Family Burden After Out-of-Hospital Cardiac Arrest in Children

Kathleen L. Meert, MD[1,2]; Beth S. Slomine, PhD[3,4]; James R. Christensen, MD[4,5];
Russell Telford, MAS[6]; Richard Holubkov, PhD[6]; J. Michael Dean, MD[6]; Frank W. Moler, MD[7];
for the Therapeutic Hypothermia after Pediatric Cardiac Arrest Trial Investigators

[1]Children's Hospital of Michigan, Detroit, MI.

[2]Department of Pediatrics, Wayne State University, Detroit, MI.

[3]Department of Neuropsychology, Kennedy Krieger Institute, Baltimore, MD.

[4]Department of Pediatric Rehabilitation, Kennedy Krieger Institute, Baltimore, MD.

[5]Johns Hopkins University, Baltimore, MD.

[6]Department of Pediatrics, University of Utah, Salt Lake City, UT.

[7]Department of Pediatrics and Communicable Diseases, University of Michigan, Ann Arbor, MI.

Objectives: To describe family burden among caregivers of children who survived out-of-hospital cardiac arrest and who were at high risk for neurologic disability and examine relationships between family burden, child functioning, and other factors during the first year post arrest.

Design: Secondary analysis of data from the Therapeutic Hypothermia after Pediatric Cardiac Arrest Out-of-Hospital trial.

Setting: Thirty-six PICUs in the United States and Canada.

Patients: Seventy-seven children recruited to the Therapeutic Hypothermia after Pediatric Cardiac Arrest Out-of-Hospital trial who had normal prearrest neurologic functioning and were alive 1 year post arrest.

Interventions: Family burden was assessed using the Infant Toddler Quality of Life Questionnaire for children less than 5 years old and the Child Health Questionnaire for children 5 years old or older at baseline (reflecting prearrest status), 3 months, and 12 months post arrest. Child functioning was assessed using the Vineland Adaptive Behavior Scale II, the Pediatric Overall Performance Category, and Pediatric Cerebral Performance Category scales and caregiver perception of global functioning.

Measurements and Main Results: Fifty-six children (72.7%) were boys, 48 (62.3%) were whites, and 50 (64.9%) were less than 5 years old prior to out-of-hospital cardiac arrest. Family burden at baseline was not significantly different from reference values. Family burden was increased at 3 and 12 months post arrest compared with reference values ($p < 0.001$). Worse Pediatric Overall Performance Category and Pediatric Cerebral Performance Category, lower adaptive behavior, lower global functioning, and higher family burden all measured 3 months post arrest were associated with higher family burden 12 months post arrest ($p < 0.05$). Sociodemographics and prearrest child functioning were not associated with family burden 12 months post arrest.

Conclusions: Families of children who survive out-of-hospital cardiac arrest and have high risk for neurologic disability often experience substantial burden during the first year post arrest. The extent of child dysfunction 3 months post arrest is associated with family burden at 12 months. (*Pediatr Crit Care Med* 2016; 17:498–507)

Key Words: adaptive behavior; caregiver burden; family; parent; pediatric; resuscitation

Out-of-hospital cardiac arrest (OH-CA) in children often results in death or poor quality neurologic survival (1–3). Only about 10% of children experiencing OH-CA survive to hospital discharge. Among survivors, global ischemia during cardiac arrest often results in serious cognitive and physical impairments (4, 5). Most children surviving OH-CA are discharged home to be cared for by their families. Caregiver burden is important to consider for these families because it can reduce caregiver health, which can further impair the health of the disabled child.

Theoretical models have been proposed to describe relationships between caregiving and caregiver health. Raina et al (6) developed a model of caregiving for parents of disabled children. Constructs proposed in the model to affect caregiver health include the severity of the child's disability; social and economic characteristics of the family; and parental caregiving demands, intrapsychic factors, coping strategies, and social supports. Empirical data exist supporting various components of the model. For example, health problems have been shown to be common among caregivers of disabled children, including sleep disorders, depression, substance abuse, and self-reported decrements in physical health (7). In addition, the severity of the child's disability has been shown to be a predictor of family burden for conditions, such as traumatic brain injury (8). Other factors, such as reduced social support, higher financial burden, higher help needs in the household, and poor family coping, have been shown to contribute to health risks for caregivers (7, 9).

