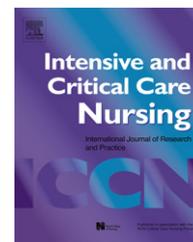




available at www.sciencedirect.com



journal homepage: www.elsevier.com/icc



ORIGINAL ARTICLE

Do parents benefit from the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial

Gillian A. Colville^{a,b,*}, Penelope R. Cream^b, Sally M. Kerry^b

^a Paediatric Psychology Service, St George's Hospital, London UK

^b St George's University of London, UK

Accepted 24 February 2010

KEYWORDS

Post-traumatic stress;
Depression;
Intervention;
Outcomes;
Follow-up

Summary

Objective: The study aim was to evaluate the psychological impact on parents of the provision of a paediatric intensive care follow-up clinic.

Design: Exploratory randomised controlled trial. Families were allocated to intervention (follow-up clinic appointment two months after discharge) or control (no appointment) condition.

Setting: An eight-bed Paediatric Intensive Care Unit (PICU) in an inner city teaching hospital.

Measurements: Parents' baseline stress was assessed using the Parental Stressor Scale: PICU. Post-traumatic stress, anxiety and depression were assessed at five months using the Impact of Event Scale and the Hospital Anxiety and Depression Scale.

Results: Only 18/72 families (25%) in the intervention group chose to attend the clinic. Outcome data were provided by 55/82 parents in the intervention group and 50/72 in the control group. Although no significant differences were found between the groups as a whole, parents with higher baseline stress reported lower rates of post-traumatic stress ($n=8/32(25\%)$ vs. $n=13/23(57\%)$, $p=0.018$) and depression ($n=6/32(19\%)$ vs. $n=12/23(52\%)$, $p=0.009$) at five months if they had been offered an appointment than if they had not.

Conclusions: Whilst these results do not justify routine follow-up for all, they suggest that, for the most traumatised parents, rates of long-term distress could be reduced by this intervention.

© 2010 Elsevier Ltd. All rights reserved.

* Corresponding author at: Consultant Clinical Psychologist/Hon Research Fellow, Paediatric Psychology Service, 2nd Floor Clare House, St George's Hospital, Blackshaw Rd, London SW17 0QT, UK. Tel.: +44 208 725 2214; fax: +44 208 725 2251.

E-mail address: gcolvill@sgul.ac.uk (G.A. Colville).

The new guideline on rehabilitation after intensive care (NICE, 2009) stresses the need for continued monitoring and support of patients and their families following intensive care treatment. Furthermore, adult intensive care survivors report that, if they feel they need it, they value having an opportunity to meet with staff as outpatients, both to review their recovery and to give feedback about what they

regard as a unique experience, which they do not feel is understood by other health care professionals (Prinjha et al., 2009). The United Kingdom, in response to Department of Health recommendations (Department of Health, 2000), has led the way internationally in setting up intensive care follow-up services. Yet despite the fact that as many as 30% of adult units now offer follow-up clinic services (Griffiths et al., 2006), we still do not have an evidence base for this form of intervention and therefore cannot say who is most likely to benefit. Also there is no consensus on how these services should be delivered, although many units restrict services to patients who live nearest to the hospital or have been admitted for a certain number of days (Williams and Leslie, 2008).

The only randomised controlled trial of a nurse-led intensive care follow up programme has found no significant effect on patient physical or psychological outcomes at one year (Cuthbertson et al., 2009). However the authors concede that the need to adhere to a standardised research protocol may have detracted from the potential impact of this form of intervention and they may have underestimated the need to address the complexity of the role of relatives in patients' recovery. Commentators on this study have also suggested that a more individualised approach with a greater focus on the changing support needs of survivors may yield more promising results for follow-up services (Lee et al., 2009).

Little information is available about the impact of follow-up clinics on relatives, who suffer significant distress in their own right (Azoulay et al., 2005), although when they attend follow-up clinics, they often raise the issue of the impact of their loved one's critical illness on their own mental health (Hall-Smith et al., 1997; Jones et al., 1994).

Another gap in the literature in this area relates to the provision of follow-up services in *paediatric* settings. Given that 47% of patients in paediatric intensive care are aged under 12 months (Paediatric Intensive Care Audit Network, 2005), such services need to be aimed primarily at parents. There is a growing body of evidence that parents report significant levels of distress relating to their child's intensive care admission (Balluffi et al., 2004; Board and Ryan-Wenger, 2003; Bronner et al., 2008; Colville and Gracey, 2006; Colville et al., 2009; Rees et al., 2004) and, in a recent survey, two thirds of parents indicated that they would have appreciated a follow-up clinic appointment to discuss their child's admission (Colville et al., 2003) but to date only one paediatric intensive care follow-up clinic has been described in the literature (Bronner et al., 2008).

