The use of patient diaries in an intensive care unit

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SUMMARY
- Many patients experience posttraumatic stress disorder following a stay in intensive care; this can be due to a lack of recall of their stay.
- Retrospective patient diaries (n~8) with follow-up have been used to try and help patients' recovery but have been found to be impersonal.
- Prospective diaries (n~35) were implemented and trialled with follow-up at 2, 6 and 12 months post discharge.
- Patients' and relatives' initial feedback regarding diaries is extremely positive. Benefits included better understanding of the events of the critical illness, helping with more realistic goal setting during the recovery period, improving communication within families through discussion of the diary and providing a source of comfort for the bereaved.
- More formal audit of these diaries is required and is currently being undertaken.

Key words: Follow-up clinic • Intensive care • Patient diaries • Posttraumatic stress disorder

INTRODUCTION
Up until fairly recently, a patient leaving an intensive care unit (ICU) for less intensive treatment was deemed a success with little regard to their subsequent quality of life (Waldemann, 1998). This, combined with the fact that many life-threatening conditions were fatal in the past, can now be averted due to constant improvements in technology and highly trained ICU staff, which has lead to an increased focus and importance concerning aftercare (Department of Health, 2000).

The national review 'Critical to Success' (Audit Commission, 1999) recommended the provision of aftercare following a stay in ICU. This stance was reinforced by the Department of Health (2000) document 'Comprehensive Critical Care' which states that all hospitals in the UK should provide a rehabilitation service for the critically ill. In response to this mandate and other literature, a local trust in East Anglia introduced an Intensive Care Follow-Up Clinic which commenced in January 2001.

BACKGROUND
In ICU, emphasis has always been placed on regaining the patient's physical health and function, albeit short-term, so that they can be transferred to a ward. However, the psychological state of the patient and the adverse effects of being critically ill in an ICU environment are increasingly acknowledged as important factors in long-term recovery (Perrins et al., 1998).

The incidence of depression, anxiety or psychological illness following ICU is high (Jones et al., 2001; Scragg et al., 2001). Many patients report hallucinations, delusional memories and nightmares for up to 12 months after their ICU stay. Furthermore, it has been suggested that the presence of delusional memories contribute to long-term psychological ill health (Skirrow, 2000).

Jones (2001) has examined the relationship between memory of ICU, delusions and the development of posttraumatic stress disorder (PTSD). He studied the memories and anxiety levels of 30 patients after ICU discharge and again at 8 weeks to assess memory stability and development of acute PTSD-related symptoms. His findings reveal that the presence of even unpleasant memories (as compared with none) may give protection against anxiety, panic attacks and other PTSD-related symptoms.

Perrins et al. (1998) looked at the long-term psychological well-being following ICU in a study involving 72 general ICU patients and reported that there were more symptoms of PTSD (avoidance behaviour and intrusive thoughts up to 12 months) in those patients who had no recall of their ICU experience. It appears that they find it more difficult to reject the delusional memories because there are no facts to explain them (Griffiths and Jones, 2001).
Having no memory of their experience in ICU can also affect the patient's expectations of recovery time. They will appreciate neither the severity of their illness nor the understanding of the symptoms of weakness, weight loss, lethargy and poor appetite, which can follow on from critical illness.

PURPOSE OF THE ICU FOLLOW-UP CLINIC
The purpose of our intensive-care follow-up clinic was twofold: firstly, to help patients after ICU with a variety of potential problems and secondly, to seek their perceptions of their experience in ICU, with a view of using this information to improve care.

PARTICIPANTS AND PROCEDURES
Between January and December 2001, we followed-up 35 patients whose length of stay exceeded 4 days of stay in ICU. Patients were seen weekly when transferred to the ward by the follow-up sister and then in clinic 2, 6 and 12 months postdischarge home. Patients seen were between the ages of 24 and 82 years old, with 22 male and 13 female. The follow-up appointments were 45 min for the first and 30 min for the second and the third. Structured interviews took place in a discussion room near the ICU with the consultant intensivist, follow-up sister and a physiotherapist. Family members were also invited to attend. Information about the patient's physical, psychological and social well-being was sought using a questionnaire.

