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Abstract Title

Centering Patients' Voice: How Lived Fertility Experiences of Adolescents and Young Adults are Reshaping Oncofertility Care and Priorities in a Canadian Province

Background

Adolescents and young adults (AYAs) with cancer often face complex fertility preservation decisions. While guidelines recommend timely fertility discussions and referrals, real-world gaps persist, particularly in geographically dispersed and underserved populations.

Objective

To better understand these gaps and inform improvements to oncofertility services, we conducted focus groups and interviews with AYAs with lived experience of cancer in Manitoba.

Methods

We conducted three online focus groups and four interviews, facilitated by the AYA Program's Clinical Nurse Specialist and Program Coordinator, with nine AYAs aged 18–39 diagnosed with cancer between the ages 15 and 39. Sessions lasted 30–60 minutes and explored experiences with fertility discussions, access to care, cultural considerations, and system navigation. Transcripts were analyzed thematically.

Results

Nine participants took part in the study, including one male and three from ethnically diverse backgrounds. Cancer types included testicular (n=1), nasopharyngeal (n=1), lymphoma (n=2), breast (n=2), and gynecological cancers (n=3). Thematic analysis identified multiple system- and patient-level barriers to equitable oncofertility care. These included suboptimal timing and framing of fertility discussions, non-comprehensive counselling by oncology providers, and limited access to specialized fertility services. Participants reported a lack of system-level coordination between oncology and fertility services, limited availability of accessible educational resources (digital and print), absence of tailored care pathways for ethnoculturally diverse AYAs, and financial barriers to fertility preservation. The emotional burden of fertility-related decision-making at diagnosis and the need for longitudinal fertility support throughout survivorship were consistently emphasized. These findings are directly informing the co-development of patient-facing educational materials, enhancement of clinical workflows, and province-wide provider educational materials on oncofertility.

Conclusion

Our findings underscore the importance of incorporating patient perspectives into the design and implementation of oncofertility services. Early and continuous engagement of AYA cancer survivors in informing the work ensures contextually relevant, equity-focused strategies for enhancing the responsiveness and accessibility of fertility care across the province.

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