The Value of Screening Parents for Their Risk of Developing Psychological Symptoms After PICU: A Feasibility Study Evaluating a Pediatric Intensive Care Follow-Up Clinic*

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Objectives: This study aimed to assess whether prospectively screening parents for psychological vulnerability would enable beneficial targeting of a subsequent follow-up clinic.

Design and Setting: Parents of children consecutively admitted to a PICU were assessed for risk of developing posttraumatic stress disorder at discharge using the Posttraumatic Adjustment Scale.

Interventions: High-risk parents were then randomized to the intervention (follow-up clinic, 2 mo after discharge) or control condition.

Measurements and Main Results: All parents completed Impact of Event Scale-Revised and Hospital Anxiety and Depression Scale at 6 months. Of the 209 parents of 145 children recruited to the study, 78 (37%) were identified, on the basis of their Posttraumatic Adjustment Scale score at baseline, as being at risk of developing posttraumatic stress disorder, and randomized to the control or intervention condition. Follow-up data were provided by 157 of 209 parents (75%). Logistic regression analyses controlling for parent gender and child length of stay showed that high-risk control parents ($n = 32$) were significantly more likely to score above the clinical cutoff for all three psychological outcomes than parents deemed low risk at baseline ($n = 89$) (posttraumatic stress: odds ratio = 3.39; 95% CI, 1.28–8.92; $p = 0.014$; anxiety: odds ratio = 6.34; 95% CI, 2.55–15.76; $p < 0.001$; depression: odds ratio = 4.13; 95% CI, 1.47–11.61; $p = 0.007$). Only 14 of 38 (37%) high-risk intervention parents attended the follow-up clinic appointment they were offered. At follow-up, there were no statistically significant differences between the intervention and control groups, but there were small effect sizes in favor of the intervention for anxiety scores (Cohen $d = 0.209$) and depression scores (Cohen $d = 0.254$)

Conclusions: Screening parents for psychological vulnerability using measures such as the Posttraumatic Adjustment Scale may enable more efficient targeting of support. However, further research is needed on how best to provide effective follow-up intervention for families. (*Pediatr Crit Care Med* 2015; 16:808–813)

Key Words: anxiety; depression; intervention; outcomes; posttraumatic stress

***See also p. 877.**

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There is considerable evidence that parents whose children have been admitted to PICU are a group at high risk of psychological sequelae, with between 18% and 45% of parents reporting clinically significant rates of posttraumatic stress symptoms regardless of the severity of their

child's illness or length of stay (1–6) as well as other symptoms such as anxiety and depression. Furthermore, a recent review (7) identified subclinical parental symptoms of posttraumatic stress disorder (PTSD) approaching 84%. There is evidence that this distress may persist long after discharge, with nearly half of families found to be still experiencing significant symptoms 12 months after discharge and many parents experiencing delayed reactions (8).

However, despite the high rates of psychological difficulties reported in patients' relatives, few studies in adult or pediatric intensive care settings have reported on interventions aimed at mitigating these symptoms. There is also minimal reference in the literature regarding how to identify those most at risk of poor outcomes (9), although there is some evidence that parents do worse if they experience higher rates of stress acutely and specifically if they fear that their child could die, irrespective of the objective risk to the child's life (1).

The National Institute for Health and Clinical Excellence guidelines (10) on rehabilitation after intensive care recommend that follow-up services are provided for patients and families. However, while a third of adult units in the United Kingdom provide this (11), and most pediatric units provide follow-up in the event of a child's death, follow-up for survivors is not routinely offered. Only two PICU follow-up clinics are reported on in the literature (3, 12), and of these, only one reported on the impact of the clinic per se in a randomized trial (12). In this study, there was no impact on parental distress overall, but a subgroup of parents who had been more acutely distressed at the time of the admission were significantly more likely both to attend the clinic and to benefit from it in terms of lower scores on self-report measures of posttraumatic stress and depression.

This research, along with national U.K. guidance on PTSD (13), which recommends directing interventions only at those most likely to benefit, suggests that screening parents to establish who are most at risk of poorer outcomes might be a worthwhile exercise in terms of both maximizing the effectiveness of the intervention and making the best use of available resources.

