

Validation of the Pediatric Family Needs Questionnaire: A Partnership Approach Across Five Countries

Caron Gan^{1,2}, Virginia Wright², Ingrid Van Hooft³, Naomi Brookes⁴, Audrone Prasauskiene⁵, Carolyn Dunford⁶

¹Holland Bloorview Kids Rehabilitation Hospital, ²Bloorview Research Institute, ³Astrid Lindgren Children's Hospital, ⁴Sydney Children's Hospital, ⁵Children's Rehabilitation Hospital, ⁶The Children's Trust

Background

- The need for family support after a child has an acquired brain injury (ABI) is well-documented.
- Lack of validated measures to assess family needs during this critical time of recovery is a serious clinical and research gap.
- Identifying family priorities is essential given evidence of a strong relationship between unmet needs and increased family burden.
- The well-validated *Family Needs Questionnaire* (FNQ-R) for adults with ABI was adapted to create a pediatric version (*Pediatric Family Needs Questionnaire* [FNQ-P]).

Objectives

- To conduct reliability and validity testing of the newly developed FNQ-P in five countries.

Methods

- **Study sample:** Family caregivers of children, 2-19 years with ABI from pediatric rehabilitation centers in the 5 countries.
- **Reliability:** Test-retest reliability evaluation of the FNQ-P.
- **Concurrent validity:** Associations between FNQ-P score and child's age, injury severity and time post-injury.
- **Construct validity:** Evaluation of associations with *Family of Burden of Injury Inventory* (FBII; short form) and *Strengths and Difficulties Questionnaire* (SDQ)
- **Analysis:** Test-retest reliability evaluated via intra-class correlation coefficients (ICCs). Pearson correlations (r) for validity evaluations.

Family Needs Questionnaire – Pediatric Version (FNQ-P)



Family needs after childhood brain injury – do you know what you don't know?



Results

Reliability (4 study sites, n=65)

- **Mean total FNQ-P score** = 64.1% (SD 22.3) and 58.8% (SD 22.6) on test and retest respectively
- **Good test-retest reliability** (ICC=0.75, 95% CI 0.63-0.84)
- **Small score shift** (-5.3% points, SD 150) on retest towards more unmet needs (P=0.005)

Validity (5 study sites, n=75)

- **No association** between FNQ-P scores and:
 - Time post-injury ($r=-0.09$, $P=0.43$)
 - Child's age ($r=0.14$, $P=0.24$)
 - Injury severity score ($r<0.10$, $P=0.44$)
 - SDQ ($r=0.16$, $P=0.15$)
- **Weak inverse association** between FNQ-P and FBII ($r=-0.23$, $P=0.049$)

Conclusions

- Lack of relationship between FNQ-P score and **age, injury severity or time post-injury** suggests family needs that are **independent** of these factors.
- Lack of association with SDQ score suggests that family needs are **independent** of problems experienced by the child.
- Weak association with family burden suggest that family needs require assessment **regardless** of level of burden.
- **Good test-retest reliability**
- **Important to assess family needs directly** since needs cannot be assumed based on characteristics of the child, injury severity, or family burden
- Anticipate the FNQ-P will provide a valuable **roadmap of family needs** over the course of a child's development and recovery.

Impact on Clinical Care & Research

- Enable **systematic assessment** of family needs for service and transition planning.
- Offer **long-term monitoring** of family needs over the care continuum for program planning.
- Enable **multi-centre use** in clinical pediatric ABI research.
- FNQ-P has been downloaded from **17 countries**.
- Translated into **Swedish, Lithuanian, Norwegian and Spanish**.

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