

The Response to Stress Questionnaire for Parents Following Neonatal Brain Injury

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Abstract

Objective The Response to Stress Questionnaire-Brain Injury (RSQ-BI) was adapted utilizing a patient-oriented approach, exploring parental stress, coping, and associated mental health outcomes in parents of children with neonatal brain injury. The contributions of social risk, child adaptive functioning, and brain injury severity were also explored. **Methods** Using a mixed-method design, this study explored adapted stressor items on the RSQ-BI. Parents and clinicians engaged in semistructured interviews to examine key stressors specific to being a parent of a child with neonatal brain injury. The adapted RSQ-BI was piloted in a parent sample ($N=77$, child mean age 1 year 7 months) with established questionnaires of social risk, child adaptive functioning, severity of the child's injury, coping style, and parent mental health. Descriptive statistics and correlations examined parent stress, coping, and their association with parent mental health. **Results** The final RSQ-BI questionnaire included 15 stressors. Factor analysis showed stressors loaded onto two factors related to (a) daily role stressors and (b) brain injury stressors. Using the RSQ-BI, parents reported brain injury stressors as more stressful than daily role stressors. When faced with these stressors, parents were most likely to engage in acceptance-based coping strategies and demonstrated lower symptoms of parent depression and anxiety. **Conclusions** The RSQ-BI provides a valuable adaptation to understand both stressors and coping specific to being a parent of a child with neonatal brain injury. Relevant interventions that promote similar coping techniques are discussed for future care and research.

Key words: coping; mental health; neonatal brain injury; parenting; stress.

Introduction

Neonatal brain injury affects a significant minority of infants with two of the largest mechanisms including hypoxic-ischemic encephalopathy (HIE) and neonatal stroke, affecting ~0.1–0.8% (Kurinczuk et al., 2010)

and 0.025% (Lynch & Han, 2005) live births, respectively. Past studies have predominantly focused on the cognitive and psychosocial outcomes following neonatal brain injury (e.g., Westmacott et al., 2009, 2010; Williams et al., 2017a, b). However, there is

increasing attention to the emotional experience and distress among families of children with neonatal brain injury and the impact this has on child outcomes (e.g., Bemister et al., 2014; Williams et al., 2018). It is essential to identify how to best support parents of children with neonatal brain injury given the heterogeneity of the diagnosis with respect to prognosis and long-term outcomes. That is, a one-size-fits-all approach to intervention might not be appropriate for this population. Further, it remains unclear what specific stressors are most salient for these families following the acute period and, equally as important, how parents cope with these stressors (Compas et al., 2012). The Response to Stress Questionnaire (RSQ; Compas et al., 1997) takes a unified approach in evaluating stress and coping and has been successfully adapted for the needs of other pediatric populations (e.g., cancer, epilepsy) that may serve as a useful tool in collectively targeting these processes in parents of children with neonatal brain injury. This study had two objectives: (a) adapt the RSQ with/for parents of children with neonatal brain injury and examine the acceptability of the measure, and (b) explore the measure's utility through investigating associations among parental stress, coping, and mental health outcomes.

Contrasting several other chronic illnesses and disabilities, neonatal brain injury is a unique condition where children's outcomes are challenging to predict (Racine et al., 2017; Westmacott et al., 2009). Some children demonstrate remarkable resilience while others show greater challenges than expected (Williams et al., 2019). Parents often report that they are "confused" about their child's prognosis and appropriate treatment directions given the ambiguity of their child's long-term outcomes (Williams et al., 2018). As a result, parents often demonstrate elevated mental health concerns on top of the everyday challenges they face with their child (Bemister et al., 2014). It is critical to develop and/or adapt assessment tools for clinical and research purposes that are specific to this population in order to provide optimal care for families. Specifically, to our knowledge, there are no measures exploring stress and coping specific to being a parent of a child with neonatal brain injury. The RSQ has yet to be adapted for use with this population, despite its relevance for intervention development and the relationship between parent mental health and positive development in children with other chronic health and developmental conditions (e.g., Rodriguez et al., 2016). Bemister et al. (2014) introduced the Parental Outcome Measure, focusing on the psychosocial impact, guilt, and self-blame associated with raising a child with perinatal stroke. Another more recent measure, the Parent Experiences Questionnaire (PEQ), explores service delivery and clinical care in parents of children with neonatal brain

injury (Williams et al., 2018). Although these measures describe several important perspectives and needs of parents of children with neonatal brain injury, they do not capture the specific relationship between parental stress and coping. Understanding impactful stressors and the coping skills that are most effective among parents of young children following neonatal brain injury may contribute to more specific and successful intervention programming.