The primary objectives of this exploratory study were 1) to establish whether a screening instrument, developed for use with people following traumatic events (14), successfully identified parents at risk of poorer psychological outcome and 2) to ascertain whether the offer of a follow-up clinic appointment to those parents deemed at risk would be associated with lower rates of symptoms of psychological distress in the longer term.

A secondary objective was to determine feasibility and acceptability of the intervention in order to inform future research.

It was hypothesized that the risk factors known to be associated with the development of PTSD would apply to this population and that consequently the screening instrument would identify those most at risk. It was further hypothesized that a follow-up clinic after PICU admission would provide parents with the opportunity to discuss their child's admission, which would result in more complete emotional processing of the event (15) thus reducing their later levels of posttraumatic stress, anxiety, and depression.

MATERIALS AND METHODS

Design

A randomized controlled design (NCT01628263) was used. Full approval for the study was granted by the National Research Ethics Committee. All subjects signed written informed consent.

Participants

Participants were parents of children consecutively admitted to the PICU of a University Teaching Hospital for a duration of at least 12 hours, between December 5, 2011, and October 17, 2012. Exclusion criteria were subsequent death of child, admission for nonaccidental injury, subsequent readmission in the study period, or health professional deeming it inappropriate to make contact with the family for other reasons, for example, social problems. Parents of children discharged for palliative care were also excluded, as follow-up for bereaved families was already routinely offered by the unit.

Procedure

All participants completed a baseline assessment (see below) at the time of the child's discharge, to identify their risk of developing PTSD as a result of their experiences on PICU. The self-completion measure took approximately 5 minutes for parents to complete and was distributed and collected by an assistant psychologist.

Families containing a parent scoring "at risk" on the screener were randomized to either the intervention or control condition using the "sealed envelope" method of randomization. In the intervention condition, if both parents had agreed to take part but only one had a high-risk score, they were both invited to attend the clinic, but data from the low-scoring spouse were omitted from subsequent analyses examining the predictive utility of the baseline screen.

1. Intervention—offer of a follow-up clinic appointment, 2 months after PICU discharge.
2. Control—treatment as usual.

All parents, including controls and those who had screened at low risk of future distress, were then sent two questionnaires by post, 6 months after discharge (see below). Parents who did not return these outcome questionnaires were offered the opportunity to complete them by telephone if they preferred.

Finally, all parents were thanked for taking part in the study, and those scoring above clinical cutoffs on any of the questionnaires were informed of this at the end of the study, as was their general practitioner. A resource list detailing relevant services and support organizations locally was also provided.

The Clinic

The clinic took place in a nonmedical location opposite the children's hospital and was led by the PICU clinical psychologist along with a PICU consultant and PICU nurse. A proforma was used to ensure that the same topics were raised at each appointment. Parents were given the opportunity to ask staff questions about their child's PICU admission and were able to raise any concerns

about their child's current health. They were also asked about how their child's admission had impacted on them. For most parents, reflection on the emotional experience of their child's admission formed the predominant focus of the clinic discussion. Clinic staff also advised families regarding accessing further support services if specific psychological issues were identified.

Measures

Posttraumatic Adjustment Screen. Baseline vulnerability to psychological distress was assessed using the 10-item Posttraumatic Adjustment Screen (PAS) (14). The PAS was developed to identify risk of PTSD and depression after traumatic events and covers the main variables known from meta-analyses in the field to be associated with poorer outcomes. Scores range from 0 to 40, with a score of at least 16 indicative of elevated risk of developing PTSD. The authors recommend that it is used as a way of screening out the less vulnerable, as it has been proved to have good sensitivity (0.80) and specificity (0.84) but lower positive predictive value (0.28) in terms of identifying people with a diagnosis of PTSD at 1 year by means of a gold standard clinical interview (16).

Although the PAS has not been used before in parents of children following PICU admission, the authors have invited its use on different populations, in order to establish its utility more widely. For this study, the phraseology was amended slightly, with kind permission of the developers, for example, "I thought *I* was about to die" was edited to "I thought *my child* was about to die."

