CLINICAL INVESTIGATION ARTICLE

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The Caring Intensively Study: Three-Year Follow-Up Findings From a Mixed Methods Study of Children's Psychological and Behavioral Responses After PICU Hospitalization

Janet E. Rennick, RN, PhD[1]

Geoffrey Dougherty, MDCM, MSc, FRCPC[2]

Karen Dryden-Palmer, RN, PhD(c)[3]

Marsha Campbell-Yeo, RN, NNP-BC, PhD, FAAN[4]

Alyssa M. Knox, RN, MSc(A)[5]

Christine T. Chambers, PhD, RPsych, FRSC, FCAHS[6]

Dale M. Stack, PhD, CPA Fellow[7]

Stephanie Treherne, RN, MSc(A)[5]

Robyn Stremler, RN, PhD, FAASM, FAAN[8]

OBJECTIVES: To report the 3-year follow-up results of the "Caring Intensively" study, which examined children's psychological and behavioral responses after PICU hospitalization.

DESIGN: Prospective mixed methods, concurrent triangulation design. In the quantitative arm, study group (SG) and comparison group (CG) children and their parents were administered a battery of measures assessing psychological and behavioral outcomes, and telephone survey data were collected 6 weeks, 6 months, 1, 2, and 3 years post-discharge. In the qualitative arm, SG interviews were conducted 1 and 3 years post-discharge. Recruitment 2014–2018, with follow-up completed 2021.

SETTING: SG recruited from PICUs of three Canadian quaternary care pediatric hospitals; CG from two hospitals' ear, nose, and throat (ENT) day surgery units.

PATIENTS: Age (3–12 yr) and gender-matched PICU children (SG, 158) or day surgery ENT children (CG, 169) and their parents were recruited; 62% of families completed the study (SG, 97; CG, 106). Selected SG families were interviewed at year 1 (17 families, 30 participants) and year 3 (14 families, 27 participants).

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: No group differences on primary or secondary outcomes. Both groups reported emotional and behavioral changes in children via telephone survey; however, group findings diverged on their nature and attribution. SG parents attributed changes primarily to PICU hospitalization; CG parents attributed changes to other life events. At year 3, 40.3% of SG parents still reported negative emotional and behavioral changes in children suggesting a chronic trajectory of recovery. Qualitative interview findings converged with SG survey responses, reflecting the adaptive and relational challenges confronting children and families.

CONCLUSIONS: This study highlights children's emotional and behavioral responses over the 3 years post-PICU and the need to study child recovery within the family. These findings contribute to our understanding of the nature and duration of trajectories of recovery and emphasize the importance of providing clinical follow-up and prioritizing family-identified outcomes in future research.

KEYWORDS: longitudinal studies; outcomes; pediatric intensive care unit; pediatric medical traumatic stress; post-intensive care syndrome-pediatrics

Child morbidities following PICU hospitalization have been conceptualized as Post-Intensive Care Syndrome in pediatrics (PICS-p) (1). PICS-p impacts child health along a dynamic developmental trajectory within the family context. Potential risk factors for adverse long-term psychological

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RESEARCH IN CONTEXT

- “The Caring Intensively” post-PICU, longitudinal mixed methods study recruited children and parents (2014–2018), with the purpose of collecting 3-year follow-up data (2014–2021).
- This report examines the magnitude and duration of children’s psychological and behavioral responses over the 3 years post-PICU and compares them to those of children following ear, nose, and throat day surgery.
- This study highlights the importance of understanding the child’s trajectory of recovery within the context of the family and supports the notion of multiple extended pathways of recovery post-PICU.

outcomes are only beginning to be understood and include the child’s prior history of emotional or behavioral problems, emergency admission status, illness severity, and duration of sedation, along with post-discharge medical comorbidities, and maternal and child post-traumatic stress (PTS) symptoms (2–6). While PICS-p recognizes the potential for multiple extended pathways of recovery, little is known about their nature and duration. Children and parents are typically studied separately, further limiting our understanding of recovery pathways and potential interventions (7, 8). Thus, we adapted the integrative model of pediatric medical traumatic stress (PMTS), a conceptual framework for understanding children’s responses to illness and injury to guide this study (9). Each phase of the model corresponds to part of the PICU critical illness and recovery process and incorporates child, illness, PICU, and family factors. Multiple trajectories of PMTS have been identified, illustrating a range of psychological responses to children’s medical experiences (10).

In 2014, we started “The Caring Intensively” study (11), which aimed to examine age-appropriate psychological and behavioral response indicators in the 3 years post-PICU hospitalization and to explore children’s and parents’ perceptions of their responses to provide a comprehensive understanding of longitudinal outcomes. Our objectives were to: 1) examine the magnitude and duration of children’s psychological and behavioral responses over the 3 years post-PICU and compare them to those of children following ear, nose, and throat (ENT) day surgery; 2) identify explanatory factors associated with children’s psychological and behavioral responses; 3) describe parents’ and children’s perceptions of PICU hospitalization; and 4) explore areas of convergence (corroboration, complementarity) and divergence (inconsistency, discrepancy, contradiction) in the quantitative and qualitative findings. Our two underlying hypotheses in this work are, first, that post-PICU children exhibit more negative psychological and behavioral responses over the 3 years post-discharge than post-ENT day surgery cases. Second, that responses over 3 years post-PICU will be associated with factors at baseline or during or post-PICU.

METHODS

The study protocol for this research project was published in 2014 (11), and 1-year follow-up results of the qualitative study arm were reported in 2021 (12). Briefly, a prospective mixed methods study was conducted using concurrent triangulation design (13, 14), with participants recruited between 2014 and 2018 from PICUs of three university-affiliated pediatric hospitals in three Canadian provinces. Quantitative and qualitative data were collected simultaneously over a 3-year period following PICU discharge in the study group (SG) and the ENT day surgery comparison group (CG). Follow-up was completed in 2021, with full data available for analysis in 2022 following delays in transcription and data cleaning due to the COVID-19 pandemic.