Most measures evaluating stress and coping collectively are not necessarily derived from relevant theory and models, failing to adequately capture the diversity of responses to stressors and the specificity of stressors targeted in coping (Connor-Smith et al., 2000). The RSQ was developed to consider the relationship between targeted stressors and coping strategies among parents and children with many different chronic medical and mental health care needs (Compas et al., 1997). There are several sources of potential stressors for parents following their child's neonatal brain injury that are similar to stressors observed in other chronic health care conditions such as: the child having multiple doctor or medical appointments, worrying about the long-term effects of the child's diagnosis, and concerns over future injuries or illnesses. Additionally, general stress inherent to the parenting daily role may be equally impactful, as well as stressors related to understanding and communicating the effects of the child's diagnosis. There may also be stressors unique to raising a child following neonatal brain injury, such as concerns about the child's development in school and in social situations, worries that the child will have another brain injury, and communicating with others about neonatal brain injury. Considering the impact of specific domains of stress in parents of children with neonatal brain injury through factor analysis could provide unique insight into the categories of stressors that are most detrimental to parent mental health.

One of the strengths of the original RSQ measure is the simultaneous consideration of both current stress and endorsed coping strategies. Compas et al. (2001) define coping as purposeful efforts to control properties of the self and external surroundings during stressful situations. Three types of control and coping styles are described: primary control engagement coping (e.g., problem solving), secondary control engagement coping (e.g., acceptance), and disengagement coping (e.g., avoidance; Compas et al., 2015). The RSQ has been used to explore parental coping in other pediatric medical illnesses including parents of children with cancer and diabetes (Compas et al., 2015; Jaser et al., 2014). Across these studies, problem solving (primary) and acceptance (secondary) coping strategies were associated with the most positive psychological outcomes for parents, children, and for overall family

functioning. In contrast, disengagement coping or avoiding reminders of the problem and wishing the problem would go away, was largely observed to have a negative relationship with parent mental health (Compas et al., 2015; Jaser et al., 2014). Although specific coping strategies have not been explicitly explored among parents of children with neonatal brain injury, qualitatively Williams et al. (2018) outlined that following their infant's diagnosis of neonatal brain injury, some parents experience difficulties coping and as a result they may feel "left in the dark" as to how they should be supporting their child with complex needs. However, some engage in adaptive coping strategies, despite their stress, in order to support their own and their child's mental health, such as working collaboratively with multidisciplinary teams, engaging in early interventions for their child, and seeking psychosocial supports for themselves (Williams et al., 2019).

It is also important to consider how parent stress and coping may be influenced by other important factors such as the severity of the child's brain injury and the child's developmental stage. In prior work, parents of children with severe neonatal brain injury and greater physical, cognitive, and academic challenges reported more distress than parents of children with less severe injury (Bemister et al., 2014). The child's age can also moderate the relationship between parenting stress and parent perceptions of child vulnerability, with increased parental concern among older children in some neurological populations (e.g., Driscoll et al., 2018). Social risk and environmental factors including parental education and household income are also known factors impacting parent stress, coping, and mental health following a child's early brain injury (e.g., Bemister et al., 2014).

Following a patient-oriented approach, this study employed a mixed-method design to address two objectives. In objective 1, we aimed to adapt the RSQ-BI specific to the experience of parents of infants with neonatal brain injury. In objective 2, we sought to consider the adapted tool's utility and association with parental coping and parent and child mental health. For this objective, it was hypothesized that parent and child factors including older child age, higher severity of injury, and lower child adaptive functioning would be associated with higher parent stress levels and more difficulties engaging in adaptive coping strategies (Bemister et al., 2014; Westmacott et al., 2009). It was also hypothesized that parents who engaged in problem solving (primary) and or acceptance (secondary) coping strategies, would endorse lower symptoms of depression and anxiety than those who engage in avoidant (disengagement) coping, and that disengagement coping would be related to higher mental health symptomatology (Compas et al., 2015).

Materials and Methods

This study utilized a mixed-method research design engaging in both qualitative and quantitative methods. Semistructured interviews were conducted followed by online participant involvement to pilot the RSQ-BI for parents of children with neonatal brain injury. Following Williams et al. (2018), the current investigation utilized an iterative process consisting of: (a) content selection through semistructured interviews, (b) interview response analysis, and (c) process analysis including piloting and exploring the measure's associations with current parent mental health and child development measures. Ethical approval was provided by the authors' institutional research ethics board.

