

Parent Activation and Traumatic Stress in the Pediatric Intensive Care Unit

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Abstract

Background

Nearly all parents in the PICU experience traumatic stress. Separately, *parent activation* is a measure of knowledge, confidence, and willingness to engage in the management of a child's health. We aimed to identify associations between parent activation, parent traumatic stress, the passage of time, and factors that may influence parent traumatic stress in the PICU.

Methods

This was a single-center, prospective study of parents with a child in the PICU. Data were obtained via two surveys, one within 48 hours of PICU admission and a second one month later.

Results

A sample of 101 parents of 74 patients completed the initial survey. Of these, 44 completed the follow-up. Parent activation and traumatic stress near PICU admission were associated with activation ($r = 0.61$, $p < 0.001$) and traumatic stress ($r = 0.63$, $p < 0.001$) one month later, respectively. On admission, parents with more preexisting depression and anxiety reported more traumatic stress ($r = 0.36$, $p = 0.001$ and $r = 0.35$, $p = 0.004$), and parents who reported more background life stressors also reported more traumatic stress ($r = 0.29$, $p = 0.002$). One month after admission, parents who thought having a written daily schedule for their child was or could be helpful reported less stress (0.34 vs. 1.05, $p = 0.001$), and the more helpful they found the schedule, the less stress they reported ($r = -0.65$, $p = 0.003$). The perceived helpfulness of a chaplain correlated with parent activation at admission ($r = 0.3$, $p = 0.009$) and follow-up ($r = .48$, $p = 0.007$), and parental use of a support website was associated with higher parent activation at admission (80 vs. 70, $p = 0.010$).

Conclusions

Parent activation and parent traumatic stress symptoms within 48 hours of PICU admission predict activation and traumatic stress at one-month follow-up. Parent traumatic stress is associated with parent depression, anxiety, and background life stressors. It is inversely associated with the recognition, use, and perceived helpfulness of parent supports. Parent activation is positively associated with the recognition, use, and perceived helpfulness of supports. These findings advance the theory that parent activation is a relevant concept in the framework of factors that influence parent traumatic stress in the PICU.

Background

Nearly all parents in the pediatric intensive care unit (PICU) experience traumatic stress, and up to one quarter of parents with a child in the PICU meet the diagnostic criteria for post-traumatic stress disorder (PTSD) (1–4). The high incidence of PICU parent traumatic stress is significant. Parents in the PICU describe “near-panic” traumatic stress symptoms including insomnia, anorexia, difficulty concentrating, and an inability to ask questions (5). Parent traumatic stress adversely impacts the psychological outcomes of PICU patients, as well (6).

Miles et al. presented a conceptual framework which proposes parent traumatic stress arises from environmental, situational, and personal factors (7). Loss of the parental role is a key element of the PICU environment that contributes to parent traumatic stress (8). Separately, parent *activation* is a measure of parent knowledge, confidence, and willingness to engage in the management of a child’s health (9).

We hypothesized that parent activation would be associated with parental recognition, utilization, and perceived helpfulness of parent supports in the PICU. Parents with higher activation may feel more secure in their parental role, so we hypothesized that parent activation would be inversely related to parent traumatic stress. Finally, we aimed to identify associations between parent activation, parent traumatic stress, the passage of time, and the environmental, situational, and personal factors that may influence the parent traumatic stress experience in the PICU.

Methods

Study Design

This was a single-center, prospective, survey-based study of parents with a child in the PICU approved by the hospital’s institutional review board. We measured parent traumatic stress and parent activation and assessed environmental, situational, and personal factors which may influence the parent traumatic stress experience. Parent recognition, utilization, and perceived helpfulness of supports was also measured. Data were obtained via two surveys and chart review, as summarized in Table 1.

Table 1
Study Design

T₁ Survey Packet	T₂ Survey Packet	Chart Review
1. Acute Stress Disorder Scale	1. Impact of Events Scale-Revised	1. Source of admission (direct, ER, OR, acute care, or NICU)
2. Parent Patient Activation Measure	2. Parent Patient Activation Measure	2. Presentation by car, ambulance, or flight
3. Inventory of Life Changes	3. Parent Support Perception Inventory	3. Scheduled vs. unplanned admission
4. PROMIS-SF for Anxiety		4. Presence of common PICU diagnoses (asthma, pneumonia, and bronchiolitis)
5. PROMIS-SF for Depression		5. Consulting services involved
6. Parent Support Perception Inventory		6. Respiratory support required
7. Demographic questions		7. Type of alimentation
		8. Neurotropic infusions required
		9. Operative procedures preformed
		10. Length of PICU and hospital stays
		11. Readmissions to the hospital or PICU within a month of discharge (yes vs. no)
		12. Insurance type
Abbreviations: PROMIS-SF: Patient-Reported Outcomes Measurement Information System, short forms; ER: Emergency Room; OR: Operating room; NICU: Neonatal intensive care unit; PICU: Pediatric intensive care unit		

