



Views of breast and colorectal cancer survivors on their routine follow-up care

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ABSTRACT

Objective

Our understanding of optimum health care delivery for cancer survivors is limited by the lack of a patient-centred perspective. The objectives of the present study were to explore the views of breast and colorectal cancer survivors on their routine follow-up care, with respect to needs, preferences, and quality of follow-up, and their views on cancer specialist—compared with family physician (FP)—led follow-up care.

Methods

In Nova Scotia, Canada, 23 cancer survivors (13 breast, 10 colorectal) participated in either a focus group or a one-on-one interview. Participants were asked to reflect upon their lives as cancer survivors and on the type and quality of care and support they received during the follow-up period. Each focus group or interview was transcribed verbatim, and the transcripts were audited and subjected to a thematic analysis.

Results

Six themes were identified:

- My care is my responsibility
- How I receive information on follow-up care
- I have many care needs
- I want to be prepared and informed
- The role of my FP in my cancer experience and follow-up care
- The role of media

Survivors often characterized the post-primary treatment experience as lacking in information and preparation for follow-up and providing inadequate support to address many of the care needs prevalent

in survivor populations. Despite valuing FP participation in follow-up care, many survivors continued to receive comfort and reassurance from specialist care.

Conclusions

Our findings point to the need to implement strategies that better prepare breast cancer and colorectal cancer survivors for post-treatment care and that reassure survivors of the ability of their FP to provide quality care during this period.

KEY WORDS

Breast cancer, colorectal cancer, oncology, follow-up care, survivorship

1. INTRODUCTION

The number of cancer survivors has grown to encompass an estimated 22.4 million survivors globally¹. This increase is attributable mainly to the combination of increased cancer incidence and of improved cancer survival through earlier detection and better treatments. Considering all cancer types, two thirds of all individuals diagnosed today are expected to be long-term survivors. For those patients, routine follow-up marks the transition from intensive (post-primary) treatment to long-term survivorship². For breast cancer (BC) and colorectal cancer (CRC) survivors alike, available clinical practice guidelines inform physicians on providing routine follow-up care^{3,4}. The guidelines recommend periodic physician visits and specific tests or investigations to detect disease recurrence or new primary cancers, to prevent or manage morbidity, and to provide psychosocial support.

However, the growing prevalence of cancer survivors raises clinical and health service questions about how best to provide routine follow-up care⁵. The traditional practice of providing routine follow-up care through specialist cancer clinics^{5,6} greatly

strains those clinics because of the large numbers of cancer survivors in the face of concurrent demands on cancer specialist resources from increasing cancer incidence, new treatments, and insufficient human and material resources^{7,8}. In Canada, concern about the mismatch between demand and availability of cancer resources, together with evidence that follow-up provided by the patient's family physician (FP) is a safe and effective alternative to follow-up provided in cancer specialist clinics^{9,10}, has led some cancer centres to transfer follow-up to the FP¹¹. However, wide variation in follow-up practice remains^{11,12}. This variation likely depends on many factors, including the expectations and preferences of survivors.

Numerous studies have examined best-practice models for survivorship care, resulting in several systematic reviews^{13–15}, but less research has investigated the perspectives of cancer survivors, specifically in relation to the delivery of their routine follow-up care, including their views on the quality of care received after primary treatment and their preferences about who provides that care. Indeed, the 2005 U.S. Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*¹⁶ highlighted the lack of a patient-centred perspective in the understanding of health care delivery for cancer survivors, stating that there is “a limited amount of research regarding cancer survivors’ expectations and experience with their care following primary treatment” (p. 199).

The objectives of the present study were to explore the views of BC and CRC survivors on their routine follow-up care with respect to needs, preferences, and quality of follow-up, and on cancer specialist-led versus FP-led follow-up care.

