

Development of the Family Needs Questionnaire - Pediatric Version (FNQ-P) - Phase I

Project Summary

Centre for Leadership in Acquired Brain Injury

Caron Gan, Virginia Wright, Sarah Sheffe, Kathy Gravel and Sharon St. Jean

Holland Bloorview
Kids Rehabilitation Hospital

Bloorview
RESEARCH INSTITUTE

SHARING OUR WORK

- Brain injury family intervention training workshop for rehabilitation professionals in June 2015
- Presented at the First International Conference on Paediatric Acquired Brain Injury on September 16-18, 2015
- Bringing the FNQ-P to Sweden and Australia for testing

WHAT WAS THIS STUDY ABOUT?

The objective of this study was to develop a questionnaire about the needs of family members after a child or youth has an acquired brain injury (ABI).

The author of the adult Family Needs Questionnaire (FNQ - Kreutzer) gave us permission to adapt the FNQ for families of children with ABI. This new measure is named the Family Needs Questionnaire – Pediatric Version (FNQ-P). We also determined the suitability of the content, details, and wording of the FNQ-P. The FNQ-P is designed to be filled out by a primary caregiver of a child or youth with an ABI.

WHAT DID WE DO?

- Held an expert panel of family caregivers and rehabilitation clinicians to provide input on the questions to include and the changes needed to adapt the original FNQ measure
- Used a series of online questionnaires with these experts to refine the questions to be included in the pediatric version
- Developed the FNQ-P, a new measure of family needs after pediatric brain injury, through this process
- Conducted caregiver interviews as an early test of the new FNQ-P

IMPACT FOR CLIENTS, FAMILIES AND CLINICAL PRACTICE

The outcome of Phase 1 is a measure that will be ready for more detailed testing before it is ready for use by clinicians.

- We created a Pediatric Family Needs Questionnaire that has questions specific to families of children and youth after ABI.
- We anticipate clinicians will be able to use this questionnaire to learn how well they are doing at meeting families' needs and how they can improve.
- The use of a standardized family needs questionnaire is also a cost-effective tool for long-term monitoring of family needs and for program evaluation.

WHAT DID WE LEARN?

Many changes were made by the expert panel to the adult Family Needs Questionnaire to make it suitable for use in pediatric settings:

- 26 new items were created and 14 original items were reworded
- 23 original FNQ items were removed or merged with new items
- School was included as a central setting of many family needs
- Language use and terms changed significantly:
 - Changed “patient” to “child”
 - Changed “problems” to “challenges”
- Increased focus on child and family strengths
- Increased focus on family involvement

More detailed testing to confirm the questionnaire content will take place in Phase 2.

NEXT STEPS:

Phase 2 of the research, titled “Validation of the Pediatric Family Needs Questionnaire (FNQ-P) Across Three Countries” will test the measure with 60 family caregivers of children and youth with ABI in Canada, Australia, and Sweden.

TO LEARN MORE ABOUT THIS STUDY, PLEASE CONTACT:

Caron Gan

cgan@hollandbloorview.ca

416-425-6220 extension 3514

WHO ARE WE?

Caron Gan, Principal Investigator

Virginia Wright, Principal Investigator

Sarah Sheffe, Research Coordinator

Kathy Gravel, Clinician Collaborator

Sharon St. Jean, Family Collaborator

THANK YOU!

We would like to extend our sincere thanks to the six family members and 11 clinicians who offered invaluable input around the creation of the FNQ-P. Additional thanks are extended to the three family members who helped with pilot testing of this new measure.

THIS PROJECT WAS FUNDED BY: the Centre for Leadership in Acquired Brain Injury