

Adult survivors of childhood cancers

WHO IS BEST PLACED TO PROVIDE FOLLOWUP CARE?

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STUDY SUMMARY: Views of primary care providers and survivors in Alberta

Russell B, Reynolds K, Spavor M, Giese-Davis J. Transition to primary care: physician perspectives and survivors' unmet needs. Presented at CAPO 2018, Abstract S109.2.

Presented in a symposium focused on the transition to primary care for survivors of cancer, 2 studies explored different perspectives on the transition of adult survivors of childhood cancers (ASCC) to primary care in Alberta. In the first study, primary care providers (PCP) (n=7) participated in telephone interviews, answering questions about gaps and barriers to providing ASCC followup care, potential solutions to identified gaps and barriers, educational opportunities, and ideal followup care models. In the second study, ASCCs (n=94) answered open-ended questions about their unmet needs, healthcare services, and the effect that cancer had on their lifestyle.

The most noteworthy finding from the studies was PCPs' knowledge deficit on ASCC followup care, despite their preference for PCP-led care and stated desire for informational resources. The studies also found that ASCCs recognized that their PCP lacked this knowledge. One of the PCPs stated feeling confident but not competent in caring for ASCCs. Furthermore, ASCCs themselves lacked knowledge about late effects and were dissatisfied with the services provided to them. They also reported feelings of distress, such as shame and guilt about surviving, and expressed a desire for counseling. Other barriers to appropriate followup

care identified by PCPs were lack of communication and time, especially when trying to reach specialists for consultation.

Findings from these studies suggest increased knowledge is needed for ASCCs and PCPs, as well as better communication between treating centres, ASCCs and PCPs so that knowledge about survivorship care can be properly translated. Findings also point to the need for psychosocial services offered throughout the cancer trajectory, such as counseling and peer support, as indicated by the survivors themselves.

COMMENTARY: Treatment advances over time have increased childhood cancer survival rates significantly, so that approximately 80% of children now survive their cancer, representing over 1,200 childhood cancer survivors living in Alberta in 2015.¹ The increase in the number of ASCCs has been accompanied by an increase in morbidity, with two-thirds of childhood cancer survivors living with a long-term side effect resulting from cancer and/or its treatment.² Long-term side effects include: cardiac toxicity, endocrine dysfunction, motor impairment, growth and development impairment, cognitive difficulties, and psychological distress.^{3,4} As a result, ASCCs require lifelong followup so they can be monitored for long-term and late effects.⁵ However, currently lacking in research is an evidence-based approach to determining ideal long-term followup care models and healthcare transition practices for ASCCs.^{5,6}

While the studies presented at the CAPO conference found that, in general, PCPs preferred PCP-led care, other research has found the opposite, with 46% of PCPs preferring that followup be undertaken by a specialized clinic, compared to only 8% of PCPs preferring to be responsible for followup care.⁷ Freidman indicated that there are 3 main models of followup care for ASCCs: the cancer centre-based model, consisting of the oncology and survivorship team; the community-based model, which is PCP-led; and a model combining both cancer centre- and community-based models. While more research is needed to determine the optimal model of followup care for ASCCs, pros and cons for each of these models have been identified.⁵ For example, the cancer centre-based model is advantageous because it allows for continuity of care in an environment familiar to patients, where medical professionals have expertise in survivorship care and knowledge about long-term and late effects.⁵ However, this model is disadvantageous in that it may not be geographically accessible for everyone, and patients may feel dependent on the medical team and systems.⁵ The community-based model may save money, be more conveniently located, and empower patients to be independent about their health, but there may be lack of care specific to survivorship needs, which could lead to discontinuity of care.⁵

Russell et al's studies stress that if survivors are going to transition over to PCP-led followup care, there needs to be improvement in the current state of that model. Specifically, there appears to be a need for increased knowledge and education. The studies found that both PCPs and ASCCs lacked knowledge on cancer-related followup care, which is consistent with previous research.^{5,6,7} Russell et al explained that this was troublesome, given that children's hospitals

within Alberta do provide followup care plans to patients and their PCP at the time of discharge, and that the Children's Oncology Group regularly updates guidelines. There is obviously a need for better knowledge translation and communication between treating centre, patient and PCP; at present, this information is going missing.

Some research has been accomplished to come up with solutions to this problem. Berg had some suggestions, including increased access to information, such as medical records, for both PCPs and patients, and technology-based tools, such as social media, to engage younger ASCCs. The Institute of Medicine proposed the use of survivorship care plans between treating centres, ASCCs and PCPs that describe the cancer treatment history and provide recommendations for followup care.⁸ However, Iyer et al argued that the survivorship care plan may not be the best method for survivorship care, as approximately 30% of PCPs felt very uncomfortable using it. This might explain Russell et al's findings that PCPs lack followup care knowledge despite being provided with followup plans for ASCCs. This and other research suggests that simply sending PCPs survivorship care plans is not enough: their use can be bolstered when they are combined with proper organization within the healthcare system and improved communication between providers.^{7,9} There is consensus that further research is needed to determine whether, even with improvements, this model is effective.

Overall, the 2 studies discussed in this symposium add to our current understanding of ASCC transition to primary care. They explore both PCP and ASCC perspectives in their own words. The findings highlight the need for more research into the ideal model of followup care for ASCCs, as well as ways to improve knowledge translation and communication between all parties involved in ASCC followup care.

IN BRIEF

Already known

- Childhood cancer survival rates have increased dramatically.
- Adult survivors of childhood cancers face increased morbidity related to the cancer and its treatment and require life-long followup.

What this study showed

- Primary care providers lack the knowledge to address late effects of childhood cancers, despite preferring primary care followup to followup in cancer centers.
- Adult survivors of childhood cancers recognize the knowledge deficit and are dissatisfied with the services provided in primary care.

Next steps

- Increase knowledge, education and communication in order to improve the primary care model of followup.
- Conduct further research to evaluate different models of followup for this population.

References:

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