The main aim of this study was to evaluate whether the offer of an follow-up clinic appointment would have an impact on parents' psychological well-being. It was hypothesised that the provision of an opportunity for parents to discuss their child's admission would result in more complete emotional processing of events (Ehlers and Clark, 2000) and thereby lead to reduced levels of post-traumatic stress symptoms and associated distress.

Two secondary aims of this study, which concerned the control data only, were to establish whether parents' baseline stress was predictive of their longer term distress and whether parents in this situation report post-traumatic growth. The results of these two nested studies are reported on separately (Colville and Cream, 2006, 2009).

Method

Design

An exploratory randomised controlled design was adopted in order to determine whether the offer of a follow-up appointment would be associated with a reduction in psychological distress over and above that which might naturally occur over time. Ethical permission for the project was granted by the Local Research Ethics Committee and parents were required to provide written consent.

Participants

Participants were parents of children admitted consecutively to an eight-bed Paediatric Intensive Care Unit (PICU) in a teaching hospital in an inner city area, who were available to give consent within 48h of the child's discharge. Families were excluded if the child had been admitted for >12h as it was logistically difficult to make contact with this group but otherwise there were no further exclusions relating to length of stay or distance. Parents were however excluded if staff felt it was inappropriate to approach them (e.g. non-accidental injury), or if the child had died, since these families were followed up routinely in any case.

Procedure

Parents were asked to complete a baseline stress measure on discharge from PICU (see below). Demographic and medical variables, including the child's Paediatric Index of Mortality (PIM) score (Pearson et al., 2001), were extracted from the child's medical record and the family's level of socio-economic deprivation was estimated using the Townsend Deprivation Index (Townsend et al., 1988).

Participating families were then randomised to either the intervention or control condition, using the sequentially numbered, sealed opaque envelope method.

Those in the intervention group received a letter inviting them to the PICU Follow-up Clinic, which was scheduled two months later, in accordance with parents' stated preferences in a previous survey (Colville and Gracey, 2006). The letter indicated that there would be a PICU consultant, a senior PICU nurse and a psychologist available to discuss their child's care during admission and that attendance was optional. Families were given the option of rescheduling and asked to confirm whether they would be attending. Staff were blind as to parents' baseline stress scores. The child was not examined but the medical record was available for consultation. During the appointment parents were encouraged to provide feedback on the admission, to ask any questions they had arising from it and to reflect on how they had been affected emotionally by their experiences.

Four months after discharge, parents in both groups were sent three questionnaires by post (see below). In addition, parents in the intervention group were asked to state whether they had found the appointment helpful or to give reasons for their non-attendance and parents in the control group were asked whether they would have liked an appointment. If they did not return the questionnaires