Impact of Event Scale-Revised. The Impact of Event Scale-Revised (IES-R) is a 22-item self-report measure that assesses hyperarousal, intrusion, and avoidance symptoms caused by traumatic events (17). Respondents rate how much trauma symptoms distressed or bothered them on a 5-point scale ranging from 0 (not at all) to 4 (extremely). The IES-R yields a total score (ranging from 0 to 88) with a score of 33 or over signifying the likely presence of PTSD (18).

Hospital Anxiety and Depression Scale. The Hospital Anxiety and Depression Scale is a simple but reliable self-report measure for assessing mood in a variety of settings (19). Respondents rate their symptoms on a scale from 0 to 21 for anxiety and for depression, with a cutoff of 8 distinguishing those who have clinical levels of both conditions. The scale has been shown to have reliable psychometric properties in a number of different populations (20).

Acceptability Measures. Finally, parents were asked about distress completing the questionnaires and those who attended the clinic were asked if they had found this useful, while those randomized to the control group were asked if they would have liked to have attended a follow-up clinic. Low-risk parents, who were not offered the clinic, were also asked about their experiences of taking part in order to assess the acceptability of providing targeted follow-up.

Statistical Analyses

Descriptive data are given in the form of median (interquartile range) or *n* (%). Initial group comparisons were made using nonparametric statistics (Mann-Whitney for continuous data and Pearson chi-square for categorical data) using SPSS v21.0 (SPSS, Chicago, IL) and a *p* value of 0.05 for statistical significance. Logistic regression analyses were then performed to establish the extent of the power of a positive score on the PAS to predict clinically significant levels on the three main outcomes (after controlling for parent gender and child length of stay) for those parents who were not offered the intervention. Finally, as the main outcome data were not normally distributed, Box-Cox transformation procedures (21) were used to achieve adequate normality to test for effect sizes using Cohen *d* (22).

RESULTS

Participants, Recruitment, and Attrition

Of the 645 children admitted over the study period, $n = 31$ died, $n = 24$ were excluded because the child was subsequently readmitted, and $n = 40$ were excluded for the other reasons given above. Of the remainder, $n = 272$ families were missed because they were not on the unit when the researcher was available to consent them. The response rate in terms of the proportion of those approached who took part was 145 of 278 families (52%) (**Fig. 1**). Of the 209 parents enrolled in the study, 157 (75%) provided outcome data at follow-up. Sample characteristics

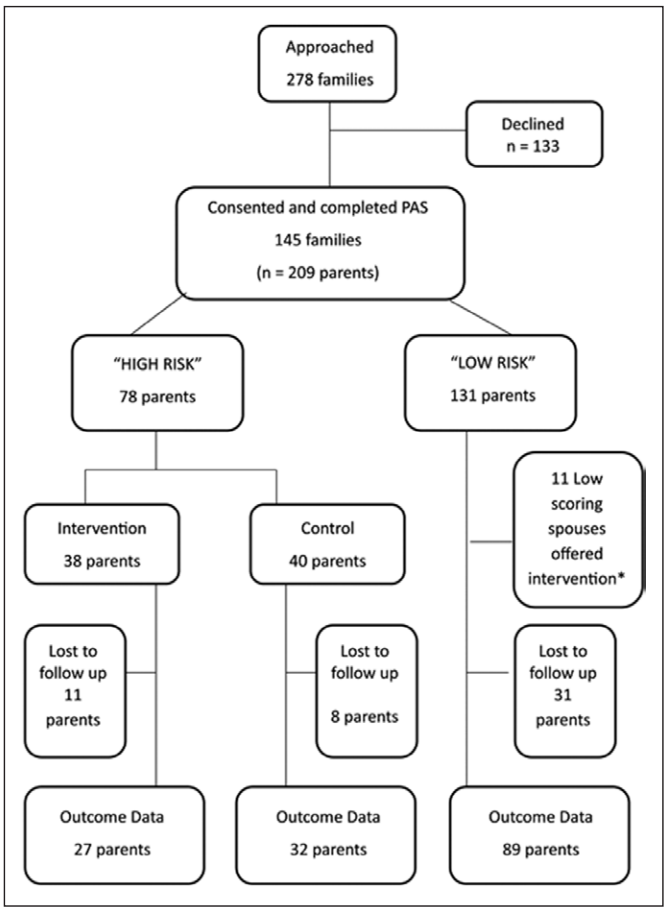

Figure 1. Study flow diagram. PAS = Posttraumatic Adjustment Screen. Excluded from subsequent analyses as allocated to intervention on basis of spouse's score.