All research procedures were followed in accordance with the ethical standards of the responsible committee on human experimentation and with the 1975 Declaration of Helsinki. Each site’s Research Ethics Board approved the study (McGill University Health Centre, Centre for Applied Ethics, April 8, 2013, no. 2013-507 12-350-PED; The IWK Research Ethics Board, October 22, 2013, no. 1014431; and The Hospital for Sick Children Research Ethics Board, April 24, 2014, no. 1000041389).

Setting and Participants

The CG participants were recruited at two of the study sites, as one stopped conducting ENT day surgery. Parents were approached at discharge and provided written informed consent; children 7 years old or older provided verbal or written assent.

Quantitative Arm. SG children were 3–12 years old, admitted to the PICU for a minimum of 24 hours, spoke English or French, had one parent who spoke, read, and wrote English or French, and were ready for discharge. Those with a previous PICU admission or neurological impairment rendering evaluation with standardized measures impossible were excluded. A CG with a brief hospital experience and no previous PICU experience was chosen. CG children were matched for age and sex and met the same inclusion and exclusion criteria. All participants were eligible for telephone follow-up.

Qualitative Arm. A subgroup of SG families in the quantitative arm were purposively selected to maximize variation and representation based on child age, sex, admitting diagnosis, length of stay, and invasive procedure score (IPS). Home interviews (telephone interviews for those residing more than 100 km from the hospital) took place 1 and 3 years following questionnaire completion.

Procedure

We used the Mixed Methods Appraisal Tool (v. 2018; Department of Family Medicine, McGill University, Montreal, QC, Canada) to ensure methodological integrity (15, 16). SG families were recruited and baseline data collected before the child's PICU discharge. CG families were recruited in the day surgery units and baseline data collected postoperatively, before discharge. The recruitment period ran from 2014 to 2018, and quantitative data were collected prospectively using standardized measures mailed to families' homes 6 weeks, 6 months, and 1, 2, and 3 years post-hospitalization. Two weeks after 6-month, 1-, 2-, and 3-year questionnaire mailings, telephone follow-up calls were made by research nurses to reestablish contact and gather complimentary survey data. Parents were asked closed- and open-ended questions about their child's recovery.

In the qualitative arm, SG families were contacted by telephone and invited to participate in two 1-hour interviews at the end of years 1 and 3. Open-ended, semi-structured interview questions were designed to elicit children's and parents' narratives of the recovery process and gain deeper insight into children's responses following PICU hospitalization. The integration of the quantitative and qualitative data facilitated analyses that provided a comprehensive understanding of children's responses (13, 14).

Measures

The primary outcome measure was the Behavioral Symptoms Index (BSI) composite score of the Behavioral Assessment Scale for Children, v2 (BASC-2) Parent Report Scale, which assesses children's overall behavioral and emotional functioning across age levels (17). Secondary outcome measures assessed the child's emotional and behavioral problems and their impact on the child and the family, and the child's adaptive skills. They included the Strengths and Difficulties Questionnaire (SDQ + Impact Scale) (18) and two child self-report scales: the Emotional Symptoms Index (ESI) of the BASC-2 Self Report Scale, 8 years+ (17) and the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (PSPCSA), ages 4–7 years (19). Potential predictors included the child's hospital IPS (20); Pediatric Risk of Mortality score, v3 (PRISM-III) (21); the Children's Critical Illness Impact Scale (CCIIS), self-report, 6 years+ (22); Post-Hospital (child) Behavior Questionnaire (PHBQ) (23, 24); State-Trait (parent) Anxiety Measure (STAI) (25); and the Parenting Stress Index (PSI) (26). The measures are described in **Supplemental Digital Content** (**Table S1**, http://links.lww.com/PCC/C592).

Data Analysis

Quantitative questionnaire data were analyzed using SAS, Version 9.3 (SAS Institute, Cary, NC). Survey data were analyzed using descriptive statistics for closed-ended questions, and open-ended questions were summarized categorically. Two coders analyzed the qualitative interview transcripts independently using the constant comparison method (27). Audiotaped data were transcribed verbatim, and open and axial coding used to identify themes and connect emergent categories within and across time points (28). NVivo, Version 12 software (QSR International, Burlington, MA, 2018) supported data management and sorting. Following independent analysis of the qualitative and quantitative data, results were mixed and the convergence and divergence of the data explored during the final stage of interpretation (13, 29). The sequential nature of the longitudinal design meant that data collected in each study arm informed the other.

RESULTS

Quantitative Arm

In the "baseline dataset," there was a total of 327 families (SG $n = 158$; CG $n = 169$) who were recruited. There were no significant group differences at baseline and hospital characteristics varied as expected across groups (**Table 1**). We estimated a 30% attrition rate over 3 years and adjusted enrollment accordingly (11). Attrition was highest at year 1 when 29% of families (94/327) were lost to follow-up (**Table S2**, http://links.lww.com/PCC/C592). By year 3, attrition was 38%, with 62% of families (203/327) completing the study (SG $n = 97$; CG $n = 106$).

The "questionnaire data" on the primary and secondary outcome variables and clinical cutoff scores, based on population norms, for parent-report outcomes are shown in **Tables 2** and **3**, respectively. There were no group differences on the BASC-2 BSI. SG and CG scores fell mainly within the normal range; however, 18% of both groups' scores were considered "at risk" or 'clinically significant' at year 3. Parents' descriptions of heightened child anxiety, among other concerns, were reported in the telephone follow-up survey and family interviews (**Table S3**, http://links.lww.com/PCC/C592). We used the BASC-2 Internalizing Problems Composite Scale that includes anxiety, depression (as does the BSI), and somatization scales to further explore these findings and found no significant group differences.

On the secondary outcome measures, there were no group differences on SDQ Total Difficulties or Impact Scale scores. Within groups, Total Difficulties mean scores were slightly higher than established population norms (mean = 8.4, SD = 5.8), while Impact Scale mean scores were much higher than the norm (mean=0.4, SD = 1.1) (18). Approximately 12% of SG and 13% of CG children had abnormal ("high" or "very high") Total Difficulties scores at years 1, 2, and 3, while 22–34% of SG and 27–35% of CG had abnormal Impact Scale scores. On the child self-report scales, statistically significant group differences in perceived general competence were found at year 2 on the PSPCSA; however, the mean difference (MD) in group scores (0.35 out of a possible 4.0) was not clinically significant. No significant group differences were found on the BASC-2 ESI, which includes scale from the Internalizing Problems composite and the Personal Adjustment composite, and 95–98% of children scored within the normal range (**Table S4**, http://links.lww.com/PCC/C592).

