SHORT RESEARCH PAPER: Post-traumatic stress trajectories of children and their parents over the year following intensive care discharge: a secondary analysis

Gillian Colville PhD1

Christine M Pierce MBBS2

1Population Health Research Institute, St George’s, University of London, UK

2Paediatric Intensive Care Unit, Great Ormond St Hospital, London, UK

Address for correspondence:

Dr Gillian Colville, Consultant Clinical Psychologist

Population Health Research Institute, St George’s, University of London

Cranmer Terrace, London SW17 0RE

gcolvill@sgul.ac.uk

ORCID ID 0000-0001-8530-2822

ETHICS: Ethics approval was obtained from the Great Ormond Street Hospital/Institute of Child Health Research Ethics Committee (ref 03AR12)

CONFLICT OF INTEREST: The authors declare they have no conflicts of interest

PATIENT CONSENT: Written informed consent was obtained for all participants

DATA: available from authors on request

FUNDING: The original study was funded by a Leading Practice Through Research Award to the first author from The Health Foundation, UK

Keywords: Post-Intensive Care Syndrome (PICS); Post-traumatic stress disorder (PTSD); outcomes; resilience; recovery

ABSTRACT

Background: New research in the field of psychological trauma has emphasised a) the heterogeneity of psychological reactions after traumatic events and b) the existence of distinct symptom trajectories.

Aims: In this study, existing data on post-traumatic stress disorder (PTSD) symptoms in 66 parent-child dyads, were re-examined in the light of this literature in order to establish whether a similar pattern of symptom trajectories also applies to this population.

Design: A prospective observational cohort study

Method: Participants’ Post-traumatic stress disorder (PTSD) symptoms were assessed 3 months and 12 months after discharge from a Paediatric Intensive Care Unit (PICU), using a short form of the Davidson Trauma Scale with parents and the Child Revised Impact of Events Scale with children aged 7y to 17y.

Results: Results confirmed that the majority of children (58%) and parents (46%) exhibited a ‘Resilient’ PTSD trajectory over the year, in the sense that their scores remained in the non-clinical range at both timepoints. Children displaying a ‘Resilient’ trajectory were more likely to have a parent who also displayed a ‘Resilient’ trajectory (*p*=0.018). However, there was also evidence of a ‘Recovery’ trajectory in a significant minority in this sample and over 1 in 4 children and parents exhibited a ‘Chronic’ or ‘Delayed’ symptom trajectory.

Conclusions: Although average PTSD scores reduced over time in this sample and ‘Resilient’ trajectories were common, a significant proportion of children and parents exhibited ‘Chronic’ and ‘Delayed’ symptom trajectories.

Relevance to clinical practice: These results suggest that, although the majority do well, a significant number of children and family members may develop chronic or delayed symptoms of Post-traumatic stress disorder in the year following PICU discharge. The monitoring of individual family members symptoms beyond 3 months post-discharge may help to determine those who might most benefit from further support.

(295 words)

What is known:

* PICU admission is associated with elevated risk of developing symptoms of Post-traumatic stress disorder (PTSD) in a proportion of children and parents
* The majority of people display resilient reactions in the aftermath of trauma
* A number of common PTSD symptom trajectories have been empirically confirmed after a range of different traumatic events

What this study adds:

* Resilient PTSD symptom trajectories were common in children and parents after PICU admission
* Resilent trajectories in parents were significantly associated with resilient trajectories in children
* A significant proportion of children and parents (more than 1 in 4) displayed a chronic or delayed trajectory of PTSD symptoms in the year following PICU discharge

Recent longitudinal research on psychological recovery after traumatic events has

Recent longitudinal research on psychological recovery after traumatic events has demonstrated considerable heterogeneity in responses over time. A number of distinct Post-traumatic stress disorder (PTSD) symptom trajectories have been identified, which appear to be common across different trauma types, in both adults1 and children2. These include ‘Resilient’ (ie scores remaining in the normal range) which has generally been found to be the most common pattern, irrespective of the nature of the traumatic event; ‘Chronic’ (where symptoms remain high); ‘Recovery’ (where high initial symptoms reduce over time) and ‘Delayed’ (where the initial rate of symptoms is low but increases later on). More generally, in the field of paediatric psychology the concept of the ‘trajectory’ is also receiving greater prominence3 in relation to the understanding of longer term adaptation in families after illness and injury.

In the field of paediatric intensive care this ‘trajectory’ approach to examining psychological recovery has recently been adopted in studies examining psychological outcomes in children4 and parents5. This has been in recognition that the more traditional analytic strategy of reporting group means and proportions scoring above clinical cut-offs, can be misleading as it fails to distinguish individual differences and can give rise to mistaken inferences about the course of psychological distress over time.