Participants

An initial participant advisory group of 12 parents ($N=6$) and clinician participants ($N=6$) were recruited to be part of semistructured interviews to assist in adapting the RSQ stressor items through discussing their experiences and relevance of preliminary stressors items from the RSQ. All parents were raising children with neonatal brain injury. Participants in the initial group were predominantly mothers (5/6), employed full-time (5/6, 1 preferred not to say), and all reported a high school education or greater. Ages of their children ranged from 6 months to 7 years. Clinician participants were recruited through hospital rounds, email announcements, and neurology meetings. All clinician participants had over than 10 years expertise working in neonatal brain injury and associated conditions. Clinicians' professional expertise included: neurology (1), psychology (2), nursing (2), and social work (1). Clinicians did not have direct clinical relationships with participants in the advisory group.

Following this, a large group of parent participants were recruited to participate in a broader study piloting the adapted measure (RSQ-BI) in addition to established measures of parent and child mental health and adaptive functioning (Table I). All families were approached during clinic visits about their interest in study participation and were currently being followed in the hospital's neonatal neurology follow up clinic. Inclusion criteria for this group included: (a) raising a child diagnosed with a neonatal stroke or HIE, (b) child between the ages of 3 months and 4 years at the time of participation. Exclusion criteria were (a) child's age at injury outside of the neonatal period (i.e., >28 days of age), (b) <35 weeks postmenstrual age at birth, (c) inability to complete questionnaires/interviews in English at an approximately grade 5 literacy level (self-disclosed by parents), (d) comorbid genetic and/or metabolic disorder related to a significant neurocognitive disability beyond that attributed to brain injury alone (i.e., Trisomy, PKU etc.), or (e) major anomalies of the

Table I. Family Demographics and Child Neurological Clinical Characteristics.

	Total (N = 77)	Stroke (N = 28)	HIE (N = 49)
Parent who completed the form ^a			
Mother	63 (82%)	24 (86%)	39 (80%)
Father	8 (10%)	3 (11%)	5 (10%)
Mother and father together	6 (8%)	1 (3%)	5 (10%)
Parent current age M (SD)			
Mother	32 years 5 months (5 years 3 months)	32 years 3 months (4 years 2 months)	32 years 7 months (5 years 9 months)
Father	34 years 7 months (5 years 9 months)	34 years 8 months (5 years 4 months)	34 years 6 months (6 years 3 months)
Total social risk score			
Low risk (%)	36 (47%)	16 (58%)	20 (41%)
Medium risk (%)	18 (23%)	6 (21%)	12 (24%)
High risk (%)	23 (30%)	6 (21%)	17 (35%)
Mother's age > 21 years at childbirth	75 (97%)	28 (100%)	47 (96%)
Parent education ^b			
>High school diploma	58 (77%)	22 (79%)	36 (76%)
Full-time employment status ^b	72 (94%)	25 (89%)	47 (96%)
"Skilled" occupation	41 (53%)	19 (68%)	22 (45%)
Married family structure	61 (79%)	22 (79%)	39 (80%)
English as primary language	68 (88%)	25 (89%)	43 (88%)
Age of child M (SD)	1 year 7 months (1 year 3 months)	2 year 2 months (1 year 2 months)	1 year 5 months (1 year 3 months)
Gender—males	49 (64%)	21 (75%)	28 (57%)
Gestational age at birth in weeks M (SD)	39 (1.6)	39 (1.4)	39 (1.7)
Birthweight in g M (SD)	3,322 (643)	3,421 (589)	3,268 (670)
Current seizures	3 (4%)	3 (11%)	0 (0%)
SIB-ED; adaptive functioning M (SD)	107 (26)	101 (32)	110 (22)
Severity of injury ^c			
Low (%)	46 (60%)	12 (43%)	34 (69%)
High (%)	31 (40%)	16 (57%)	15 (31%)

^aAll parents were biological parents. ^bEducation and employment status were based on primary income earner. ^cPattern of injury was coded dichotomously for both groups according to patterns of injury with highest risk of early negative outcomes. For hypoxic-ischemic encephalopathy, this included children with injuries to basal ganglia/thalamus or total pattern of injury. For neonatal stroke, this included combined cortical and subcortical lesions and/or stroke lesions categorized to be large.

brain (e.g., lissencephaly). Of the potential parents eligible, 113 were invited to participate in the study. Seventeen declined interest and of the 96 who consented to participation, 77 completed the questionnaire of interest (RSQ-BI) and were included in the final sample. See Table I for parent and child demographics, and children's neurological clinical characteristics by condition type (e.g., seizures and severity of injury). All children were living with at least one biological parent. There were no differences in diagnosis, age, or gender of the child between RSQ-BI completers or noncompleters ($p > .50$ for all analyses).

