

Amputation Patient Decision Aid for Osteosarcoma of the Lower Extremity: Which Option is Best for My Child - Amputation, Rotationplasty, or Limb Salvage Surgery?

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Background and Aims

Osteosarcoma is primarily a pediatric cancer diagnosis with bony tumors occurring around the knee joint during periods of rapid bone growth. While a standard of chemotherapy is required for survival, there is no single objective choice for local control that increases those odds. Three surgical options include amputation, limb salvage surgery, or rotationplasty in which the foot and ankle are amputated and rotated 180 degrees with the ankle becoming the knee joint. All three options have radically different appearances and functional outcomes with varying risks and benefits.

Decision aids are most often used for preference-sensitive decisions, or decisions in which the clinical evidence does not indicate one best option over another. Making decisions based on long-term quality-of-life goals can be a burdensome for patients and families who need to consider complicated medical information in conjunction with personal values. A patient decision aid that clearly details each option as well as real-world patient stories is paramount to understanding the lifelong impact of the surgical decision. The purpose of this study is twofold: to identify knowledge gaps in the patient population and to develop a tool to reduce decision conflict and decision regret and increase decision satisfaction.

This patient decision aid is stakeholder driven by patients/families as well as pediatric oncologists and orthopedic surgeons from Johns Hopkins, Cleveland Clinic, MD Anderson, University of North Carolina, Indiana University, University of Utah, University of Missouri, Texas Children's Hospital, and Harvard University. Decision satisfaction outcomes are tracked longitudinally over time.

Methods

In year one, a qualitative inquiry of questions posed in social media by patients as well as in depth interviews with patients and families identifies knowledge gaps for decision-making. The interviews are guided by the interactive model of knowledge translation and include suggestions for development of the decision aid by participants. Years 2-3 develop and test a complex interactive decision aid that includes patient narratives in video form with orthopedic surgeons, pediatric oncologists, and patient/family stakeholders. Years 4-5 beta test and revise the final model in a pre/post design with decision conflict, decision regret, and decision satisfaction scales and qualitative interviews.

Results

Data collection concludes in November 2020. Preliminary results indicate themes of uncertainty and knowledge gaps when making the surgical decision, retrospective regret, and patient stories with potential long-term outcomes of the surgical decision. This is a five funded study with the Amputee Coalition and the Administration for Community Living; the National Limb Loss Resource Center will house the decision aid. Results will be available at the time of ACPOC 2020.