FINDINGS
Patients seen in the ward often said that they had no recollection of their stay in the ICU. Many appeared troubled or distressed by this gap in time where they felt they had lost control over what had happened to them. This appeared to be a negative factor in coming to terms with their illness and reorientating to normal life. This finding is consistent with other studies that show the ability to cope with stressful events is reduced when the subject has no control over them (Moller, 1979). Our findings reflected those of similar more established clinics visited in other trusts.

RETROSPECTIVE DIARIES
Building on the above findings, it was hypothesized that giving patients and their families personalized information about their stay in ICU might reestablish a degree of control over their illness. Equipping patients with a better understanding of their illness and what happened to them in ICU may help them set more realistic time scales for recovery and minimize the risk of adverse long-term problems. Bergbom et al. (1998) undertook a small study involving 10 patients in a general ICU, who were given diaries. Her findings suggested that the diary helped patients in coming to terms with their serious illness and ICU stay.

To this end, retrospective diaries of stay were introduced at follow-up clinic. This was based on the findings following a visit to a more established clinic in another region that had positive feedback following their implementation. Diaries were offered to patients who, at first clinic appointment, appeared particularly distressed by the fact that they had no recall of their time there or reported nightmares, dreams or hallucinations. These were also usually the patients who scored positive for PTSD.

These retrospective diaries were compiled by the ICU follow-up sister and involved trawling through ICU notes in some detail. The diary included the sequence of events during their ICU stay, including care and treatment.

Over a period of 9 months, eight retrospective diaries were compiled for such patients. The diaries were given 2–4 weeks after clinic, and then, arrangements were made for the patients to come back to the hospital to discuss their diary, care and treatment.

Feedback from the patients and families was that, while the diary was useful in conveying information about the ICU stay, patients found it impersonal and difficult to relate to. Many still had difficulty in believing that this reported sequence of events had actually happened to them. It was felt that a more patient-centred record of stay was vital to fill the gap and thus help patients reorientate to their lives. However, collating a retrospective diary was extremely time consuming for the follow-up sister.

PROSPECTIVE DIARIES
Carl Backman, a senior critical-care nurse in an ICU in Norrkopping, Sweden, has led a project offering prospective diaries to long-stay patients (Backman and Wallber, 2001).

Backman's study involved the use of patient diaries over a 3-year period in a general ICU. An ongoing record of their stay was kept for patients with reports of their condition, events of stay and all relative/visitor involvement. The opportunity for photographs of the patient was offered at stages during their recovery. Backman reported that the diaries were a useful debriefing tool following a stay in ICU and helpful in facilitating recovery.

IMPLEMENTATION OF PROSPECTIVE DIARIES
Prospective ICU diaries were considered a way of keeping a very patient-centred record of stay, which would hopefully be more meaningful than retrospective
diaries. In particular, it was thought that the use of photographs would show the patient exactly what they had been through and how sick they had been. Therefore, after discussion with senior nurses and the medical staff, it was decided to trial this approach. The local research ethics committee (LREC) was informed of our planned project, and we were given permission to proceed under the auspices of service improvement.

Patients' families and visitors were provided with written information about the diary and given an opportunity to discuss the project with the follow-up sister.

INCLUSION CRITERIA
Diaries were offered to patients who were likely to be in the unit for more than 3-4 days. On day 3, the patient and family would be assessed as to whether they would benefit from a diary. Drawing on the findings of the follow-up clinic, it was felt that particular benefit would be gained by ventilated/sedated patients.

EXCLUSION CRITERIA
Patients under the age of 18 and those with head injuries were excluded from the study. Other categories of exclusion were senile dementia, gross visual impairment and where English was not the first language.

PHOTOGRAPHS
Backman's study in 2001 involved 51 general intensive care patients and families who were given diaries. He used photographs as an aid in the debriefing process during their recovery from critical illness. He demonstrated that the patients found the photographs helpful in showing what they had been through in a visual way. There were no negative outcomes reported.

It was decided to include photographs in the diaries within this project.

Relatives were offered the opportunity to have photographs taken during the patients' stay in ICU. Information about the perceived benefits of having photos taken was given to the relatives. Verbal assent from the relatives was sought before any photographs were taken. All the relatives were encouraged to have photographs included in the diary, but no pressure was placed on them to agree. Reassurance was given that no copies of photographs would be taken and that the diary would be the property of the patient and their family.