Procedures

For objective 1, a semistructured interview script (Drennan, 2003) was developed in line with Williams et al. (2018) that asked participants to comment on the original 12 RSQ stressor items (e.g., comprehension, modifications, and redundancy). All interviews were conducted individually with each of the participants by the senior author (T.W.). Interviews were recorded and transcribed verbatim.

For objective 2, clinic nurses prescreened families from the larger group of participants for eligibility and parents/legal guardians of patients that met inclusion criteria were then provided with information about the study during their clinic visit. If they expressed interest, a research assistant met with the family and obtained consent. Each consenting participant was provided with three online questionnaires in addition to the questionnaire of interest (RSQ-BI) through an electronic link using the REDCap system (research electronic data capture; Harris et al., 2009). Participants were compensated with a \$10 gift certificate.

Measures

Demographics and Social Risk

A background survey collected basic parent and child demographic information. From this data, a total social risk score was computed based on prior work (Roberts et al., 2008) to reflect six aspects of social status coded as: family structure (0—two caregivers (nuclear); 1—separated parents with dual custody, or cared for by other intact family; 2—single caregiver),

Table II. Response to Stress Questionnaire–Brain Injury Factor Loading after Rotation

Item	Factor 1: daily role	Factor 2: brain injury
Concerns about my own quality of life	.88	–.05
Concerns about my job or my spouse's job	.86	–.11
Paying bills and family expenses	.84	–.07
Taking time off work for child care and appointments	.78	.01
Having less time and energy for my other children	.69	.22
Having multiple doctor appointments	.61	.09
Thinking about my child's future independence	.59	.37
Needing to rely on support from family and friends	.49	.23
Concerns about my child having trouble learning in school	–.10	.90
Concerns about my child in social situations	–.02	.88
Long-term side effects of the brain injury	.07	.74
Concerns about another brain injury	.01	.65
Understanding information about brain injury	.35	.46
Talking to my other children and family about brain injury	.42	.45
Talking with my child about his/her brain injury	.23	.43
Eigenvalues	8.37	1.37
Cumulative % of variance	55.8%	9.16%
Cronbach's α	.92	.89

Note. Factor loadings noted in bold indicate which factor the item was retained to in the RSQ (i.e., daily role factor or the brain-injury factor).

education of primary caregiver (0—tertiary educated; 1–11–12 years of formal schooling; 2—<11 years of formal schooling), occupation of primary income earner (0—skilled/professional; 1—semiskilled; 2—unskilled), employment status of primary income earner (0—full-time employment; 1—part-time employment; 2—unemployed/pension), language spoken at home (0—English only; 1—some English; 2—no English) and maternal age at birth (0—>21 years; 1—18–21 years; 2—18 years). Families were then categorized as low social risk (0), medium social risk (1), or high social risk (2+) for descriptive purposes and low social risk (score of 0 or 1) or high social risk (score of 2+) for analyses.

Questionnaire of Interest

RSQ-BI Condition-Specific Stressors

Parental stress was measured using the adapted version of the RSQ (Connor-Smith et al., 2000): the RSQ-BI. Respondents were asked to report on recent encounters with 15 specific stressors related to being a parent of a child under 18 years with an early brain injury and the degree to which these events were stressful (e.g., long-term side effects of the brain injury, understanding information about brain injury, talking to my other children and family about brain injury, etc.). Consistent with prior RSQ versions, responses range from 1 (not at all) to 4 (very stressful) and total parental stress raw scores range from 15 to 60; mean scores were generated for each stressor domain (see Rodriguez et al., 2012), with higher means indicating higher stress. For descriptive purposes, items were examined continuously as well as dichotomized (<2 = a little to no stress and >2 somewhat to very stressful).

See Table II for the RSI-BI's psychometric properties and specific items.

Note. Factor loadings noted in bold indicate which factor the item was retained to in the RSQ (i.e., daily role factor or the brain-injury factor).