2. METHODS

This phenomenology study was conducted to gain a fuller understanding of the perspectives and experiences of BC and CRC survivors with respect to routine follow-up care. Phenomenology intends “to understand the phenomena in their own terms—to provide a description of human experience as it is experienced by the person herself” (p. 96)¹⁷. Ethics approval was obtained from the Capital District Health Authority Research Ethics Board, Halifax, Nova Scotia, Canada. The funding agency had no role in the collection, analysis, or interpretation of data, or in the approval or disapproval of the finished manuscript.

2.1 Participants

Participants were recruited using both clinic- and community-based methods. Recruitment took place at both of the tertiary care cancer centres in Nova Scotia. Health care professionals at those centres (including oncologists, nurse practitioners, and ostomy

consultants) identified eligible survivors and invited them to participate in the study. Recruitment also occurred by outreach through local cancer support and advocacy groups and a provincial cancer patient and survivor network. After identification or initial contact, a research coordinator discussed the nature and purpose of the study with each participant and obtained written informed consent.

Participants had to be BC or CRC survivors who had completed primary treatment (which may have consisted of any combination of surgery, radiotherapy, and chemotherapy) and who were currently receiving routine follow-up care by a cancer specialist, a FP, or both. Inclusion criteria were a diagnosis of invasive cancer within the preceding 12–48 months, no current evidence of disease, and freedom from complications of primary treatment. Exclusion criteria were primary treatment not completed at least 3 months earlier (except for continued use of tamoxifen or an aromatase inhibitor for BC) and English language skills insufficient to participate. For CRC survivors, the diagnosis inclusion criterion was extended to 12–72 months from 12–48 months to improve recruitment.

2.2 Data Collection

Data were collected through semi-structured focus groups and interviews. The original intention had been to recruit participants for focus groups only, but one-on-one interviews were also conducted with some CRC survivors because of scheduling or logistics issues. An experienced qualitative researcher facilitated each session and recorded notes. The focus group script included open-ended questions and related probes to elicit views on the general topic of routine follow-up care, specific experiences of the survivors with follow-up care (including use and quality of medical and supportive care), and the issue of cancer specialist-led compared with FP-led follow-up care. Routine follow-up care was defined as the period after completion of primary treatment and before the onset of symptoms, signs, or test results indicting possible recurrence. The interview scripts were modified for a one-on-one scenario, but covered the same topic areas covered in the focus groups.

All sessions were audiotaped and transcribed verbatim, with each session being carefully reviewed immediately afterward to facilitate understanding and to adapt the script, if necessary, to further explore important concepts and emerging themes¹⁸. Data collection continued until data saturation was reached or until further discussion with participants would not yield a fuller understanding of the phenomenon¹⁹.

2.3 Data Analysis

Data collection and analyses occurred concurrently to allow emergent concepts and themes to

be incorporated and explored in subsequent focus groups or interviews. A thematic analysis was conducted, in which the transcripts underwent coding, constant comparison, categorizing, and theme identification^{18,20}. Specifically, two investigators (AF and JB for the BC transcripts, and RU and JB for the CRC transcripts) independently listened to all audiotapes, read and re-read the transcripts and field notes to systematically code the transcripts, and routinely revisited previous codes for refinement purposes. All coding was inductive, with no *a priori* coding framework. Investigators manually coded the data without assistance from qualitative software.

After coding, the same investigators independently examined and compared the data within the identified codes, and then examined and compared data across codes. The coded text was then collapsed into categories, which were subsequently grouped into broad themes relevant to the study objectives. Once themes were identified, defined, and reflected upon, a third investigator compared the themes to ensure the validity and consistency of each investigator's analysis. All three investigators then met to discuss, refine, and modify themes; participant quotations were extracted to provide a basis for understanding the findings.

