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Original Article

Development, Reliability, and Validity of the Alberta Perinatal Stroke Project Parental Outcome Measure

Taryn B. Bemister MSc[a,b], **Brian L. Brooks PhD**[b,c,d,e], **Adam Kirton MD, MSc**[b,d,e,f,*]

[a] *Department of Psychology, University of Calgary, Calgary, Alberta, Canada*
[b] *Alberta Children's Hospital Research Institute, University of Calgary, Calgary, Alberta, Canada*
[c] *Neurosciences (Brain Injury and Rehabilitation Programs), Alberta Children's Hospital, Calgary, Alberta, Canada*
[d] *Department of Paediatrics, University of Calgary, Calgary, Alberta, Canada*
[e] *Department of Clinical Neurosciences, University of Calgary, Calgary, Alberta, Canada*
[f] *Calgary Pediatric Stroke Program, Calgary, Alberta, Canada*

ABSTRACT

BACKGROUND: Perinatal stroke is a leading cause of cerebral palsy and lifelong disability, although parent and family outcomes have not yet been studied in this specific population. The Alberta Perinatal Stroke Project Parental Outcome Measure was developed as a 26-item questionnaire on the impact of perinatal stroke on parents and families. **METHODS:** The items were derived from expert opinion and scientific literature on issues salient to parents of children with perinatal stroke, including guilt and blame, which are not well captured in existing measures of family impact. Data were collected from 82 mothers and 28 fathers who completed the Parental Outcome Measure and related questionnaires (mean age, 39.5 years; mean child age, 7.4 years). Analyses examined the Parental Outcome Measure's internal consistency, test-retest reliability, validity, and factor structure. **RESULTS:** The Parental Outcome Measure demonstrated three unique theoretical constructs: Psychosocial Impact, Guilt, and Blame. The Parental Outcome Measure has excellent internal consistency (Cronbach $\alpha = 0.91$) and very good test-retest reliability more than 2-5 weeks ($r = 0.87$). Regarding validity, the Parental Outcome Measure is sensitive to condition severity, accounts for additional variance in parent outcomes, and strongly correlates with measures of anxiety, depression, stress, quality of life, family functioning, and parent adjustment. **CONCLUSIONS:** The Parental Outcome Measure contributes to the literature as the first brief measure of family impact designed for parents of children with perinatal stroke.

Keywords: perinatal stroke, caregivers, family impact, parent impact, APSP Parental Outcome Measure, POM, reliability, validity

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Introduction

Perinatal stroke is a common but poorly understood focal cerebrovascular brain injury occurring between 20 weeks of gestation and 28 days of postnatal life.[1] With an incidence of more than one in 2500 live births, it remains a leading cause of pediatric neurological disability and the primary cause of hemiplegic cerebral palsy. Although motor impairments are the most prevalent deficit (affecting 60% to 80%), other common outcomes include developmental delays, cognitive deficits, behavioral problems, and epilepsy.[2,3] Such morbidities last decades with potentially severe and longstanding impacts on the child and family.

Parents of children with perinatal stroke not only need to adjust to their child's diagnosis but also the additional caregiver demands that accompany raising a child with a disability. Although there are currently no published studies on the impact of raising a child with perinatal stoke, a myriad of research exists on the impact of raising a child with other neurological conditions, such as cerebral palsy,[4] epilepsy,[5] and developmental disabilities.[6] These studies indicate that parents of children with neurological diagnoses tend to have poorer psychological well-being than parents of children

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[*] Communications should be addressed to: Dr. Kirton; Section of Neurology; Alberta Children's Hospital; Room C1-320, 2888 Shaganappi Trail NW; Calgary, Alberta, Canada. T3B 6A8
E-mail address: adam.kirton@albertahealthservices.ca

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with typical development, albeit the majority of these families adapt well. Recognizing the variation that exists in parent outcomes, researchers have begun to focus on why some parents and families cope better than others.[7]

Many caregiver stress models help to explain differences in the impact of caring for a child with a disability, the most influential in the literature being the Double ABCX Model.[8] According to this model, parent adaptation is based on the balance between the pileup of stressors and the parent's capabilities for meeting those demands. Although most of the research studies in this area fail to note a conceptual framework (as highlighted by Turnbull et al.[9]), studies that assess the impact of pediatric disability on parents and families tend to measure stressors and resources that are interpersonal, emotional, and physical in nature.

Parents of children with perinatal stroke may share many of the same stressors as parents of children with other disabilities and medical conditions, which are captured in widely used questionnaires of family impact (e.g., Impact on Family Scale,[10] Child Health Questionnaire,[11] Beach Centre Family Quality of Life Scale,[12] and PedsQL Family Impact Module[13]). These questionnaires tend to measure family functioning, parent well-being (e.g., social, emotional, and physical), and resources (e.g., finances and time). However, they fail to directly assess guilt and blame, which has been noted as a salient concern among mothers of children with perinatal stroke[14] but has received limited attention in the literature thus far.