Assessment of potential "explanatory factors" (see children's IPS and PRISM-III scores in Table 1) failed to show any significant group differences in children's reported distress measured by the CCIIS at 6 weeks and 6 months. SG parents reported significantly more behavioral changes in their children at 6 weeks on the PHBQ (MD = 4.8; t score = 3.46; $p < 0.001$). SG parent STAI state anxiety was significantly higher at 6 weeks (MD = 5.8; t score = 4.11; $p < 0.001$); however, SG parent STAI trait anxiety was significantly higher at baseline (MD = 4.4; t score = 4.21; $p < 0.001$). No group differences were found on the PSI.

In the "follow-up telephone survey" data collected from parents in both groups at 6 months, 1, 2, and 3 years post-discharge, we failed to find any differences in baseline characteristics between those who did or did not respond (**Table S5**, http://links.lww.com/PCC/C592). Parents in both groups described more negative than positive behavioral/emotional changes in their children, with more SG children exhibiting negative changes at each time point (**Table 4**).

For the question, "Have you noticed any emotional or behavioral changes in [child] since she/he was admitted to hospital?," parents who responded "yes" (year 3: SG = 45.8%, CG = 25.7%) were asked to describe those changes. Responses were grouped into six categories: 1) heightened anxiety; 2) health- and hospital-related fears/memories; 3) emotional challenges; 4) physical and cognitive challenges; 5) emotional growth; and 6) physical and cognitive improvements (Table S3, http://links.lww.com/PCC/C592). SG parents tended to attribute children's negative changes (year 3: SG = 40.3%, CG = 21.2%) to PICU hospitalization. CG parents tended to attribute changes to normal growth and development (e.g., becoming a teenager), other life events (e.g., starting/changing schools), a diagnosed mental health disorder (e.g., attention deficit hyperactivity disorder, oppositional defiant disorder), or developmental delay as opposed to the day-surgery experience. Positive changes (year 3: SG = 8.3%, CG = 4.5%) were observed less frequently in both groups and attributed primarily to hospitalization (i.e., medical or surgical intervention) (Table 4).

Qualitative Arm

Twenty SG families participated in semi-structured "interviews" (50 min average duration). Seventeen

TABLE 1.
Demographics and Hospital Baseline Characteristics

Participant Characteristics	Full Sample SG ($n = 158$), Mean (SD)	Full Sample CG ($n = 169$), Mean (SD)	Telephone Follow-Up[a] SG ($n = 114$), Mean (SD)	Telephone Follow-Up[a] CG ($n = 128$), Mean (SD)	Interviews[b] SG ($n = 20$), Mean (SD)
Child age at enrollment (yr)	6.8 (2.91)	6.3 (2.46)	7.0 (2.96)	6.2 (2.46)	5.8 (2.79)
PICU LOS[c]	4.6 (5.87)	NA	4.7 (5.47)	NA	4.8 (4.58)
Total hospital LOS[c]	14.0 (21.37)	0.1 (0.28)	14.7 (23.99)	0.1 (0.26)	22.1 (44.03)
Invasive procedure score (20)	125.8 (145.52)[d]	1.2 (0.70)	130.1 (156.72)[e]	1.2 (0.72)	145.6 (211.43)
Pediatric Risk of Mortality III (23)	5.5 (6.18)	0.1 (0.58)	5.5 (5.73)	0.1 (0.59)	5.1 (6.61)
	Count (%)	**Count (%)**	**Count (%)**	**Count (%)**	**Count**
Child's sex					
Female	79 (50.0)	72 (42.6)	58 (50.9)	56 (43.8)	8/20
Male	79 (50.0)	97 (57.4)	56 (49.1)	72 (56.2)	12/20
Analgesics/sedatives (yes/no)					
Opioids	109 (69.0)	132 (78.1)	82 (71.9)	104 (81.3)	14/20
Benzodiazepines	94 (59.5)	4 (2.4)	69 (60.5)	4 (3.1)	9/20
Other sedatives	90 (57.0)	3 (1.7)	67 (58.8)	3 (2.3)	12/20
Primary diagnostic category					
Respiratory	49 (31.2)		33 (28.9)		6/20
Cardiology/cardiac surgery	35 (22.3)		26 (22.8)		4/20
Neurology/neurosurgery	33 (21.0)		28 (24.6)		7/20
Infectious disease	11 (7.0)		9 (7.9)		0/20
Trauma	10 (6.4)		6 (5.3)		2/20
Other[f]	20 (13)		12 (10.5)		1/20
Ear, nose, and throat		169 (100)		128 (100)	
Diagnosed mental health disorder	8 (5.1)	8 (4.7)	7 (6.1)	6 (4.7)	1/20
Language spoken at home					
English	115 (72.8)	137 (81.1)	85 (74.6)	109 (85.2)	15/20
French	43 (27.2)	32 (18.9)	29 (25.4)	19 (14.8)	5/20

(Continued)

TABLE 1. (*Continued*)

Demographics and Hospital Baseline Characteristics

	Count (%)	Count (%)	Count (%)	Count (%)	Count
Parent highest level education					
Elementary	3 (1.8)	2 (1.2)	2 (1.8)	1 (0.8)	0/20
High school	33 (20.9)	24 (14.2)	25 (21.9)	18 (14.1)	3/20
College/Collège d'enseignement general et professionnel (Quebec, Canada)	39 (24.7)	56 (33.1)	26 (22.7)	43 (33.6)	3/20
University	78 (49.4)	81 (47.9)	59 (51.8)	61 (47.7)	14/20
Did not respond	5 (3.2)	6 (3.6)	2 (1.8)	5 (3.8)	0/20
Parent employed	99 (62.7)	117 (69)	79 (69.3)	93 (72.7)	14/20

CG = comparison group, LOS = length of stay, NA = not applicable, SG = study group.

[a] Telephone follow-up survey respondents contacted over 3 yr.

