Wellness Beyond Cancer Program: building an effective survivorship program

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ABSTRACT

Background The Wellness Beyond Cancer Program (wbcp) was launched in 2012, first accepting patients with colorectal cancer (crc) and, subsequently, those with breast cancer (bca), with the aim of standardizing and streamlining the discharge process from our cancer centre. Patients are discharged either to the wbcp nurse practitioner or to their primary care provider (pcp). The program incorporates survivorship care plans (scps) and education classes; it also has a rapid re-entry system in case of recurrence. The objective of this paper is to describe the process by which a cancer survivorship program was developed at our institution and to present preliminary evaluation results.

Methods Qualitative surveys were mailed to patients and PCPS 1 year after patients had been referred to the wBCP. The surveys addressed knowledge of the program content, satisfaction on the part of patients and providers, and whether SCP recommendations were followed. Questions were scored on the level of agreement with each of a list of statements (1 = strongly disagree to 5 = strongly agree).

Results From March 2012 to November 2014, 2630 patients were referred to the wBCP (809 with CRC, 1821 with BCa). Surveys were received from 289 patients and 412 PCPs. Patients and PCPs gave similar scores (average: 4) to statements about satisfaction; PCPs gave scores below 4 to statements about communication with the wBCP.

Conclusions At 1 year after discharge, patients and PCPS were satisfied with program content, but there is an opportunity to improve on communication and provision of cancer-specific information to the PCPS. Using the WBCP to ensure a safe transition to the most appropriate health care provider, we have standardized the discharge process for CRC and BCA patients.

Key Words Survivorship programs, breast cancer, colorectal cancer

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INTRODUCTION

In Canada, the incidence of cancer is rising annually, with new cases of cancer reaching an estimated 191,300 in 2014¹. Advances in treatment and screening have led to an increased number of cancer survivors; 63%¹ of Canadians with cancer are expected to live at least 5 years post-diagnosis.

The unique needs of cancer survivors include screening for disease recurrence, detecting new primary malignancies, managing the late physical effects of cancer treatment, and promoting routine health maintenance^{2–4}. Psychosocial effects of survivorship can include anxiety, depression, and post-traumatic stress disorder^{5,6}. To ensure

that survivors have access to coordinated, interdisciplinary, and psychosocial supportive care services during the transition from active treatment to extended survival, health care providers have to be informed on all aspects of survivorship care.

The unique needs of cancer survivors have been an increasing priority in cancer care since the U.S. Institute of Medicine published its report on cancer survivorship in 2005². Their report identified that, after completion of active treatment, cancer patients have important unmet needs; often, they feel lost as they transition back to the care of their primary care provider (PCP), lacking clear guidelines for ongoing care. The Institute of Medicine emphasized that survivorship care should focus on

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monitoring for the late effects of cancer, surveillance for cancer recurrence, interventions to address illness secondary to cancer and its treatment, and finally, coordination of care between specialists and PCPS. By 2006, a series of publications had recognized the paucity of research on cancer survivors⁷; the needs of survivors were not always identified, and effective guidelines for ongoing care were not always in place⁴. There was consensus that survivorship care in cancer was not well organized, and most clinicians did not have clear and consistent plans for their patients.

In 2013, the American Society of Clinical Oncology (ASCO) released its assessment of survivorship care in adult cancers⁸. It noted that clear consensus guidelines for providing survivorship care in adults had yet to be established, and ASCO subsequently made a commitment to develop clinical practice guidelines for survivorship care. In the resulting report, the organization made a number of recommendations, including advocating for a "shared-care model" of delivery (care shared between specialists and PCPS), supporting survivorship research, and increasing education about cancer survivorship issues for patients and providers alike.

The delivery model is an important aspect of survivorship care. Historically, patients have been followed by their primary oncologist for an undefined period of time and eventually discharged back to their PCP. A risk-stratified approach is used in the pediatric cancer population: Patients considered low-risk are discharged back to their PCP; moderate-risk patients continue in a shared-care model; and those at high risk continue with their oncologist^{9,10}. That approach has been further refined to utilize a nurse practitioner (NP)-led survivor clinic^{9,11}. No model has been shown to be superior^{12–14}. In the adult population, models of survivorship care are heterogeneous. In 2015, Halpern et al. 15 published a technical brief covering models of delivery that had been demonstrated in the literature. Their report confirmed the earlier asco findings that survivorship care is not standardized. Further, no evidence that one model is superior to another has been generated. Halpern and colleagues highlighted the need for research into survivorship care models and clinical outcomes for patients. Cancer Care Ontario, the provincial body overseeing cancer care in the province of Ontario, published its clinical guidelines on survivorship care in 2012¹⁴. The authors of that work found evidence to support delivery of survivorship care either by PCPs in the community or by nurses in an institutional setting for survivors of either breast cancer (BCa) or colorectal cancer (CRC).

Survivorship care plans (SCPS) are documents intended for patients and PCPS alike. The Institute of Medicine recommended SCPS², which were further described by Earle in 2006¹⁶. A useful communication tool, the SCP ensures that PCPS are aware of surveillance requirements and patient needs. The ideal SCP has standardized content, with descriptions of disease-site-specific guidelines for recommended follow-up tests, frequency of appointments, late and long-term effects of a patient's cancer and it treatment, and psychosocial concerns; it should simultaneously highlight the need for non-cancer health maintenance.