RSQ Coping Strategies

Parental coping strategies were measured using the validated items from the standard version of the RSQ. This part of the questionnaire includes 57 items that ask parents to indicate on a 4-point scale their level of engagement in certain coping strategies in relation to the outlined stressors endorsed. Responses range from 1 (not at all) to 4 (a lot). Following previous studies, three specific coping strategies (i.e., factors) were identified: problem solving (i.e., primary control engagement), acceptance (i.e., secondary control engagement), and avoidance (i.e., disengagement; Compas et al., 2006, 2015; Connor-Smith et al., 2000). Proportion scores out of the total for each of the three coping strategies were calculated following Compas et al. (2001), such that higher scores reflected greater engagement with each coping strategy. Cronbach's alpha reliability coefficient for the present sample is strong (.93).

Parent Mental Health

The Depression and Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) was used as a self-report measure of parental depression and anxiety symptoms. There are 42 items divided into three scales (depression, anxiety, and stress) each containing 14 items. The items are rated 0 (never) to 3 (almost always) yielding a total raw score ranging from 0 to 42

per scale. High scores indicate more severe symptoms of depression or anxiety. In addition, the DASS correlates well with similar validated mental health screeners ($r = .76$, Dahm et al., 2013). A Cronbach's alpha of .98 indicates acceptable reliability of the DASS in the present sample.

Child Adaptive Functioning

The Scales of Independent Behavior-Revised Early Developmental Form (SIB-ED) was used to measure parent evaluation of adaptive functioning of each child (Bruininks et al., 1984). There are 40 items with ratings of 0 (never does) to 3 (does very well) yielding a total score ranging from 0 to 120. Raw scores are converted into age-standardized scores ($M = 100$, $SD = 15$) with high scores indicating greater developmental achievement or adaptive functioning. Internal consistency and test-retest reliabilities of the Early Developmental Form are reported to be high (.98 and $>.97$, respectively, Bruininks et al., 1996). Cronbach's alpha is similarly acceptable for the present sample (.97).

Severity of Injury

Information about the child's brain injury was obtained using neonatal clinical MRIs and corresponding neuroradiology reports. Pattern of HIE injury was confirmed by the study's neonatal neurologist (E.W.Y.T.) using standard ratings of typical patterns of HIE (Barkovich et al., 1998). For HIE, this included children with injuries to basal ganglia/thalamus or total pattern of injury. For neonatal stroke, this included combined cortical and subcortical lesions and/or stroke lesions categorized to be large (involving at least 2/3 of the volume of a single lobe or major subcortical structure or involving at least 1/2 of the volume of two or more lobes/subcortical structures; Westmacott et al., 2009). Stroke lesions and pattern of injury was coded dichotomously for both groups according to patterns of injury with highest risk of early negative outcomes based on prior research (Barkovich et al., 1998; Westmacott et al., 2010). For HIE, this included children with injuries to basal ganglia/thalamus or a more diffuse pattern of injury. For neonatal stroke, this included combined cortical and subcortical lesions and/or stroke lesions categorized as large.

Statistical Analyses

Objective 1

Qualitative data collected through interviews with parents, were analyzed through content analyses (Braun & Clarke, 2006; Wu et al., 2016). Specifically, in line with Williams et al. (2018), transcripts were analyzed using both deductive and inductive approaches, which involved a theoretical lens armed to identify

participants' thoughts and ideas related to the RSQ questionnaire. Specifically, this process involved an interview response analysis, which included an examination of: main topics regarding item comprehension, format, item importance and acceptability, and suggestions or modifications of stressors. Two individuals coded the transcripts independently [i.e., a psychology researcher (PhD) and a psychology research coordinator (MA)]. The data were analyzed through familiarization with interviews, followed by generating initial codes, collapsing topics, reviewing overarching suggestions and content, and eventually reporting overall patterns in the data. Following this process, revisions to the questionnaire were suggested iteratively by group consensus. Discrepancies in coding were discussed and resolved with the senior author of the broader study.

An exploratory principal axis factor analysis was conducted on responses to the final items among the larger sample ($N = 77$) with oblique rotation (direct oblimin). The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis and the initial analysis was run to obtain eigenvalues for each factor in the data. Exploration of the communalities identified that the majority of values (11/15) were ≥ 0.6 , suggesting an adequate proportion of variance from each variable can be explained by the factors loading. In addition, the KMO and communalities analysis, previous research has suggested that a minimum sample of 50 is reasonable for exploratory factor analysis (de Winter, et al., 2009). Factor loadings were then examined to assess whether it would be appropriate to differentiate stressors across domains. Correlational analyses between the RSQ-BI and the DASS were examined to evaluate construct validity.