3. RESULTS

A total of 23 survivors (13 with BC, 10 with CRC) participated in the study. All 13 BC survivors participated in one of three focus groups (all conducted in 2009); 6 of 10 CRC survivors participated in one of two focus groups; the remaining 4 participated in semi-structured interviews (all conducted in 2010). All BC survivors were female; 4 of 10 CRC survivors were female. Of the 10 CRC survivors, 4 had permanent ostomies, 2 had ostomies and were anticipating a reversal, and 2 had received ostomies that had been reversed. Most survivors were receiving routine follow-up care from specialists (oncologist or surgeon, or both) and from their FP.

Six themes were identified in the data, one of which pertained to BC survivors only. Table 1 presents representative quotations for each of the themes.

3.1 My Care Is My Responsibility

Survivors overwhelmingly described the transition from active treatment to routine follow-up care as a shift in personal responsibility. That is, they moved from having the oncologist manage their care and treatment ("doing nothing") to taking responsibility for their cancer-related care ("doing everything"). The shift in responsibility often led to feelings of distress and abandonment after the completion of primary treatment.

With respect to self-management, BC and CRC survivors both described feeling guilty for contacting

professionals about their post-primary treatment concerns. Indeed, many CRC survivors frequently reported not seeking professional help for many unmet physical needs (for example, sexual health, bowel function) because they felt they ought to deal with their problems themselves and be content that they were cancer-free. The BC survivors also discussed feelings of guilt when not strictly following recommendations or guidelines—namely, in terms of exercise and nutrition.

3.2 How I Receive Information on Follow-Up Care

Participants frequently discussed communication issues related to language use (for example, medical jargon); information overload; consistency, currency, and timing of information; and a lack of information on specific areas of follow-up care (for example, exercise, nutrition, and psychological well-being). As a result, many participants reported using the Internet as a source of information and support in the survivorship period, even though they often expressed skepticism about that resource. Nonetheless, some participants felt that they received appropriate and timely information from their cancer care team about what to expect in the follow-up period.

Participants also indicated that tangible information—in the form of booklets, brochures, and videos—could not replace a conversation with a real person. Although they valued tangible information, they wanted their care providers to review the information with them to facilitate their understanding and decision-making with respect to the physical and emotional cancer- and treatment-related changes they might experience as cancer survivors.

3.3 I Have Many Care Needs

Participants spoke of many physical, psychological, emotional, and supportive care needs during the follow-up period, many of which were largely unmet by their care providers. Physical and psychological needs involved issues related to exercise, nutrition, weight management, sexual health, depression, memory loss, sleep, persistent fatigue, pain, lymphedema (BC), bowel function (CRC), and other late effects of treatment. Most participants reported difficulties accessing allied health professionals to help with those needs, although they spoke positively of their experiences when they did receive professional help. The BC and CRC survivors both also reported a high level of need related to returning to work after their cancer diagnosis and treatment.

Emotionally, participants wanted their care providers to be personable, and they particularly valued having someone to talk to who had gone through similar experiences (that is, a BC or CRC diagnosis). Participants also spoke positively about their family

TABLE 1 Quotations from breast cancer (BC) and colorectal cancer (CRC) survivors supporting the six themes identified in the study