[b] Interviews with PICU cohort families enrolled at year 1 and year 3.

[c] LOS calculated by subtracting discharge date from date of admission.

[d] PICU invasive procedure score (IPS) ranged from seven to 890, with a median score of 76.

[e] PICU IPS ranged from 14 to 890, with a median score of 78.

[f] Other: oncology, endocrinology, orthopedics, general surgery, transplant, gastrointestinal, rheumatology, and plastic surgery.

families participated at year 1, with six families lost to follow-up. Another three families (purposively selected from the larger cohort) agreed to participate at year 3. Year 1 participants included nine children (three girls, six boys), 16 mothers and five fathers (*n* = 30). Year 3 participants included ten children (five girls, five boys), one sibling, 13 mothers and three fathers (*n* = 27).

While PICU families were trying to find a new normal at year 1, as previously reported (12), by year 3 they were moving on (**Table 5**). Parents and children continued to experience reminders and memories of the PICU at year 3, while slowly integrating them into the child's life story. Parents expressed gratitude for their child's recovery even if they continued to experience limitations, and some intentionally put the experience behind them. Parents in nine families noted that over the past 3 years they had accessed (*n* = 5) or wished they had been offered (*n* = 4) support services such as psychologists, social workers, or PICU follow-up services.

Most parents still perceived their child as medically vulnerable, and some attempted to protect their child from distress by attempting to hide their own worries. Heightened vigilance concerning the child's health was reported by parents of 15 children at year 1, and ten at year 3 with five siblings remaining vigilant about the child's health. At year 3, changes in how family members perceived the child's health continued to impact their relationships, with one child continuing to reassure his mother whenever he felt sick that he was never going to leave her.

Mixed Methods Data Integration

The percentage of abnormal (i.e., elevated) SDQ Impact Scale scores within groups (Table 3) suggests all parents perceived their children's emotional and behavioral responses as substantially impacting the child and family over 3 years post-hospitalization. Findings converge with parent telephone survey responses regarding the presence of emotional and behavioral changes in their children. Both groups identified more negative than positive changes, and when asked to describe them, responses revealed issues similar to those assessed by the outcome measures (e.g., anxiety, behavioral problems, and school difficulty).

Survey findings subsequently diverged, however, when the nature of children's responses was described

TABLE 2.
Group Differences on Primary and Secondary Outcome Variables

	Study Group		Comparison Group		t Test	
Timepoint	***n***	**Mean (SD)**	***n***	**Mean (SD)**	**Statistic (Degrees of Freedom)**	***p***
Behavioral Assessment Scale for Children, v.2, Behavioral Symptoms Index, parent report						
Baseline	156	51.2 (8.76)	168	51.6 (9.89)	−0.32 (322)	0.75
Month 6	105	51.2 (10.98)	112	51.3 (10.32)	−0.08 (215)	0.93
Year 1	97	51.6 (11.30)	109	51.7 (10.99)	−0.02 (204)	0.98
Year 2	90	51.6 (10.68)	91	51.0 (10.00)	0.35 (178)	0.73
Year 3	85	50.3 (10.93)	88	51.3 (11.05)	−0.64 (171)	0.52
SDQ total difficulties score, parent report						
Month 6	105	9.0 (6.13)	112	9.8 (5.94)	−0.25 (215)	0.81
Year 1	98	9.0 (5.92)	109	8.8 (6.01)	0.28 (205)	0.78
Year 2	90	9.0 (6.16)	92	9.0 (6.35)	−0.01 (180)	0.99
Year 3	86	8.6 (6.28)	88	8.8 (6.33)	−0.18 (172)	0.86
SDQ impact scale score, parent report						
Month 6	105	1.3 (1.95)	109	1.3 (2.04)	0.01 (212)	0.10
Year 1	98	1.1 (1.70)	108	1.6 (2.15)	−1.14 (204)	0.25
Year 2	88	1.6 (2.49)	92	1.5 (1.85)	0.22 (178)	0.83
Year 3	86	1.3 (2.15)	87	1.4 (1.88)	−0.25 (171)	0.80
Behavioral Assessment Scale for Children, v.2, Emotional Symptoms Index, child report (8 yr+)						
Month 6	40	45.9 (6.20)	29	46.9 (6.38)	−0.71 (67)	0.48
Year 1	40	46.2 (5.96)	36	46.4 (6.79)	−0.16 (74)	0.44
Year 2	48	45.7 (5.80)	42	47.8 (6.62)	−1.57 (88)	0.12
Year 3	57	46.7 (6.26)	51	46.0 (5.75)	0.95 (106)	0.34
PSPCSA, perceived peer acceptance (child report 4–7 yr)						
Month 6	54	2.9 (0.63)	68	3.0 (0.64)	−0.99 (120)	0.32
Year 1	59	3.0 (0.59)	72	3.0 (0.65)	0.39 (129)	0.70
Year 2	40	2.8 (0.58)	50	3.1 (0.65)	−1.89 (89)	0.06
Year 3	28	2.9 (0.79)	25	3.0 (0.67)	−0.66 (61)	0.51
PSPCSA, perceived general competence (child report 4–7 yr)						
Month 6	54	3.3 (0.59)	68	3.4 (0.54)	−0.92 (120)	0.36
Year 1	59	3.3 (0.56)	72	3.4 (0.52)	−0.74 (129)	0.46
Year 2	41	3.2 (0.61)	50	3.5 (0.51)	−3.01 (89)	0.00
Year 3	28	3.2 (0.67)	35	3.4 (0.50)	−1.69 (61)	0.10

PSPCSA = Pictorial Scale of Perceived Competence and Social Acceptance for Young Children, SDQ = Strengths and Difficulties Questionnaire.

in an open-ended survey question (Table S3, http://links.lww.com/PCC/C592). Over time, CG parents increasingly attributed their children's changes to development and other life events, or a diagnosed mental health disorder or developmental delay. Conversely, SG parents consistently attributed changes in their children primarily to PICU hospitalization. They described trauma, frightening memories and fears related to hospitalization, and physical and cognitive changes due to ongoing disabilities, medications, and technology dependence. SG parents observed differences in their children's perceptions of health and illness leaving them with a heightened sense of vulnerability, similar to qualitative interview findings in which families linked child vulnerability to heightened parental and sibling vigilance.