Objective 2

Descriptive statistics were used to examine prevalence of RSQ-BI stressors and coping strategies. Total parent stress and coping scores were also compared by parent and child factors (social risk, child's condition, current age, adaptive functioning, and severity of injury) using relevant correlational and univariate analyses between group statistics. To analyze the relationship between parent stress, coping and parental mental health, Pearson and point-biserial correlations were used to explore associations between parental stress, coping (primary, secondary, and disengagement) and parent mental health. G*Power 3.1 software determined a priori that a sample size of 73 is adequate to detect a medium effect size, a power level of .90, and an alpha level of .05 (Cohen, 1992). In order to account for multiple comparisons, p values were adjusted using the false discovery rate criteria (Benjamini & Hochberg, 1995). Data analyses were conducted using Statistical Package for the Social

Sciences version 25 (IBM SPSS Statistics for Windows, Version 25. Armonk, NY: IBM Corp, USA).

Results

Objective 1

The original 12 RSQ stressor items were reviewed by parents and clinicians. Parents and clinicians reinforced the chosen stressors through positive feedback. All participants indicated that the 12 items were relevant, straightforward and did not recommend dropping any items. One parent (P02) described the stressors as “everything need(ed) to be asked. . .to understand what a parent with a child with brain injury goes through.” Another shared that although some items may not be currently relevant to them, they would be in the future so suggested having a “not applicable option” which was added. Similarly, another parent (P03) commented on relevancy of the item pertaining to talking to your child about brain injury, commenting how it represented “perceived trouble that might be down the road” and sharing how this item was still relevant regardless of the child’s age. Suggestions regarding wording of the original RSQ stressor concerning “paying medical bills” was pointed out as inconsistent with the country’s universal, publicly funded health care system and was reworded accordingly. Although, this item was modified to be more inclusive to the current sample (*paying bills and family expenses*), it is important to note that users from other countries may wish to include paying medical bills under the umbrella of this item and consider how results might differ depending on their own health care system. The original RSQ item regarding concerns about school was edited to reflect academic and social concerns separately, stressors that both parents and clinicians agreed were important to differentiate. Based on suggestions from parents and clinicians, three additional stressors were added regarding thinking about their child’s independence, concerns about child in social situations, and taking time off from work for child care appointments. Finally, a clinician (C04) suggested starting with a different item than “long-term side effects of their child’s brain injury,” reflecting how “this first question is like really big, it doesn’t ease into it” and recommended “something simple like, my child having multiple doctors’ appointments.”

An exploratory principal axis factor analysis was conducted on the final items and the Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO = .88 (considered “meritorious” according to Field, 2013). All KMO values for individual items were well above the acceptable limit of .5, scores ranged from .78 to .96 (Field, 2013). The initial analysis was run to obtain eigenvalues for each factor

in the data. Two factors had eigenvalues over the Kaiser’s criterion of 1, a one-factor model and a two-factor model. The two-factor model had an eigenvalue of 1.37 and in combination explained 65% of the variance. The scree plot was ambiguous and showed inflexions that justified retaining either a single or two-factor model. Based on the eigenvalues, scree plot, previous models of stress (see Rodriguez et al., 2012; Streisand et al., 2001) and expertise, we retained a two-factor model. Table II shows the factor loadings after rotation. The items that cluster on the same factors suggest that factor one represents daily role stressors and factor two represents stressors specifically related to raising a child with a neonatal brain injury. There were six items that loaded fully on the daily role factor and four items that loaded fully on the brain-injury factor. There were five items that loaded across factors. These variables were retained to either the daily role factor or the brain-injury factor based on the described factors (i.e., size, expertise, prior work, and theoretical rational; Rodriguez et al., 2012; Streisand et al., 2001). The RSQ-BI total stress score was highly correlated with the DASS total stress score ($r = .5, p < .001$).

Objective 2

Parent Stress

Means and SDs of final RSQ-BI stressor scores by domain and overall totals are presented in a supplementary appendix table (see [Supplementary Appendix Table SA1](#)). There were no significant differences in parents’ ratings of total stress or each stressor domain (daily role and brain-injury related) based on the child’s condition (HIE vs. stroke). Groups were collapsed across condition for remaining analyses. A dependent *t*-test indicated that there was a significant main effect of stressor domain, $t(76) = -4.45, p < .01, r = .45$; caring for a child with a neonatal brain injury was rated as significantly more stressful than daily role stressors.