Criticisms of SCPS include the substantial amount of time required for their preparation¹⁷ and poor use or uptake by the PCPS for whom the plans are intended^{17–20}. Further no funding is specifically dedicated for the preparation of such a document. In a randomized controlled trial involving early-stage BCa patients, Grunfeld *et al.*²¹ found SCPS to be no more effective than a standard discharge visit with respect to patient-reported outcomes and cancer-related distress. That study was criticized on the grounds that a discharge visit is not a standard of care in all countries (and so might not be a broadly generalizable result) and that complex interventions are not as simple to assess as patient-reported outcomes in a mostly well population^{22–24}.

Support for scps has appeared in the literature. A 2011 survey of 30 pcps found that scps were highly valued, increased provider knowledge, and affected care decisions²⁵. Those findings were confirmed in a national survey of 1130 oncologists and 1020 pcps about scps²⁶. Forsythe *et al.*²⁷ found that receipt of a scp improved pcp-perceived coordination of care, communication, and confidence in their knowledge of survivorship issues. In its 2014 expert statement on survivorship care planning, asco recommended use of scps to enhance survivor and pcp education, and provided a scp template.

The Ottawa Hospital is a quaternary care centre with a referral base of approximately 1.5 million patients across Eastern Ontario. In 2011, The Ottawa Hospital Cancer Program (TOHCP) embarked on the development of a survivorship program to fit the needs of its patient population. The program was piloted in March 2012 with survivors of CRC; survivors of BCA were added in February 2013. The Wellness Beyond Cancer Program (WBCP) aims to ensure that referred patients have access to the most appropriate care provider to address their individual needs. In the present report, we detail the development and structure of the WBCP survivorship program and discuss results of the quality review that was undertaken after 1 year of operation for each disease site.

PROGRAM DEVELOPMENT

After a cancer survivorship retreat held in May 2010, TOHCP committed to making survivorship a priority. These requirements to enhance survivorship care were identified:

- That all appropriate patients receive detailed information about their cancer diagnosis and treatments received
- That all patients be educated on cancer survivorship and the long-term health effects of cancer and cancer treatments
- That all patients be aware of their individual medical and psychosocial needs after completion of active cancer treatment
- That all patients have access to appropriate follow-up care and to the resources that best meet their needs

An interdisciplinary regional steering committee, including patient representatives, was struck. Based on the steering committee's working groups and the growing body of literature, TOHCP endeavoured to develop a

unique survivorship program combining previously described elements and innovative solutions to satisfy both cancer-specific guidelines and the unique survivorship needs of cancer patients. A call for submissions for survivorship program proposals had been issued by Cancer Care Ontario, and TOHCP received a grant to cover the first year of operating costs. Since then, TOHCP has funded the program internally. A risk-stratified approach, with options for either institution-based nurse practitioner—led care or community-based PCP care, was chosen. This collaborative project involves medical, radiation, and surgical oncologists; nurses; PCPS; and administrative staff at the cancer centre. We believe that the program serves a diverse group of patients and is able to respond to ever-evolving guideline recommendations.

PROGRAM DESCRIPTION

The wbcp consists of a multidisciplinary team of health care providers who work to ensure that, at the end of active cancer treatment, crc and bca patients have access to resources that best meet their individual needs and that the most appropriate health care provider provides survivorship care.

Program Objectives

At the outset of wbcp development, these five objectives to optimize survivorship care at The Ottawa Hospital Cancer Centre were identified:

- Provide cancer survivors, their families, and their PCPS with a treatment summary and follow-up plan.
- Empower patients to participate in the management of their care and overall well-being once cancer treatment is complete.
- Ensure that cancer survivors have access to high-quality post-treatment follow-up care services.
- Improve the knowledge of health providers about the needs of cancer survivors and about assessment and management strategies.
- Improve cancer program efficiency, and enhance the transition and coordination of care for cancer survivors.

The WBCP Model of Survivorship Care

The wbcp team includes of a program manager, a medical oncology program lead, two nurse practitioners, a registered nurse (RN), and clerical support. All oncology specialists from TOHCP can discharge their CRC and BCa patients to wbcp. The referring oncologist selects the discharge stream based on a clinical assessment of risk of recurrence or complexity of the required follow-up care, or both.

The wbcp was developed on a risk-stratification model. Initially, 3 discharge pathways were possible:

- Survivorship care provided exclusively by a PCP
- Shared care provided by a wbcp NP with a PCP
- Continued care by the primary oncologist, with PCPshared care

Patients are referred to one of the wBCP pathways by their oncologist, the goal being that the patient receives the care

most appropriate to their individual needs. Most patients referred to the wbcp are eligible to return to their pcp. Those patients are, for the most part, low-risk and without complex care needs. They must, however, have a pcp who is active in their care. In the Ottawa area, approximately 4%–5% of referred patients either lack a pcp or lose their pcp during the journey of their cancer diagnosis and treatment.

Patients referred to the NP stream are those who are at higher risk (for example, patients with unresolved toxicity from treatments, or those with significant psychosocial concerns), those who have more complex needs as assessed by the referring oncologist, and those who lack a PCP. Patients in the NP stream participate in a shared-care model in which the PCP remains responsible for health maintenance and routine care, and the NP offers cancer survivorship—specific care. The goal for this group is that they eventually transition back to PCP-managed cancer survivorship care once specific needs are addressed.

