Dr. Anthony Cooper

“Development of a Patient Reported Quality of Life Questionnaire for Children with Lower Limb Deformities”

Lower limb deformities represent a range of potentially debilitating conditions including one limb shorter in length, one or both limbs partially or completely absent, joint abnormalities, associated angular and rotational deformities. Lower limb deformities present substantial limitations in physical functioning, and hence have been shown to present with behavioral, emotional, psychological, and social adjustment problems. Furthermore, treatment procedures are long, complex and arduous. All of these problems have a considerable effect on the quality of life (QOL) of these children which has not been well-captured given the current lack of patient reported QOL questionnaire specific for this population. Hence the objective of this project is to develop and validate a patient reported QOL questionnaire for children and adolescents with Lower limb deformities.

Phase 1 of this study involved a systematic review to synthesize knowledge on the use of patient reported outcomes (PROs) to measure QOL of children with Lower limb deformities and developing a preliminary conceptual framework of QOL concepts. This conceptual framework was used to prepare an interview guide for the qualitative interviews. Thirty seven interviews have been conducted with the children and their parents at sites across Canada and USA. More interviews are in progress in Canada, Ethiopia and India.

Phase 2 (funded by CORL) will involve ongoing qualitative analysis and generating questions for the new questionnaire. This draft of questions will be sent out to children at each of the five participating sites. Children will be asked to provide feedback on the wording of the questions and response options. The revised questions will be sent to experts in the field of orthopedics, nursing, occupational therapy, physiotherapy and psychology. Experts in the PRO development and QOL will also be contacted for their feedback. Phase 3 will involve sending the revised draft of questions to a larger sample of children at the five participating sites and modifying the questionnaire based on their feedback.

This new patient reported QOL questionnaire will be used to measure the QOL as reported directly by the children with lower limb deformities and to look at the effectiveness of treatments for improving their QOL.