Child’s current age and adaptive functioning (SIB-ED) were unrelated to parent total stress, $r(77) = -.05, p = .66$ and $r(72) = -.20, p = .09$, respectively. When examined specifically by stressor domain, child’s current age remained unrelated; however, lower SIB-ED score was related to more concerns in terms of daily role stressors [$r(72) = -.24, p = .04$] but was not associated with brain-injury stressors. Overall, parents of a child with severe brain injury ($M = 2.33, SD = 0.81$) reported higher total stress compared with parents of a child with a less severe injury ($M = 1.91, SD = 0.85$), $t(75) = 2.13, p = .04, r = .24$. Social risk was not associated with parents’ total stress scores.

Table III. Correlations between Predictors, Stressors by Domain, and Coping Strategies

	Total stress	Daily role stress	Brain injury stress	Primary coping	Secondary coping	Disengagement coping	Depression	Anxiety
Total stress								
Child's age	-.05	.95**	.92**	-.34**	-.46**	.30**	.51**	.41**
Injury severity	.24*	-.08	-.02	-.08	.04	-.07	-.02	-.10
SIB-ED; adaptive functioning	-.20	.24*	.20	-.10	-.03	.09	.05	-.02
Depression	.51**	-.24*	.13	.05	.19	.01	-.23	.002
Anxiety	.41**	.55**	.39**	-.39**	-.56**	.28*		
		.45**	.30**	-.32**	-.44**	.17		

* $p < .05$ and ** $p < .01$.

Parent Coping

A repeated measures analysis of variance (ANOVA) indicated a significant main effect of coping strategy, $F(2, 75) = 104.44, p < .01, \eta_p^2 = .74$. Parents were more likely to engage in secondary coping strategies ($M = 0.27, SD = 0.07$) compared with primary ($M = 0.19, SD = 0.05$) and disengagement ($M = 0.14, SD = 0.03$) strategies, $t(76) = -11.66, p < .01, r = .80$ and $t(76) = 13.91, p < .01, r = .85$, respectively. Primary coping strategies were engaged in more often than disengagement coping, $t(76) = 6.25, p < .01, r = .58$. Coping strategies did not differ by child's condition, child's current age, adaptive functioning, severity of injury, or social risk score.

Parent Stress, Coping, and Mental Health

As shown in Table III, parents' total stress score was negatively associated with primary and secondary coping strategies with greater engagement in these strategies associated with lower total stress scores. Disengagement strategies were associated with higher stress. Engagement in both primary and secondary coping strategies was associated with lower ratings of depression and anxiety on the DASS. Conversely, the use of disengagement coping was associated with higher depression ratings, but was not associated with anxiety. In terms of potential covariates, child's current age was unrelated to coping strategies or parent mental health symptoms. Severity of injury was unrelated to coping strategies or mental health symptoms, but was related to total stress score and daily role stressors. Lower child adaptive functioning (SIB-ED) was associated with higher parental depression ratings at $p = .05 [r(72) = -.23, p = .052]$.

Discussion

This study describes the adaptation of the RSQ to understand stressors specific to being a parent of a child with a neonatal brain injury. Both parents and clinicians endorsed high acceptability and relevance of existing RSQ items and added some additional items to differentiate stress regarding social and academic experiences for their child. Consistent with prior research (Rodriguez et al., 2012), stressors divided into factors regarding daily role and brain-injury-specific stress. The adapted measure showed that for parents of children with neonatal brain injury, stress was highest for aspects regarding care specific to the child's injury and acceptance base coping strategies supported positive parent mental health with these issues.

Salient brain-injury-related stressors included thinking about long-term side effects of the condition, concerns about learning in school and thinking about the child's future independence, with no significant differences between brain-injury etiology (i.e., stroke

and HIE). Daily role stressors were reported as comparatively less stressful. This is consistent with findings among families facing other significant pediatric medical conditions (Rodriguez et al., 2012). For example, stressors related to caring for the child's diagnosis are rated as most stressful among mothers and fathers of children with cancer. Heightened stressors surrounding the child's neonatal brain injury are not surprising given the difficulties parents face in initially processing the diagnosis of their infant's brain injury. They may also be particularly salient given difficulties are not immediately noticeable during infancy but parents are prepared that their child may grow into challenges. Despite these findings, it is important to highlight that the parents in our study had mild-to-moderate reports of stress overall compared with higher stress documented in other parent health populations including parents of children with cancer or diabetes (Jaser et al., 2014; Rodriguez et al., 2012). The differences in stress levels among chronic health populations might be related to differences in parents' perceived control regarding their child's outcome and prognosis ambiguity.