At program launch, there was a third referral stream in which patients could be referred to the wbcp and continue follow-up with their oncologist. Examples of patients included in that stream are those who were on clinical trial or who had medically complex outstanding needs. Over time, this third stream was determined not to be required, and it was removed from the program in 2013. Figure 1 illustrates the current program model.

Enrolment into the WBCP

At the time of referral, patients complete a needs assessment to self-identify their outstanding physical and psychosocial needs. The completed needs assessment is forwarded, with the program referral, to the wbcp. The wbcp clerk receives the referrals and electronically enters the patient information, including the appropriate referral stream and needs assessment content, into the wbcp database. The clerk then books education sessions and appointments.

All referred patients are invited to attend a 2-hour survivorship education class and are given educational booklets, which include both general and disease-site-specific information. Topics include understanding the coordination of care beyond cancer treatment, the roles of health professionals in survivor care, signs of cancer return for which to watch, recommendations for cancer prevention and screening, late and long-term effects of cancer, common psychological and emotional needs, and the process for re-entry to the cancer centre when necessary.

Survivorship care plans provide details of a patient's disease, a treatment summary, information about their cancer care team, recommended follow-up surveillance, and outstanding self-identified needs. The scps are created electronically by the wbcp nurse, who pulls relevant information from existing tohcp electronic patient records. The unmet needs self-identified by patients in their needs assessments are automatically populated to the individual care plan. Patients are contacted, and either a wellness appointment is arranged with the RN responsible for the discharge process to the PCP, or the patient is booked into the NP clinic for the initial consultation. If the patient is being transitioned to the PCP after the discharge visit, care plans are reviewed with and given to the patient by the wbcp RN, and a discharge letter and copy of the care plan are sent to the PCP.

Wellness Beyond Cancer Program (WBCP) Co-ordinating Care After Cancer Treatment Follow-up Discharge to Primary Care Care Plan Review /isit with WBCP RN Primary Care Completion of Provider eds Assessme Group Education Referral to WBCP "Living Well and Managing your Health After Discharge Strean by Oncologist Care Plan review Discharge to Follow-up Visit(s) and Discharge: WBCP with WRCP Follow-up with Nurse Practitioner Nurse Practitione Primary Care Completion of Provider eeds Assessmen Expedited Reassessment and Re-Entry to the Cancer Centre if Required

FIGURE 1 Diagram of the patient pathways through the Wellness Beyond Cancer Program (WBCP), illustrating the two different discharge pathways currently in place: back to the primary care provider, or care shared between the WBCP nurse practitioner and the primary care provider. RN = registered nurse.

Appointments with the WBCP RN last approximately 30 minutes. At this visit, the SCP is reviewed in detail, and symptom management to help address the patient's outstanding self-identified needs is provided. For patients entering the NP stream, the initial appointment is similar to a new consultation by a physician; it lasts 30–45 minutes. The frequency with which a patient sees the NP in follow-up depends on the complexity of that patient's medical needs. Patients in the NP stream will be discharged back to their PCP (if one is available) as soon as their survivorship needs allow. The timing is unique for each patient, and there is no limit to the number of appointments or the length of time a patient spends with their NP survivorship care provider.

Hormone Reassessment Referral System

A significant proportion of women with early-stage BCa are hormone receptor–positive. The standard of care mandates a discussion concerning an adjuvant program incorporating an aromatase inhibitor for postmenopausal women and extended adjuvant therapy for suitable higher-risk individuals. In the past, such women would then have been followed at our centre for up to 10 years. Cancer Care Ontario endorses the discharge of BCa patients back to PCP or institution-based nurse-led care while those patients are still on hormonal treatment ¹⁶.

We developed a "hormone reassessment referral" for such patients as they transition from their specialist to their PCP. The referral is a formal way to track patients who will require follow-up for more than 1 year in the future to address potential changes to the hormonal therapy, something that would normally require a new referral from an outside physician in our health care system. At the time

of discharge, the referring oncologist requests a hormone reassessment at a specified month and year. That date is captured electronically and logged within the cancer centre database; the patient is then appropriately booked for a future reassessment with their primary oncologist. To be respectful of the wait times for a primary consultation, reassessment appointments are restricted to no more than 2 per week per oncologist. Although this unique process was developed for BCa, the concept could, where indicated, be broadened to other cancer disease sites in consideration of future therapeutic innovations.

Rapid Re-entry Process

An integral part of the WBCP design is our rapid re-entry process for discharged patients with either suspected or documented recurrence or new primary cancers. The PCPS have access to the WBCP-dedicated telephone number for consultation purposes. That number reaches the WBCP RN, who triages and expedites a rapid re-entry referral as necessary. This process minimizes anxiety about disease recurrence for patients and PCPS alike.

Implementation

The program was launched in 2012 for CRC patients. Because the region served by TOHCP is large, we travelled to various communities, holding meetings with stakeholders (especially PCPs and NPs) to educate them about the program and its resources. Information was disseminated throughout the TOHCP to educate clinicians of its availability. Formal presentations were made to oncologists treating patients with BCa and CRC. As with any program, the early adopters helped the WBCP gain general

acceptance. The program met a need to help formalize the discharge process from a busy cancer centre trying to keep up with the demand to see new patients, and so it was well received by many. Although some oncologists initially resisted participating, the program has, over time, become an integral part of the standard of care for all providers for their CRC and BCa patients. Ongoing communication and program updates have been provided by the WBCP team, and feedback has been invited at every stage of development.