We invited up to two parents per child to participate. The study included a convenience sample of adult parents in a 72-bed, quaternary-care, medical and surgical PICU. The parents of children admitted for suspected child abuse, suicide attempt, and immediately fatal conditions were excluded. Parents with limited English proficiency were also excluded if they could not complete the consent process and surveys in English.

Data Collection

The survey packets evaluated the primary variables (parent activation and parent traumatic stress), psychosocial and demographic factors, and perception of parent support resources. Parents were approached at their child's bedside and received the enrollment survey packet within 48 hours of PICU admission (T₁). One month later (T₂), we administered a follow-up survey packet. If the children were not

in the hospital at T₂, we mailed the parent a survey packet with a self-addressed, stamped envelope. We did not follow up with non-respondents. All responses were entered into a Research Electronic Data Capture (REDCap) database (10). To study our primary variables in the context of clinical factors that might influence parent stress, one author (MJO) performed a chart review to identify the clinical variables shown in Table 1.

Psychometric Instruments

Parent activation was measured by Patient Activation Measure® - Parent (PPAM) from Insignia Health, a self-report inventory of parental knowledge, confidence, and willingness to manage a child's health (9). Content validity was established by the PPAM's parallel structure to the well-validated Patient Activation Measure (11). The PPAM's 13 items (Additional File 1) are presented to subjects who state their level of agreement using a 4-point modified Likert scale. Greater agreement with the instrument's statements corresponds to higher parent activation.

Parent traumatic stress was measured with inventories of traumatic stress specific to the time of measurement. The Acute Stress Disorder Scale ($\alpha = 0.94$), based on *Diagnostic and Statistical Manual of Mental Disorders-IV-TR* (DSM-IV-TR) criteria for the disorder (12), was used at T₁. The Impact of Events Scale-Revised ($\alpha = 0.79-0.92$), which measures traumatic stress symptoms consistent with DSM-IV-TR criteria for PTSD (13), was used at T₂. Neither instrument is diagnostic of its respective disorder; rather, each provides a numeric assessment of the symptomatic burden of stress related to a traumatic event.

The psychological factors of preexisting parent anxiety and depression were measured by the Patient-Reported Outcomes Measurement Information System short forms for anxiety and depression ($\alpha = 0.93-0.95$) (14). The Inventory of Life Changes ($\alpha = 0.81$) was used to measure parents' background life stressors (15).

To study parent recognition, utilization, and perceived helpfulness of supports in the PICU, we designed a Parent Support Perception Inventory. Nurses, chaplains, social workers, physicians, and child life specialists created an exhaustive list of supports available to parents in the PICU. Three authors (MJO, KJL, and KAM) shortened the list to 17 items (Additional File 2) for instrument brevity, clarity, and relevance. For each support item, subjects were asked if they recognized that the support was available, whether they used the support, and if they thought the support was or could be helpful.

Analysis

After descriptive analysis, Wilcoxon rank sum tests were used to compare medians, and Spearman's *rho* was used to assess for correlations. To eliminate correlated errors between parents of the same child, median scores were reported separately for mothers and fathers.

One-third of the PICU bed spaces were dedicated to cardiac surgery patients; therefore, sub-group analysis of parent activation and parent stress was performed for children who required procedures with cardiopulmonary bypass. Sub-group analysis was also performed for dyad (patient and only one parent

reporting) and triad (patient and two parents reporting). These *a priori*-planned subgroup analyses were reported only if groups contained 10 or more subjects.

Exploratory analyses were conducted to identify potential relationships between the environmental, situational, and personal factors from the framework and parent activation and parent traumatic stress. Given the large number of variables and relatively small sample size, results were considered statistically significant only if $p \leq 0.01$. All analyses were performed in R Version 3.6.0 (16).