The Therapeutic Hypothermia after Pediatric Cardiac Arrest Out-of-Hospital (THAPCA-OH) trial was a randomized controlled trial comparing the efficacy of therapeutic hypothermia with that of therapeutic normothermia on survival with good neurobehavioral outcome in children 1 year after OH-CA (ClinicalTrials.gov, NCT00878644) (10). All children recruited to the THAPCA-OH trial required mechanical ventilation after return of circulation and were at high risk for neurologic disability. Results of the trial showed that neither treatment arm conferred a significant benefit in survival with good functional outcome. In the context of the THAPCA-OH trial, we evaluated the extent of family burden experienced by caregivers (i.e., parents or guardians) of children who survived OH-CA at baseline and 3 and 12 months post arrest. We hypothesized that family burden would be associated with child functioning. The objective of the study is to describe family burden among caregivers of children who survived OH-CA and who were at high risk for neurologic disability and examine relationships between family burden, child functioning, and other factors during the first year post arrest.

MATERIAL AND METHODS

Study Design and Setting

The study is a secondary analysis of data collected in the THAPCA-OH trial (10). The THAPCA-OH trial was conducted at 36 PICUs in the United States and Canada between September 1, 2009, and December 31, 2012. Details of the THAPCA-OH trial have been previously published (10–13). The study was approved by the Institutional Review Boards at the Data Coordinating Center at the University of Utah and all sites. Parental permission was obtained for all participants.

Study Participants

Children were eligible for inclusion in the THAPCA-OH trial if they were more than 48 hours old and less than 18 years old, experienced an OH-CA with chest compressions for at least 2 minutes, and required mechanical ventilation after return of circulation. Major exclusion criteria included the inability to be randomized within 6 hours of return of circulation, a Glasgow Coma Scale motor score of 5 or 6 (14), a decision by the clinicians to withhold aggressive treatment, and OH-CA caused by trauma. Of 295 children randomized, 270 had normal prearrest neurologic functioning and were eligible for inclusion in the THAPCA-OH primary efficacy analysis. Normal prearrest neurologic functioning was defined as a baseline Vineland Adaptive Behavioral Scale II, second edition (VABS-II), score greater than or equal to 70 (15), or in the absence of a baseline VABS-II assessment, Pediatric Overall Performance Category (POPC), and Pediatric Cerebral Performance Category (PCPC) scores of 1 (normal) or 2 (mild disability) (16). Of these 270 subjects, 87 were alive 12 months post arrest; 77 of whom had undergone assessment of family burden at baseline and 12 months post arrest. Of these, 76 also had assessment of family burden at 3 months post arrest. These 77 children are the subjects of this report.

Data Collection

All baseline measures were completed by caregivers (i.e., parents and/or guardians) at the local sites within 24 hours of randomization. Trained research coordinators assisted caregivers with completing baseline measures and informed caregivers that baseline was intended to reflect prearrest status. Three- and 12-month measures were performed by the Kennedy Krieger Institute by telephone interviews conducted by trained interviewers unaware of THAPCA-OH treatment group assignment.

Outcome Measures

The primary outcome was family burden 12 months after OH-CA. Family burden was assessed using two scales from the Infant and Toddler Quality of Life Questionnaire (ITQOL) (17, 18) for children less than 5 years old and three scales from the Child Health Questionnaire (CHQ) (19) for children 5 years old or older. Family burden was assessed at baseline and 3 and 12 months post arrest.

The Family Burden scales of the ITQOL cover two domains, including (1) parent impact-emotion and (2) parent impact-time (17). The parent impact-emotion domain consists of seven items in which the parent is asked to rate how much anxiety or worry each of the child characteristics described in the items has caused during the past 4 weeks (i.e., feeding/sleeping/eating habits; physical health; emotional well being; learning abilities; ability to interact with others; behavior;

and temperament). The parent impact-time domain consists of seven items in which the parent is asked to rate how much of his/her time was limited for personal needs because of the problems with the child's personal needs during the past 4 weeks. For each scale, the mean of the responses is transformed to 0–100 with higher scores, indicating lesser burden. Normative reference data from a U.S. population are not available, but Dutch reference data exist (18).

The Family Burden scales of the CHQ cover three domains, including (1) parent impact-emotion (2), parent impact-time, and (3) family activities (19). The parent impact-emotion and the parent impact-time domains are similar to the corresponding domains of the ITQOL except that the CHQ domains each have three items, which pertain to the child's physical health, emotional well being, and learning abilities. The family activities domain consists of six items, which assess how often the child's health or behavior has interfered with family activities during the past 4 weeks. For each scale, the mean of the responses is transformed to 0–100 with higher scores, indicating lesser burden. Normative reference data from a U.S. population are available (19).

Independent Variables

Other data included child and family sociodemographics; family functioning as assessed by the General Functioning Scale of the Family Assessment Device (FAD-GF) (20); and child functioning as assessed by the VABS-II (15), the POPC, and PCPC scales (16); and caregivers' perception of global functioning. Sociodemographics and the FAD-GF were assessed at baseline; the VABS-II and global functioning were assessed at baseline and 3 and 12 months; and the POPC and PCPC were assessed at baseline, PICU discharge, and 3 and 12 months.

