Gaps and delays in survivorship care in the return-to-work pathway for survivors of breast cancer—a qualitative study

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ABSTRACT

Introduction The number of survivors of breast cancer (BCa) in Canada has steadily increased thanks to major advances in cancer care. But the resulting clientele face new challenges related to survivorship. The lack of continuity of care and the side effects of treatment affect the resumption of active life by survivors of BCa, including return to work (RTW). The goal of the present article was to outline gaps and delay in survivorship care in the RTW pathway of survivors of BCa.

Methods This qualitative interpretative descriptive study recruited 9 survivors of BCa in the province of Quebec. Interviews were conducted at the end of cancer treatments ($n = 9$), 1 month before RTW ($n = 9$), and after RTW ($n = 5$). In an iterative process, a content analysis was performed.

Results The interviews highlighted gaps in survivorship care and the paucity of dedicated resources for cancer survivors. Participants received neither a survivorship care plan nor information about cancer survivorship (for example, transition to a new normal, side effects, RTW).

Conclusions Support for survivors of BCa resuming their active lives has to be optimized. We suggest that health professionals have to intervene at 1, 3, and 6 months after cancer treatment. At those points, survivors of BCa need support for side-effects management, the RTW decision, resource navigation, and reintegration of daily activities. Also, delay in clinical pathways seems to be longer, and much attention is needed to accompany the transition to a “normal life” after cancer.

Key Words Survivorship, health care services, return to work

INTRODUCTION

A 2018 report from the Canadian Partnership Against Cancer states that the hardest part of the cancer journey is after cancer treatment. Many patients diagnosed with cancer experience delays in survivorship care in terms of lack of continuity, guidance, and resources. The scarcity of dedicated survivorship care can affect patients as they transition to a normal life, including return to work (RTW), which is a meaningful step in the survivorship experience.

Since 2014, our research team has been gathering data on RTW after breast cancer (BCa) treatments. Given that survivorship care and follow-up are still major issues in RTW, the goal of the present article was to outline gaps and delay in survivorship care in the RTW pathway for survivors of BCa. Specifically, we present our results explaining the health care context of RTW after cancer treatments.

METHODS

A qualitative study using an interpretative descriptive approach set out to document the RTW pathway of 9 survivors of BCa. The interpretative descriptive approach aims to generate knowledge relevant to the clinical context of applied health disciplines. Participants were Francophones between 30 and 60 years of age who received chemotherapy treatments and who planned an RTW in the subsequent 6 months. Data collection was longitudinal. The qualitative interviews were performed at the end of cancer treatments ($n = 9$), 1 month before RTW ($n = 9$), and after RTW ($n = 5$).
The interview varied in length from 30 to 60 minutes. We used an interview guide, and the interviews took place face-to-face or by telephone. All interviews were recorded and transcribed.

In an iterative process, a qualitative content analysis was performed. We used a coding grid based on the various systems identified by the Arena of Work Disability (personal factors, the workplace, health care, and the compensation system). The QDA Miner software application (version 5.0.19; Provalis Research, Montreal, QC) was used to manage the qualitative data. In addition, a logbook documented the experience of data collection and included methodologic and interpretative notes, and details of the research process. These measures were all taken by the researchers to ensure credibility (internal validity) and transferability (external validity):

- Back-and-forth communication with all authors and the research assistant, and frequent return to the transcripts and field notes
- Documentation of the study context in a detailed fashion

The study was approved by the Research Ethics Board of the Charles-LeMoyne Hospital Research Centre (no. AA-HCLM-15-016). All participants signed consent forms and were assured that their data would remain confidential. They also received a copy of the consent form.

RESULTS

All 9 study participants received at least 3 treatments (surgery, chemotherapy, and radiotherapy); 7 were also receiving hormonal therapy. Mean age of the participants was 49 years. At the time of data collection, 2 participants had no family doctor. All participants attended planned follow-up appointments (surgeon, oncologist, radiation oncologist) during data collection. All participants had been employed at the time of their cancer diagnosis.

Our results show that, 1 month after cancer treatments, survivors of cancer are aware of the effects of cancer. They felt exhausted and were experiencing long-term side effects of cancer (for example, brain fog). Despite the presence of side effects, participants initiated procedures for rtw and mobilized resources to regain a “normal routine.” Participants were proactive despite a lack of support from the health care system.