As the program developed, experience and feedback led to changes. The education component was condensed from two survivorship classes into a single disease-specific class. In addition, in the initial risk stratification, a small number of patients, primarily those on clinical trial, stayed with their oncologist. Subsequently, mechanisms to ensure adherence with clinical trials were implemented, and this third referral option was removed. In the first phase of the program, all treating specialists had been required to agree whether a patient was ready for discharge from the cancer program. Because that requirement caused some disagreement, an oncologist can now refer a patient to the wbcp, and their oncology colleagues might choose to personally continue follow-up care until they are also confident to discharge to the PCP.

PROGRAM EVALUATION

Methods

One year after referral to the wBCP, patients and their PCPS were mailed surveys to assess program satisfaction. A survey was also distributed to the members of the TOHCP team. We obtained institutional research ethics board approval for quality assurance projects relating to the wBCP. Data were compiled from the surveys that were returned by mail. Survey responses were anonymous, no patient- or PCP-identifying information was collected as part of the quality review. An electronic survey was also sent to TOHCP staff inquiring about their experiences with the program and their views on the utility of the program. Questions for that survey were asked on an agree/disagree/not applicable scale.

The wbcp team designed the surveys with questions structured to obtain feedback and to determine whether the program is meeting its objectives. The patient survey asked questions concerning knowledge of care received, care plans, and satisfaction. The pcp survey inquired about content and satisfaction with program resources and support. Most questions were scored 1–5 based on level of agreement with each statement (from 1, strongly disagree, to 5, strongly agree). In other questions, patients were asked to pick their top 2 most useful elements of the program and to indicate any and all late effects of cancer they might have been experiencing. Patients and providers both had the opportunity to provide comments and feedback about the program experience. Appendix A presents the patient and provider surveys.

Results

Each year, TOHCP sees more than 6000 new referrals. At time of program launch, estimates placed the number of

eligible patients at 4000 with BCa and 550 with CRC. From March 2012 to November 2014, 2630 patients were referred to the wBCP: 809 with CRC, and 1821 with BCa. Most referred patients have been directed through the PCP stream (n=1657), followed by the NP stream (n=956). A few patients (n=17) continued to be followed by their primary oncologist. Of all referred patients, 53 have returned to the TOHCP: 26 from the PCP stream, and 27 from the NP stream. Reasons for re-entry were disease recurrence (n=49), a new primary (n=3), and planned hormonal therapy reassessment (n=1).

Surveys were mailed to 126 CRC and 163 BCa patients 1 year after their discharge from the program to the PCP stream. Of the 126 CRC patients, 56 (44%) responded, and of the 163 BCa patients, 73 responded (45%). Table I presents the results of the patient surveys. Almost all questions received a median score of 4 (range: 1–5), which correlates with the "strongly agree" response to the questions posed about satisfaction with the program. The CRC patients identified ongoing concerns with bowel function, sexual dysfunction, peripheral neuropathy, and fatigue. The BCa patients identified a greater number of issues 1 year after discharge: menopausal symptoms, weight gain, joint pain, fatigue, memory concerns, anxiety or depression, lymphedema, and sexual dysfunction.

Surveys were also sent to 261 PCPs of CRC patients and 151 PCPS of BCa patients. Responses were received from 70 PCPS of CRC patients (27%) and from 43 PCPS of BCa patients (28%). Table II presents the results of the PCP surveys. Survey scoring by the PCPS was similar whether they were treating BCa or CRC patients. Median scores of 4 (range: 2-5) were obtained for questions concerning comprehension of care plans, comfort in ordering tests, and PCP understanding of program operations. Overall, 79% of CRC PCPs and 85% of BCa PCPs answered yes when asked if the WBCP has assisted them in coordination of care for their patients. Feedback was collected from the PCPs as well. For reporting purposes, the comments were categorized and are shown at the bottom of Table II. The comments most commonly gave positive feedback (CRC 38%, BCa 35%); requests for increased communications from the WBCP was the next most common feedback (CRC 18%, BCa 12%). Only 4% of CRC PCPs and 6% of BCA PCPS felt that the WBCP led to worse patient care.

The opinion of TOHCP staff is also an important component of measuring the success of the WBCP. A survey was sent to TOHCP staff 1 year into operations. Responses to the questions (with agree/disagree answers) were received from 10 staff members in various disciplines (Table III).

DISCUSSION

Although the incidence of cancer continues to rise, advances in diagnosis and treatment have led to exponential growth in the number of cancer survivors being followed in cancer centres. At our institution, implementation of the wbcp was critical to ensuring that we could safely transition patients back to their pcps while ongoing cancer-specific health care needs were being met after completion of acute treatment. It was also necessary to ensure best practice and to meet tohcp's target for newly diagnosed cancer patients to be seen in the cancer centre within 2 weeks of referral where possible.