The FAD-GF is a 12-item measure to distinguish between healthy and unhealthy family functioning (20). Respondents rate how well each item describes their own family using a four-point scale. Total scale scores are the mean of the item responses and range from 1 to 4. Higher scores indicate worse family functioning. A score of greater than or equal to 2 indicates problematic functioning.

The VABS-II is a measure of adaptive behavior from birth through adulthood (15). Adaptive behavior is defined as the individual's performance on daily life activities necessary for personal and social independence. The VABS-II covers domains of communication, daily living, socialization, and motor skills. The number of items (i.e., tasks) that can be performed in each domain is standardized for the child's age. In normative U.S. populations, the mean VABS-II score is 100 and the SD is 15. Higher scores indicate better functioning.

The POPC and PCPC are scales to assess overall functional morbidity and cognitive impairment, respectively (16). Both are six-point graded scales of increasing disability. Scores are 1 for good/normal, 2 for mild disability, 3 for moderate disability, 4 for severe disability, 5 for coma or vegetative state, and 6 for death.

Caregiver perception of global child functioning was assessed by investigator-developed items. At baseline, caregivers were asked "compared with children of the same age, were your child's home, school, or social activities limited before his/her cardiac arrest?" Response categories were "not limited, limited a little, and limited a lot." At 3 and 12 months, caregivers were asked (1) "Compared with children of the same age, are your child's home, school or social activities limited now?" Response categories were "not limited, limited a little, and limited a lot," and (2) "Thinking about your child since his/her cardiac arrest, has he/she gained a lot of new skills, gained a few new skills, stayed the same, lost a few skills, or lost a lot of skills."

Statistical Analyses

Baseline characteristics were summarized using frequencies and percentages for categorical variables and medians and quartiles for continuous variables. The Family Burden scales and VABS-II were summarized at baseline, 3 months, and 12 months using the mean and SD. The Family Burden scales at each time point were compared with reference values using the t test, and the difference between these scales from 3 to 12 months was examined using the paired t test. Spearman correlations were used to assess associations between the Family Burden scales and the independent variables. The reference values for each Family Burden scale were used to calculate z scores at month 12. These z scores were used to categorize Family Burden scale score as mildly elevated/normal (z score, –1.5 to 1.5), moderately elevated (z score, –3 to –1.5), or highly elevated (z score, < –3). All analyses were completed using SAS software version 9.4 (SAS Institute, Cary, NC).

RESULTS

Baseline characteristics of children and their caregivers are shown in **Table 1**. Overall, 56 (72.7%) children were boys, 48 (62.3%) were whites, and 50 (64.9%) were less than 5 years old prior to the OH-CA. Child adaptive behavior before arrest was similar to reference norms with median VABS-II scores of 99.0 for children less than 5 years old and 107.0 for children 5 years old or older. Seventy-one children (92.2%) had prearrest POPC in the good or mild disability range, and 74 (96.1%) had prearrest PCPC in the normal or mild disability range. Seventy-four children (96.1%) were globally assessed by their caregivers as not limited or limited a little. Etiology of arrest was a respiratory disorder in 54 children (70.1%). Thirty-three caregivers (42.9%) had at most a high school diploma or passed a General Education Development test. Family functioning before arrest was reported as normal by 66 caregivers (86.8%).

Family burden at baseline and 3 and 12 months post arrest for children less than 5 years old (ITQOL) and for children 5 years old or older (CHQ) is shown in **Tables 2** and **3**, respectively. Two children whose caregivers completed the ITQOL at baseline were administered the CHQ at 3 and 12 months because the children turned 5 years between the baseline and 3-month assessment. Five children whose caregivers completed the ITQOL at baseline and 3 months were administered the CHQ at 12 months because the children turned 5 years between the 3- and 12-month assessments. Family burden (i.e., parent impact-emotion, parent impact-time, and family activities) at

