

What barriers do South Island adolescent and young adult (AYA) cancer patients face during survivorship?

STUDENT

Eleanor Wilding

SUPERVISOR(S)

Dr. Tristan
Pettit, Louise
Sue

SPONSOR

The Ruth
Spearing
Cancer
Research Trust

PHOTO

Introduction: The South Island Cancer service cares for 15-24 year-olds diagnosed with cancer. This adolescent and young adult (AYA) age group is at risk due to the finding that pediatric and adult oncology patients have superior improvements in survival trends than AYA cancer patients.

Survivorship is inclusive of living with, through, and beyond cancer diagnosis and treatment. International research has shown that this age group has high unmet needs during survivorship, which are poorly managed and worsen quality of life. Barriers that are faced by AYA during survivorship include difficulties accessing information, fertility, physical and mental health, returning to work or school, finances, cognition, cultural safety, gender identity, social isolation, and relationships. Empowering AYA cancer survivors to overcome these barriers is integral to improve overall health and well-being. Due to their developmental stage, AYAs often do not have the life skills or preparation to cope with these challenges during the post-treatment survivorship phase. It can be difficult to maintain engagement with AYA patients due to the lack of age-appropriate facilities and support services and transitioning from pediatric to adult medical services. Cancer support services must understand and address these concerns to improve the quality of care.

Aim: To identify the extent and nature of barriers faced by South Island AYA cancer survivors compared to other age-matched study populations and discover the current support provided to overcome these barriers.

Impact: These results will inform regional AYA cancer services in Aotearoa to improve survivorship care to target the current unmet needs of this population.

Method: An observational cross-sectional audit was performed using an online survey to collect quantitative and qualitative data relating to established AYA survivorship barriers. The questionnaire was reviewed by AYA cancer specialists, AYA keyworkers, clinical psychologists and an AYA cancer survivor. The study's inclusion criteria required a living AYA cancer survivor who received their cancer diagnosis between 15-24 years of age and finished treatment in the last ten years. They needed to be known to the regional AYA cancer service and contactable via phone. Initial contact was made via text message. The patient was then called to discuss the study and invited to participate. Those who were keen were sent a link to the online survey via email or text message. Following initial contact, follow-up reminders were sent to non-respondents. The

feasibility of the study was evaluated using the first ten survey responses. There were no issues with participant uptake rates or the survey design therefore, the research team decided to progress with the study.

Results: This is a preliminary analysis of the first 60 responses, as study recruitment is ongoing. Figure 1 is a summary of all the barriers assessed by the survey. Our results suggest physical and mental health had the most significant impact on AYA cancer survivors after finishing treatment, followed by difficulties with Work/Education and Thinking/Memory.

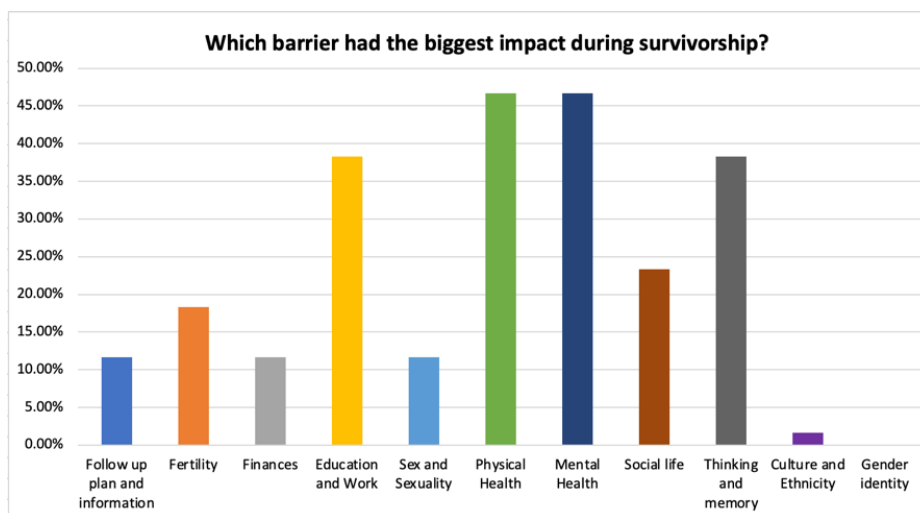


Figure 1. Quantitative bar graph demonstrating the AYA survivorship barriers that had the biggest impact on the study population of South Island AYA cancer survivors (n =60). Physical health and Mental health had a prevalence of 47.67%. Work/Education and Thinking/Memory had a prevalence of 38.33%.

Physical health: 74% of participants reported at least one physical symptom, but only 37% sought help that met their needs. Mental health: 70% of participants experienced at least one mental health concern, the most prevalent was anxiety (52%). Of those facing mental health difficulties, only 28% were able to seek appropriate help. Work/Education: 75% reported difficulty returning to work or school, and 68% described unmet needs for re-entry assistance. Almost half (47%) had to change their dreams or goals for work/education due to their cancer experience. Cognition: 57% of participants reported problems with their long/short term memory, and 54% had slower thought processes.

Conclusion:

Physical health: While some physical side effects of cancer cannot be cured, a smaller proportion of our study group accessed help from a health professional for symptom management when compared to other age-matched populations.

Mental health: Mental health concerns were common and often severe. There is a higher prevalence of anxiety and/or depression in our study population than other similar, age-matched populations. The majority (72%) of our group did not receive useful help from a health professional; this is almost double the prevalence previously reported in the literature. This unmet need was reinforced by qualitative answers, emphasizing the demand for better mental health support.

Work/Education: There is a higher prevalence of South Island AYA cancer survivors experiencing difficulties returning to school or work than other equivalent study populations. Given that much of a person's wage growth occurs in the first decade of their career, interference with education or employment from a cancer diagnosis may impact long-term career opportunities and financial status. Return to work services are essential, with improved uptake by AYA cancer survivors.

Cognition: There are lasting effects of treatment on thinking and memory, limiting cancer survivors' mental performance. A goal for healthcare teams could be to validate these concerns and develop interventions for cognitive rehabilitation.

This research has identified survivorship barriers in the South Island AYA cancer survivor population. It provides an opportunity for regional AYA cancer services to improve future survivorship care to target these unmet needs. It may include establishing a dedicated AYA survivorship clinic that links the AYA cancer survivor with specific resources to resolve a particular barrier. It will be accessible (either virtually or in-person), age-appropriate, and tailor care to the individual's specific needs.

Instructions:

DO NOT change the margin size

Please use Open sans 10pnt font

Save in word format

File name should be SURNAME, first name