
TRANSITIONS TO PRIMARY CARE

Colleen Riley, NP(F), BSc, BScN, MSN, BC Cancer Agency

STUDY SUMMARY: The followup experience of early-discharge breast cancer survivors

Luctkar-Flude M, Langley H, Tyerman J. Exploring the perspectives of early-discharge breast cancer survivors following the transition to primary care followup, presented at the 2016 CANO/ACIO Conference, Calgary, Alberta.

The purpose of this study is to explore the perspectives of early-discharge breast cancer survivors following their transition to primary care followup, and to inform the development of knowledge translation interventions to support survivors and primary care providers (PCPs) in delivering comprehensive survivorship care. Breast cancer survivors

(N=144) being discharged from the Cancer Centre of Southeastern Ontario were invited to participate in this descriptive, mixed methods study. Enrolled participants (N=68) were asked to complete surveys upon discharge and at 6 and 12 months post discharge. Qualitative interviews were conducted at 12 months post discharge. Data collection and recruitment for interviews is ongoing.

Results from the first stage of this study suggest that, while transition to primary care was rated highly, participants identified gaps, including lack of information about resources, supports and self-management tools. Although participants reported excellent oncology care and high confidence in PCPs, some described feeling unready to leave and abandoned by the cancer centre. In terms of primary care followup, many participants reported that they were receiving excellent care, although some identified challenges regarding a lack of communication between the cancer

centre and their PCPs, and concerns about PCPs' lack of familiarity with followup guidelines.

With respect to symptoms, participants most commonly reported fatigue, anxiety, shortness of breath, sleep and weight problems, and concentration/memory problems at time of discharge. Most of these symptoms persisted through followup at similar rates. Despite their high prevalence in this sample, data around comprehensiveness of primary care followup care suggest that fatigue and distress screening were infrequently conducted.

Preliminary data from this study suggest that, although early-discharge breast cancer survivors are relatively healthy, many continue to have psychologic and physical symptoms well beyond discharge. Breast cancer survivors in this study had mixed experiences with transitioning to primary care, and perceived gaps similar to those identified by PCPs in previous studies.

COMMENTARY: Breast cancer is both the most prevalent cancer and the leading cause of new cancers among Canadian women.¹ As the number of women diagnosed with breast cancer increases and survival rates improve, demand for oncology care is increasing.² As such, cancer centres are looking at ways to assure early discharge for some survivors, and are looking to PCPs to provide posttreatment followup.³ However, PCPs, who may only infrequently encounter breast cancer survivors in practice, report a lack knowledge about survivorship care and may have difficulty keeping abreast of followup guidelines.³

In previous work, Luctkar-Flude et al developed a comprehensive clinical framework, including key recommendations to support PCPs in the provision of breast cancer survivorship care.³ In a followup study, Luctkar-Flude et al examined PCP knowledge and implementation of these recommendations.⁴ Results demonstrated that less than half of the 21 key guideline recommendations were routinely being implemented with breast cancer survivors, and that PCPs were unaware of 28.5% of these recommendations.⁴

In the current study, breast cancer survivors reported a number of physical and psychologic symptoms, including fatigue (54.8%), anxiety (35.7%), shortness of breath (35.7%), pain (31%), sleep and weight problems (28.6%), and concentration/memory problems (21.4%) at baseline. Similar findings were reported at followup: fatigue (64%), pain (50%), depression (39%), shortness of breath (36%), sleep and weight problems (28.6%), and concentration/memory problems (21.4%). Despite the high prevalence of problematic symptoms, only 7% of participants reported undergoing fatigue and distress screening initiated by their PCPs, and only 16% of participants reported that their PCP addressed physical activity. Results also show that survivors rarely mentioned these important issues to their PCPs (0% brought up fatigue, 9% distress, and 11% physical activity). These findings support previous reports that implementation of followup recommendations is as low as 14.6% and 11.0% for distress and fatigue, respectively.⁴

