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Development of a Paediatric Toronto Extremity Salvage Score

Janine Piscione[1], Alexandra Malkin[2], Wendy Barden[1], Sevan Hopyan[2]

1 Rehabilitation Department
2 Division of Orthopaedics

The Hospital for Sick Children and University of Toronto,
Toronto, Canada

Background: Children diagnosed with primary malignant bone tumours are faced with potentially devastating functional limitations as a result of surgical treatment. However, there is a paucity of literature evaluating the functional outcomes from the perspective of the child and/or adolescent as most studies examine adult survivors of bone tumours. A self-report measure of function that is valid for children and adolescents would be potentially very useful given the tremendous growth and development that takes place in many different domains. Paediatric data could be compared with adult data for longitudinal appreciation of functional changes following sarcoma surgery.

Purpose: Here we aimed to create a paediatric-specific self-report measure of physical function that is based upon the adult-validated Toronto Extremity Salvage Score (pTESS). Our intention is that this scale will facilitate preoperative discussion of anticipated functional outcomes with families and serve as a valid clinical research tool.

Methods: Cognitive debriefing was employed to modify both upper and lower extremity versions of TESS for a paediatric population (pTESS). Saturation of new ideas that altered the scale was sought from children with sarcoma aged 5-17.9 years.

Results: During interviews with children, all items from TESS pertaining to physical function were evaluated and altered. Modifications of the content and wording of individual questions were made until saturation was achieved. Child and adolescent – relevant questions regarding physical function for day to day activities form the core of both upper and lower extremity scores.

Conclusions: A paediatric functional score for sarcoma patients has been generated and is currently in validation phase in multiple Canadian centres. pTESS has the potential to improve our ability to predict functional outcomes and we would welcome more collaborating centres internationally.