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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

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Post-traumatic stress;
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Intervention;
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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.

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

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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 48 h of the child's discharge. Families were excluded if the child had been admitted for >12 h 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 socioeconomic 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