In this report, a re-analysis of data on the PTSD symptoms of 66 parent-child dyads reported previously6 is presented, examining membership of the four most common putative PTSD trajectories in the literature, as outlined above. It was hypothesised that there would be a significant level of heterogeneity with regard to responses in this group, but that the ‘Resilient’ profile would be the most common.

METHOD

Ethical permission for the original follow-up study was provided by .the Great Ormond Street Hospital/Institute of Child Health Research Ethics Committee (Ref 03AR12). Families of children aged 7y to 17y, consecutively admitted to a PICU at a tertiary hospital between 1/1/2004 and 31/7/2005, were informed about the study during admission and approached again, 6 weeks after discharge, to ask if they would be prepared to be involved. Data collection was by face-to-face interview at 3 months in the hospital outpatient clinic or at home, depending on family preference. Follow-up data were collected by postal questionnaire or telephone interview, at 12 months. Demographic and medical information were extracted from the child’s medical record. Further detail on procedure and on the sample is available in Colville and Pierce (2012)6.

Child PTSD symptoms were assessed using self-report on the 8-item Child Revised Impact of Event Scale (CRIES-8)7, with scores of >=17 on this scale found to distinguish those with probable PTSD. Health related quality of life (HRQoL) was also assessed by child self-report at the same timepoints using the Pediatric Quality of Life Inventory (PedsQL)8. This provides normed scores ranging from 0-100 for Physical, Emotional, Social and School related quality of life.

Parents completed the short form of the Davidson Trauma Scale9, on which a score of >=5 denotes risk of probable PTSD. They also completed the Hospital Anxiety and Depression Scale (HADS)10 at the same timepoints. In addition, at 12 months they completed an overprotection measure, scored 0-4,11 which assessed the degree to which they continued to worry about their child and needed to know their whereabouts. Overprotectiveness is a feature of parenting that has been endorsed in qualitative workin this situation12 and has been found to be associated with the persistence of PTSD11.

For the purposes of this study, children and parents were categorised using the a priori clinical cut-off method2, whereby the trajectories of those with scores below the relevant clinical cut-off at 3m and 12m were termed ‘Resilient’; those with scores in the clinical range initially, which later moved into the normal range were termed ‘Recovery’; those with initial low scores that had moved into the clinical range by 12m were termed ‘Delayed’ and finally participants with high scores at both timepoints were described as displaying a ‘Chronic’ trajectory.

The sample size precluded investigation of factors associated separately with each of these four profiles but univariate associations with a dichotomous categorisation of ‘Resilient’, compared with the other trajectories, were conducted using Pearson’s Chi Square or Fisher’s Exact tests for categorical variables and the Mann-Whitney test for continuous variables, using IBM SPSS version 29.0 statistical software (Armonk, New York: IBM Corporation), with the level of significance set at *p*<0.05.

RESULTS

Of the 132 families approached to take part, 102 provided data at 3m (77%) and 72 at 12m. Of the 72 families with data at 12m, 66 provided complete PTSD data for both child and parent. Analyses below are based on these 66 dyads.

The distribution of the four main trajectories described in the literature is illustrated diagrammatically in Figure 1. The most common trajectory found was ‘Resilient’, which applied to 38 (58%) children and 30 (46%) parents. Similar proportions of both groups were found to have a ‘Chronic’ profile (10 (15%) children and 10 (15%) parents) with a slightly higher proportion of parents, 18 (27%), exhibiting a ‘Recovery’ profile than children, 11 (17%). Finally, 7 (11%) children and 8 (12%) parents reported an increase in symptoms, from the non-clinical to the clinical level, by one year after discharge, suggestive of a ‘Delayed’ response.

Comparisons between those whose symptoms followed a ‘Resilient’ trajectory with the rest are provided in Table 1. Where the child was admitted as an emergency, ‘Non-Resilient’ profiles (ie. ‘Chronic’, ‘Recovery’ or ‘Delayed’) were more common, in both children (*p*=0.002) and parents (*p*<0.001). There was also an association with higher severity of illness score and ‘Non-Resilient’ trajectory for children over the year following discharge (*p*=0.029). ‘Resilient’ parents reported lower anxiety and depression at 3m (*p*<0.001) and 12m (*p*=0.003, *p*=0.001) and a lower overprotection score at 12m (*p*<0.001). ‘Resilient’ children reported better Emotional health related quality of life (HRQoL) at 3m (*p*<0.001) and better Emotional (*p*<0.001), Social (*p*<0.012) and School-related(*p*<0.001) HRQoL at 12m than their ‘Non-Resilient’ counterparts. Finally, children whose parents exhibited a ‘Resilient’ trajectory were more likely to report symptoms consistent with a ‘Resilient’ trajectory, and vice versa (*p*=0.018).