Theme	Supporting quote
My care is my responsibility	<p>“It’s shocking that you had to be, like, you had to constantly be on alert. You had to be the one seeking people rather than people coming.”—CRC survivor</p> <p>“I cried because I was abandoned. I got used to somebody making my appointments, my tests, and my mammograms ... my family doctor ... he wasn’t really that aware of my problems. Who was going to find more cancer? ... Are there tests that I had to look for, for myself?”—BC survivor</p> <p>“And then I’m saying, ‘Oh my god, what are you complaining about?’ It could be so much worse and I’m lucky ... but it’s still an adjustment.”—CRC survivor</p> <p>“Going to McDonalds or Burger King.... I haven’t been there in a year, and if I see one more salad on top of yogurt, I am going raving mad, but you feel like you have to, you know, or then [the cancer] is going to be my fault if it comes back.”—BC survivor</p>
How I receive information on follow-up care	<p>“Another thing we don’t get any of at all [is] new information on the drugs we are taking, what to expect, things they find out after we had it ... that we don’t know about.”—BC survivor</p> <p>“Well, the information that I received about aftercare was during my final meetings with my oncologist and surgeon, and I thought that was the appropriate time to be told about this information because, for one thing, I was feeling great that I was declared cancer-free, so I was ready to listen.”—CRC survivor</p> <p>[On healthy eating] “You have read it yourself ... you need somebody ... to sit down and explain it to me: ‘You need to eat so many vegetables a day’ because ... of what they do for me and how they help me rebound from cancer.”—BC survivor</p>
I have many care needs	<p>“The radiation messed me up. Basically, I’m probably one step away from Viagra. The sex drive just isn’t there.”—CRC survivor</p> <p>“The transition back to being [in the] office from 9 to 5 is, I found, very difficult because ... I am never going to have the energy that I had before.... I go home, and I go to bed.”—BC survivor</p> <p>“When you speak to someone who has had [cancer], they understand. To talk to someone who hasn’t had the experience, they don’t know what you’re talking about.... They haven’t been through it.”—BC survivor</p> <p>“I have more issues with this [ostomy] than with the cancer. It’s stupid, but I think it’s just, it’s a reminder of what I went through. If I had surgery and just a scar and that would have been it, I think it would have been a lot better. So, I’m fighting through this. It’s getting better.... It’s more up here [mental] than the physical.”—CRC survivor</p>
I want to be prepared and informed	<p>“I would like to have like a tracking, like for a courier package, you can go online and see, okay, your test is here ... and this is when you can expect it.”—BC survivor</p> <p>“Can you tell me what to expect? Can you tell me, you know, what would be some normal things? ... I’m smart enough to recognize that this is just a guideline, but could you tell me something, because this is all new to me, and I have no idea where to even begin.”—CRC survivor</p> <p>“Nearly everybody gets depressed.... Nobody told me to expect that.”—BC survivor</p>
The role of my family physician in my cancer experience and follow-up care	<p>“[My family physician is] not a surgeon. That’s about the only thing.... As far as my other ailments ... he takes excellent care of me.”—CRC survivor</p> <p>“In a family physician setting ... it depends on, you know, what your family doctor has read recently.”—BC survivor</p> <p>“My assumption is that [my family physician] is knowledgeable to know enough about what I’ll be going through. If not, she will put the referral in to another doctor anyway.”—CRC survivor, whose family physician had an active presence throughout the cancer experience</p> <p>“If something happened, I would feel like I could get in. That’s my sense, and I don’t even think about it, but just the fact that I, like, if I have to go through my family doctor, it would take longer because I would be out of the system.”—BC survivor</p>
The role of media (BC only)	<p>“If you pay attention to the media ... it is, like, okay, I worked out and, look, I still got cancer and your people are on the radio saying ... now do this and it won’t come back.”—BC survivor</p> <p>“With October being breast cancer month, you can’t go anywhere without the reminder. It is everywhere.”—BC survivor</p>

and friends, viewing them as important sources of emotional support during and after treatment.

The CRC participants with ostomy appliances overwhelmingly discussed needs related to their ostomy. Specific issues raised included body image, sexual health, finding appropriate appliances, caring for the ostomy, and costs associated with purchasing ostomy supplies. Despite reporting difficulty reaching ostomy nurses or consultants, participants viewed those people as the most important professionals in terms of their ostomy care, valuing their help and expertise.

3.4 I Want to Be Prepared and Informed

Participants wanted to feel prepared for and informed about their follow-up care. They emphasized that knowledge of specific tests and investigations is an arduous element of managing your own care, and that one of their most prominent concerns was being unaware of the types and frequency of tests and investigations that are recommended. Many stated they would value having someone “map” their care, or provide them with a tool that would help them to coordinate and track the care they should be receiving. Participants also wanted information on what could happen and what their needs might be during the follow-up period.