Gaps in Survivorship Care

Participants reported lack of information about late side effects. Participants also highlighted the lack of dedicated services for cancer survivors. Most of the participants had no access to their cancer teams after the end of treatments. Some reported that, during cancer treatments, interprofessional support wasn’t appropriate for their situation. They explained that they needed these dedicated resources (for example, a psychologist, a physiotherapist) at the end of the active treatments:

We feel lost, really. There is a lot of information missing. Information about knowing what to do, where to call, is missing. We need an educational program or a resource person.
— Participant 5, Interview 1

Also, although some support groups were technically offered to cancer survivors, they were cancelled because of a lack of registrations or resources. Younger participants were the most disappointed about that situation. They wanted to meet other women who had had the same experiences (for example, rtw, seeking childcare). All participants mentioned receiving confusing guidance about rtw. They would have liked to know the best timing for rtw and the components of a progressive rtw:

I asked them, “Can you tell me what is progressive rtw?” They said, “We are expecting a long-term progressive rtw, because it’s been a long time since you left.” But nothing more.
— Participant 2, Interview 2

Delays in Survivorship Care Delivery

The description of the rtw pathways for survivors of cancer highlighted delays in survivorship care. Participants received neither a survivorship care plan nor information about cancer survivorship (for example, transition to a “new normal,” side effects, rtw). Only 2 participants were referred to another professional for survivorship issues (for example, arm pain, low income). Also, contact with a primary care physician was mostly episodic and not related to follow-up after cancer treatments:

I find it very strange to spend so much time at the hospital; then, suddenly, you find yourself facing nothing.
— Participant 9, Interview 1

DISCUSSION AND CONCLUSIONS

Our examination of the rtw pathway has put gaps and delays in survivorship care into evidence. We interviewed participants at the very beginning of survivorship—that is, at the end of active cancer treatments (corresponding to a time interval of 6 months after treatments). During that period, our participants didn’t receive enough information to face the long-term side effects of cancer, to regain a “normal life,” and to handle rtw. In light of those results, we propose recommendations to better facilitate the transition to a new normal (Table 1). We believe that supporting rtw is an integral element of survivorship care. Thus, our recommendations could clarify and drive the role of health care professionals in both cancer care and primary care settings. Given that perspective, we propose starting the transition in the cancer care setting. The end of active treatment (chemotherapy, radiation therapy) is a teachable moment in which to give information about late side effects, resources for cancer survivors, and rtw. At 1–3 months after treatments end, survivors of cancer could attend an appointment with a primary care professional (physician, nurse, nurse practitioner), which would be a good opportunity to evaluate new or late side effects (for example, fatigue related to hormonal therapy). Survivors of cancer are willing to...
receive more information about managing side effects (for example, fatigue, cognitive impairment) and the rtw process. Evidence shows that it is important that an individual keep contact with the workplace during a sick leave. Health care professionals can encourage patients to contact their supervisor. Follow-up of side effects can also be pursued 4–8 months after treatments end. Discussion about work capabilities, timing the re-entry to work, and work accommodations can be initiated at that time. Professionals can assess work capabilities, ask questions about work requirements and tasks (for example, physical or mental demands), refer their patients to vocational rehabilitation services (for example, occupational therapist, ergonomist) depending on the complexity of the rtw (Table 1).

Our results also underscore delays in the provision of survivorship care and even lack of dedicated services and rtw support. Evidence shows that this clientele requires survivorship care, including management of late symptoms that persist over time, facilitation of rtw, and job retention. More attention is required to understand why delays in survivorship care still occur. In past years, some works have explicitly addressed delays in the cancer care pathway. The “phases of the clinical pathway” proposed by Olesen et al. illustrate the cancer pathway from first symptoms to treatment. Their work defines 3 main types of delay—patient, doctor, and system—and illustrates key milestones to avoid patient delay. Given our results, we propose to identify “survivorship care delay,” which accords with the recommendations from the U.S. Institute of Medicine about cancer survivorship as a distinct phase of cancer care. As illustrated in Figure 1, we add a “follow-up care starts” phase. We could not determine whether follow-up care can be affected by a system delay (for example, communication, administrative issues), a doctor delay (for example, survivorship knowledge, lack of role clarity), or patient delay (for example, reluctance to return to the primary care setting, lack of knowledge about survivorship issues). Our adaptation could be useful for providing an overview of delays occurring during survivorship and generating awareness among health care professionals about offering survivorship care promptly. To enhance the transition of survivors of cancer to a “normal life” after cancer, including rtw, delay in the delivery of survivorship care must be avoided (Figure 1).

Finally, our results show gaps and delays in access to survivorship care in the rtw pathway. Health care professionals, decision-makers, and researchers must work together to avoid delay in the cancer survivorship transition and help survivors of cancer to resume an active life.

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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.

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**REFERENCES**