Interview findings were concordant with survey findings (Table 5; and Table S3, http://links.lww.com/PCC/C592). Importantly, questionnaire content did not reflect the issues children and families struggled with, pointing to a lack of conceptual convergence in the measures. The BASC-2 BSI composite scale, for example, combines hyperactivity, aggression, depression, atypicality, withdrawal, and attention problems scales. While children in both groups manifested symptoms on some scales, interviews revealed that challenges not captured included heightened fears, heightened child vulnerability, increased child and family vigilance, and ongoing reminders and memories of the illness experience. Further, important relationships between family members' responses were described in the interviews that were not identified in the quantitative arm (e.g., "When she saw us [parent and sibling] starting to panic, she started panicking as well").

DISCUSSION

The "Caring Intensively" study (11, 12), aimed to prospectively examine age-appropriate psychological and behavioral response indicators in the 3 years

TABLE 3.

Clinical Cutoff Scores: Primary and Secondary Outcomes, Years 1–3 (Parent Report[a])

		Study Group		Comparison Group		
Time	**Cutoff Scores**	***n***	**Count (%)**	***n***	**Count (%)**	**χ^2 Test**
Behavioral Assessment Scale for Children, v.2, Behavioral Symptoms Index[b]						
Year 1	Normal	97	82 (84.5)	109	88 (80.7)	$\chi^2(2) = 1.52$; $p = 0.47$
	At risk		6 (6.2)		12 (11.0)	
	Clinically significant		9 (9.3)		9 (8.3)	
Year 2	Normal	90	75 (83.3)	91	72 (80.0)	$\chi^2(2) = 5.18$; $p = 0.08$
	At risk		6 (6.7)		14 (15.6)	
	Clinically significant		9 (10.0)		4 (4.4)	
Year 3	Normal	85	70 (82.4)	88	72 (81.8)	$\chi^2(2) = 0.03$; $p = 0.99$
	At risk		9 (10.6)		10 (11.4)	
	Clinically significant		6 (7.1)		6 (6.8)	
SDQ total difficulties score[c]						
Year 1	Normal	98	78 (79.6)	109	89 (81.7)	$\chi^2(3) = 0.29$; $p = 0.96$
	Slightly raised		8 (8.2)		9 (8.3)	
	High		6 (6.1)		5 (4.6)	
	Very high		6 (6.1)		6 (5.5)	
Year 2	Normal	90	71 (78.9)	92	73 (79.4)	$\chi^2(3) = 1.30$; $p = 0.73$
	Slightly raised		8 (8.9)		5 (5.4)	
	High		5 (5.6)		5 (5.4)	
	Very high		6 (6.7)		9 (9.8)	
Year 3	Normal	86	72 (83.7)	88	68 (77.3)	$\chi^2(3) = 2.46$; $p = 0.48$
	Slightly raised		3 (3.5)		8 (9.1)	
	High		5 (5.8)		6 (6.8)	
	Very high		6 (7.0)		6 (6.8)	

(*Continued*)

TABLE 3. (*Continued*)

Clinical Cutoff Scores: Primary and Secondary Outcomes, Years 1–3 (Parent Report[a])

		Study Group		Comparison Group		
Time	**Cutoff Scores**	***n***	**Count (%)**	***n***	**Count (%)**	**χ^2 Test**
SDQ impact scale score[d]						
Year 1	Normal	98	48 (49.0)	108	44 (40.7)	$\chi^2(3) = 1.43$; $p = 0.70$
	Slightly raised		28 (28.6)		35 (32.4)	
	High		6 (6.1)		8 (7.4)	
	Very high		16 (16.3)		21 (19.4)	
Year 2	Normal	88	40 (45.5)	92	37 (40.2)	$\chi^2(3) = 1.62$; $p = 0.66$
	Slightly raised		23 (26.1)		21 (22.8)	
	High		7 (8.0)		11 (12.0)	
	Very high		18 (20.5)		23 (25.0)	
Year 3	Normal	86	42 (48.8)	87	36 (41.4)	$\chi^2(3) = 2.05$; $p = 0.56$
	Slightly raised		23 (26.7)		23 (26.4)	
	High		6 (7.0)		11 (12.6)	
	Very high		15 (17.4)		17 (19.5)	

SDQ = Strengths and Difficulties Questionnaire.

[a] Child-report clinical cutoff scores for the Behavioral Assessment Scale for Children, v.2, Emotional Symptoms Index are in Table S3 (http://links.lww.com/PCC/C592).

[b] Behavioral Assessment Scale for Children, v.2, Behavioral Symptoms Index clinical cutoff *t* scores: normal: < 60; at risk: 60–70; and clinically significant: > 70.

[c] SDQ total difficulties clinical cutoff *t* scores: normal: < 14; elevated: 14–16; high: 17–19; and very high: > 19.

[d] SDQ impact scale clinical cutoff *t* scores: normal: 0; elevated: 1; high: 2; and very high: > 2.

post-PICU hospitalization. In the quantitative arm, no group differences were found on the primary and secondary outcome measures. Findings from the telephone survey with a representative subsample of questionnaire respondents were expected to be consistent. While parents in both groups identified emotional and behavioral changes in their children, the nature of those changes and what they attributed them to differed substantially. Qualitative interview findings converged with SG parents' survey responses and provided a deeper understanding of the challenges confronting children and families. These findings suggest that our outcome measures failed to capture group differences due to a lack of conceptual convergence with reported child and family challenges post-PICU.

Other PICU cohort studies have explored children's psychological and behavioral outcomes within 1-year post-discharge using an external control group. Multidimensional measures, including the SDQ and Child Behavior Checklist (30, 31) did not identify group differences when a ward CG was used (32), but the SDQ did when a healthy CG was used (33). Measures

WHAT THIS STUDY MEANS

- Following PICU discharge, 44.3% of PICU parents at year 1 and 40.3% at year 3 reported negative emotional or behavioral changes in their children in our telephone survey suggesting a high proportion of children followed a chronic trajectory of pediatric medical traumatic stress.
- The interview findings were concordant with the survey findings in describing children's emotional and behavioral responses and their impact on the family; however, there were no group differences in outcomes suggesting they did not reflect the challenges confronting children and families.
- Families' perceptions of how the PICU experience impacted them are central to understanding children's psychological and behavioral outcomes.