DISCUSSION

These analyses demonstrate the importance of examining individual trajectories of psychological distress in children and parents, in the year following PICU discharge. Although, as expected, the majority reported ‘Resilient’ PTSD symptom trajectories, there was considerable heterogeneity in the responses found over time, in this sample. The main clinical implication of these findings is that health professionals involved in following up and supporting this population should guard against extrapolating from group level statistics and instead monitor individual symptom trajectories where possible.

The findings relating to parents are broadly consistent with trajectories of distress and family functioning in caregivers of children admitted to PICU after septic shock5. However,

the proportion of children found to display ‘Non-Resilient’ trajectories was significantly higher than that reported by Le Brocque et al (2020)4, who did not find evidence supporting the existence of a ‘Delayed’ trajectory group in PICU survivors. These different findings may relate to sample differences in age and illness severity, or to the higher initial recruitment rate in the present study, but it is true that the evidence for ‘Delayed’ trajectories in children is more mixed than that in adults and the analytic strategy used in this study is regarded as more likely to classify those scoring around the cut-off as ‘Delayed’2. Conversely, however, Le Brocque et al4 used a significant degree of data imputation, which can be associated with a higher risk of misclassification of ‘Delayed’ and ‘Chronic’ trajectories where there is a significant level of attrition2 and there are other studies which report that children’s symptoms increase over time. One such study, conducted in the aftermath of Hurricane Katrina, found a trajectory of increasing PTSD symptoms in 18% of a sample of over 4000 children over 4 years16.

Strengths of this study include a high initial recruitment rate, the use of direct self-report measures with the children, and the length of follow up. However, the size of the sample was a limitation and, together with the fact that measures were only collected at two timepoints, precluded the use of more sophisticated, data-driven analysis of individual trajectories. Also, as the original data were collected some time ago, there may be issues about the degree to which they are representative of families’ current experience, Nevertheless, the fact remains that there are still very few longitudinal studies of psychological distress in children beyond the first three months after discharge and fewer still that also report on their parents’ symptoms4. Future longitudinal research with this population, based on larger samples and three or more data collection points, could usefully employ statistical techniques, such as latent class growth analysis17, to confirm the presence or otherwise of the profiles suggested by these data. A larger sample would also facilitate a more nuanced analysis of the risk factors associated with ultimate membership of the different trajectories.

Candidate risk factors for chronic distress in children include early childhood adversity, which is more common in the PICU population18, and lower pre-morbid quality of life, which is associated with increased acute distress19. Recent research has also shown that PTSD symptoms in parents are associated with previous traumatic experiences and mental health difficulties20, can persist well beyond the year following discharge21, and are associated with decreased family functioning over time22. These findings are consistent

with the expansion of the concept of Post-Intensive Care Syndrome (PICS) to include family members (PICS-F)23 and the particular emphasis in paediatrics (PICS-p)24 on the dependence of children on parents for their emotional well-being.

In the spirit of Trauma-informed Care25, screening for past adversity in children and parents, as well as any other factors found in future research to predict ‘Chronic’ or ‘Delayed’ trajectories, may help identify those families most at risk of poorer long term outcomes.

