

ACPOC Peds Collaboration Abstract

Title: Challenges to Success and Support in the Pediatric Limb Loss/Limb Difference Population: An Interdisciplinary Research Collaboration

Background and Aims

Patient reported outcomes in the pediatric limb loss/limb difference population are largely understudied and underreported. Tracking statistics and long-term outcomes for infants, children, youth, and teenagers remain unknown primarily due to HIPAA concerns and issues surrounding ICD codes.

In an effort to better understand the challenges faced by the parents and families of child amputees, three organizations/institutions are collaborating in one needs assessment survey for stakeholders in the pediatric limb loss/limb difference community.

- The Amputee Coalition seeks to identify knowledge gaps for education and support with families who experience congenital limb difference or acquired limb loss due to trauma, cancer, or other causes. Their responses and those of healthcare professionals will inform and guide a new series of pediatric booklets aimed at providing the information that stakeholders identify as lacking or valued.
- The University of North Carolina – Chapel Hill seeks to identify barriers that individuals or families of child amputees have when trying to provide care for their children. This includes barriers the families have encountered when trying to find providers, support groups, and social development resources for their children.
- The American Congress of Rehabilitation Medicine’s Limb Restoration Rehabilitation Networking Group seeks to identify needs both with families and healthcare professionals in pediatric prosthetic componentry. A qualitative inquiry around limitations in available prosthetic options and specific devices as well as barriers to ordering/providing new options for pediatric patients will be identified.

This multi-organizational approach to research supports the 2018 Limb Loss Task Force recommendations for research across interdisciplinary groups and stakeholders for the purposes of implementation research and dissemination. Studies with research questions aiming to define success and value are needed to include the perspectives of all stakeholders including patients, caregivers, clinicians, funders, and payers (Limb Loss Task Force/Amputee Coalition of America, Roadmap for Improving Patient-Centered Outcomes Research and Advocacy, 2019).

Methods

A multiple choice needs assessment and qualitative survey were developed with experts from the ACRM Limb Restoration Rehabilitation Networking Group, UNC-Chapel Hill, and the Amputee Coalition. Experts from areas across the limb difference pediatric community contributed to the research design, from orthopedic surgery, physical medicine and rehabilitation, nursing, physical therapy, occupational therapy, health communication, prosthetics and orthotics, and healthcare professionals who were either caregivers for pediatric patients or pediatric patients themselves. The survey was IRB approved and approved by the Amputee Coalition research subcommittee of the Scientific Medical Advisory

Committee. Participants were recruited through social media and eblasts with the Amputee Coalition and snowball sampling with organizations like ACPOC, AOPA, AAOP, and ACRM. Quantitative data were analyzed for descriptive and inferential statistics and qualitative responses were thematically coded and analyzed using QSR International's NVivo 12.

Results

Data collection concludes in early 2020 and the results will be available at the time of ACPOC 2020.