

Young People with Cancer Deserve Better Care — Here's What We Found

Regional cancer care for young people: what's working, what's missing, and what needs to change.

About this research: This study explores the experiences of adolescents and young adults with cancer, along with their caregivers and healthcare providers, in Southwestern Ontario, Canada. Fourteen participants contributed through in-depth interviews. The goal is to improve how regional communities support young people through cancer.

WHO ARE WE TALKING ABOUT?

Adolescents & Young Adults (AYAs) with Cancer

In our study, the sample comprised young people aged 15 to 24 who were diagnosed with cancer during a critical stage of their lives, when they are forming their identities, building relationships, finishing school, and starting careers. Cancer disrupts all of this.

Caught in the middle



They often fall between pediatric and adult care systems, where neither is fully aligned with their needs.

Living far from specialty centres



Many rely on regional and community hospitals that may not have all the resources they need.

14 people shared their stories



Youth, parents, and healthcare providers all participated in this study.

What Young People Go Through



Physical Toll

Pain, nausea, fatigue, and repeated hospital stays during treatment. Even after it ends, recovery takes years — some relearn how to walk.



Emotional Struggles

Shock at diagnosis, anxiety, anger, and trauma that can linger long after treatment. Some also experience unexpected personal growth and resilience.



Social Isolation

Suddenly cut off from friends during a time when belonging matters most. Treatment pulls youth away from the peer connections essential to growing up.



Family Under Pressure

Caregivers — mostly mothers — described caregiving as all-consuming, often at the cost of their own jobs, health, and other children.



System Doesn't Fit

Care environments are designed for children or adults — not for young people in transition who need age-appropriate support and independence.



Navigating Alone

Families often had to piece care together themselves, travelling to distant hospitals and bridging communication gaps between their local and tertiary teams.

In Their Own Words

"I finally found my people... and then out of nowhere it just all went away. I wasn't allowed to really interact with them because of my chemotherapy."

— Youth participant

"Everything that she did prior to treatment, now she had trouble walking... she had to learn how to walk again."

— Caregiver participant

"Patients come back for follow-up, and it is not in the discharge note. I don't know what I am supposed to do — patients have to wait while we figure it out."

— Healthcare provider

"Having her face — that same face — time after time, was hugely impactful."

— Caregiver on consistent nursing care

Gaps in the System

1 Fragmented Communication

Regional and tertiary hospital teams don't always talk to each other. Families are left to relay information and fill in the blanks.

2 Inconsistent Expertise

Not all community hospitals have oncology-trained nurses or access to specialized medications, forcing extra travel to larger centres.

3 Overreliance on Champions

Care coordination often relies on individual providers, and when there is turnover, continuity of care can be affected.

4 Youth Voices Need More Space

Young people's preferences and opinions matter. Care decisions often default to parents, but greater involvement of youth as partners in their own care can lead to better outcomes.

5 Mental Health Support is Scarce

Psychosocial and emotional support services are unevenly available — especially when treatment ends and the hardest feelings emerge.

6 Survivorship is an Afterthought

When treatment finishes, structured support largely disappears — even though youth still need guidance navigating life after cancer.

What's Working



Local Satellite Clinics

Community-based clinics reduce travel burden and keep families close to home — a major relief during treatment.



Compassionate Providers

Familiar, kind healthcare workers who remember birthdays and treat youth as people — not just patients — make an enormous difference.



Community Organizations

Local support groups and charities provide ongoing emotional and financial help that the healthcare system alone cannot offer.

What Needs to Change



Coordinated Care Plans

Tertiary and regional teams need structured ways to communicate so nothing falls through the cracks.



Youth at the Table

Young people must have a real say in their care — their voices and preferences should shape treatment decisions.



Mental Health Access

Consistent psychosocial support — during and long after treatment — must be built into the standard of care.



System-Wide Change

Good care should not depend on a single individual. We need team-based, resilient structures that last.

RESEARCH OUTPUTS

- 2 Research Papers
Peer-reviewed publications
- 1 Local Conference
WE-SPARK Health Research Conference
- 1 National Conference
Canadian Cancer Research Conference

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