Results

Sample Description

We approached caregivers from 123 of 144 eligible families during a 2-month study window in 2015; 101 parents of 74 patients enrolled and completed the initial survey packet. Of these, 44 completed the follow-up survey packet. Follow-up completers and non-completers had similar stress and activation at T_1 . Demographic and clinical characteristics of the children and parents are presented in Tables 2 and 3.

Table 2
Patient Demographic and Clinical Characteristics

Demographic / Characteristic	Number	Percentage
Patient Sex		
Male	44	59%
Patient Age		
Mean and SD	4 years ± 4	
Range	5 days – 12 years	
Prenatal Diagnosis		
Yes	26	35%
Medical Complexity Team Consultation		
Special Needs	13	18%
Palliative Care	5	7%
Nature of Admission		
Scheduled	21	28%
Unplanned	51	69%
Origin of PICU Admission		
Emergency room	25	34%
Operating room	22	30%
Admitting or inter-facility transport	21	28%
Intra-facility transport	8	11%
Procedures and Support Required		
At least one procedure	44	59%
Cardiopulmonary bypass	19	26%
Brain surgery	2	3%
Spinal surgery	5	7%
Otolaryngology procedure	16	22%
Laparotomy	8	11%
Endotracheal tube	28	38%
Tracheostomy tube in situ	11	15%

Demographic / Characteristic	Number	Percentage
Hospital Length of Stay		
Mean and SD	12 days ± 20	
Range	2-162 days	
PICU Length of Stay		
Mean and SD	6 days ± 7	
Range	2-54 days	
Abbreviation: SD, standard deviation		

Table 3
Parent Demographic Characteristics

Participation Category	#	%
One parent-child dyad	47	47%
Two parent-child triad	54	53%
Relationship Status (if a parent-child triad)		
Living with other parent	42	78%
Living apart from other parent	12	22%
Relationship to Child		
Mother	68	67%
Father	28	28%
Other (excluded from analysis)	5	5%
Age of Parent		
Teens (18 and 19 years old)	2	2%
20s	24	24%
30s	43	43%
40s	25	25%
50s or older	7	7%
Parent Race		
Black	8	8%
White	90	89%
Other or did not answer	3	3%
Parent Ethnicity		
Hispanic	4	4%
Non-Hispanic	87	86%
Not reported	10	10%
Parent Education Level		
Not a college graduate	54	53%
College graduate	47	47%
Health Insurance Status		

Participation Category	#	%
Only government-subsidized insurance	36	36%
At least some private insurance	65	64%

Over half of the children (n = 44, 59%) required at least one surgical procedure, and one-quarter of the children underwent procedures that required cardiopulmonary bypass. The average length of PICU stay was just under one week.

Parent Activation and Parent Traumatic Stress

Parent activation at T₁ was moderately associated with activation at T₂ (r = 0.61, p < 0.0001), and parent traumatic stress at T₁ was moderately associated with traumatic stress at T₂ (r = 0.63, p < 0.0001). That association between early and late parent activation and traumatic stress was also observed among several analyzed subgroups (Table 4).

Table 4
Parent Activation and Traumatic Stress at T₁ Predict Activation and Stress at T₂

	A. Activation at T ₁ and T ₂			B. Stress at T ₁ and T ₂		
	n	r	p	n	r	p
All Parents	41	0.61	< 0.001*	39	0.63	< 0.001*
Mothers	31	0.61	< 0.001*	30	0.62	< 0.001*
Fathers	10	0.62	0.057	9	NR	
Dyad Mothers	19	0.60	0.007*	18	0.51	0.032
Triad Mothers	12	0.62	0.032	12	0.79	0.002*
NCPB Mothers	25	0.47	0.018	24	0.59	0.002*
CPB Mothers	6	NR		6	NR	

Abbreviations: r, Spearman's rho; NCPB Mothers, mothers of children who did not require cardiopulmonary bypass; CPB Mothers, mothers of children who required cardiopulmonary bypass; NR, not reported; *indicates statistical significance

With the exception of one subgroup of 19 dyad mothers (mothers-child dyads without a second parent), there were no significant associations between parent stress and activation (Table 5). Amongst the group of mothers who participated without a second parent, there was a moderate correlation between stress at T₁ and activation at T₂ (r = 0.64, p = 0.004).