Results of these studies support the concern that, even

when guidelines are available, uptake by PCPs may be limited. As the authors of the current study suggest, knowledge translation (KT) strategies are needed to improve uptake of survivorship guidelines. As part of their current project, the authors are working to develop KT interventions, including a mobile application ("iAM APP") that will provide PCPs with a quick and easy tool to review guidelines for survivorship care. Future research could also explore where and how PCPs are accessing care guidelines in general, and align KT strategies with common avenues of knowledge acquisition. Another approach to improving survivorship care in the primary care setting may be to provide incentives to PCPs for the delivery of comprehensive care. In British Columbia, for example, chronic disease management incentives have been created to provide funding for general practitioners to develop care plans and work through flowsheets to improve care for individuals with chronic diseases such as diabetes, hypertension and congestive heart failure.⁵ Providing similar financial incentives to recognize the complex care needs of cancer survivors may facilitate more comprehensive survivorship care.

In addition to gaps in the comprehensiveness of survivorship care, the current study highlights unmet needs in the process of transitioning from specialized oncology care to primary care. Although survivors in this study reported being happy with the transition to primary care, they also identified issues with the transition, including unexpected discharge from the cancer centre, feelings of abandonment and being unready to leave, difficulties accessing primary care, and a lack of communication between the cancer centre and PCPs. To address these issues, the authors point out that women should be informed in advance of transition to primary care. Educating women themselves about survivorship recommendations may serve to empower them in the transition process and ensure they are equipped with the knowledge to practice self-advocacy with their PCP.


Concerns about lack of communication between PCPs and cancer centres have been highlighted in previous studies.^{6,7} The use of tailored survivorship care plans to improve

LANDMARKS

communication and comprehensiveness of survivorship care has been endorsed by the Institute of Medicine in the US.⁸ Patients have identified essential components of survivorship care plans, such as diagnostic and treatment summaries, information about lifestyle, nutrition and exercise, information about expected side effects and recovery, information about signs and symptoms of recurrence, recommended followup schedules, and guides to resources and available support groups.⁷ In addition to having this information provided to their PCPs, patients preferred to have an in-person consultation with an oncology specialist, such as an oncology nurse, to review this information.⁷ Survivorship care plans may be valuable tools for the communication of treatment-related information and followup recommendations. However, uptake of survivorship care plans has not yet become widespread, and the limited literature presently available suggests that these tools may not actually improve outcomes for survivors of breast cancer.⁹

Other strategies for improving the transition from oncology care to primary care have been discussed in the literature. For example, Railton et al found that 71% of female participants who had early-stage breast cancer — 67.5% of whom had been discharged to PCPs for survivorship care — would have accessed a breast cancer telephone clinic if one had been available.¹⁰ Further, Ganz et al discuss the use of consultation teams for the delivery of survivorship care, as well as the integration of PCPs into oncology settings to provide specialized survivorship care.² In British Columbia, nurse practitioners are available in some communities to assure ongoing primary care with a focus on survivorship,

although this service is only available to survivors who lack a PCP.

The current study adds to our knowledge of issues around transitions to primary care and the comprehensiveness of survivorship care delivered in the primary care setting from the perspective of survivors themselves. As data collection and recruitment continue, we may learn more about survivors' experiences. It is clear from the preliminary data that, although many survivors are doing well, there are gaps in both the transition process and the comprehensiveness of primary care followup that need to be addressed. Future directions should focus on developing innovative solutions for improving transitions in care, and KT strategies for improving survivorship care in the primary care setting. 

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IN BRIEF

Already known

- Knowledge and practice gaps in the provision of breast cancer survivorship care are reported by primary care providers.

What this study showed

- Early-discharge breast cancer survivors perceive similar gaps in the comprehensiveness of survivorship care delivered in the primary care setting as those identified in earlier studies by primary care providers.
- Breast cancer survivors report varied experiences with the transition to primary care followup.

Next steps

- Future work should focus on the development of knowledge translation strategies to promote the use of survivorship care guidelines in the primary care setting.
- Innovative strategies are needed improve the process of transition from specialized oncology care to primary care followup.