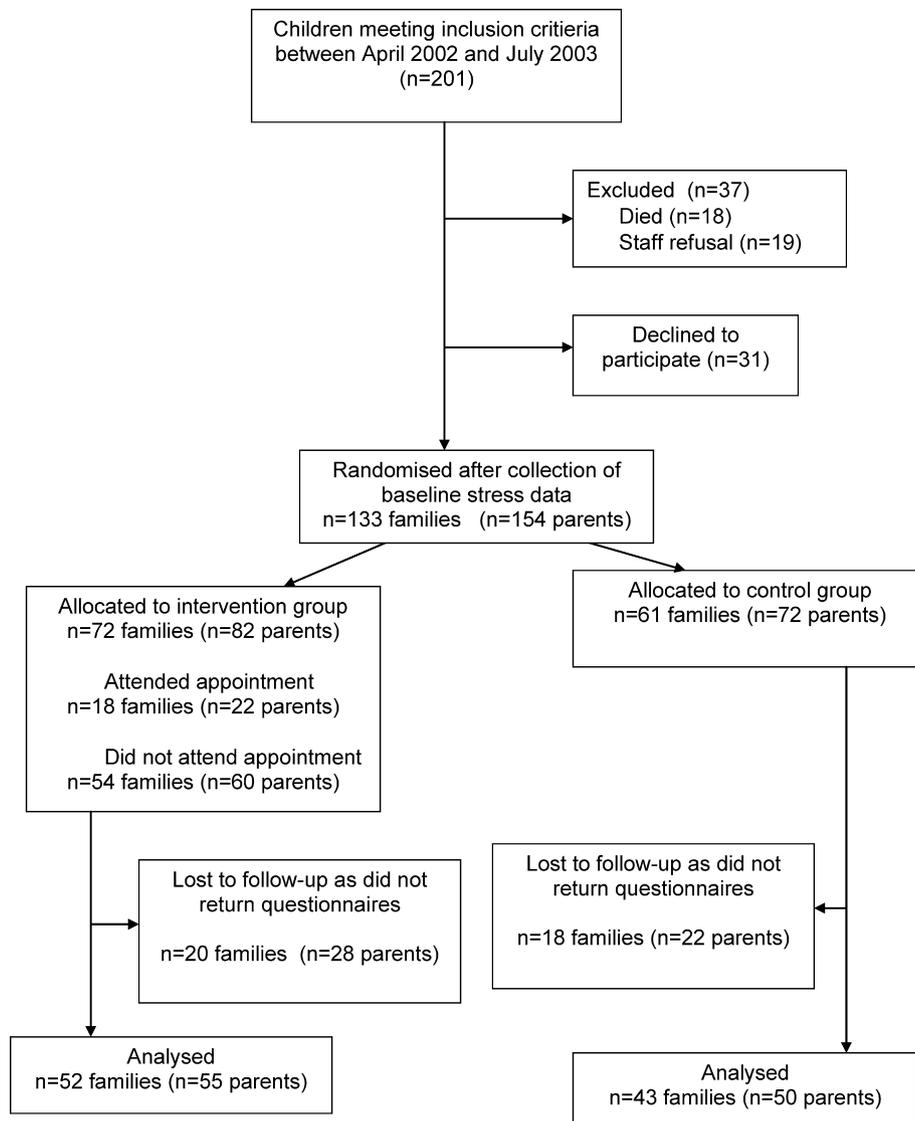


Fig. 1 Study flow diagram.

after a second mailing, parents were given a telephone reminder.

Psychological measures (see ESM for more information)

Parents' baseline stress was measured using the Parental Stressor Scale: PICU (PSS:PICU), which measures parents' perceptions of PICU related stress on seven different dimensions (Carter and Miles, 1989). The total score is the mean of the seven subscale mean item scores and ranges between 1 ('not stressful') and 5 ('extremely stressful'). The developers have demonstrated construct validity for this measure, in terms of strong correlations with an established measure of anxiety, and good internal reliability for the main scale and the subscales, confirmed by subsequent research by other teams (Curley and Wallace, 1992; Haines et al., 1995; Seiderman et al., 1997). Since its development the PSS:PICU has been used to determine the impact of short-term nursing interventions on parents' stress levels during

admission (Curley and Wallace, 1992; Smith et al., 2007), but has not been used previously to predict risk of longer term psychopathology.

The primary outcome measure was derived from parents' scores on the Impact of Event Scale (IES) (Horowitz et al., 1979) which is a widely used, self-report measure of specific responses to trauma, with good psychometric properties (Sundin and Horowitz, 2002). Total scores of 35 or above are regarded as suggestive of a high risk of post-traumatic stress disorder (Neal et al., 1994), although the scale should not be used as a diagnostic tool in isolation.

Parents' anxiety and depression levels were also measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). This is a self-report questionnaire, made up of two separate scales measuring anxiety and depression, with scores of 8 and above, on either scale, shown to discriminate best in terms of risk of psychiatric 'caseness' (Hermann, 1997). It is widely used internationally and has been shown to have good internal consistency and reliability (Bjelland et al., 2002).

Table 1 Baseline characteristics of intervention and control group families who provided outcome data at 5 months.

	Intervention group	Control group
Children	(<i>n</i> = 52)	(<i>n</i> = 43)
Age, years ^a	2.3 (0 to 16.2)	2.8 (0 to 16.5)
Male ^b	30 (58%)	27 (63%)
White UK ^b	41 (79%)	30 (70%)
TDI ^{a,c}	-0.1 (-4.0 to 9.9)	0.05 (-4.8 to 10.9)
Length of stay, days ^a	2.0 (0.5 to 26.6)	2.9 (0.5 to 42)
Emergency ^b	38 (73%)	35 (81%)
Respiratory	10	13
Sepsis	8	9
Trauma	3	4
Neurological	5	3
Other	12	6
Elective ^b	14 (27%)	8 (19%)
Plastic surgery	3	3
Oncology surgery	3	4
Other surgery	8	1
Ventilated ^b	22 (42%)	24 (56%)
PIM ^a	1.6 (0.2 to 18.4) (<i>n</i> = 55)	2.1 (0.2 to 7.6) (<i>n</i> = 50)
Parents		
Fathers ^b	7 (13%)	11 (22%)
PSS:PICU score at 48 h ^a	2.6 (1.1 to 4.3)	2.4 (1.1 to 4.3)

TDI, Townsend Deprivation Index; PIM, Paediatric Index of Mortality; PSS:PICU, Parental Stressor Scale: PICU

^a Median (range).