TABLE 1. Baseline Characteristics of Children and Their Caregivers

Characteristic	Assessment Completed at Baseline	
	Infant Toddler Quality of Life (n = 50)	Child Health Questionnaire (n = 27)
Age at Randomization (yr): median (Q1, Q3)	1.9 (0.6, 3.1)	14.5 (9.8, 16.2)
Male, n (%)	34 (68.0)	22 (81.5)
Race, n (%)		
American Indian or Alaska Native	0 (0.0)	1 (3.7)
Asian	0 (0.0)	2 (7.4)
Black or African American	9 (18.0)	9 (33.3)
White	34 (68.0)	14 (51.9)
Other/unknown	7 (14.0)	1 (3.7)
Ethnicity, n (%)		
Hispanic or Latino	8 (16.0)	6 (22.2)
Not Hispanic or Latino	40 (80.0)	20 (74.1)
Unknown	2 (4.0)	1 (3.7)
Caregivers' highest education received, n (%)		
Some high school or less	5 (10.0)	8 (29.6)
High school graduate or General Education Development	17 (34.0)	3 (11.1)
Vocational school or some college	13 (26.0)	5 (18.5)
College degree	8 (16.0)	6 (22.2)
Graduate or doctoral degree	7 (14.0)	5 (18.5)
Primary etiology of cardiac arrest, n (%)		
Cardiac	7 (14.0)	8 (29.6)
Respiratory	39 (78.0)	15 (55.6)
Other/unknown	4 (8.0)	4 (14.8)
Precardiac arrest Vineland Adaptive Behavioral Scale II, second edition, Adaptive Behavior Composite score: median (Q1, Q3)	99.0 (89.0, 111.0)	107.0 (92.0, 121.0)
Precardiac arrest Pediatric Overall Performance Category, n (%)		
Good = 1	41 (82.0)	20 (74.1)
Mild disability = 2	4 (8.0)	6 (22.2)
Moderate disability = 3	5 (10.0)	1 (3.7)
Precardiac arrest Pediatric Cerebral Performance Category, n (%)		
Normal = 1	45 (90.0)	24 (88.9)
Mild disability = 2	2 (4.0)	3 (11.1)
Moderate disability = 3	3 (6.0)	0 (0.0)
Precardiac arrest global child functioning: caregiver perception of limitations, n (%)		
Not limited	43 (87.8)	18 (66.7)
Limited a little	6 (12.2)	7 (25.9)
Limited a lot	0 (0.0)	2 (7.4)
Precardiac arrest Family Assessment Device family functioning, n (%)		
Healthy family functioning	46 (93.9)	20 (74.1)
Unhealthy family functioning	3 (6.1)	7 (25.9)

TABLE 2. Family Burden at Baseline and 3 and 12 Months After Out-of-Hospital Cardiac Arrest for Children Less Than 5 Years Old Using the Infant Toddler Quality of Life Questionnaire

Assessment	Reference	Time Point						
		Baseline, $n = 50$	p^a	Month 3, $n = 48$	p^a	Month 12, $n = 43$	p^a	p^b
ITQOL: standardized score for parent impact-Emotion								
Mean (SD)	92.1 (10.84)	90.5 (19.46)	0.575	71.1 (26.91)	< 0.001	76.8 (24.96)	< 0.001	0.119
ITQOL: standardized score for parent impact-time								
Mean (SD)	93 (10.92)	91.7 (16.60)	0.591	77.8 (26.64)	< 0.001	77.3 (27.07)	< 0.001	0.784
VABS Adaptive Behavior Composite score								
Mean (SD)	100 (15)	99.0 (15.32)		73.1 (27.19)		75.9 (25.67)		

ITQOL = Infant Toddler Quality of Life.
[a]p values from t test comparing Family Burden measure with reference.
[b]p values from t test comparing the change in Family Burden measure from month 3 to month 12.

TABLE 3. Family Burden at Baseline and 3 and 12 Months After Out-of-Hospital Cardiac Arrest for Children 5 Years Old and Older Using the Child Health Questionnaire

Assessment	Reference	Time Point						
		Baseline, $n = 27$	p^a	Month 3, $n = 28$	p^a	Month 12, $n = 34$	p^a	p^b
CHQ: standardized score for parent impact-emotion								
Mean (SD)	80.3 (19.1)	74.4 (30.48)	0.322	44.6 (35.08)	< 0.001	52.2 (34.41)	< 0.001	0.440
CHQ: standardized score for parent impact-time								
Mean (SD)	87.8 (19.9)	87.2 (22.37)	0.898	45.6 (37.45)	< 0.001	55.9 (33.67)	< 0.001	0.007
CHQ: standardized score for family activities								
Mean (SD)	89.7 (18.6)	87.0 (12.89)	0.293	61.2 (32.71)	< 0.001	63.1 (28.91)	< 0.001	0.697
Vineland Adaptive Behavioral Scale II, second edition, Adaptive Behavior Composite score								
Mean (SD)	100 (15)	107.0 (16.45)		64.1 (29.04)		66.1 (29.51)		

CHQ = Child Health Questionnaire.
[a]p values from t test comparing Family Burden measure with reference.
[b]p values from t test comparing the change in Family Burden measure from month 3 to month 12.
Note: one patient did not complete the month 3 Child Health Questionnaire (CHQ) assessment; $n = 28$ for CHQ domains and $n = 29$ for Vineland Adaptive Behavioral Scale II, second edition.

baseline was not significantly different from reference values for either age group. However, family burden was significantly greater (i.e., lower ITQOL and CHQ domain scores) at 3 and 12 months post arrest compared with reference values. Family burden tended to improve between 3 and 12 months, but only the parent impact-time scale of the CHQ was significantly different. Adaptive behavior was reduced (i.e., lower VABS-II scores) 3 and 12 months post arrest compared with reference norms.

