

PLAIN LANGUAGE SUMMARY



SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données
probantes de la SRAP
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research

SPOR
Putting Patients First

How Do Surgeries That Keep or Remove the Arm or Leg Affect Children With Cancer and Their Caregivers?

Date prepared: June 26, 2026

Summary

This review examined the experiences of children and adolescents undergoing limb saving surgery or amputation for bone or soft tissue cancer, and their caregivers. We found 27 studies that helped address this aim. Patients face a wide range of challenges, most commonly physical (22 studies), followed by social (15 studies) and emotional (15 studies) outcomes. Fewer studies examined caregiver experiences (4 studies).

What does this mean?

These findings show that children and their families need more support not just for physical recovery but also for emotional well-being and daily life. More research is needed to develop strategies that help families prepare for surgery, adjust afterwards, and return to normal activities.

We would like to acknowledge our patient partners, Ms. Leah Deans and Ms. Erica Deans, for the conceptualization and partnership in conducting this parent-initiated scoping review.

For more information, please contact Dr. Lindsay Jibb
(lindsay.jibb@sickkids.ca).

What is the current situation?

Bone and soft tissue cancers make up about 10% of all children with cancer. They are usually treated with surgery to remove the tumour but keep the arm or leg (limb saving surgery) or amputation (removing part or all of the arm or leg). Caregivers, usually parents, also experience stress when supporting their child. As more of these children survive into adulthood and face long-term challenges, it is important to better understand their experiences, so healthcare teams can provide support that improves their quality of life.

What questions did we aim to answer in our research?

Our research aimed to answer the following questions about children and adolescents with bone or soft tissue cancer who had limb saving surgery or amputation, as well as their caregivers:

- What health outcomes do they experience after these procedures?
- What needs do they have following these procedures?

How did we approach these questions?

We conducted a scoping review, which summarizes research studies to describe the current state of knowledge on a topic.

We searched several scientific databases for studies on the health outcomes and needs of children and adolescents who have had limb saving surgery or amputation due to bone or soft tissue cancer, as well as those of caregivers.

We found 27 studies published between 1989 and 2023 that helped to answer our research questions. Following this, we collected key information from those studies and summarized what they showed.

What answers did we find from our research?

Children and teenagers who have limb saving surgery or amputation face a range of challenges after surgery. The most reported challenges were related to physical ability, including moving around, doing things on their own, and pain. Social challenges, such as participating in activities with family and friends or missing school, were also frequently reported. Many patients described concerns about mental health and body image, including how their artificial leg or arm (prosthesis) or scars looked. Caregivers also experienced emotional strain and financial challenges, but few studies included caregivers.

How confident are we in these findings?

We believe in the value of these findings. We included studies from multiple countries that examined physical, emotional, and social outcomes for both patients and caregivers, which is unique to our study. However, many studies looked at a small number of participants, focused mainly on leg-related surgeries, and measured outcomes in ways that means findings cannot be synthesized. More research is needed to understand child and family experiences holistically.