Mothers of children with perinatal stroke may be highly susceptible to feelings of guilt and blame because the approximate timing of the stroke is known, but the causes are not well understood. Some mothers consequently turn to apparent perinatal events as possible explanations, such as personal actions during pregnancy or medical staff actions approximating delivery. Unaddressed, these feelings may exacerbate caregiver burden, depression, and anxiety as evidenced by previous studies on caregiver guilt.[15-17] Feelings of guilt and blame may also adversely affect parent adaptation to their child's condition,[18,19] which consequently can have detrimental effects on the child's well-being.[20] Furthermore, our clinical experiences suggest that these feelings of guilt and blame are amendable to simple psychoeducation interventions regarding the generally unpreventable nature of perinatal stroke.

There is currently no measure of the impact of raising a child with a disability or medical condition that quantifies parent guilt and blame. The Parent Experience of Child Illness scale (PECI[21]) is a family adaptation measure that examines a related but distinct construct of "Guilt and Worry." Thus, currently available family impact measures fail to assess all of the issues salient to families affected by perinatal stroke.

The purpose of this study was to develop and validate a family impact measure designed for parents affected by perinatal stroke. The questionnaire was constructed to quantify guilt and blame, as well as assess the general impact of perinatal stroke on parents' psychological well-being, personal activities, resources, and family functioning. We predicted that the questionnaire would strongly correlate with other measures of family impact and emotional well-being (stress, depression, and anxiety), although uniquely capturing parents' sense of guilt and blame.

Methods

Participants

Parents of children with perinatal stroke were identified through the Alberta Perinatal Stroke Project (APSP), a population-based research cohort of >180 perinatal stroke patients in southern Alberta. Inclusion criteria were biological parents of children 0-18 years with clinicoradiographically confirmed perinatal stroke according to validated criteria (i.e., neonatal arterial ischemic stroke, periventricular venous infarction, or arterial presumed perinatal stroke).[22] Children with neurological conditions not attributable to stroke and parents with less than grade 9 education or unable to read English (self-report) were excluded to ensure comprehensibility of the questionnaires.

Questionnaire development

The APSP Parental Outcome Measure (POM) was developed by a multidisciplinary team with expertise in perinatal stroke. Team members included a pediatric stroke neurologist (A.K.), neuropsychologist (B.B.), doctoral clinical psychology student (T.B.), and stroke nurse (S.R.; see Acknowledgments). This team reviewed the literature on caring for children with disabilities and, combined with their clinical experiences, created a list of 34 items relevant to parents of children with perinatal stroke. The list included both resources and stressors (e.g., adequate support caring for child and financial strain).

A draft of the POM was then distributed to 10 health care professionals familiar with the target population and six parents of children with perinatal stroke. Feedback was obtained regarding the POM's item content, face validity, and wording. Recommendations included simplifying the wording (14 items), adding one item about family planning, and removing four items because of redundancy.

The resulting scale of 31 items was later revised to 26 items based on exploratory factor analysis (see Appendix for the scale). Each item is scored on a 5-point Likert scale from 0 (strongly disagree) to 4 (strongly agree) with higher scores indicating poorer functioning. The final questionnaire takes approximately 5 minutes to complete and is at a grade 7.6 reading level (Flesch-Kincaid Grade Level).

Data collection

Approval was obtained from the Conjoint Health Research Ethics Board at the University of Calgary. APSP parents previously consented to be contacted for research were approached via telephone or e-mail depending on their preference. The study was explained and informed consent was obtained. Participants were e-mailed a URL to a battery of questionnaires, including the POM, at time point 1 (closed survey design). They were able to save and alter their responses before submission. Two weeks after submission, participants were e-mailed a second URL to the POM (time point 2). Those failing to submit responses were e-mailed reminders after 2 weeks. Participants received a $10 e-Gift card in recognition of their contribution.

Questionnaires were administered between August 2012 and June 2013 with the online survey software, Qualtrics. Data were downloaded from Qualtrics and stored in a secure database at the Alberta Children's Hospital.

General measures

Demographics

The Demographics Questionnaire is a 26-item scale created for this study to assess basic demographic information.

Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS[23]) is a 14-item scale that measures self-reported symptoms of anxiety (HADS-A) and depression (HADS-D) within the past week. Comprehensive reviews have indicated that the subscales have good reliability and validity.[24,25] Although the HADS was originally developed for medical patients in hospital settings, the scale has since been validated in community populations[24] and used among populations similar to the current study.[26,27]