^b *n* (%).

^c Positive scores indicate a greater level of socio-economic deprivation

Statistical analysis

Statistical comparisons were made on the basis of the original group allocation to the intervention (offer of appointment) or control (no appointment) conditions. The primary outcome measure was the proportion of parents scoring above the cut-off for probable post-traumatic stress disorder (IES ≥ 35). Proportions scoring above clinical cut-offs for anxiety (HADS Anxiety ≥ 8) and depression (HADS Depression ≥ 8) were also examined. Group comparisons were made using non-parametric statistics (Mann Whitney U-test/Pearson's Chi-square test) using SPSS version 16.0 (SPSS Inc, Chicago IL). Power calculations indicated that a sample of 128 would be sufficient for 80% power to pick up a medium-sized difference (i.e. 0.5 SD) in IES score at $p < 0.05$ (Uitenbroek, 1997). Assuming an attrition rate of 20%, the aim was therefore to recruit between 150 and 160 parents.

Results

Recruitment, attrition and randomisation (Fig. 1).

Of the 164 families approached to take part in the study, 133 consented (154 parents), representing a recruitment rate of 81%. The children of those who declined to take part were less sick in terms of admission length and ventilation status and were more likely to belong to an ethnic minority and live in a socially deprived area but were otherwise comparable (see ESM Table A).

The baseline characteristics of the families who supplied outcome data ($n = 95/133$ (71%)) were similar for the inter-

vention and control groups and are provided, together with the main medical diagnoses of children, in Table 1. Rates of attrition were similar in both the intervention (30%) and control (28%) groups, with fathers and parents whose children were less sick statistically more likely to drop out (see ESM Table B).

Impact of intervention on psychological outcomes

Parents completed the postal questionnaires a mean (SD) of 5.33 (1.49) months after their child's PICU discharge. The prevalence rates for each psychological outcome examined and results of statistical comparisons between intervention and control groups are provided in Table 2. Although parents in the control group reported higher levels of all three forms of distress, these differences were not statistically significant

Further exploratory sub-group analyses were then performed in order to examine whether parents' stress at the time of their child's discharge from PICU had any bearing on their response to the offer of a follow-up appointment. Parents were classified 'high stress' or 'low stress' according to whether they had scored above or below median score (2.48) on the PSS:PICU. The proportions of 'high stress' and 'low stress' parents in each intervention condition scoring above clinical cut-offs at five months are illustrated in Fig. 2(a)–(c).

'High stress' parents who were offered an appointment reported lower rates of post-traumatic stress ($n = 8/32$ (25%) vs. $n = 13/23$ (57%), $\chi^2 = 5.63$, $p = 0.018$) and depression ($n = 6/32$ (19%) vs. $n = 12/23$ (52%), $\chi^2 = 6.79$, $p = 0.009$).

Table 2 Psychological outcomes at 5 months for parents in the intervention and control groups (whole sample analyses).

	Intervention group, <i>n</i> (%) <i>n</i> =55	Control group, <i>n</i> (%) <i>n</i> =50	<i>p</i> ^a	OR (95% CI)
Post-traumatic stress ^b	12 (22%)	16 (32%)	0.239	0.59 (0.25 to 1.42)
Anxiety ^c	26 (47%)	26 (52%)	0.628	0.83 (0.38 to 1.78)
Depression ^c	9 (16%)	15 (30%)	0.097	0.46 (0.18 to 1.16)

OR, Odds Ratio; CI, Confidence Interval.

^a Pearson Chi-square.

^b Impact of Event Scale Scale ≥ 35 .

^c Hospital Anxiety and Depression Scale ≥ 8 .

Table 3 Baseline characteristics of intervention group families who attended the follow-up clinic compared with those of families who did not.