Table 5
Associations between Parent Activation and Parent Stress

	A. Activation at T ₁ and Stress at T ₁			C. Activation at T ₂ and Stress at T ₁		
	n	r	p	n	r	p
All Parents	96	0.04	0.690	41	0.23	0.148
Mothers	68	0.17	0.161	31	0.38	0.028
Fathers	28	-0.38	0.047	10	-0.31	0.380
Dyad Mothers	41	0.32	0.043	19	0.64	0.004*
Triad Mothers	27	-0.09	0.653	12	-0.15	0.649
NCPB Mothers	57	0.14	0.308	25	0.38	0.059
CPB Mothers	11	0.4	0.219	6	NR	
	B. Activation at T ₁ and Stress at T ₂			D. Activation at T ₂ and Stress at T ₂		
	n	r	p	n	r	p
All Parents	39	0.06	0.735	39	-0.06	0.724
Mothers	30	0.12	0.544	30	0.04	0.853
Fathers	9	NR		9	NR	
Dyad Mothers	18	0.33	0.177	18	0.09	0.713
Triad Mothers	12	-0.31	0.332	12	0.09	0.783
NCPB Mothers	24	0.24	0.267	24	0.01	0.968
CPB Mothers	6	NR		6	NR	
Abbreviations: r, Spearman's rho; NCPB Mothers, mothers of children who did not require cardiopulmonary bypass; CPB Mothers, mothers of children who required cardiopulmonary bypass; NR, not reported; *indicates statistical significance						

Parent Activation and Context Variables

The use and perceived helpfulness of supports was significantly associated with parent activation by two variables (Table 6). The perceived helpfulness of a chaplain correlated with parent activation at T₁ ($r = 0.3, p = 0.009$) and T₂ ($r = .48, p = 0.007$), and parental use of a support website was associated with higher parent activation at T₁ (80 vs. 70, $p = 0.010$). Other observed associations between parent activation and study variables ($0.01 < p < 0.05$) are displayed in Table 6 and discussed below.

Table 6
Variables Associated with Parent Activation

Variable	Variable Measure	Activation Measure	Median Activation No vs. Yes	r	n	p
Perceived helpfulness of a chaplain	T ₁	T ₁		0.30	68	0.007*
Perceived helpfulness of a chaplain	T ₂	T ₂		0.48	29	0.007*
Did the parent visit a support website?	T ₁	T ₁	70 vs. 85		68	0.010*
Did the parent consult a chaplain?	T ₁	T ₁	70 vs. 81		68	0.015
Did the parent look at pictures of the PICU?	T ₁	T ₁	70 vs. 81		68	0.017
Perceived helpfulness of pictures of the PICU	T ₁	T ₁		0.25	68	0.023
Did the parent know frequent physician updates were available?	T ₂	T ₁	53 vs. 73		30	0.024
Were/could frequent updates from physician (be) helpful?	T ₂	T ₁	53 vs. 73		30	0.024
Perceived helpfulness of a way to share your story	T ₂	T ₂		0.41	29	0.024
Was/could a list of daily goals (be) helpful?	T ₂	T ₂	61 vs. 77		29	0.026
Did the parent meet with a chaplain?	T ₁	T ₂	70 vs. 100		30	0.028
Did the parent stay at the Ronald McDonald House?	T ₁	T ₁	70 vs. 63		68	0.029
Was/could a glossary of common PICU terms (be) helpful?	T ₁	T ₁	74 vs. 65		68	0.031
Did the child receive a continuous paralytic medication?	CR	T ₁	70 vs. 59		68	0.032
Was the parent older than 39 years old?	T ₁	T ₁	73 vs. 65		68	0.033
Perceived helpfulness of a list of daily goals	T ₂	T ₂		0.38	29	0.033
Did the parent know supplies to groom child were available?	T ₁	T ₁	57 vs. 70		68	0.035

Variable	Variable Measure	Activation Measure	Median Activation No vs. Yes	r	n	p
Perceived helpfulness of parent support groups	T ₂	T ₁		0.34	30	0.036
Was/could a chaplain (be) helpful?	T ₂	T ₂	69 vs. 81		29	0.036
Was/could a chaplain (be) helpful?	T ₁	T ₁	68 vs. 75		68	0.037
Was/could an online video about the PICU (be) helpful?	T ₁	T ₁	71 vs. 65		68	0.038
Was a plastic surgeon consulted?	CR	T ₁	70 vs. 49		68	0.041
Did the parent know they could stay in child's room?	T ₁	T ₁	65 vs. 73		68	0.042
Perceived helpfulness of a glossary of common PICU terms	T ₁	T ₁		-.24	68	0.044
Was/could having a way to share your story (be) helpful?	T ₂	T ₂	68 vs. 83		29	0.044
Were/could parent-child activities (be) helpful?	T ₂	T ₂	61 vs. 75		29	0.048
Perceived helpfulness of frequent physician updates	T ₂	T ₁		0.31	30	0.050
Abbreviations: r = Spearman's rho; PICU = pediatric intensive care unit; CR = chart review; *indicates statistical significance.						
Median activation scores are reported for dichotomous variables, and Spearman's <i>rho</i> is reported for continuous variables.						