3.5 The Role of My FP in My Cancer Experience and Follow-Up Care

Participants discussed receiving comfort from specialist care, specifically being assured by the knowledge and authority of their oncologist. Although survivors valued participation by their FP in follow-up care, many continued to want specialist-led care. The CRC survivors frequently discussed the FP role as one that ought to work in conjunction with the roles of other care professionals. Nonetheless, BC and CRC participants whose FPS were an active presence throughout their cancer journey were both much more likely to trust their FPS to manage their follow-up care.

Some participants were uncertain about whether FPS could order or prescribe all of the appropriate tests and investigations for cancer follow-up; others viewed FP-led care as an obstacle to quick access to cancer care services. Indeed, BC participants consistently expressed a sense of security from staying in the cancer “system,” specifically in terms of rapidly accessing the formal system should they experience a recurrence (or possible recurrence) in the future. Only 2 CRC participants explicitly expressed concerns about staying within the cancer system.

3.6 The Role of Media (BC Only)

While discussing perspectives on follow-up care and survivorship, BC survivors frequently voiced

their negative feelings toward mass media and how the media shape the lives of survivors after treatment. Specifically, participants continually pointed to the media as a source of anxiety and guilt related to their cancer and a constant reminder of their cancer diagnosis.

4. DISCUSSION

This study provides additional and important insights into how survivors experience and perceive the transition from active treatment to routine follow-up care and how they feel about nontraditional care delivery models (that is, FP-led follow-up care). Overall, our findings suggest that the post–primary treatment experience is characterized by a lack of information and preparation about follow-up care and inadequate support to address many of the physical, psychological, and supportive care needs prevalent in survivor populations (for example, sexual health, depression, and return to work). Moreover, despite viewing FP participation as a valuable component of follow-up care, many continued to receive comfort and reassurance from specialist care. Importantly, our study also demonstrated much similarity across both cancer sites in terms of the issues and experiences recounted by survivors.

After active treatment, survivors experienced a sudden and unforeseen shift in medical responsibility whereby they felt that they became the primary person responsible for their cancer-related care. For many, that shift resulted in feelings of distress and abandonment; others have reported similar feelings during this period of transition^{21,22}. Survivors in the present study also reported frequent guilt, which influenced their decisions not to seek care when experiencing aftereffects of treatment. A recent study also found that BC survivors report guilt upon visiting cancer specialists and taking them away from patients with active cancer²³. Feelings of guilt may be mitigated by ensuring that survivors have a better understanding of their post-treatment concerns and of the goals for quality follow-up care (for example, preventing or managing morbidity).

Consistent with literature from across the cancer care continuum^{24,25}, survivors routinely described communication issues related to receiving information on routine follow-up care. Those issues included poor timing of information, an absence of information in specific areas (for example, exercise, nutrition, psychological issues), and limited time for care providers to discuss educational materials with them in a way that enhanced their ability to apply the information. Regarding timing, many reported receiving information about follow-up care during or immediately after primary treatment and yet overwhelmingly feeling that this time was a poor one for receiving information on follow-up, given that “chemo brain” was so prevalent during that period.

Similar issues were recently described by leukemia and lymphoma survivors during their transition from active treatment to follow-up care²². Survivors in the present study also felt ill-informed about the types and frequency of tests and investigations that they should receive during routine follow-up care, and they felt particularly apprehensive about this lack of knowledge.

The 2005 U.S. Institute of Medicine report on cancer survivors emphasized the multiple medical, psychosocial, and supportive care needs that cancer survivors experience as they transition from active treatment to survivorship¹⁶. Not surprisingly, participants in the present study reported that late effects of treatment—including fatigue, sleep disruptions, sex drive and function, depression, lymphedema, and bowel function (or dysfunction)—were prevalent in the follow-up period and were areas in which they lacked appropriate information, support, and resources. They also expressed wanting information on what is “normal” compared with what requires medical attention. Prior research found that survivors do not feel well-informed about the physical and emotional aftereffects of treatment²² and that they find it difficult to determine whether their health problems are related to one or more of their previous cancer, their treatment, or other factors (for example, comorbid illness, aging)²³.