	Attendees (<i>n</i> = 18)	Non-Attendees (<i>n</i> = 54)	<i>p</i> ^a
Children			
Age, years ^b	1.2 (0 to 9.5)	3.0 (0 to 18.5)	0.416
Male ^c	12 (67%)	31 (57%)	0.488
White UK ^c	13 (72%)	43 (80%)	0.513
TDI ^{b,d}	0.4 (−4.0 to 9.9)	0.9 (−4.0 to 9.7)	0.630
Distance from hospital, miles ^b	18.2 (1.7 to 79.7)	5.7 (0.6 to 55.1)	0.042*
Length of stay, days ^b	4.3 (0.8 to 15.4)	1.2 (0.5 to 26.6)	0.001**
Emergency ^c	15 (83%)	33 (61%)	0.083
Ventilated ^c	11 (55%)	17 (31%)	0.068
PIM ^b	3.6 (0.2 to 18.4) (<i>n</i> = 22)	1.3 (0.2 to 11.0) (<i>n</i> = 60)	0.087
Parents			
Fathers ^c	4 (18%)	13 (22%)	0.730
PSS:PICU score at 48 h ^b	2.7 (1.1 to 4.0)	2.6 (1.1 to 4.3)	0.040*

TDI, Townsend Deprivation Index; PIM, Paediatric Index of Mortality; PSS:PICU, Parental Stressor Scale: PICU

^a Mann Whitney *U*-test/Pearson's Chi-square.

^b Median (range).

^c *n* (%).

^d positive scores indicate greater level of socio-economic deprivation.

* *p* < 0.05.

** *p* < 0.01

than 'high stress' parents in the control group. Comparisons relating to anxiety levels in the 'high stress' parents were not statistically significant (intervention *n* = 18/32 (56%) vs. control *n* = 16/23 (70%), $\chi^2 = 0.83$, *p* = 0.362).

For 'low stress' parents the proportions scoring above cut-off were as follows: post-traumatic stress: intervention *n* = 4/23 (17%) vs. control *n* = 3/27 (11%), $\chi^2 = 0.05$, *p* = 0.823; depression: intervention *n* = 3/23 (13%) vs. control *n* = 3/27 (11%), $\chi^2 = 0.05$, *p* = 0.823; anxiety: intervention *n* = 8/23 (35%) vs. control *n* = 10/27 (37%), $\chi^2 = 0.03$, *p* = 0.869). (see ESM for relevant power calculations).

Demand for follow-up clinic

Of the 72 families in the intervention group who were offered an appointment, only 18 (25%) families attended but, of these, 17 indicated they found it helpful. They commented in particular on the importance of being able to provide feedback and on having a formal opportunity to thank staff for their care as well as having a chance to clarify information and reflect on how they had been affected emotionally by their experiences.

Attendance at the clinic was positively associated with distance between home and hospital, length of stay and higher baseline stress (Table 3). 'High stress' parents were significantly more likely to attend the appointment (*n* = 15/40 (38%)) than 'low stress' parents (*n* = 7/42 (17%), $\chi^2 = 4.53$, *p* = 0.033).

Of the 41 families *not* offered an appointment who provided feedback, only 9 (22%) stated that they would have attended, given the opportunity and 10 explicitly stated they did not need follow-up (see ESM for further information on parents' comments).

Discussion

In a recent editorial, Querques (2009) has proposed that a follow-up clinic meeting may be psychologically beneficial to adult intensive care survivors. The results of this study appear to support the contention that such a meeting might be also be beneficial to some relatives.

Parents in this study who had reported high levels of baseline stress, reported lower rates of post-traumatic stress and depression 5 months after discharge, if they had been