TABLE I Results from the outcomes survey conducted after patients had spent 1 year in the Wellness Beyond Cancer Program

Question	Sco	re ^a by resp	spondent group		
	Colorecta (n=		Breast (n=		
	Median	Range	Median	Range	
Questions about care received					
I know which type of surgery I had for my cancer	5	1–5	4.5	1–5	
I which type of chemotherapy medication I received for my cancer	5	1–5	4	1–5	
I know which type of radiation I received for my cancer	4	1–5	4	1–5	
I know which type of hormonal therapy I received	Ν	Α	4	1–5	
I know when and how often I need to get follow-up visits for my cancer	4	1–5	4	1–5	
I know the common and significant health risks that I may face due to my cancer treatments	4	1–5	4	1–5	
I know what symptoms to report to my family doctor or nurse practitioner	4	1–5	4	1–5	
Questions about the wellness care plan					
I found the plan clear	4	1–5	4	1–5	
I found the plan useful	4	1–5	4	1–5	
I think the plan has been useful to my family doctor/nurse practitioner	4	1–5	4	1–5	
Satisfaction with the Wellness Beyond Cancer Program					
Overall support	N	Α	5	1–5	
Overall care received	4	1–5	5	1–5	
Overall quality of information provided	4	1–5	5	1–5	
Late side effects of cancer and treatment	[n (%)]	[n (%)]	
Concerns about surgical site	8 (14)	N	A	
Changes in bowel habits	17 (30)	Ν	Α	
Peripheral neuropathy	20 ((36)	23	(32)	
Fatigue	17 (30)	26	(36)	
Concerns with sexual function	11 (20)	15 ((21)	
Memory or concentration effects	9 (16)	25 ((34)	
Psychological or emotional effects	5 ((9)	22 ((30)	
Joint pain	Ν	A	39	(53)	
Menopausal symptoms	Ν	A	29 (
Weight changes	Ν	A	26 ((36)	
Lymphedema	Ν	A	13 ((18)	
Most useful parts of care plans ^b					
Information on follow-up testing	40	(71)	29 ((40)	
Information on disease	25 ((45)	23	(32)	
Information on cancer treatments received	21 ((38)	21 ((29)	

Answer scale of 1–5 (1 = strongly disagree; 2 = disagree; 3 = neither disagree or agree; 4 = agree 5 = strongly agree).
 Patients could select 2 items.
 NA = not applicable.

TABLE II Results from the satisfaction survey of primary care providers (PCPs) whose patients were involved in the Wellness Beyond Cancer Program (WBCP)

Question		Scorea by	PCP group	
	Colorecta (n=		Breast (n=	
	Median	Range	Median	Range
Questions about the WBCP				
The process for transition of care from cancer centre to you was clear	4	2-5	4	2-5
The care plan was helpful in outlining required follow-up testing	4	2-5	4	2-5
I am comfortable ordering the required follow-up tests	4	2-5	4	2-5
I have found the care plan educational	4	2-5	4	2-5
The program has improved coordination of follow-up care	4	2–5	4	1–5
I know who to contact should I have any additional questions	4	1–5	4	2-5
I know the process for re-entry back to the WBCP if required	4	1–5	4	1–5
	[n (%)]	[n (%)]
Do you feel that WBCP has assisted you in coordinating care for your patients?	55 (79)	39 ((85)
Summary of feedback on program content				
Improved patient care or clear care plan	17 ((23)	12 ((28)
Request for increased communication	8 (11)	4 ((9)
Not familiar with WBCP	7 (*	10)	2 ((5)
General positive comments	5 ((4)	5 (12)
Improved comfort with cancer patient care	3 ((4)	2 ((5)
Worse patient care	2 ((3)	2 ((5)

^a Answer scale of 1–5 (1 = strongly disagree; 2 = disagree; 3 = neither disagree or agree; 4 = agree 5 = strongly agree).

TABLE III Results from the survey of cancer program staff^a about their early impressions of the Wellness Beyond Cancer Program

Question	"Agree" response [n (%)]
Understand objectives of WBCP	10 (100)
Easy to explain to patients	10 (100)
Understand referral process	10 (100)
Understand referral streams	10 (100)
Able to explain what to expect to patients during transition of care	8 (80)
WBCP booklets are helpful	8 (80)
WBCP has improved coordination of follow-up care	7 (70)
Overall feel WBCP is working well	8 (80)

The 10 respondents included 4 radiation oncologists, 3 nurses, 2 medical oncologists, and 1 surgical oncologist.

As developed for TOHCP, the WBCP combines previously reported models of care, including risk stratification,

shared-care models, and the use of scps. Despite the criticisms scps receive, our program uses them because we feel that the clear communication they offer is valued by patients and providers alike, and our survey responses seem to support that perception of their value. Nevertheless, when asked for feedback, almost 20% of PCPS still felt that more communication would be helpful.

Through experience and receipt of stakeholder feedback, the wbcp has been enhanced by changes such as streamlining the education classes and removing the stream in which patients stayed with their treating oncologist. More enhancements will be required as research emerges. Recent data suggest that extended adjuvant therapy is the standard of care for many women with early-stage hormone receptor–positive BCa. The long durations of care that result have presented challenges with respect to being able to discharge patients with specific and unique recommendations. We have therefore developed a "hormone reassessment" system that allows for BCa patients to be discharged to their PCP for a defined period, with a planned re-consult with their oncologist being booked in advance.