are provided in **Table 1**. There were no significant differences between those who dropped out and those who remained in the study in terms of parent or child characteristics (**Supplemental Table 1**, Supplemental Digital Content 1, http://links.lww.com/PCC/A183).

Utility of the Baseline Screening Instrument: Comparison Between Outcome Data for High-Risk Controls and Low-Risk Parents

In total, 78 of 209 parents recruited (37%) scored at or above the cutoff of 16 on the PAS and were therefore deemed to be at high risk of developing significant symptoms of posttraumatic stress relating to their child's admission.

As a check on the predictive utility of the PAS with this population, outcome data from the high-risk controls who were not invited to the follow-up clinic ($n = 32$) were compared with the outcome data from the parents deemed at baseline to be at low risk ($n = 89$). High-risk control parents were significantly more likely to report clinical levels of symptoms for all three psychological outcomes than low-risk parents, 6 months after discharge ($p < 0.01$) (**Fig. 2**). The proportions of parents scoring above cutoffs in the low-risk group were comparable to community norms for such measures (23, 24).

Logistic regression analyses controlling for parent gender and child length of stay showed that parents deemed to be high risk on the PAS at discharge had a significantly increased risk of scoring above the cutoff for clinically significant levels of symptom for all three outcomes (posttraumatic stress: odds ratio [OR] = 3.39; 95% CI, 1.28–8.92; $p = 0.014$; anxiety: [OR] = 6.34; 95% CI, 2.55–15.76; $p < 0.001$; depression: OR = 4.13; 95% CI, 1.47–11.61; $p = 0.007$).

TABLE 1. Sample Characteristics ($n = 145$ Children)

Variable	*n* (%)/Median (IQR)
Male	74 (51)
Length of stay (d)	3 (2, 6)
Age at discharge (yr)	0.89 (0.16, 4.50)
Emergency admission	84 (58)
Ventilated	129 (89)
Admission reason	
Cardiac	80 (55)
Respiratory	37 (26)
Surgical	9 (6)
Sepsis	6 (4)
Neurologic	5 (3)
Trauma	2 (1)
Other	6 (4)

IQR = interquartile range.

Comparison Between Intervention (Clinic) and Control Group Outcome Data

The randomization was effective in that the intervention and control groups did not differ significantly in terms of child or parent demographics or baseline scores on the PAS (**Supplemental Table 2**, Supplemental Digital Content 1, http://links.lww.com/PCC/A183).

Of the 38 parents offered the follow-up clinic, only 14 parents (37%) chose to attend. Median length of time between PICU discharge and clinic appointment was 2.5 months. Parents who attended the clinic did not differ from those that did not attend in terms of gender, baseline PAS score, or length of child's PICU admission but did have slightly older children (**Supplemental Table 3**, Supplemental Digital Content 1, http://links.lww.com/PCC/A183).

No significant differences were found between the intervention group and the control group at 6 months postdischarge, but there was some evidence of a small effect in favor of the intervention on both anxiety and depression scores, in terms of Cohen *d* (**Table 2**).

Acceptability Data

Of the 124 parents who responded to the screening acceptability question, 85% did not report any distress completing the measure. Of the 28 of 38 parents invited to clinic who provided a response, 27 (96%) appreciated the offer. The most significant barriers to attendance cited by the 19 of 32 of the nonattending parents who provided feedback were difficulties arranging time off work or finding childcare ($n = 7$; 37%) and travel costs or distance from hospital ($n = 5$; 26%). Of the 25 of 40 parents in the control group who responded, 14 (56%) said they would have liked to attend the clinic. None of the 39 of 131 low-risk group parents indicated that the lack of invite to the clinic was upsetting.