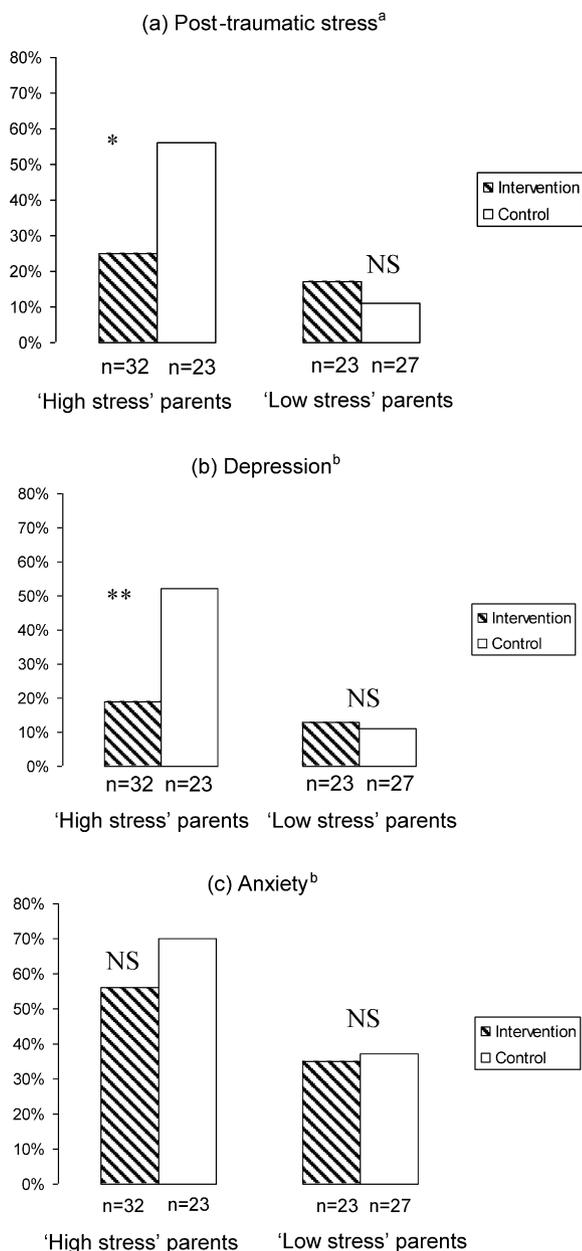


Fig. 2 Proportions of parents in the intervention and control groups scoring above clinical cut-offs at 5 months, by baseline stress levels. Parents were grouped as either 'high stress' ($n = 55$) or 'low stress' ($n = 50$) on the basis of whether they had scored above or below median (2.48) on the Parental Stressor Scale: PICU at the time of the child's discharge. Comparisons using Pearson's Chi-square test showed that 'high stress' parents who were offered an appointment reported lower rates of post-traumatic stress and depression but similar rates of anxiety, to those who were not offered follow-up. For 'low stress' parents, differences in psychological outcome between the intervention (appointment offered) and control (no appointment) conditions were not statistically significant. ^aImpact of Event Scale ≥ 35 . ^bHospital Anxiety and Depression Scale ≥ 8 . * $p < 0.05$; ** $p < 0.01$; NS = non-significant statistical difference.

offered a follow-up appointment than if they had not been offered an appointment. This finding, which was masked by initial whole group analyses, was both clinically and statistically significant.

The overall level of demand for follow-up from parents in this prospective study, however, was low. Only one in four intervention families who were offered an appointment chose to attend and a similarly small proportion of the control group stated that they would have attended if they had been offered an appointment.

However, the fact that parents with higher baseline stress were more likely to attend appears to indicate that parents self-selected for the appointment on the basis of their experiences during admission. This would be consistent with the finding that parents with higher post-traumatic stress scores 8 months after PICU discharge are more likely to say they would have liked follow-up (Colville et al., 2003) and with qualitative research that has found that adult patients only attend follow-up if they feel they need it (Prinjha et al., 2009).

The fact that families who attended the clinic lived significantly *further away* from the hospital than those who did not, is likely to be explained by the fact that the sickest children were often retrieved from some distance in this study. This is interesting finding, nevertheless, since it shows that distance from the hospital was not necessarily a barrier to attendance, although it is often given as an exclusion criterion by adult intensive care clinics (Williams and Leslie, 2008).

Strengths and limitations

To our knowledge, this is the first randomised controlled trial of a paediatric intensive care follow-up clinic, and is also the first to examine the link between parents' scores on the PSS:PICU at the time of admission and their longer term distress. The recruitment rate of over 80%, the measurement of parents' baseline stress and the collection of information on their views about follow-up were all strengths of this study.

However, the lower participation rates for those in ethnic minority and socially deprived groups are a concern given the evidence that these parents suffer higher levels of stress in relation to PICU (Balluffi et al., 2004) and that non-English speaking relatives receive less emotional support from ICU staff than other relatives (Thornton et al., 2009).

The low attendance rate at the clinic was disappointing, but a previous survey (Colville et al., 2003) had suggested that a higher proportion of families would attend. The only other PICU follow-up clinic in the literature reported a higher attendance rate at 69%, but they recruited a lower proportion of families at the outset and restricted their clinic to families of ventilated children and/or those admitted for over a week (Bronner et al., 2008). Williams and Leslie (2008) report that attendance rates at adult clinics vary, with the sickest patients being more likely to attend.

The attrition rate between baseline and the collection of outcome measures was higher than anticipated and reduced the power of the main analyses. Other researchers have reported similar problems retaining intensive care families in longitudinal studies (Balluffi et al., 2004; Melnyk et al., 2004). It is possible that telephone contact in between

assessments (Scott et al., 2006), would have resulted in lower rates of attrition, but this might also have had a therapeutic impact, which would have been difficult to disentangle from that of the intervention. Fathers were contacted separately to mothers in order to maximise their involvement (Phares et al., 2005), but were under-represented.