After 1 year in the program, patients and PCPs alike were sent surveys in the mail. Median satisfaction scores

on our 5-point scale were consistently high, regardless of the respondent type (patient or PCP) or the disease site (CRC or BCa). Based on direct feedback, the results show that there is room to grow in areas of program communication, especially with PCPs. Because of the requirement that patients and their PCPS be 1 year out from enrolment, the number of patients surveyed was small relative to the number currently enrolled in the program. Although more than 3000 patients have now been referred to the wbcp, early referrals—regardless of disease site—were slow, which limited the number of patients selected to receive a survey. The response rate (45% of patients, 28% of PCPs) was lower than we would have liked. Survey results did not control for differences in time since the cancer diagnosis or active treatment. The range of variance is potentially wide; some patients might have been discharged at 6 months after treatment; others, at more than 5 years after. Similarly, the surveys did not control for stage of disease. Either of those factors might affect satisfaction with the program from the perspective of either the patient or the PCP and thus limit our ability to draw firm conclusions about the levels of satisfaction that patients and PCPS are experiencing. We assumed that those who had strongly negative feelings would respond to the survey and would therefore skew the results negatively. If anything, the positive response suggests that patients and providers are more satisfied than the survey results would indicate. For future evaluations, we are considering other methods such as direct contact for patient surveys and use of e-mail for PCPs. We also have to include the NP stream in our next round of quality assurance, because that stream was not part of the present study.

Currently, the clinical outcomes needed to evaluate the safety of our survivorship program are missing. We felt that not enough time has passed to draw any conclusions about clinical outcomes. It is encouraging to note that only 2% of patients have been referred back to TOHCP for reasons of either disease recurrence or a new primary cancer. We are currently tracking all patients who are referred back to determine whether early discharge was a contributing factor in their re-referral. To date, no reports of adverse cancer-specific outcomes have been received; however, we will continue to monitor patients for a future safety analysis.

CONCLUSIONS

The wbcp ensures that the most appropriate provider is selected for all crc and bca patients transitioning from active cancer treatment. Early data and stakeholder feedback demonstrate that the wbcp has improved the programming offered to cancer survivors and has allowed crc and bca patients to move beyond being a cancer patient to being a cancer survivor. To ensure the ongoing success and sustainability of this much-needed program, we are endeavouring to undertake a full program review, including, as already mentioned, safety data relating to patient outcomes.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none. The authors maintain complete control of all data used in this paper and will make them available on request.

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APPENDIX A

TABLE AI Primary care provider survey

The Ottawa Hospital Cancer Program — Wellness Beyond Cancer Program (WBCP) PRIMARY CARE PROVIDER SURVEY An important aspect of the Wellness Beyond Cancer Program (WBCP) pilot project, is feedback from our community partners and primary care providers like yourself. We will use the information, along with feedback from patients being discharged via the WBCP, to ensure that we have a high quality program. Please provide the following information: Your status: Family physician □ Nurse practitioner Other Please specify: 1. For each of the statements about the WBCP, please indicate your level of agreement with each statement by placing an "X" in the appropriate column. Statement Strongly Neither Disagree Strongly Agree agree disagree agree nor disagree (a) The process for transition of care for your patient from the cancer center to you was clear. The Wellness Care Plan was helpful in outlining the follow-up tests required. (c) I am comfortable ordering the required follow-up tests. I have found the additional information on Breast Cancer Follow-up: Late and Long Term Effects, helpful. The program has improved the co-ordination of follow-up care. I know who to contact should I have any additional questions. (g) I know the process for re-entry back to the WBCP, if required. 2. Please share any benefits you feel the program has provided. 3. Do you feel the WBCP has assisted you in co-ordinating care for your patients? Yes □ No □ If no, what suggestions do you have for improvement? 4. Any additional comments or suggestions you would like to share with the Wellness Beyond Cancer Program team?

If you have a concern or issue, please contact us so that we can understand the context of your concern and address as appropriate.

We can be reached at (613) 737–7700 ext. 70256.

Thank you, The Wellness Beyond Cancer team

TABLE All Breast cancer patient survey

FOLLOW-UP CARE AND SERVICES SURVEY

Your care is important to us, and we would like to ask your opinion about your health care experience.

Please note that your name will be not included on this form. Your answers are completely private and confidential. The data collected will be presented in summary form only and for the purpose of program evaluation. Understanding your opinion about the quality of care you received will improve our services.

Completion of the survey is voluntary. You can skip any question that you do not want to answer. If you decide not to complete the survey it will not affect your care. There is no financial incentive to participate.