TABLE 4.
Telephone Follow-Up Survey Questions

Time Post-Discharge	Survey Questions	Study Group		Comparison Group	
		n	%	*n*	%
1 year	Completed survey	79		88	
	Had trouble filling out the questionnaires? (yes)	7	8.9	5	5.7
	Child readmitted to the hospital since last follow-up call? (yes)	12	15.2	2	2.3
	Emotional or behavioral changes observed in child since last follow-up call?[a] (yes)	44	55.7	35	39.8
	1) Negative changes	35	44.3	25	28.4
	i) Attributed to hospitalization[b]		88.6		40.0
	ii) Attributed to normal developmental change/other life event[b]		5.7		44.0
	iii) Attributed to diagnosed mental health disorder/developmental delay[b]		5.7		16.0
	2) Positive changes	12	15.1	10	11.4
	i) Attributed to hospitalization[b]		91.7		100
	ii) Attributed to normal developmental change/other life event[b]		8.3		0
	Emotional or behavioral changes observed in child since last follow-up call?[a] (no)	35	44.3	53	60.2
	Spoke to family doctor or other support person about concerns? (yes)[c]	16	48.0	10	38.5
2 years	Completed survey	78		86	
	Had trouble filling out the questionnaires? (yes)	4	5.1	7	8.1
	Child readmitted to the hospital since last follow-up call? (yes)	13	16.7	3	3.5
	Emotional or behavioral changes observed in child since last follow-up call?[a] (yes)	43	55.1	29	33.7
	1) Negative changes	33	42.3	27	31.4
	i) Attributed to hospitalization[b]		93.9		37.0
	ii) Attributed to normal developmental change/other life event[b]		3.0		44.4
	iii) Attributed to diagnosed mental health disorder/developmental delay[b]		3.0		18.5
	2) Positive changes	10	12.8	3	3.4
	i) Attributed to hospitalization[b]		80.0		33.3
	ii) Attributed to normal developmental change/other life event[b]		2.0		66.7
	Emotional or behavioral changes observed in child since last follow-up call?[a] (no)	35	44.9	57	66.3
	Spoke to family doctor or other support person about concerns? (yes)[c]	11	31.4	13	48.1

(*Continued*)

TABLE 4. (*Continued*)
Telephone Follow-Up Survey Questions

Time Post-Discharge	Survey Questions	Study Group *n*	Study Group %	Comparison Group *n*	Comparison Group %
3 years	Completed survey	72		66	
	Had trouble filling out the questionnaires? (yes)	4	5.5	1	1.5
	Child readmitted to the hospital since last follow-up call? (yes)	11	15.3	0	0
	Emotional or behavioral changes observed in child since last follow-up call?[a] (yes)	33	45.8	17	25.7
	1) Negative changes	29	40.3	14	21.2
	i) Attributed to hospitalization[b]		93.0		21.4
	ii) Attributed to normal developmental change/other life event[b]		6.9		42.9
	iii) Attributed to diagnosed mental health disorder/developmental delay[b]		0		35.7
	2) Positive changes	6	8.3	3	4.5
	i) Attributed to hospitalization[b]		100		66.7
	ii) Attributed to normal developmental change/other life event[b]		0		33.3
	Emotional or behavioral changes observed in child since last follow-up call?[a] (no)	39	54.2	49	74.2
	Spoke to family doctor or other support person about concerns? (yes)[c]	18	60.0	11	64.7

[a] Both positive and negative changes identified in some children.

[b] Categories based on parents' descriptions of what changes were attributed to (open-ended question). Percent calculated based on total number of identified negative or positive changes.

[c] Percent calculated based on total number of parents who identified negative behavioral or emotional changes.

tailored to identify anxiety and depression showed no group differences (20, 32, 34). For post-traumatic stress disorder (PTSD), results vary. In two studies using a ward CG, one found more PTSD symptoms in the PICU group (34), whereas the other did not (20). A third study found no differences between the PICU SG and a CG of children who previously survived a fire disaster (35). Our findings highlight the need for careful CG selection and underscore the need to identify measures that tap into post-PICU psychological and behavioral challenges, echoing the recent development of a PICU core outcome set (PICU COS) (36), and PICU Core Outcome Measurement Set (37). In particular, the PICU COS-extended includes a family function domain, which our findings suggest reflects issues of central importance in the psychological recovery of children and families post-PICU and, as such, should be prioritized going forward.

The importance of family report to understanding long-term post-PICU recovery in children and their families was highlighted in qualitative interviews. By year 3, the PICU stay had become part of the child's and the family's narrative. While life would never be the same for some, the overall trajectory was toward recovery as parents better understood the child's condition regarding threat to life, risk for illness recurrence, or ongoing medical needs. Yet, many parents struggled to cope themselves while trying to protect their children from challenging medical information and their own emotional responses. Children, in turn, were aware their parents worried about them, and this dynamic impacted family relationships. As proposed in the PICS-p framework, future research must seek to understand child recovery within the context of the family (1).