Figure 1 shows the percent of caregivers reporting normal to mildly elevated, moderately elevated, and highly elevated burden for each of the family burden scales 12 months post arrest. For caregivers of children less than 5 years old, 16 (37.2%) reported moderate to highly elevated burden for the parent impact-emotion domain, and 16 (37.2%) reported moderate to highly elevated burden for the parent impact-time domain. For caregivers of children 5 years old or older, 19 (55.9%) reported
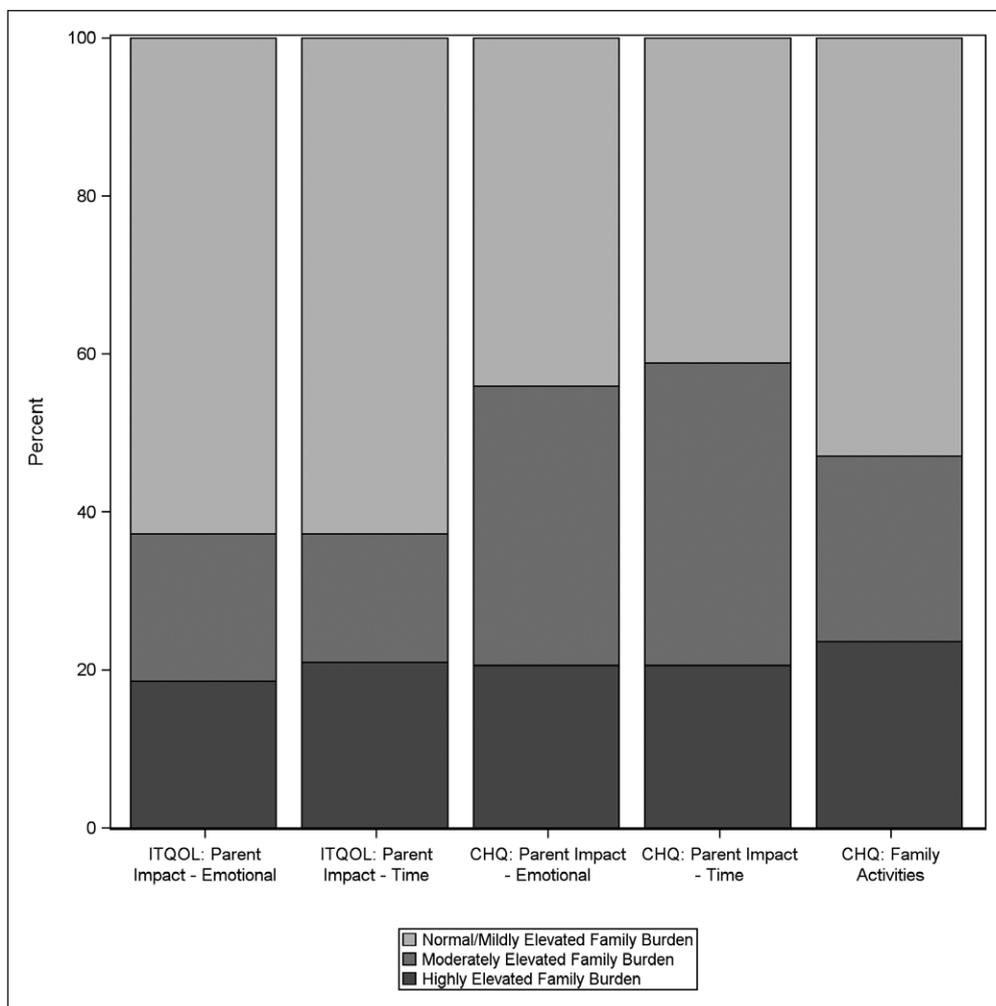
Figure 1. Percent of caregivers reporting normal/mild, moderate, and high levels of burden for each assessed family burden domain 12 mo after their child's cardiac arrest. CHQ = Child Health Questionnaire, ITQOL = Infant Toddler Quality of Life.

family functioning, child adaptive behavior, and POPC and PCPC, were not associated with family burden 3 months post arrest. Child sex, race, and ethnicity were also not associated with family burden 3 months post arrest (data not shown).