A further limitation was that screening measures were used to establish rates of psychopathology rather than full diagnostic interviews, which would have been more definitive, but more costly.

Research implications

The results of this study must be regarded as preliminary, since they derive in part from post-hoc analyses, but they are worthy of further investigation. Further research on a larger sample could target parents judged to be at highest risk of poor outcome, in accordance with recent guidelines on post-traumatic stress disorder (NICE, 2005). Also, research on adult services might usefully consider examining the impact of intensive care clinics on relatives, given the increasing acknowledgement of the importance of the caregiver's role in the recovery of patients (Cameron et al., 2006).

Conclusions

Despite repeated recommendations in scholarly reviews (Board and Ryan-Wenger, 2000; Shudy et al., 2006), there are very few reports of intervention studies in this field, possibly because of the inherent problem of engaging potentially traumatised populations who, by definition, often avoid experiences that remind them of the traumatic event (Weisaeth, 1989). However, it is only by systematically testing out interventions that researchers will be able to advise on their effectiveness and feasibility in the clinical setting (Kazak et al., 2007).

These results appear to show that, for some parents, the chance to attend a follow-up clinic has a significant beneficial impact on psychological well-being. The high prevalence of distress in parents in this study serves as a reminder that more research on psychological intervention with families in this situation is urgently required.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.iccn.2010.02.005](https://doi.org/10.1016/j.iccn.2010.02.005).

References

- Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005;171:987–94.
- Balluffi A, Kassam-Adams N, Kazak A, Tucker M, Dominguez T, Helfaer M. Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatr Crit Care Med* 2004;5:547–53.
- Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression scale: an updated literature review. *J Psychosom Res* 2002;52:69–77.
- Board R, Ryan-Wenger N. State of the science on parental stress and family functioning in pediatric intensive care units. *Am J Crit Care* 2000;9:106–22.
- Board R, Ryan-Wenger N. Stressors and stress symptoms of mothers with children in the PICU. *J Pediatr Nurs* 2003;18:195–202.
- Bronner MB, Knoester H, Bos AP, Last BF, Grootenhuis MA. Follow-up after pediatric intensive care treatment: parental posttraumatic stress. *Acta Paediatr* 2008;97:181–6.
- Cameron JI, Herridge MS, Tansey C, McAndrews MP, Cheung AM. Well-being in informal caregivers of survivors of acute respiratory distress syndrome. *Crit Care Med* 2006;34:81–6.
- Carter MC, Miles MS. The Parental Stressor Scale: Pediatric Intensive Care Unit. *Maternal-Child Nurs J* 1989;18:187–98.
- Colville G, Cream P. Screening for post traumatic stress in parents after their child's admission to PICU. *Pediatr Crit Care Med* 2006;7:410.
- Colville G, Cream P. Post-traumatic growth in parents after a child's admission to paediatric intensive care: maybe Nietzsche was right? *Intensive Care Med* 2009;35:919–23.
- Colville GA, Cream PR, Gracey D. Parents' views on follow up after paediatric intensive care. *Br J Anaesth* 2003;90:548–9.
- Colville GA, Gracey D. Mothers' recollections of PICU: psychopathology and views on follow up. *Intensive Crit Care Nurs* 2006;22:49–55.
- Colville G, Darkins J, Hesketh J, Bennett V, Alcock J, Noyes J. The impact of a child's admission to intensive care: integration of a qualitative findings from a cross-sectional study. *Intensive Crit Care Nurs* 2009;25:72–9.
- Curley MA, Wallace J. Effects of the Nursing Mutual Participation Model Of Care on parental stress in the pediatric intensive care unit—a replication. *J Pediatr Nurs* 1992;7(6):377–85.
- Cuthbertson BH, Rattray J, Campbell MK, Gager M, Roughton S, Smith A, et al. The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: a pragmatic randomised controlled trial. *Brit Med J* 2009 Oct 16;339:b3723. [doi:10.1136/bmj.b3723](https://doi.org/10.1136/bmj.b3723).
- Department of Health, Comprehensive Critical Care: A Review of Adult Critical Care Services. HMSO, London, 2000.
- Ehlers A, Clark DM. A cognitive model of posttraumatic stress disorder. *Behav Res Ther* 2000;39:319–45.
- Griffiths JA, Barber VS, Cuthbertson BH, Young JD. A national survey of intensive care follow-up clinics. *Anaesthesia* 2006;61:950–5.
- Haines C, Perger C, Nagy S. A comparison of the stressors experienced by parents of intubated and non-intubated children. *J Adv Nurs* 1995;21(2):350–5.
- Hall-Smith J, Ball C, Coakley J. Follow-up services and the development of a clinical nurse specialist in intensive care. *Intensive Crit Care Nurs* 1997;13(5):243–8.
- Hermann C. International experience with the Hospital Anxiety and Depression Scale. *J Psychosom Res* 1997;42:17–41.
- Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979;41:209–18.
- Jones C, Macmillan RR, Griffiths RD. Providing psychological support to patients after critical illness. *Clin Intensive Care* 1994;5:176–9.
- Kazak AE, Rourke MT, Alderfer MA, Pai A, Reilly AF, Meadows AT. Evidence-based assessment, intervention and psychosocial care in pediatric oncology: a blueprint for comprehensive services across treatment. *J Pediatr Psychol* 2007;32:1099–110.
- Lee CM, Herridge MS, Matte A, Cameron JI. Education and support needs during recovery in acute respiratory distress syndrome survivors. *Critical Care* 2009; 13:R153. ([doi:10.1186/cc8053](https://doi.org/10.1186/cc8053)).
- Melnik BM, Alpert-Gillis L, Feinstein NF, Crean HF, Johnson J, Fairbanks E. Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes

- of critically ill young children and their mothers. *Pediatrics* 2004;113:597–607.
- NICE (National Institute for Health and Clinical Excellence). Post-traumatic stress disorder: National Clinical Practice Guideline no 26. London, Gaskell and the British Psychological Society, 2005.
- NICE (National Institute for Health and Clinical Excellence). Rehabilitation after critical illness. National Clinical Practice Guideline no 83. London, Author, 2009.
- Neal LA, Busuttill W, Rollins J, Herepath R, Strike P, Turnbull G. Convergent validity of measures of post-traumatic stress disorder in a mixed military and civilian population. *J Trauma Stress* 1994;7:447–55.
- Pearson G, Stickley J, Shann F. Calibration of the paediatric index of mortality in UK paediatric intensive care units. *Arch Dis Child* 2001;84:125–8.
- Phares V, Lopez E, Fields S, Kamboukos D, Duhig AM. Are fathers involved in pediatric psychology research and treatment? *J Pediatr Psychol* 2005;30:631–43.
- Paediatric Intensive Care Audit Network. Annual Report 2003–2004. Universities of Leeds, Leicester and Sheffield; 2005. ISBN 0 85316 254 9.
- Prinjha S, Field K, Rowan K. What patients think about ICU follow-up services: a qualitative study. *Crit Care* 2009; 13:R46 [doi:10.1186/cc7769](https://doi.org/10.1186/cc7769).
- Querques J. Can reading a diary improve psychological outcomes in the intensive care unit? *Crit Care Med* 2009;37:356–7.
- Rees G, Gledhill J, Garralda M, Nadel S. Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive Care Med* 2004;30:1607–14.
- Scott CK, Sonis J, Creamer M, Dennis ML. Maximizing follow-up in longitudinal studies of traumatized populations. *J Trauma Stress* 2006;19:757–69.
- Seiderman RY, Watson MA, Corff KE, Odle P, Haase J, Bowerman JL. Parent stress and coping in NICU and PICU. *J Pediatr Nurs* 1997;1:169–77.
- Shudy M, de Almeida ML, Ly S, Landon C, Groft S, Jenkins TL, et al. Impact of pediatric illness and injury on families: a systematic literature review. *Pediatrics* 2006;118:S203–18.
- Smith AB, Hefley GC, Anand KJ. Parent bed spaces in the PICU: effect on parental stress. *Pediatr Nurs* 2007;33(3):215–21.
- Sundin EC, Horowitz MJ. Impact of Event Scale: psychometric properties. *Br J Psychiatry* 2002;180:205–9.
- Thornton JD, Pham K, Engelberg RA, Jackson JC, Curtis JR. Families with limited English proficiency receive less information and support in interpreted intensive care unit family conferences. *Crit Care Med* 2009;37:89–95.
- Townsend P, Phillimore P, Beattie A., Health and Deprivation: inequality and the North. Andover, Croom Helm, 1988.
- Uitenbroek DG. Binomial. SISA. 1997. <http://www.quantitativeskills.com/sisa/calculations/power.htm>. (Accessed 2 Jan 2010).
- Weisaeth L. Importance of high response rates in traumatic stress research. *Acta Psychiatr Scand* 1989;80:131–7.
- Williams TA, Leslie GD. Beyond the walls: a review of ICU clinics and their impact on patient outcomes after leaving hospital. *Aust Crit Care* 2008;21:6–17.
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361–70.