Backman's study indicated that patients seemed comforted by the inclusion of family members and staff in photographs, as this provided tangible evidence that they had not been left alone. Therefore, efforts were made to include staff and relatives in photographs to show a realistic view of their time in ICU.

Family and staff members who were willing and comfortable to appear in photographs participated. The LREC was happy that this fitted with informed consent. Concerns by staff about legal and ethical issues were assuaged by the practical implementation of the diaries. The trust was in agreement with the decision of the LREC.

It was recognized that photographs should be used with care.

STAFF INPUT
All allied health professionals and members of the ICU team were given written information about the background to the diaries project and how these should be used. In addition, regular sessions were arranged, detailing how to input information and to discuss any queries that emerged.

HOW THE DIARY WAS USED
Once consent had been obtained, the diary was started as A4 size paper kept in a bright folder at the bedside. The diary began with a brief summary of events leading up to admission to the unit. Thereafter, anyone who had been involved in the care of the patient was invited to write in the diary.

Nursing staff were encouraged to write once a day, giving factual information about the patient's condition, events of the day and any changes in treatment. Staff were encouraged to use straightforward language, so that the patient derived maximum benefit from reading the diary when they had recovered.

Relatives were encouraged to read the diary in order to keep up to date with what was happening to their loved ones. This supplemented information given verbally by staff. They were encouraged to contribute to the diary, so that it contained their reflections, individual thoughts and ideas. Relatives could also use it to give messages to the patient about what had been happening at home, who had called or how the patient seemed to appear to them on that day. If there were young children in the family, who may not be visiting, their paintings/letters, etc. were included alongside news of particular interest to the patient such as football results. The diaries were collated and bound and given to the patient at their first follow-up clinic appointment.

PRELIMINARY RESULTS
- During the first 12 months, 28 families were offered the opportunity to keep a diary of their relative's stay.
• Three relatives declined the offer to compile such a record.
• Four families did not assent to photographs.
• Five diaries belonged to patients who subsequently died. In this situation, the follow-up sister wrote to their families offering them the diary. Four out of the five families wished to receive the diary. It was given to them with offers of support and further explanations if necessary.

When patients received their diaries, they and their relatives were invited to an informal meeting with the follow-up sister to discuss their care and treatment and ask any questions. Brief notes were taken, and a plan was drawn up of any ongoing care. This had 100% uptake with the majority of patients returning within 6 weeks of discharge. However, some patients took a while, before they felt able to revisit their ICU experience, and three patients took longer than 3 months, before they felt able to start reading their diaries.

MAIN FINDINGS

• Patients found the photographs helpful in showing what they actually looked like while in ICU and just how ill they were. At later clinic appointments, this reality check has appeared useful when setting goals for recovery. Care and sensitivity have to be taken with these images, in particular, regarding the impact of the image on the family of patients.

• Unsurprisingly, a patient’s experience in ICU was very different from that of their family. The diary appeared to be helpful in resolving what did and did not happen and thereby allowed different perceptions to be grounded in the facts of the stay. It also seemed to open up communication channels between patients and their families, often initiating discussion between them about important personal issues.

• Patients reported that, having been given the facts of their stay, they felt able to move on from the experience and thus help reorientate more easily to normal life. For some patients, the diary seemed to act as a debriefing tool containing the facts of their stay which, when addressed, could be put aside before getting back to normal. They benefited from knowing dates and times particular to their condition and treatment while in ICU.

• Bereaved families stated that they were pleased to receive a diary of their relative’s stay and glad to have something to look back on. They felt that they had some concrete memory of their loved ones’ last days before they died. There were, however, a minority who reported feeling upset after seeing photographs of their loved ones after they had died.

FUTURE PLANS

This pilot study has established the logistics of compiling ICU diaries and their general acceptability to patients. The feedback has been very positive from patients, relatives and staff who have experienced them. Our next steps are to

• Design an audit tool to evaluate the use of diaries on a more formal basis.
• Consider evaluating the diaries in relation to impact on PTSD levels.
• Critically explore benefits to the bereaved.

Diaries are now an integral part of the patient’s care within the Trust. The use of prospective diaries as a rehabilitation tool following critical illness is highly recommended.

To establish whether any identified benefits persist over time, patients and their families will be followed up for 1 year.

REFERENCES