REFERENCES

1. Galatzer-Levy IR, Huang SH, Bonanno GA. Trajectories of resilience and dysfunction following potential trauma: A review and statistical evaluation. *Clin Psychol Rev*. 2018;63:41-55
2. Lai BS, Lewis R, Livings MS, La Greca AM, Esnard AM. Posttraumatic Stress Symptom Trajectories Among Children After Disaster Exposure: A Review. *J Trauma Stress* 2017;30:571-582
3. Price J, Kassam-Adams N, Alderfer MA, Christofferson J, Kazak AE. Systematic Review: A Reevaluation and Update of the Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress. *J Pediatr Psychol* 2016;41:86-97
4. 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
5. Murphy LK, Palermo TM, Meert KL, et al. Longitudinal Trajectories of Caregiver Distress and Family Functioning After Community-Acquired Pediatric Septic Shock. *Pediatr Crit Care Med* 2020;21:787-796
6. Colville G, Pierce C: Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Med* 2012; 38:1523–1531
7. Perrin S, Meiser-Stedman R, Smith P: The Children’s Revised Impact of Event Scale (CRIES): Validity of a screening instrument for PTSD. *Behav Cogn Psychother* 2005; 33:487–498
8. Varni JW, Seid M, Rode CA: The PedsQL: Measurement model for the pediatric quality of life inventory. *Med Care* 1999; 37:126–139
9. Meltzer-Brody S, Churchill E, Davidson JR. Derivation of the SPAN, a brief diagnostic screening test for post-traumatic stress disorder. *Psychiatry Res* 1999 18;88:63-70
10. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361-70
11. McFarlane AC. Family functioning and overprotection following a natural disaster: the longitudinal effects of post-traumatic morbidity. *Aust N Z J Psychiatry* 1987;21:210-8
12. Colville G, Darkins J, Hesketh J, Bennett V, Alcock J, Noyes J. The impact on parents of a child's admission to intensive care: integration of qualitative findings from a cross-sectional study. *Intensive Crit Care Nurs* 2009;25:72-9
13. Pearson G, Stickley J, Shann F: Calibration of the paediatric index of mortality in UK paediatric intensive care units. *Arch Dis Child* 2001; 84:125–128
14. Townsend P, Phillimore P, Beattie A. *Health and deprivation: Inequality and the North*. Andover, Croom Helm, 1988
15. Jones C, Griffiths RD, Humphris G, Skirrow PM. Memory, delusions, and the development of acute posttraumatic stress disorder-related symptoms after intensive care. *Crit Care Med* 2001;29:573-80
16. Osofsky JD, Osofsky HJ, Weems CF, King LS, Hansel TC. Trajectories of post-traumatic stress disorder symptoms among youth exposed to both natural and technological disasters. *J Child Psychol Psychiatry* 2015;56:1347–1355
17. Nagin DS. *Group-based modeling of development.* Cambridge, MA: Harvard University Press, 2009.
18. Andrist E, Riley CL, Brokamp C, Taylor S, Beck AF. Neighborhood Poverty and Pediatric Intensive Care Use. *Pediatrics* 2019;144;e20190748
19. Nelson LP, Lachman SE, Goodman K, Gold JI. Admission Psychosocial Characteristics of Critically Ill Children and Acute Stress. *Pediatr Crit Care Med* 2021;22:194-203
20. Woolgar FA, Wilcoxon L, Pathan N, et al. Screening for Factors Influencing Parental Psychological Vulnerability During a Child's PICU Admission. *Pediatr Crit Care Med* 2022;23:286-295
21. Whyte-Nesfield M, Kaplan D, Eldridge PS, et al: Pediatric Critical Care–Associated Parental Traumatic Stress: Beyond the First Year. *Pediatr Crit Care Med* 2023; 24:93–101
22. Riley AR, Williams CN, Moyer D, et al: Parental posttraumatic stress symptoms in the context of pediatric post intensive care syndrome: Impact on the family and opportunities for intervention. *Clin Pract Pediatr Psychol* 2021; 9:156–166
23. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: post intensive care syndrome–family. *Crit Care Med* 2012;40:618–624
24. Manning JC, Pinto NP, Rennick JE, Colville G, Curley MAQ. Conceptualizing Post Intensive Care Syndrome in Children-The PICS-p Framework. *Pediatr Crit Care Med* 2018;19:298-300
25. Demers LA, Wright NM, Kopstick AJ et al. Is Pediatric Intensive Care Trauma-Informed? A Review of Principles and Evidence. *Children (Basel)* 2022;9:1575

Figure 1: Post-traumatic stress disorder (PTSD) symptom trajectories in a) children and b) their parents in the year following PICU discharge

1. Children (n=66)

 3 months 12 months

**CHRONIC**

PTSD score in clinical range

PTSD score in clinical range

**DELAYED**

**RECOVERY**

Normal range

Normal range

**RESILIENT**

1. Parents (n=66)

 3 months 12 months

 

**CHRONIC**

PTSD score in clinical range

PTSD score in clinical range

**DELAYED**

**RESILIENT**

**RECOVERY**

Normal range

Normal range

Trajectories: Chronic = PTSD score above cut-off at 3m and 12m (n=10 (15%) children and n=30 (15% parents); Delayed = PTSD score in normal range initially but rising above clinical cut-off by 12m (n=7 (11%) children and n=8 (12% parents); Recovery = PTSD score above clinical cut-off at 3m but in normal range at 12m (n=11 (17%) children and n=18 (27%) parents) and Resilient = PTSD scores below clinical cut-off at both timepoints (n=38 (58%) children and n=30 (46% parents). Figures produced using free software SankeyMATIC available from htpps://www.sankeymatic.com.

Table 1: Univariate associations with ‘Resilient’ PTSD trajectories in children (n=66) and their parents in the year following PICU discharge



PTSD=Post-traumatic Stress Disorder (measured by SPAN9 in parents and CRIES-87 in children); PIM=Paediatric Index of Mortaliy13; HRQoL=Health related quality of life (measured by PedsQL8)

aResilient trajectory refers to PTSD score below clinical level at 3m and 12m after discharge; bNon-Resilient trajectory refers to PTSD score in clinical range at 3m only (Recovery trajectory), 12m only (Delayed trajectory) or both (Chronic trajectory); c Mann-Whitney test for continuous variables and Pearson’s Chi Square/Fisher’s Exact test for categorical variables; dmeasured by Townsend Deprivation Index14) ; emeasured using Intensive Care Memory Tool (ICUM)15; fmeasured with Hospital Anxiety and Depression Scale (HADS)10  ,g measured using MacFarlane Overprotection Scale11; honly available for those children who had returned to school by 3m