Several variables reflecting reduced child functioning prior to 12 months post arrest were moderately correlated with increased family burden at 12 months post arrest (Table 5). Worse POPC and PCPC at PICU discharge correlated with increased family burden in all domains for children less than 5 years old and with increased caregiver worry (i.e., parent impact-emotion) in children 5 years old or older. Worse POPC and PCPC, lower adaptive behavior, and lower global functioning 3 and 12 months post arrest were associated with increased family burden in all domains 12 months post arrest. Family burden at 3 months post arrest was also moderately to highly correlated with the corresponding family burden scale at 12 months post arrest. Baseline child and family characteristics were not associated with family burden 12 months post arrest.

moderate to highly elevated burden for the parent impact-emotion domain, 20 (58.8%) for the parent impact-time domain, and 16 (47.0%) for the family activities domain.

Correlations of variables with 3- and 12-month family burden domain scores are shown in **Tables 4** and **5**, respectively. Several variables reflecting reduced child functioning prior to 3 months post arrest were moderately correlated with increased family burden at 3 months post arrest (Table 4). Specifically, reduced global functioning before arrest was associated with greater caregiver limitations in personal time (i.e., parent impact-time) 3 months post arrest for children less than 5 years old. Worse POPC and PCPC at PICU discharge were associated with increased family burden in all domains 3 months post arrest for children 5 years old or older. Worse POPC and PCPC 3 months post arrest were associated with increased caregiver worry (i.e., parent impact-emotion) in children less than 5 years old and with all family burden domains in children 5 years old or older. Lower adaptive behavior and global functioning 3 months post arrest were associated with increased family burden in all domains 3 months post arrest in both age groups. Baseline characteristics, including child age, caregiver education,

Caregivers of two children 5 years old or older with VABS-II scores at least 70 at 12 months post arrest reported a high degree of worry (i.e., parent impact-emotion scores, < 10). VABS-II scores declined from 99 at baseline to 92 at 12 months for one of these children and from 98 to 77 for the other. Caregivers of seven children (three < 5 yr and four ≥ 5 yr) with VABS-II score less than 70 at 12 months post arrest reported no burden for at least one family burden domain (i.e., ITQOL or CHQ domain score = 100).

DISCUSSION

Our findings suggest that caregivers of children who survive OH-CA and are at high risk for neurologic disability often experience substantial family burden during the first year post arrest. Most children in our study had no or mild disability before arrest based on VABS-II scores and were a part of families with healthy family functioning. Family burden before arrest was similar to that experienced by families of healthy children. However, following the arrest, family burden increased substantially. At 3 months post arrest, caregivers reported increased levels of anxiety and worry and interference with meeting their own personal needs and conducting family activities. Although

TABLE 4. Correlations of Variables With 3 Month Family Burden Domain Scores Using the Infant and Toddler Quality of Life Questionnaire for Children Less Than 5 Years Old, and the Child Health Questionnaire for Children 5 Years Old and Older

Covariate	ITQOL Parent Impact-Emotion	ITQOL Parent Impact-Time	CHQ Parent Impact-Emotion	CHQ Parent Impact-Time	CHQ Family Activities
Precardiac arrest					
Age at randomization (yr)	−0.084	−0.158	0.105	0.058	0.151
Caregiver's highest education received	0.021	−0.051	−0.010	−0.188	−0.101
Global Child Functioning: caregiver perception of limitations	−0.253	−0.368[a]	0.052	−0.073	0.145
Average FAD score	0.246	0.043	−0.128	0.021	−0.142
VABS Adaptive Behavior Composite Score	0.138	0.023	0.071	0.045	0.231
POPC	−0.126	−0.152	0.311	0.138	0.231
PCPC	−0.034	−0.033	0.274	0.124	0.179
PICU discharge					
POPC	−0.239	−0.128	−0.376[a]	−0.439[a]	−0.449[a]
PCPC	−0.241	−0.119	−0.386[a]	−0.421[a]	−0.461[a]
Month 3					
VABS Adaptive Behavior Composite score	0.511[a]	0.325[a]	0.557[a]	0.423[a]	0.585[a]
POPC	−0.415[a]	−0.217	−0.563[a]	−0.477[a]	−0.620[a]
PCPC	−0.422[a]	−0.205	−0.616[a]	−0.479[a]	−0.647[a]
Global Child Functioning: caregiver perception of limitations	−0.460[a]	−0.487[a]	−0.483[a]	−0.382[a]	−0.466[a]
Global Child Functioning: caregiver perception of skills	−0.540[a]	−0.421[a]	−0.481[a]	−0.343	−0.502[a]

ITQOL = Infant Toddler Quality of Life, CHQ = Child Health Questionnaire, FAD = Family Assessment Device, VABS = Vineland Adaptive Behavioral Scale II, second edition, POPC = Pediatric Overall Performance Category, PCPC = Pediatric Cerebral Performance Category.
[a]$p < 0.05$.

some gain in ability to meet personal needs was observed by 12 months post arrest for caregivers of older children, family burden at 12 months remained high for many families.