DISCUSSION

One of the aims of this study was to establish whether the screening instrument employed, the PAS, would reliably identify those parents most likely to report significant levels of distress 6 months later. The PAS assesses a number of factors known from the literature to be most strongly associated with the development of PTSD after a traumatic event and was originally designed for use with adults following a traumatic injury. In this study, analysis of the outcome data for parents who were not offered the intervention (either because they were high risk but allocated to the control condition or they were deemed low risk) showed that those who were identified as high risk by the PAS reported significantly higher rates of posttraumatic stress, anxiety, and depression at follow-up than those deemed low risk. These results, taken together with the acceptability of the measure to parents, suggest that such an instrument might be a useful tool both in future research and clinically, to determine which parents are most likely to need support after their child's PICU admission.

The decision to offer a follow-up clinic was informed by research on parental preferences (25), which suggested that the

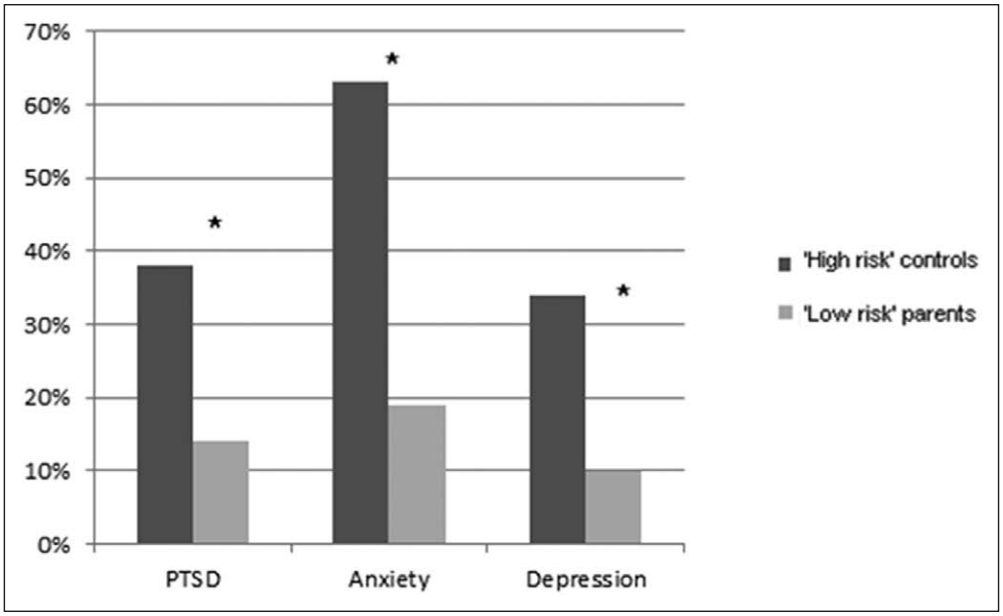

Figure 2. Utility of Posttraumatic Adjustment Scale at baseline in predicting parental distress 7 mo later ($n = 121$). Posttraumatic stress disorder (PTSD) defined as ≥33 on Impact of Event Scale-Revised. Anxiety and depression defined as ≥8 on the Hospital Anxiety and Depression Scale. 'High risk' and 'Low risk' categories determined by score ≥16 on Posttraumatic Adjustment Scale at discharge. 'High risk' group rates: PTSD $n = 12/32$ (38%); anxiety $n = 20/32$ (63%); depression $n = 11/32$ (34%). 'Low risk' group rates: PTSD $n = 12/89$ (14%); anxiety $n = 17/88$ (19%); depression $n = 9/88$ (9%). *$p < 0.01$ Pearson chi square..

