

CHANGES IN QUALITY OF LIFE FOR YOUTH WITH CHRONIC CONDITIONS: THE IMPACT OF PERSONAL, INTERPERSONAL, AND ENVIRONMENTAL FACTORS

INVESTIGATORS: Janette McDougall (PI), Thames Valley Children's Centre
Virginia Wright (Co-PI), Bloorview Kids Rehab/Bloorview Research Institute
Linda Miller, University of Western Ontario

FUNDING SOURCE: Canadian Institutes of Child Health - \$742,340

SUMMARY

Optimizing quality of life for children and youth is a key goal of the Ontario Association of Children's Rehabilitation Services (OACRS) centres. Many supports and interventions are directed toward this goal. It is important for clients, families, service providers, and policy makers to understand the key factors that influence changes in life quality throughout childhood and adolescence for children and youth with chronic conditions.

To this end, researchers at Thames Valley Children's Centre (TVCC), Bloorview Research Institute, and the University of Western Ontario have received funding from the Canadian Institutes of Health Research to examine the impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions.

This research endeavour includes a five-year survey-based study and a qualitative study. The survey-based study will address two unexplored research areas: 1) the changing nature of quality of life for youth with chronic conditions over a three-year period, and 2) the factors that influence change in quality of life for youth. Approximately 575 youth aged 11 to 17 years (and one of their parents) who receive services from 6 OACRS centres across Ontario will participate. Youth and parents will each complete a brief questionnaire at four time points that include questions about quality of life and the factors that past research and conceptual thinking suggest influence changes in life quality for youth with chronic conditions. Some of the factors to be explored are: youths' physical and emotional functioning, self-determination, social participation, and family and environmental supports. Advanced statistical analysis techniques will be used to evaluate changes in quality of life and to determine the factors related to change.

Twenty to thirty youth from TVCC will be involved in the qualitative study. The youth will take part in individual interviews and focus groups to consider what "quality of life" means to them and what aspects of life they feel are most important for enhancing their life quality. These findings will be examined alongside those of the survey-based study.

Findings from this research will help us to understand more about quality of life from the perspectives of youth and their families, and can help guide program and policy development toward optimizing life quality for youth with chronic conditions!

Please attend this session to learn more about: 1) the approach used by the study's researchers to conceptualize quality of life; 2) the study methods, measures, and data analysis techniques to be employed; and 3) the plan for knowledge dissemination.