A systematic review of the integrative model of PMTS using 216 studies of childhood trauma found that after exposure to a potentially traumatizing event most children and parents followed a resilient or recovery trajectory. That is, PTS symptoms resolved

TABLE 5.
Qualitative Themes

	Year 3: Becoming Part of the Family Story
	Theme 1. Moving past the PICU experience
Subthemes	Reframing and choosing to let go “We are trying to cope with it day after day. Okay, he’s not going to be a surgeon because he [won’t] be able to use both hands…But [saying], ‘he’s not okay’ doesn’t do you much good. He might be an English teacher. It’s the ‘he might’...and exposing him to [that].” (F8)
	Importance of ongoing support “She had a lot of support, a lot from the teachers, from the social worker, from the doctors. The weight of the feeling that she’s sick is not that heavy on us [now] because of the kind of support system around.” (F18)
	Integrating reminders and memories “It doesn’t take much for me to think back to [the PICU]. As time goes by, I see him grow and get better—not just physically, not just medically, just the anxiety and stuff. It’s getting better for both of us but it’s a slow process…it’s still [in] progress.” (F9)
	Theme 2. Learning to live with physical and cognitive changes
Subthemes	Integrating physical changes Yeah, you can see [his shunt]. If anybody asks or points, because like I said kids are weird, “What is this?,” he’s like “Transformers.” I had something to do with that. I said the transformers put a machine there.” (F3)
	Learning to parent a child with a cognitive disability He loves videogames. It’s a way of connecting socially as much as anything…We found certain games he just couldn’t handle. So, we found [one that’s] a little more manageable. (F14)
	“I am less sick than before” “I get out of breath less quickly and all that.” (F16, child)
	Theme 3. Altered relationships: persistent vulnerability and vigilance
Subthemes	Ongoing vigilance “We’re still super protective… much more so than I would like to be… It’s finding that delicate line between trying to encourage confidence and abilities and protecting. I don’t know if I always work it that well, but I try.” (F14)
	The vulnerable child “Even now when I go skating [dad’s] like ‘oh, don’t hurt yourself, don’t hurt yourself’… he didn’t want me to start skating again.” (F11, child)
	Trying to buffer difficult memories Parent 1: “It’s really tough.” Parent 2: “Because I have to be strong for her.” Parent 1: “Even at your lowest points, you have to be encouraging her. You don’t want her to see you in that state.” (F18)

within 3 months, vs. exhibiting a chronic (PTS symptoms/PTSD for 6–24 mo) or delayed-onset trajectory (10). In our survey, 44.3% of SG parents at year 1 and 54.2% at year 3 observed no emotional or behavioral changes in their children suggesting just over half of children followed a resilient or recovery trajectory of PMTS post-PICU. Further investigation into predictors of long-term emotional and behavioral resiliency and recovery post-PICU is warranted.

Negative emotional or behavioral changes were reported by 44.3% of SG parents at year 1 and 40.3% at year 3 suggesting they followed a chronic trajectory of PMTS. While CG-reported negative changes decreased over time, SG-reported changes did not and children continued to exhibit PTS symptoms such as ongoing health and hospital-related fears, frightening memories, heightened anxiety and ongoing emotional challenges at year 3. Consistent with year 3 interview findings, SG parents observed differences in their children’s perceptions of health and illness, leaving them with a heightened sense of vulnerability. When interviewed, parents linked their child’s vulnerability to heightened parental and sibling vigilance. Findings further underscore the need to understand child recovery within the context of the family and support the notion of multiple extended pathways of recovery post-PICU (1, 10).

There are some limitations to the "Caring Intensively" study (11, 12). First, it was limited by a 3-year attrition rate of 38%, which was slightly higher than expected. Those lost to follow-up did not differ significantly from those who remained in the study (**Table S6**, http://links.lww.com/PCC/C592). In addition, children who experienced repeated PICU admissions before enrollment were excluded, limiting generalizability. While we collected data regarding traumatic stress symptoms, we did not use standardized trauma measures. Inclusion in future studies is warranted. Finally, as is typical in longitudinal designs, families experienced life events that may have impacted the findings.

In conclusion, the "Caring Intensively" study enhances our understanding of children's psychological and behavioral responses over 3 years post-PICU hospitalization. Complementary survey and interview data provide critical insight into children's emotional and behavioral responses and their impact on the family, highlighting the need to study child recovery within the context of the family. Findings also contribute to our understanding of the nature and duration of trajectories of recovery following PICU hospitalization. The lack of conceptual convergence between outcome measures and family-reported challenges emphasizes the importance of prioritizing family-identified outcomes and speaks to the importance of mixed methods research in understanding child recovery following PICU hospitalization.

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1 *Department of Nursing and Division of Critical Care, Montreal Children's Hospital, McGill University Health Centre and Ingram School of Nursing and Department of Pediatrics, McGill University, Montreal, QC, Canada.*

2 *Division of General Pediatrics, Montreal Children's Hospital, McGill University Health Centre and Department of Pediatrics, McGill University, Montreal, QC, Canada.*

3 *Department of Critical Care, The Hospital for Sick Children (SickKids) and Child Health Evaluative Sciences, SickKids Research Institute, Toronto, ON, Canada.*

4 *School of Nursing, Dalhousie University and Department of Pediatrics, Neonatal-Perinatal Division, IWK Health, Halifax, NS, Canada.*

5 *Child Health and Human Development, Research Institute of the McGill University Health Centre, Montreal, QC, Canada.*

6 *Department of Psychology and Neuroscience, and Department of Pediatrics, Dalhousie University and the Centre for Pediatric Pain Research, IWK Health, Halifax, NS, Canada.*

7 *Department of Psychology and Centre for Research in Human Development, Concordia University, Montreal, QC, Canada.*

8 *Lawrence Bloomberg Faculty of Nursing, University of Toronto and SickKids Research Institute, The Hospital for Sick Children, Toronto, ON, Canada.*

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For information regarding this article, E-mail: janet.rennick@mcgill.ca

REFERENCES

1. Manning JC, Pinto NP, Rennick JE, et al: Conceptualizing post intensive care syndrome in children—the PICS-p framework. *Pediatr Crit Care Med* 2018; 19:298–300