majority would appreciate such an intervention. Also on the basis of previous findings (12), it was anticipated that attendance rates at such a clinic would be improved by targeting the intervention at those parents most likely to be distressed. However, the improvement achieved in attendance by screening was relatively small (37% in this study compared with 25% in the earlier study). It was also interesting to note that only half of the control high-risk group who provided feedback claimed that they would have attended if they had had a chance. At 6-month follow-up, there was some evidence in favor of the intervention in terms of a small effect on anxiety and depression scores, but this was not statistically significant. In relation to this, it is interesting to note that a recent randomized controlled trial failed to find an effect of a follow-up clinic on psychological or physical outcomes in adult ICU patients (26), suggesting that practice and associated guidelines may have run ahead of the evidence base in this field. Also the fact that, in practice, only a minority of parents in this situation were able or willing to come back to the unit for a meeting suggests that other forms of support should be investigated for this vulnerable group.

It is important to examine the feasibility of this type of labor intensive intervention before embarking on larger trials, in the interests both of cost-effectiveness and of ensuring that the support provided is acceptable to those it is aimed at. From the feedback provided in this study, parents would appreciate ongoing contact with the PICU team but are often overwhelmed by the logistics of arranging to come back to the hospital in person. There are a number of encouraging reports from adult ICU follow-up studies regarding the use of alternatives modes of delivery of support, such as by telephone (27, 28). Such options may be worth pursuing in future PICU research.

Strengths of the study include: the use of a prospective screening tool to enable a targeted approach; the fact that all parents were followed up at the same time point; successful randomization and demonstration that there were no systematic differences between those who provided outcome data and those who dropped out. However, it also has a number of limitations. The response rate, although higher than that reported by another recent prevalence study in this field (6), was relatively low. Similar problems with recruitment and retention have however been encountered by other authors conducting research with this population (1, 29). The low take-up of the intervention and the rate of attrition, although similar across groups, are likely to have reduced the study's power to pick up any significant statistical effects. However, part of the aim of this exploratory study was to test the feasibility of the design before investing in a larger study, and one important aspect of feasibility is to establish the take-up rate of an intervention in a naturalistic clinical setting. It is possible that the parents who did not respond were functioning well and therefore did not feel they needed any further input, but it is also possible that some may have been avoiding reminders of their traumatic experience. Indeed, there is evidence that people with high levels of avoidance, which is recognized as a core symptom of posttraumatic stress, are less likely to take part in traumatic stress research (30).

TABLE 2. Comparisons Between Outcomes for Parents in the High-Risk Intervention and High-Risk Control Groups, 6 Months After Child's Discharge From PICU

Outcome Measure[a]	Intervention Group ($n = 27$)	Control Group ($n = 32$)	p	Cohen's d[b]
Impact of Event Scale-Revised	20 (12, 31)	26 (11.25, 42)	0.738	−0.048
HADS anxiety	8 (6, 10)	9 (6, 13.5)	0.502	0.209
HADS depression	4 (3, 7)	6 (3, 8)	0.332	0.254

HADS = Hospital Anxiety and Depression Scale.

[a]Median (interquartile range).

[b]Small effect size = 0.2; medium = 0.5; large = 0.8 (22). Box-Cox transformation procedures (21) were used to achieve adequate normality for effect size calculations.

Finally, clinical interviews would have provided more robust information about participants' psychological functioning, but the self-report questionnaires used are internationally recognized and brief, which was an important consideration in terms of the burden on the parents at such a difficult time.

CONCLUSION

This study provides further evidence of the distress experienced by parents following their child's admission to intensive care and, in doing so, underlines the importance of finding interventions that reduce this. Indeed, a recent editorial on this topic has gone as far as to suggest that there is a moral imperative for units to improve support services for parents of critically ill children, given the mounting evidence of the strain on them and points out that the costs of such support are relatively small when compared with the costs of the technology used to save their children's lives (31).

The PAS screen, which has previously only been used in injured adult populations, was acceptable to parents and identified the majority of those who were more likely to have poorer psychological outcomes at 6 months.

The follow-up clinic was well received by those that attended, and there was some evidence that it had a small positive impact on symptoms of anxiety and depression in a group prospectively identified as at risk of poorer psychological outcome. However, given that only a minority of the most distressed parents attended, other modes of delivery of support should be investigated for use with this population.

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