

### Ongoing Developments

Positive trends were reported in some centres where a team worked together for patient care. Pilot projects were occurring to navigate newly diagnosed patients and survivors through their cancer journey. New and continuing linkages with community nurses and other services, including existing support groups, were mentioned as important to survivorship experiences. Some

TABLE 1 **Characteristics of the Nurses Interviewed**

Prov.	Super- visors	Nursing Model		Time spent in patient care			
		Primary Care	Other	0- 25%	26- 50%	51- 75%	76- 100%
A	1		✓		✓		
	2		✓	✓			
B	1		✓	✓			
	2		✓	✓			
C	1	✓		✓			
D	1	✓		✓			
E	1	✓		✓			
	2	—	—	✓			
	3	✓		✓			
	4	✓		✓			
	5	✓				✓	
	6	✓		✓			
	Staff						
A	3		✓				✓
	4		✓				✓
	5		✓				✓
D	1	✓					✓
E	2	✓					✓
	7	✓					✓
	8	✓				✓	
	9	✓					✓
F	1		✓				✓
G	1	✓			✓		
				Average 80%			

✓ = Yes

Blank = A response of "No"

Dash = No response

centres were working on the creation of survivorship plans, case summaries and psycho-educational interventions. There was considerable heterogeneity in the extent to which these new initiatives were being pursued in each centre.

### Barriers to full scope of nursing practice

Similar to the last survey in 2007, barriers were identified that impede provision of the type of care nurses wished to provide for cancer survivors. For example, it was stated that no role was identified for nurses to provide supportive care in cancer centres where psychology or social work dominated. Some centres did not protect time for nurses to research and create formal plans for patients. Others did not allow overtime when nurses

TABLE 2 **Survivors, Supportive Care and Nursing Time Spent**

Prov.	Centre	Survivors reported to be receiving supportive care				Survivors reported to be receiving supportive care from their original primary nurse				Nursing time reported to be spent on supportive care for survivors			
		0-25%	26-50%	51-75%	76-100%	0-25%	26-50%	51-75%	76-100%	0-25%	26-50%	51-75%	76-100%
A	1		✓				✓			✓			
	2		✓				✓				✓		
B	1		✓				✓				✓		
	2		✓			✓				✓			
C	1	✓							✓	✓			
D	1		✓				✓				✓		
E	1	✓				✓				✓			
	2				✓		✓				✓		
	3			✓			✓				✓		
	4				✓				✓				✓
	5			✓			✓				✓		
	6		✓							✓	✓		
	<b>Totals</b>	2	6	2	2	2	7	0	3	4	7	0	1
	<b>Avg.</b>	47%				46%				33%			
Prov.	Staff	0-25%	26-50%	51-75%	76-100%	0-25%	26-50%	51-75%	76-100%	0-25%	26-50%	51-75%	76-100%
A	3		✓			✓							✓
	4		✓			✓				✓			
	5	✓				✓				✓			
D	1			✓			✓				✓		
E	2		✓			✓				✓			
	7		✓			✓				✓			
	8		✓			✓					✓		
	9			✓		✓				✓			
F	1			✓		✓				✓			
G	1	✓				✓				✓			
	<b>Totals</b>	2	5	3	0	9	1	0	0	7	2	0	1
	<b>Avg.</b>	41%				15%				25%			

✓ = Yes

Blank = A response of "No"

normally made end-of-shift follow-up calls to monitor patient or survivor adherence to plans. Limitations imposed on nurses' scope of practice also prevented provision of supportive care, and resulted in lack of development or adoption of guidelines for survivorship care, assessments for risk or screening for distress. Nurses reported poor morale and feeling undervalued when their desire to provide comprehensive care was hampered by the roles assigned to them in their respective clinics by physicians, psychologists or administrators.

### Discussion

The present survey was intended to provide a snapshot of supportive care being provided to cancer survivors by oncology nurses. Therefore, conclusions regarding the general applicability of the observations must be tempered by the limited sampling and small numbers. Nevertheless, several points did emerge.

Nurses are definitely engaged in supportive care of survivors, but the extent seems limited in the sample surveyed. First of all, in only 18 per cent of centres did

TABLE 3 **Centres Providing Supportive Care to Survivors**

Nursing Role	Alleviating Ongoing Symptoms of Treatment	Reducing risks of:		
		Delayed Onset Side Effects of Treatment	Cancer Recurrence	Other Chronic Diseases
Assess Risk factors	91%	75%	73%	65%
Develop Plan	64%	40%	41%	40%
Provide Continued Counseling/Education	95%	75%	77%	65%
Co-ordinate Access to Services	91%	70%	73%	50%
Follow-up on Adherence	77%	60%	68%	45%

the nurses report that they routinely screened survivors for distress (according to criteria described in the Methods section). Secondly, staff nurses stated that only 28 per cent of survivors receive supportive care in their centres (supervisors put this number at 41 per cent) and that they spend only 10 per cent of their time providing supportive care to the survivors within their own practices (or 44 per cent according to the supervisors). Finally, in 22 per cent of the centres, nurses reported they are not engaged in providing any support to survivors in the form of advice on how to reduce the risk of cancer recurrence, risk of delayed side effects of treatment, or risk of other chronic diseases.