Parent Stress and Context Variables

Parent traumatic stress was associated with several variables including background life stress, preexisting depression and anxiety, clinical factors, and the perceived helpfulness of various parent support items (Table 7). At T₁ parents with more preexisting depression and anxiety reported more stress ($r = 0.36, p = 0.001$ and $r = 0.35, p = 0.004$, respectively). Parents who reported more background life stressors also reported higher stress at T₁ ($r = 0.29, p = 0.002$). Parents who stayed in the hospital rather than elsewhere reported more stress at T₁ (45 vs. 31, $p = 0.006$). At T₂ parents who thought having a written daily schedule for their child was or could be helpful reported less stress (0.34 vs. 1.05, $p = 0.001$); the more helpful they found the schedule, the less stress they reported ($r = -0.65, p = 0.003$). Other observed associations between parent traumatic stress symptoms and study variables ($0.01 < p < 0.05$) are displayed in Table 7 and discussed below.

Table 7
Variables Associated with Parent Traumatic Stress

Variable	Variable Measure	Traumatic Stress Measure	Median Traumatic Stress No vs. Yes	r	n	p
Preexisting Depression Score	T ₁	T ₁		0.36	68	0.001*
Was/could a written schedule for the child (be) helpful?	T ₂	T ₂	1.05 vs. 0.34		28	0.001*
Background Life Stressors Score	T ₁	T ₁		0.29	68	0.002*
Perceived helpfulness of a written daily schedule for the child	T ₂	T ₂		-0.65	28	0.003*
Preexisting Anxiety Score	T ₁	T ₁		0.35	68	0.004*
Did the parent stay the nights in the hospital (as opposed to at home or a hotel, etc.)?	T ₁	T ₁	31 vs. 45		68	0.006*
Did the patient have a diagnosis of asthma?	CR	T ₁	38 vs. 23.5		68	0.011
Perceived helpfulness of the parent being able to stay in the child's room	T ₂	T ₂		-0.45	28	0.011
Was/could a parent staying in child's room (be) helpful? (Step 2 - Y/N)	T ₂	T ₂	1.14 vs. 0.55		28	0.012
Was a physical medicine and rehabilitation physician consulted?	CR	T ₁	36 vs. 53.5		68	0.03
Days between the last procedure and T ₂	CR	T ₂		-0.56	16	0.03
Was the patient fed via a surgical feeding tube?	CR	T ₂	1.05 vs. 0.36		28	0.030
Did the parent know a chaplain was available?	T ₂	T ₂	1.14 vs. 0.55		28	0.031
Did the parent participate in daily rounds?	T ₂	T ₁	60 vs. 32		30	0.032
Was the patient fed via a nasal or oral feeding tube?	CR	T ₂	0.55 vs. 1.05		28	0.033
Preexisting Depression Score	T ₁	T ₂		0.19	28	0.033

