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

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

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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 as 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)

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=0.23, 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.
- Week 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.

Acknowledgements
- Centre for Leadership in ABI
- Project team: Kathy Gavel, Sharon St. Jean, Marilyn Ballantyne, Claire Prescott, Sarah Sheffe, Lee Verweel
- Family leaders from Holland Bloorview
- Study participants across all five sites
- Study partners:

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