When faced with stressors, parents in the present study were most likely to engage in secondary coping, regardless of the type of stressor. This included using adaptive strategies such as: acceptance, positive thinking, and cognitive restructuring. Acceptance style coping among parents of children with a neonatal brain injury may be related to the perceived static (and potentially uncontrollable) nature of the child's neonatal brain injury. For instance, children in this population often do not require active medical treatment post-NICU discharge and there are limited intervention options outside of early physical, occupational, and speech therapies.

As anticipated, parents of children with a more severe brain injury reported higher general stress levels compared with parents with children with more mild conditions. Our findings extend this past work in perinatal stroke to parents of children with HIE and show parallel parent stressors and coping strategies. Parents may perceive stressors similarly following neonatal injury despite etiology, suggesting benefit in potential transdiagnostic approaches to consider in directing supportive psychosocial therapies for parents of children within these populations, as well as possibly other neonatal conditions who share similar outcomes.

As hypothesized, parental stress was associated with coping, as well as parent mental health outcomes. Highly consistent with prior studies in other chronic pediatric conditions, parents who reported engaging in either primary or secondary coping strategies reported lower total stress. In contrast, disengagement strategies were related to higher stress (Compas et al.,

2015; Jaser et al., 2014). Engagement in secondary coping strategies was associated with lower symptoms of depression and anxiety among parents. Many of the described coping tactics including acceptance, adaptation, and cognitive restructuring are utilized in third-wave cognitive behavioral therapies, such as Acceptance and Commitment Therapy (ACT; Hayes et al., 2006). ACT combined with other more traditional parent behavior management programs (i.e., Stepping Stones Triple P) appear successful in parents of children with acquired brain injury (Brown et al., 2015). Other programs that provide psychoeducation regarding the impact of raising a child with a brain injury may also be relevant to consider in this population (e.g., Narad et al., 2017; Wade et al., 2017).

Overall, considering both daily role and brain-injury-specific stressors in promoting positive parent and family adjustment directs emphases for psychosocial treatments. An important limitation of this study is that the children were very young, which may have contributed to potentially lower parent stress reported and different coping strategies used. Parent stress fluctuates over time with the child's development and the child's ability (Driscoll et al., 2018), as well as potential increased neuropsychological challenges (Westmacott et al., 2010). Fortunately, we did include parents of older children in the initial development of the RSQ-BI with the hope to expand the utility of this measure for parents of children across various stages of development. It would be insightful to follow families longitudinally to consider how early stress and coping predicts later family functioning as well as the child's outcome itself. Relatedly, it would also be interesting to include a measure of children's broader neuropsychological functioning to address any other potential factors contributing to parent stress. We also focused exclusively on only one parent's report and did not include consideration of the child's outcome from the perspective of other caregivers, teachers, clinicians, or through standardized outcome assessment. Finally, we did not assess whether parents were involved in ongoing mental health services, which likely influences their overall mental health outcomes.

Nonetheless, these findings are the first to describe an adapted measure that evaluates targeted stress and coping in parents of children with neonatal brain injury, including the specific stressors encountered, coping strategies utilized, and their impact on parent mental health. Findings underscore the importance of considering both daily role and brain-injury-specific stressors in programing, as well as the benefit of promoting primary and secondary coping strategies to improve psychological symptoms. To date, the RSQ has successfully informed the development of several intervention programs such as a modified primary and secondary control coping skills program to reduce mental

health symptoms in adolescents with inflammatory bowel disease (Szigethy et al., 2007). Given the diverse presentation of challenges inherent to having a child with early medical difficulties, a control-based model of coping, using the RSQ-BI could allow researchers to be precise about the types of stress that are related to coping in parents of a child with neonatal brain injury. Overall, it is essential to recognize different stressors and coping strategies among many parents of children with neonatal brain injury, which the RSQ-BI now provides, to guide future psychological care and support.

Supplementary Data

Supplementary data can be found at: <https://academic.oup.com/jpepsy>.

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