	Thank you for your	feedback!				
1.	Please let us know if you agree or disagree with the following statements a practitioner:	bout the follo	ow-up care pro	ovided by you	r family doctor o	or nurse
	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	NA
	I know which type of surgery I had for my cancer.					
	I know which type of chemotherapy medication I received for my cancer.					
	I know which hormonal therapy I am receiving for my cancer.					
	I know which radiation therapy I received for my cancer.					
	I know when and how often I need to get follow-up visits for my cancer.					
	I know how to schedule follow-up visits with my family doctor or nurse practitioner.					
	I know the common and significant health risks that I may face due to my cancer and cancer treatments.					
	I know what symptoms to report to my with my family doctor or nurse practitioner.					
	I know my family doctor or nurse practitioner's contact information.					
	I know where to get professional psychological, social support, if needed.					
	I know where to get additional help outside the hospital (for example, help with daily activities, finances, self-help or support-groups, rehabilitation services).					
2.	Please let us know if you agree or disagree with the following statement ab	out your We	llness Care Pla	n:		
	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	NA
	I found the care plan clear.					
	I found the care plan useful.					
	I think the information in the care plan might be useful to my family doctor.					
3.	Please check the 2 most helpful items in your Care Plan.					
	☐ Information about your disease					
	☐ Information about the types of treatment you received					
	☐ Information about when to have your follow-up tests					
	☐ Summary of your needs					
	☐ I did not find the care plan useful					
	□ Other, please specify:					
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4.	What could be added or removed from your Care Plan?					
5.	What other comments do you have about Care Plan?					
6.	Please let us know if you agree or disagree with the following statements a practitioner:	about the follo	w-up care pro	vided by you	ur family docto	or/nurse
	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	NA
	The doctor or nurse gave me practical advice about managing my illness and symptoms					
	The doctor or nurse seem to understand what I was going through					
	I was able to express myself and ask questions					
7.	Please rate your satisfaction with your follow-up care:					
	Statement	Extremely dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Extremely satisfied
	My doctor's or nurse's understanding of my needs					
	The extent to which my doctor or nurse looked into my needs					
	My doctor or nurse gave me information when I needed it					
	The extent to which my worry and concerns have been considered					
	The extent to which my family have been considered					
	The extent to which I have been involved in decisions about my care					
	The overall care I received from my doctor or nurse					
8.	Please rate your satisfaction with the overall care, support and information	received from	n the Wellness	Beyond Car	re Program:	
	Statement	Extremely dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Extremely satisfied
	The overall support I received					
	The overall care I received					
	The overall quality of information I was provided					
9.	As part of your care plan, the follow-up tests below may have been recom-	mended. Plea	se tell us more	about the te	ests you have h	nad.
	Which of the following tests were recommended? Please check.	16		ou get the to	est(s)? you get it dor	2
		Yes	so, when (mor	No	you get it dor	
	Physical exam	ies		NO		Date:
	Mammography	Yes		No		Date:
	Monthly breast self-exam	Yes		No		Date:
	Other, please specify:	Yes		No		Date:

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	bee 7111 Continued					
10.	. Have you had any of the foll	owing late or long-term side effects from your treatment?				
	Fatigue		Ye	es 🗆] No	
	Anxiety or depression		Ye	es 🗆) No	
	Arm lymphedema		Ye	es 🗆	l No	
	Sexual problems (that is, disc	comfort or pain)	Ye	es 🗆	l No	
	Menopausal symptoms (that	is, hot flashes, sweats, vaginal discharge)	Ye	es 🗆] No	
	Skin changes in area treated		Ye	es 🗆] No	
	Weight changes		Ye	es 🗆	l No	
	Osteoporosis or bone fractur	res	Ye	es 🗆	l No	
	Joint pain or discomfort (that	is, arthritis)	Ye	es 🗆	l No	
	Heart health concerns (that i	s, lipid changes, cardiovascular disease)	Ye	es 🗆) No	
	New cancers		Ye	es 🗆	l No	
	Tingling, numbness, or pain	in your fingers or feet	Ye	es 🗆	l No	
	Problems with your memory	or concentration	Ye	es 🗆	l No	
	Other emotional or psychological	ogical or physical side effects. Please specify:	Ye	es 🗆	l No	
11.		urces you have accessed after being discharged by the cance use any of the following resource? Please check		did you fi	nd the rese	urce helpful?
	Maplesoft Survivorship Cent		Y6		_	
	·	lephone, booklets, Web sites)	Ye	_		_
	Community peer support gro			_		_
			Ye	_	_	
	Psychosocial oncology progr	am	Υe	_		
	Cancer program Web site		Ye			_
		on Guide and Personal Record	Ye			
	Other, please specify:		Ye	es 🗆] No	
12.		out the plan for your care when your treatment was complete	d?			
	(a) Very informed	(c) Not at all informed				
10	(b) Somewhat informed	(d) My treatment is not completed				
13.	(a) Never	roviders aware of your cancer history? (d) Always				
	(b) Sometimes	(e) Unsure				
	(c) Usually	(c) Offsuic				
14.		e emotional support you have received from your care provic	ers since your tr	eatment wa	as complete	d?
	(a) Yes, I received all of the e		,		·	
	(b) Most of the time I felt em	otionally supported				
	(c) I did not receive any emo	tional support				
	(d) I did not need any emotion	onal support				
	(e) My treatment is not comp	leted				
15.		n touch with any other health professionals who helped you	with emotional s	support?		
	(a) Yes (b) No (c) Uns	sure (d) Not required				

TABLE AIII Colorectal cancer patient survey

FOLLOW-UP CARE AND SERVICES SURVEY

Your care is important to us, and we would like to ask your opinion about your health care experience.

Please note that your name will be not included on this form. Your answers are completely private and confidential. The data collected will be presented in summary form only and for the purpose of program evaluation. Understanding your opinion about the quality of care you received will improve our services.

Completion of the survey is voluntary. You can skip any question that you do not want to answer. If you decide not to complete the survey it will not affect your care. There is no financial incentive to participate.