Variable	Variable Measure	Traumatic Stress Measure	Median Traumatic Stress No vs. Yes	r	n	p
Did the parent know parent he/she was invited to participate in daily rounds?	T ₂	T ₁	64 vs. 32		30	0.034
Was/could parent participation in daily rounds (be) helpful?	T ₂	T ₁	64 vs. 32		30	0.034
Did the parent know pictures of the PICU were available?	T ₁	T ₂	0.705 vs. 0.18		28	0.035
Did the parent know support groups were available?	T ₂	T ₂	0.795 vs. 0.315		28	0.035
Did the child have medical complexity before the index admission?	CR	T ₂	1.05 vs. 0.55		28	0.036
Did the parent participate in a multidisciplinary care conference?	T ₂	T ₂	0.55 vs. 1.36		28	0.036
Was the patient seen by a pediatric general surgeon?	CR	T ₂	0.59 vs. 1.36		28	0.037
Did the patient receive a continuous infusion of opioids?	CR	T ₁	32 vs. 47		68	0.040
Did the patient have an otolaryngology or airway procedure?	CR	T ₂	0.57 vs. 1.25		28	0.042
Did the parent participate in a multidisciplinary care conference?	T ₁	T ₁	32 vs. 45		68	0.043
Was an oral or nasal breathing tube used?	CR	T ₂	0.55 vs. 1.05		28	0.046
Did the parent know a written daily schedule for the child was available?	T ₂	T ₂	0.935 vs. 0.455		28	0.047
Is involving other family members helpful?	T ₁	T ₂	0.82 vs. 0.55		28	0.048
Did the parent know an internet video of the PICU was available?	T ₂	T ₂	0.795 vs. 0.295		28	0.050
Abbreviations: r, Spearman's rho; PICU, pediatric intensive care unit; CR, chart review; *indicates statistical significance.						
Median traumatic stress scores are reported for dichotomous variables, and Spearman's rho is reported for continuous variables.						

Discussion

This is the first study to measure parent activation among parents of children in the PICU. It incorporates the concept of parent activation into complex framework of elements already known to influence parent traumatic stress in the PICU, thus giving clinicians interested in family-centered care another factor to consider when assessing parent wellbeing, traumatic stress, and ability to engage in the child's treatment. The study identified several associations among parent activation, parent traumatic stress, the passage of time, and the environmental, situational, and personal context variables for parents with a child in the PICU. The associations are meaningful with practical applications to family-centered care and implications for further research. Of particular relevance, as PICUs revise visitation policies to slow the spread of COVID-19, we must consider how altered visitation might affect parent activation and, accordingly, the parent traumatic stress experience, in total.

Parent traumatic stress and parent activation within 48 hours of PICU admission were associated with traumatic stress and activation one month later. The one-month follow-up timeframe is important because the study suggests early screening for parent traumatic stress can identify parents at higher risk for PTSD symptoms one month later. Early identification of parents at high risk of PTSD could help PICU providers prioritize limited mental health resources, such as psychology and social work consultation, for these families.

We hypothesized that parent activation would be associated with increased parental recognition, utilization, and perceived helpfulness of parent supports in the PICU. Indeed, the identified associations between parent activation and the perceived helpfulness of chaplaincy, as well as between parent activation and parent use of support websites, supports the theory that parent activation is a relevant concept in the framework of factors that may influence parent stress. Furthermore, parent recognition, use, and perceived helpfulness of nine items on the support inventory was positively associated with parent activation at p values greater than our significance criterion but still relatively low ($0.01 < p \leq 0.05$). This contrasts with only three support items negatively associated with parent activation at $0.01 < p \leq 0.05$. Any of these associations individually could be due to chance, but we believe that taken as a whole, the identified relationship is parental recognition, use, and perceived helpfulness of support items is associated with increased parent activation.

Since loss of the parental role is a key element of the PICU environment that contributes to parent stress, we hypothesized parent traumatic stress would be inversely proportional to parent activation. The study did not support this hypothesis; in fact, amid a subgroup of mothers who responded to the survey without a parent-partner, we observed the opposite relationship between parent stress at T_1 and activation at T_2 . Though we theorized parents with high activation may feel more secure in their parental role and, thus, have less traumatic stress, the hypothesis may have been flawed in that counter-regulatory relationships do not necessarily entail inverse proportionality, especially in complex systems. We think these were the most interesting findings our study. They challenge the conception that parents who seem confident in their parental role experience less traumatic stress. Further research should explore a possibly counter-

regulatory relationship between parent activation and parent traumatic stress as well as the idea that, for certain parents, early traumatic stress in the context of a child's illness may prime parent activation in the future.

Parent traumatic stress in the PICU was associated with the personal factors of depression, anxiety, and background life stressors, consistent with previous findings (17). This finding indicates an assessment of family stress may be warranted on PICU admission. Parents who stayed in the hospital reported more stress than parents who stayed elsewhere. At our significance criterion of $p \leq 0.01$, the perceived helpfulness of a written daily schedule at T_2 was associated with decreased parent stress, so emphasizing communication amongst the care team to establish daily goals for a patient may be a helpful way to decrease parent stress in the PICU. The recognition, use, and perceived helpfulness of seven items on the support inventory was associated with decreased parent traumatic stress at p values greater than our significance criterion but still relatively low ($0.01 < p \leq 0.05$). This contrasts with only one item (the use of multidisciplinary care conference) that was associated with increased parent stress at $0.01 < p \leq 0.05$.