2. Watson RS, Choong K, Colville G, et al: Life after critical illness in children—toward an understanding of pediatric post-intensive care syndrome. *J Pediatr* 2018; 198:16–24
3. Woodruff AG, Choong K: Long-term outcomes and the post-intensive care syndrome in critically ill children: A North American perspective. *Children (Basel, Switzerland)* 2021; 8:254
4. Ko MSM, Poh P-F, Heng KYC, et al: Assessment of long-term psychological outcomes after pediatric intensive care unit admission: A systematic review and meta-analysis. *JAMA Pediatr* 2022; 176:e215767
5. Le Brocque RM, Dow BL, McMahon H, et al: The course of posttraumatic stress in children: Examination of symptom trajectories and predictive factors following admission to pediatric intensive care. *Pediatr Crit Care Med* 2020; 21:e399–e406
6. de Pellegars A, Cariou C, Le Floch M, et al: Risk factors of post-traumatic stress disorder after hospitalization in a pediatric intensive care unit: A systematic literature review. *Eur Child Adolesc Psychiatry* 2023; 33:2991–3001
7. Abela KM, Wardell D, Rozmus C, et al: Impact of pediatric critical illness and injury on families: An updated systematic review. *J Pediatr Nurs* 2020; 51:21–31
8. Yagiela LM, Carlton EF, Meert KL, et al: Parent medical traumatic stress and associated family outcomes after pediatric critical illness: A systematic review. *Pediatr Crit Care Med* 2019; 20:759–768
9. Kazak AE, Kassam-Adams N, Schneider S, et al: An integrative model of pediatric medical traumatic stress. *J Pediatr Psychol* 2006; 31:343–355
10. Price J, Kassam-Adams N, Alderfer MA, et al: Systematic review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *J Pediatr Psychol* 2016; 41:86–97
11. Rennick JE, Dougherty G, Chambers C, et al: Children's psychological and behavioral responses following pediatric intensive care unit hospitalization: The caring intensively study. *BMC Pediatr* 2014; 14:1–11
12. Rennick JE, Knox AM, Treherne SC, et al: Family members' perceptions of their psychological responses one year following pediatric intensive care unit (PICU) hospitalization: Qualitative findings from the caring intensively study. *Front Pediatr* 2021; 9:724155
13. Creswell JW, Plano Clark VL: *Designing and Conducting Mixed Methods Research*. Los Angeles, CA, SAGE Publications, 2017
14. Pluye P, Hong QN: Convergence and divergence in mixed methods research. In: *International Encyclopedia of Education*. Fourth Edition. Tierney RJ, Rizvi F, Ercikan K (Eds). Amsterdam, The Netherlands, Elsevier, 2023, pp 462–477
15. Hong Q, Pluye P, Fàbregues S, et al: Mixed Methods Appraisal Tool (MMAT), Version 2018. Canadian Intellectual Property Office, Industry Canada, 2018. Available at: http://mixedmethodsappraisaltoolpublic.pbworks.com. Accessed April 15, 2020
16. Hong QN, Pluye P, Fàbregues S, et al: Improving the content validity of the mixed methods appraisal tool: A modified e-Delphi study. *J Clin Epidemiol* 2019; 111:49–59.e1
17. Kamphaus RW, VanDeventer MC, Brueggemann A, et al: Behavior assessment system for children. In: *The Clinical Assessment of Children and Adolescents*. Smith SR, Handler L (Eds). New York, NY, Routledge, 2014, pp 311–326
18. Goodman R: Psychometric properties of the strengths and difficulties questionnaire. *J Am Acad Child Adolesc Psychiatry* 2001; 40:1337–1345
19. Harter S, Pike R: The pictorial scale of perceived competence and social acceptance for young children. *Child Dev* 1984; 55:1969–1982
20. Rennick JE, Johnston CC, Dougherty G, et al: Children's psychological responses after critical illness and exposure to invasive technology. *J Dev Behav Pediatr* 2002; 23:133–144
21. Pollack MM, Patel KM, Ruttimann UE: PRISM III: An updated Pediatric Risk of Mortality score. *Crit Care Med* 1996; 24:743–752
22. Rennick JE, McHarg LF, Dell'Api M, et al: Developing the children's critical illness impact scale: Capturing stories from children, parents, and staff. *Pediatr Crit Care Med* 2008; 9:252–260
23. Vernon DT, Schulman JL, Foley JM: Changes in children's behavior after hospitalization. Some dimensions of response and their correlates. *Am J Dis Child* 1966; 111:581–593
24. Thompson RH, Vernon DT: Research on children's behavior after hospitalization: A review and synthesis. *J Dev Behav Pediatr* 1993; 14:28–35
25. Spielberger CD: *STAI Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA, Consulting Psychologists Press, 1970
26. Abidin R, Flens JR, Austin WG: *The Parenting Stress Index*. Mahway, NJ, Lawrence Erlbaum Associates Publishers, 2006
27. Burnard P: A method of analysing interview transcripts in qualitative research. *Nurse Educ Today* 1991; 11:461–466
28. Strauss A, Corbin J: *Basics of Qualitative Research Techniques*. Thousand Oaks, CA, Sage Publications, 1998
29. McCrudden MT, Marchand G, Schutz PA: Joint displays for mixed methods research in psychology. *Methods Psychol* 2021; 5:100067
30. Achenbach TM: *Manual for ASEBA School-Age Forms & Profiles*. Burlington, VT, University of Vermont, Research Center for Children, Youth & Families, 2001
31. Achenbach TM, Rescorla LA: *Manual for the ASEBA Preschool Forms and Profiles*. Burlington, VT, University of Vermont, Research Center for Children, Youth & Families, 2000
32. Boeschoten SA, Dulfer K, Boehmer AL, et al: Quality of life and psychosocial outcomes in children with severe acute asthma and their parents. *Pediatr Pulmonol* 2020; 55:2883–2892
33. Als LC, Picouto MD, Hau SM, et al: Mental and physical well-being following admission to pediatric intensive care. *Pediatr Crit Care Med* 2015; 16:e141–e149
34. Rees G, Gledhill J, Garralda ME, et al: Psychiatric outcome following paediatric intensive care unit (PICU) admission: A cohort study. *Intensive Care Med* 2004; 30:1607–1614
35. Bronner MB, Knoester H, Bos AP, et al: Posttraumatic stress disorder (PTSD) in children after paediatric intensive care treatment compared to children who survived a major fire disaster. *Child Adolesc Psychiatry Ment Health* 2008; 2:9

36. Fink EL, Maddux AB, Pinto N, et al; Pediatric Outcomes STudies after PICU (POST-PICU) Investigators of the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI) Network and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN): A core outcome set for pediatric critical care. *Crit Care Med* 2020; 48:1819–1828

37. Pinto NP, Maddux AB, Dervan LA, et al; POST-PICU Investigators of the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI) Network and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN): A core outcome measurement set for pediatric critical care. *Pediatr Crit Care Med* 2022; 23:893–907