Together, these findings indicate a need to develop strategies that help to alleviate feelings of abandonment and unpreparedness among survivors during the transition to follow-up care and that aid in the delivery of patient-centred supports and resources. Such strategies might include providing tools that allow survivors to “map” and track their care (for example, a timeline or follow-up checklist), delivering information that is better timed to meet survivorship issues and needs, and implementing “exit interviews” after primary treatment²². Another potential strategy is the provision of individualized survivorship care plans¹⁶. However, the costs of implementing such tools²⁶, combined with randomized controlled trial evidence showing no effect on various patient and health system outcomes in early-stage BC²⁷, point to the need for more study into the effectiveness of such a strategy. Nonetheless, survivors with high levels of need—or those with other cancer diagnoses—might benefit from a care plan approach²⁷.

When queried about transferring the responsibility for follow-up from cancer specialists to FPs, most survivors valued FP participation in care, but preferred to see a specialist during routine follow-up. The most common concerns about FP-led care involved the practitioner’s knowledge and competencies related to cancer care and the ability to rapidly access specialist care if needed. Concerns on the part of BC survivors about their FP’s knowledge of and ability to provide follow-up care has recently

been reported by others, as has their preference to receive follow-up care from cancer specialists^{23,28}. However, our findings indicated that when the FP played an active role throughout the course of a survivor’s diagnosis and treatment, that survivor was much more likely to trust the FP’s ability to provide high-quality follow-up care.

Survivors of BC continually voiced their desire to stay connected to the formal “cancer system.” Many reported fears that being discharged from the cancer centre (or their surgeon’s office) would mean longer waits to re-enter the system if re-entry were to be needed. However, CRC survivors seldom expressed the same concern. This disparity may be attributable to differences between BC and CRC follow-up—namely, the ongoing relationship that many CRC survivors have with their surgeon for surveillance colonoscopies and with ostomy nurses or consultants if they have an ostomy. Although CRC survivors may not visit those professionals regularly, they may be confident of their ability to access them on their own (without a FP referral) should they require specialist services. Given that cancer survivors are increasingly discharged to primary care settings, our findings call for strategies that promote confidence in the ability of the FP to provide quality follow-up care and to access cancer specialists if or when needed. Such strategies may include an expansion of the FP role during the diagnosis and treatment phases, thorough discharge planning that consistently provides patients and FPs alike with a discharge summary and an evidence-based follow-up care protocol, and introduction of telemedicine services to permit “just in time” FP consultation with specialist cancer clinics.

Our study has several limitations. The main limitation was the difficulty we experienced in recruiting CRC survivors. As a result, we modified our data collection methods and eligibility criteria to improve recruitment. Thus, the survivors who participated may not be representative of most CRC survivors. Second, the results of the study are not generalizable to the entire BC or CRC population. However, the study did not aim to produce generalizable results; rather, we aimed to explore the lived experiences of cancer survivors during routine follow-up and to provide a patient-centred perspective to our understanding of what happens during that period. Throughout the analyses, it was evident that the post-primary treatment experiences of our participants were varied and that many different factors affected the care they received and wished to receive. Nonetheless, participants voiced many common experiences and perspectives, demonstrating the value of our research in informing survivorship programs and policies, and in designing and evaluating patient-centred service delivery models after active treatment ends.

5. CONCLUSIONS

In this study, survivors felt unprepared for many aspects of routine follow-up care and continued to experience a wide range of care needs during the follow-up period. Given the increasing demands on specialist cancer clinics⁷, there is a need to implement strategies that better prepare survivors for post-treatment care and that reassure survivors of the ability of their FPs to provide quality care during this period.

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7. CONFLICT OF INTEREST DISCLOSURES

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