Conclusions

Parent activation and parent traumatic stress symptoms within 48 hours of PICU admission predicted activation and PTSD symptoms at one-month follow-up; this finding supports early screening in PICU admissions to identify parents at risk for sustained parent traumatic stress. Parent traumatic stress is associated with parent depression, anxiety, and background life stressors. It is inversely associated with the recognition, use, and perceived helpfulness of parent support items. At the same time, parent activation is associated with increased parent recognition, use, and perceived helpfulness of support items, advancing the theory that parent activation is a relevant concept in the framework of factors that influence parent traumatic stress in the PICU.

List Of Abbreviations

Pediatric intensive care unit (PICU)

Post-traumatic stress disorder (PTSD)

Research Electronic Data Capture (REDCap)

Patient Activation Measure® - Parent (PPAM)

Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR)

Declarations

Ethics Approval and Consent to Participate

The Children's Hospital Institutional Review Board approved the study (approval 649759-7), and consent to participate was obtained from parents at the time of enrollment. The study methods were carried out in accordance with all applicable institutional, state, and federal guidelines and regulations.

Consent for Publication

Not applicable

Availability of Data and Materials

The datasets generated and analyzed during the study are not publicly available due to limitations of ethical approval involving the patient data and anonymity but are available from the corresponding author upon reasonable request.

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

MO devised the project and wrote the initial manuscript draft.

RG analyzed and interpreted the data.

All authors edited the manuscript and read and approved the final version.

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Authors' Information (optional)

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References

1. Balluffi A, Kassam-Adams N, Kazak A, et al: Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatr Crit Care Med.* 2004; 5:547–553.

2. Stowman S, Kearney CA, Daphtary K. Mediators of initial acute and later posttraumatic stress in youths in a pediatric intensive care unit. *Pediatr Crit Care Med*. 2015; 16:e113-118.
3. Bronner MB, Knoester H, Bos AP, et al: Follow-up after paediatric intensive care treatment: parental posttraumatic stress. *Acta Paediatr*. 2008; 97:181–186.
4. Bronner MB, Peek N, Knoester H, et al: Course and predictors of posttraumatic stress disorder in parents after pediatric intensive care treatment of their child. *J Pediatr Psychol*. 2010; 35:966–974.
5. Huckabay LM, Tilem-Kessler D. Patterns of parental stress in PICU emergency admission. *Dimens Crit Care Nurs*. 1999; 18:36–42.
6. Melnyk BM, Alpert-Gillis L, Feinstein NF, et al: Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics*. 2004; 113:e597-607.
7. Miles MS, Carter MC. Sources of parental stress in pediatric intensive care units. *Child Health Care*. 1983; 11:65–69.
8. Carter MC, Miles MS, Buford TH, Hassanein RS. Parental environmental stress in pediatric intensive care units. *Dimens Crit Care Nurs*. 1985; 4:180–188.
9. Pennarola BW, Rodday AM, Mayer DK, et al: Factors associated with parental activation in pediatric hematopoietic stem cell transplant. *Med Care Res Rev*. 2012; 69:194–214.
10. Harris PA, Taylor R, Thielke R, et al: Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009; 42:377–381.
11. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004; 39:1005–1026.
12. Bryant RA, Moulds ML, Guthrie RM. Acute stress disorder scale: A self-report measure of acute stress disorder. *Psychol Assess*. 2000; 12:61–68.
13. Creamer M, Bell R, Failla S. Psychometric properties of the Impact of Event Scale - Revised. *Behav Res Ther*. 2003; 41:1489–1496.
14. Pilkonis PA, Choi SW, Reise SP, et al: Item banks for measuring emotional distress from the Patient-Reported Outcomes Measurement Information System (PROMIS®): depression, anxiety, and anger. *Assessment*. 2011; 18:263–283.
15. Holmes TH, Rahe RH. The Social Readjustment Rating Scale. *J Psychosom Res*. 1967; 11:213–218.
16. R Core Team (2019). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. Available at: <https://www.R-project.org/>. Accessed June 19, 2021.
17. Woolf C, Muscara F, Anderson VA, McCarthy MC. Early traumatic stress responses in parents following a serious illness in their child: a systematic review. *J Clin Psychol Med Settings*. 2016; 23:53–66.

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