A recent cross-sectional study from the Netherlands evaluated long-term health status and health-related quality of life among survivors of cardiac arrest in childhood and their parents (4). In this study, parents completed the Family Burden scales of the ITQOL ($n = 12$) or the CHQ ($n = 33$) a median of 5.6 years (range, 1.8–11.9 yr) after their child's PICU discharge. Anxiety and worry were increased among parents of children 5 years old or older compared with reference values. No differences were observed in the parent impact-time or family activity domains for parents of children 5 years old or older, and no differences were observed in family burden domains for children less than 5 years old compared with reference values. In addition to the cross-sectional design and wide postarrest recruitment period, the Dutch study differed from our study in that it attempted to recruit all children admitted to PICU who survived cardiac arrest, either in-hospital or out-of-hospital arrest, regardless of neurologic status in the immediate postarrest period. Children in the Dutch study may have

been at lower risk for poor functional outcomes and increased family burden compared with those in the THAPCA-OH trial. Despite these differences, findings from the Dutch study and our study, taken together, suggest that family burden after a child's cardiac arrest is high during the first year post arrest and gradually decreases over time. This may be related to improvement in coping or child health. Research suggests that many families gradually adapt to their children's disabilities and their own caregiving situations (7, 21).

Our findings also suggest that family burden 12 months after a child's OH-CA is associated with child functioning and family burden earlier in the course of illness. Reduced functional and cognitive status assessed by POPC and PCPC at PICU discharge were associated with increased worry 12 months post arrest for caregivers of children in the younger and older age groups and with increased interference with self-care for caregivers of younger children only. Caregiver perceptions of their child's global functioning, POPC and PCPC scores, and child adaptive behavior 3 months post arrest were all associated with family burden at 12 months. Family burden at 3 months post arrest was one of the variables most strongly

TABLE 5. Correlations of Variables with 12 Month Family Burden Domain Scores Using the Infant and Toddler Quality of Life Questionnaire for Children Less Than 5 Years Old, and the Child Health Questionnaire for Children 5 Years Old and Older

Covariate	ITQOL Parent Impact-Emotion	ITQOL Parent Impact-Time	CHQ Parent Impact-Emotion	CHQ Parent Impact-Time	CHQ Family Activities
Precardiac arrest					
Age at Randomization (yr)	0.027	0.033	−0.306	−0.021	−0.112
Caregiver's highest education received	0.172	0.093	−0.200	−0.133	−0.281
Global Child Functioning: caregiver perception of limitations	−0.079	−0.124	−0.151	−0.067	−0.048
Average FAD score	−0.065	0.084	0.063	0.263	0.130
VABS Adaptive Behavior Composite score	0.037	0.182	−0.024	0.011	0.039
POPC	0.032	−0.068	0.048	−0.020	0.007
PCPC	0.167	0.030	−0.093	−0.109	−0.178
PICU discharge					
POPC	−0.331[a]	−0.316[a]	−0.397[a]	−0.323	−0.190
PCPC	−0.315[a]	−0.301[a]	−0.394[a]	−0.315	−0.220
Month 3					
VABS Adaptive Behavior Composite score	0.507[a]	0.474[a]	0.457[a]	0.445[a]	0.458[a]
POPC	−0.495[a]	−0.422[a]	−0.417[a]	−0.522[a]	−0.429[a]
PCPC	−0.429[a]	−0.381[a]	−0.424[a]	−0.514[a]	−0.457[a]
Global Child Functioning: caregiver perception of limitations	−0.370[a]	−0.527[a]	−0.363[a]	−0.481[a]	−0.405[a]
Global Child Functioning: caregiver perception of skills	−0.450[a]	−0.408[a]	−0.330	−0.459[a]	−0.435[a]
Corresponding Family Burden measure	0.687[a]	0.543[a]	0.528[a]	0.843[a]	0.687[a]
Month 12					
VABS Adaptive Behavior Composite score	0.566[a]	0.502[a]	0.432[a]	0.423[a]	0.461[a]
POPC	−0.537[a]	−0.476[a]	−0.374[a]	−0.438[a]	−0.301
PCPC	−0.502[a]	−0.457[a]	−0.400[a]	−0.418[a]	−0.337
Global Child Functioning: caregiver perception of limitations	−0.650[a]	−0.558[a]	−0.517[a]	−0.541[a]	−0.444[a]
Global Child Functioning: caregiver perception of skills	−0.476[a]	−0.494[a]	−0.559[a]	−0.564[a]	−0.504[a]