On the other hand, nurses in all centres and clinics are providing advice to survivors on how to deal with ongoing symptoms from side effects of treatment, and 85 per cent said they can be accessed by telephone when advice was needed. In addition, when nurses were involved in providing the breadth of services indicated in Table 3, their reach was comprehensive, as evidenced by the string of responses on each item shown in the Table. They evidently are responding to the needs of survivors and providing the full gamut of services when given the opportunity to do so.

An indication of how much improvement is still required was highlighted by the fact that, in only one of 18 centres is a written survivorship plan being provided to patients after they have completed treatment.

More needs to be done for survivors and it seems clear nurses are already engaged in the endeavor. The question is to how to proceed. In regards to the psychosocial aspect, the strategies required for assisting someone to stop the spiral towards turmoil without resolve are known to nurses and could be readily incorporated in follow-up dialogue. As stated by Yu Ko and Degner,<sup>20</sup> the uncertainty is modified by facilitative patient-provider communication, cognitive reframing and problem solving, resulting in achievement of a new and stable perspective. Rancour<sup>21</sup> identifies a simple script for nurses to manage the existential crisis faced by

survivors. Open communication<sup>18</sup> is an essential element to adjustment and one that cancer nurses have identified as being practical, even if it has to be done on their own time. Moreover, nurses have the knowledge and opportunity to help individuals reduce the various life-style induced risks afflicting survivors.

This is not to say that other health care professionals should not be active participants in providing supportive care to cancer survivors. Indeed there must be assurance that interventions requiring expertise beyond the scope of nurses are readily available, such as from psychologists, psychiatrists, social workers, nutritionists, and exercise physiologists. However, nurses, as front line providers and points of contact, should and do play a central role in any multidisciplinary effort.

#### **Role of CPAC**

Fortunately, the Cancer Journey Action Group of the Canadian Partnership Against Cancer (CPAC) has recognized the deficits identified in this survey in supportive care for survivors and those on active treatment. The Action Group continues to provide leadership aimed toward changing the system of cancer care delivery so that patients', survivors', and family member needs are better served. Two strategic directions have been identified for its activity:

- One strategic direction is aimed toward achieving the vision of integrated person-centered cancer care. Two primary interventions will be mounted to accomplish this vision. Both are based on accepted standards and guidelines for supportive care of cancer patients and required additional education in person-centered care for all providers:
  - 1) Implementation of screening for distress (6th vital sign) programs in jurisdictions across the country
  - 2) Implementation of navigation (professional, peer, virtual) programs in jurisdictions across the country.

- The second strategic direction is survivorship. A Task Group is being organized to provide leadership in cancer survivorship based on the priorities agenda established at the Canadian Workshop for Cancer Survivorship held in March 2008.

### Conclusions and Recommendations

Based on the survey evidence, the literature and work proposed by CPAC, CACC recommends the following:

#### Cancer survivors have a unique risk of recurrence, distress or sequelae therefore:

- All survivors should be screened for distress at appropriate intervals, and as clinically indicated especially with changes in disease status;
- Screening should identify the level, nature and causes of the distress;
- Distress identified through screening should be managed according to evidence-based clinical practice guidelines;
- Screening should also identify high risk survivors especially at risk because of the intensity of the treatment received or because of their past medical history.

#### Looking at scope of nursing practice/team practice:

- Adequately supported and educated nurses should play a critical and leading role in providing supportive care to survivors for health, screening, education and referral where needed
- Emphasize the role and scope of nursing;
- Screen for and manage first level distress and referral criteria for those requiring it.

#### National leadership:

- CPAC to develop national guidelines for survivorship addressing distress, treatment sequelae and criteria to be included in a screen at follow-up.

#### Local action:

- Multidisciplinary institutional committees should be formed to establish standards for distress management and guide the application of supportive measures in survivors.

*Dr. Dauna Crooks is Dean, Faculty of Nursing, University of Manitoba. She has been a researcher in supportive cancer care issues since the 1990s.*

*Rosemary Colucci is a graduate of Ryerson University and a consultant to the health sector in strategic planning, stakeholder relations and advocacy strategy.*

*Dr. Margaret Fitch, Head of Oncology Nursing and Supportive Care, Odette Cancer Centre, Sunnybrook Health Science Centre and Leader of the Cancer Journey Action Group of the Canadian Partnership Against Cancer.*

*Daniel Gillespie, BSc, is a graduate of the University of Toronto. He has been a consultant and research assistant to the CACC for the past four years.*

*Lynn Hryniuk, RN, MSN, is currently an oncology nurse case manager with CAREpath Inc. Her experience encompasses nurse*

*management of an oncology ward, research in supportive care and nurse educator.*

*William Hryniuk, MD, FRCPC, is a Medical Oncologist in Dundas, ON and past Chair of the CACC. He has developed and directed major cancer centres in the US and Canada as well as established regional cancer control programs. He is currently Medical Director of CAREpath Inc.*

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