Thank you for your feedback!

Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	NA
I know which type of surgery I had for my cancer.						
I know which type of chemotherapy medication I received for my cancer.						
I know which radiation therapy I received for my cancer.						
I know when and how often I need to get follow-up visits for my cancer.						
I know how to schedule follow-up visits with my family doctor or nurse practitioner.						
I know the common and significant health risks that I may face due to my cancer and cancer treatments.						
I know what symptoms to report to my family doctor or nurse practitioner.						
I know my family doctor or nurse practitioner's contact information.						
I know where to get professional psychological and social support, if needed.						
I know where to get additional help outside the hospital (for example, help with daily activities, finances, self-help or support groups, rehabilitation services).						
Please let us know if you agree or disagree with the following statement ab	out your V	Vellness Ca	e Plan:			
Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	
I found the care plan clear.						
I found the care plan useful.						
I think the information in the care plan might be useful to my family doctor.						
Please check the 2 most helpful items in your Care Plan.						
☐ Information about your disease						
☐ Information about the types of treatment you received						
☐ Information about when to have your follow-up tests						
☐ Summary of your needs						
☐ I did not find the care plan useful						
Other please specify:						

4. What could be added to or removed from your Care Plan?

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TA	BLE AIII Continued					
5.	What other comments do you have about your Care Plan?					
6.	Please let us know if you agree or disagree with the following statements practitioner:	about the foll	ow-up care pro	ovided by yo	ur family docto	or or nurse
	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	The doctor or nurse gave me practical advice about managing my illness and symptoms					
	The doctor or nurse seem to understand what I was going through					
	I was able to express myself and ask questions					
7.	Please rate your satisfaction with your follow-up care:					
	Statement	Extremely dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Extremely satisfied
	My doctor's or nurse's understanding of my needs					
	The extent to which my doctor or nurse looked into my needs					
	My doctor or nurse gave me information when I needed it					
	The extent to which my worry and concerns have been considered					
	The extent to which my family have been considered					
	The extent to which I have been involved in decisions about my care					
	The overall care I received from my doctor or nurse					
8.	Please rate your satisfaction with the overall care, support and informatio	n received fro	om the Wellnes	s Beyond Ca	ire Program:	
	Statement	Extremely dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Extremely satisfied
	The overall support I received					
	The overall care I received					
	The overall quality of information I was provided					
9.	As part of your care plan, the follow-up tests below may have been recor	mmended. Ple	ease tell us mor	e about the t	tests you have l	had.
	Which of the following tests were recommended? Please check.	If so, v		get the test rear) did you	or tests? get it or them	done?
	Physical exam	Yes		No		Date:
	CEA (blood tost)	Voc	П	No	п	Data

Which of the following tests were recommended? Did you get the test or tests?							
Please check.	If so, v		-	get it or them	done?		
Physical exam	Yes		No		Date:		
CEA (blood test)	Yes		No		Date:		
Colonoscopy	Yes		No		Date:		
Abdominal CT scan	Yes		No		Date:		
Chest CT scan	Yes		No		Date:		
Pelvic CT scan (if tumour was in the rectum)	Yes		No		Date:		
Other, please specify:	Yes		No		Date:		

TABLE AIII Continued

TABLE ATT Continued						
10. Have you had any of the fol	lowing late or long-term side effects from your treatment?					
Fatigue		Yes		No		
Anxiety or depression		Yes		No		
Problems with your surgical site		Yes		No		
Sexual problems (that is, erectile problems or pain)				No		
Adjustment of lifestyle		Yes		No		
Skin changes in area treated		Yes		No		
Sexuality problems or infertility		Yes		No		
Bone fractures				No		
New cancers				No		
Tingling, numbness, or pain in your fingers or feet				No		
Problems with your memory or concentration				No		
Other emotional or psychological or physical side effects. Please specify:				No		
11. Please tell us about the resc	ources you have accessed after being discharged by the cano	cer centre.				
Did you use any of the following resource? Please check			If so, did you find the resource helpful?			
Maplesoft Survivorship Centre		Yes		No No	eipiuis	
Canadian Cancer Society (telephone, booklets, Web sites)		Yes		No		
Community peer support groups		Yes		No		
Psychosocial oncology program		Yes		No		
Cancer program Web site		Yes		No		
The Colorectal Information Guide and Personal Record		Yes		No		
Other, please specify:				No		
		Yes		INO		
12. How informed were you ab	out the plan for your care when your treatment was comple	eted?				
(a) Very informed	(c) Not at all informed					
(b) Somewhat informed	(d) My treatment is not completed					
13. How often were your care p	providers aware of your cancer history?					
(a) Never	(d) Always					
(b) Sometimes	(e) Unsure					
(c) Usually						
14. How would you describe th	e emotional support you have received from your care prov	viders since your trea	tment was	completed?		
(a) Yes, I received all of the	emotional support I needed					
(b) Most of the time I felt en	notionally supported					
(c) I did not receive any eme	otional support					
(d) I did not need any emoti	onal support					
(e) My treatment is not com	pleted					
15. Were you referred to or put	in touch with any other health professionals who helped yo	ou with emotional su	pport?			
(a) Yes (b) No (c) Ur	sure					

CEA = carcinoembryonic antigen; CT = computed tomography.