ITQOL = Infant Toddler Quality of Life, CHQ = Child Health Questionnaire, FAD = Family Assessment Device, VABS = Vineland Adaptive Behavioral Scale II, second edition, POPC = Pediatric Overall Performance Category, PCPC = Pediatric Cerebral Performance Category.
[a]$p < 0.05$.

correlated with family burden at 12 months. These findings are important because identifying factors that are associated with increased burden early after a child's OH-CA may provide increased opportunity for intervention. PICU follow-up clinics have been suggested as one type of intervention to support parents most vulnerable to psychologic distress after their child's critical illness. However, a recent study reported that only a minority of parents were able or willing to participate in a PICU follow-up clinic appointment (22). Follow-up meetings or other interventions to support caregivers of children

after OH-CA would need to be developed or adapted for this population and tested for feasibility, acceptability, and impact on family burden.

Our findings are consistent with other research, suggesting that the extent of child disability is a predictor of family burden. In a study of pediatric traumatic brain injury, Aitken et al (8) found that the extent of child dysfunction predicted family burden 3 and 12 months post injury. In a study of acquired brain injury caused by trauma and nontraumatic causes, de Kloet et al (23) found that nontraumatic brain injury,

severity of injury, and the presence of health problems prior to the injury independently predicted the impact on the family. Qualitative research has also shown that the extent of child disability impacts parental well being, especially for mothers (24, 25). Thus, the high degree of family burden reported by caregivers in our study is not surprising given the severity of dysfunction observed among children in the THAPCA-OH trial.

Despite these findings, healthcare professionals should realize that some caregivers whose children function relatively well after OH-CA may still experience substantial burden and vice versa. For example, caregivers of two children in our older age group who were functioning in the normal range 12 months post arrest reported a high degree of worry. Although still in the normal range, child functioning had declined for both of these children from baseline to 12 months post arrest. The family burden observed may have been because of this decline. This pattern of discrepancy between child functioning and family burden (e.g., good function and high burden) was not observed for children in our younger age group. Caregivers of older children may experience more burden because it is easier to recognize deficits in older children as more complex tasks are expected such as those related to self-care and school performance. In contrast, caregivers of seven children (three < 5 yr and four ≥ 5 yr) who were functioning below normal at 12 months post arrest reported no burden for at least one family burden domain. Caregivers of younger children may expect their children to be dependent for daily activities and are, therefore, less burdened by the disabilities. In addition, some caregivers may feel social or cultural pressure to answer the questionnaires about family burden in a positive manner.

Sociodemographics and baseline family and child functioning were not associated with family burden 12 months post arrest in our study. This is in contrast to other studies reporting an impact of sociodemographics on family burden and child health-related quality of life. Hinojosa et al (26) examined the family impact for white, African American, and Hispanic parents of children with life-threatening illnesses and public health insurance in Florida. Hispanic parents reported their child's illness resulted in greater negative impact on the family compared with whites, whereas African Americans were not significantly different from whites. Alonso et al (27) explored health-related quality of life using the ITQOL and CHQ among families 2 years after pediatric liver transplant. Hispanic race was associated with more parent worry and lower child health-related quality of life. Racial and ethnic variation in family burden may be related to cultural differences in caregiving and greater caregiving responsibilities for minority families. It is possible that our study did not show a relationship between sociodemographics and family burden because of the severe neurologic dysfunction among children in the THAPCA-OH trial and the important contribution of neurologic dysfunction to family burden.

Strengths of our study include the multicenter, longitudinal design, and follow-up by centralized trained interviewers. Strengths also include the use of reliable and valid measures to assess family burden and child and family functioning.

Limitations include the use of different family burden measures for children in different age groups. Splitting the primary outcome measure by age group could have reduced statistical power to detect some clinically important relationships. Because the study was part of the larger THAPCA-OH trial in which family burden was a secondary outcome, an a priori power calculation was not performed. Normal reference data from a general U.S. population are not available for the ITQOL. Other limitations include the lack of data from families of children who were eligible for the THAPCA-OH trial but did not consent to participate and the lack of data on the use of family support services. In addition, the same caregiver may not have provided data at each time point.

CONCLUSIONS

Caregivers of children who survived OH-CA and were at high risk for neurologic disability often experienced a high degree of family burden during the first year post arrest. The extent of the child's disabilities and family burden 3 months post arrest were associated with family burden at 12 months. Future research should continue to explore factors contributing to family burden after pediatric OH-CA. Greater understanding of risk factors for family burden will allow identification of families most in need of ongoing support.

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