❖RESEARCH CONNECTIONS❖

An evaluation of patient diaries in intensive care

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SUMMARY

- Patient diaries in intensive care have become increasingly popular in the last five years, with many intensive care units (ICUs) introducing them as a way of helping patients to make sense of their critical illness experience.
- Diaries are an inexpensive form of post-ICU care in comparison with formal post-ICU follow up clinics. In the United Kingdom there appears to have been little research into patients' experiences of having an ICU diary.
- A questionnaire was sent to all surviving patients who had been given a diary in the first two years following their introduction at a district general hospital ICU in England. The aim of the study was to explore the experiences of patients who received a diary and photographs of their stay in ICU.
- The findings suggest that patients find the diaries helpful in understanding the time they spent in intensive care, and in understanding what it was like for their families whilst they were ill.
- Many of the patients suggested ways in which the diaries could be improved. Suggestions included continuing diaries after patients are transferred to the high dependency unit and the general wards.
- Further research is needed to explore patients' experiences in greater depth and to explore the practicalities of continuing patient diaries after transfer from ICU.

INTRODUCTION

Patients who have been in ICU appear to have a strong need to understand their critical illness episode (Compton, 1991; Hupcey & Zimmerman, 2000; McKinney & Deeney 2002). McKinney and Deeney (2002) interviewed patients who had been transferred from ICU to a general ward, and one of the themes identified from the data was 'restoring meaning'. Patients were keen to cognitively revisit their experience, in order to restore some meaning and make sense of what happened to them. Compton (1991) revealed that patients found lack of information about their stay in ICU very frustrating and that some of them spent a lot of effort trying to piece events together. This was done mainly by asking friends and relatives to fill in the gaps in their memories.

Morse and O'Brien (1995) described a model of recovery, based on interviews with survivors of serious traumatic injury, many of whom required intensive care. The model is based on the process of preserving self and has four stages: vigilance, disruption, enduring the self, and striving to regain self. The final stage, striving to regain self, is about merging the old and the new reality. The major goals at this point are about making sense of the event, getting to know and trust the altered body and accepting the consequences of the event. Patients tried to piece together what happened to cause their accident, and link together all the events they could not recall.

After discharge from ICU patients commonly experience amnesia, often remembering little of their stay (Jones et al., 2001). An earlier study by Jones et al. (1998) talks of "almost universal amnesia experienced for the time in ICU" (p. 200) and a recent study by Weinert and Sprenkle (2007) report that 18% of a sample of 149 patients had amnesia about their entire ICU stay. What patients do remember can often be a mixture of reality and delusional memories, and for some frightening hallucinations. Such memory loss may contribute to the development of post traumatic stress disorder (PTSD) (Perrins et al., 1998; Jones et al., 2001). Levels of PTSD in post-ICU patients have been reported to be as high as 27.5% (Schelling et al., 1998). This disorder is characterised by intrusive memories of the traumatic event, avoidance of things associated with the event, and symptoms of arousal (American Psychiatric Association, 1994). Negative emotions such as sadness and anger, and guilt can commonly accompany PTSD (Brewin et al., 1996).

Lack of recall about their stay on ICU can also mean that patients do not appreciate how ill they have been and consequently have unrealistic expectations regarding their recovery period (Jones & O'Donnell, 1994). This can lead to frustration and depression. Backman and Walther (2001) and Griffiths and Jones (2001) suggest that a diary kept for patients whilst they are on ICU that includes photographs of the patient at various stages of their illness, and containing written entries from nursing staff, family and friends may help patients to make sense of their experience by filling in the gaps in their memories, and helping them to appreciate how ill they have been. Having this factual information may also help them reject delusional memories as false, and in so doing may reduce the risks of them developing PTSD (Jones et al., 2001).

Jones et al. (2001) demonstrated that post-ICU patients with delusional memories of their time in ICU but no factual memories, scored highly for PTSD when interviewed at eight weeks after discharge. They suggest that factual memories may help patients to reject delusional memories and reduce their risks of developing post traumatic stress disorder. Patient diaries are one way of providing patients with factual information about their stay on ICU.

Patient diaries for unconscious patients appear to have originated in Denmark in the 1980s (Bergbom et al., 1999), and since then they have been adopted most widely in Denmark and Sweden. In the past six years there has been increasing interest in the diaries from ICUs in the United Kingdom (Robson et al., 2006). Many ICUs have introduced the diaries, and even a web based version of the diary has been developed, known as a digital recovery environment (British Council, 2007). A search of Medline, CINAHL and PsychInfo databases, along with hand searches of relevant journals revealed only six studies directly related to the use of patient diaries in ICU. Four studies were carried out in Sweden, one in Norway, and one in the UK (see Table).

Schou et al. (1993), Norway	A questionnaire study. The sample was comprised of 15 patients who had accepted a diary kept for them whilst they were a patient on ICU. Patients generally felt that the diaries helped them remember their stay, and helped them to reconcile their stay in hospital.
Bergbom et al. (1999), Sweden	The sample was comprised of 10 patients who had accepted a diary without photographs kept for them when they were on ICU, and four bereaved relatives who had accepted the diary without photographs kept for their loved one whilst they were a patient on ICU up till their death on the unit. The majority of patients and relatives had read the diary and reported that it helped them remember their stay in ICU, and helped them appreciate that their recovery would take a long time. Patients remarked that photographs in the diaries would have been useful, as they found it hard to imagine what they had looked like when they were on ICU.
Backman and Walther (2001), Sweden	A questionnaire study. The sample was comprised of 41 patients who had accepted a diary and 10 relatives of non survivors who had accepted their loved ones diary. Many of the diaries had been read more than 10 times and comments in the questionnaires were mostly positive or very positive, and this included comments from bereaved relatives also. From this sample a subgroup of seven randomly selected patients were interviewed in depth by nursing students (see below).
Dahlin and Grahn (1999), Sweden	Unpublished essay. Backman and Walther (2001) state that the results of these interviews were in agreement with the findings from their questionnaire.
Storli et al. (2003), Norway	Describes a study carried out in 1996 involving 32 patients. A follow up programme that included a patient diary helped patients realise what had really happened to them, and helped prepare them for the recovery period.
Combe (2005), United Kingdom	Describes the use of patient diaries at a United Kingdom hospital. In the first twelve months of using them, 25 diaries were completed. All the patients who survived accepted their diaries. The feedback from patients and their relatives was positive. Patients found the photographs helped them appreciate how ill they actually were, and having all the factual information about their stay helped them move on in their lives and return to normal.

Table. Previous studies of patient diaries in ICU

Diaries were introduced into clinical practice at a district general hospital by the author. Based on the author's own experience of using diaries, there is anecdotal evidence that when diaries are handed over to patients prior to discharge from hospital patients are grateful to receive them and indicate that they believe the diaries will be very useful in helping them understand what had happened to them. In the author's ICU, patient diaries are notebooks in which nursing staff and the patients' friends and family can write entries. Occasionally physiotherapists and medical staff also make entries. A guideline is used to advise staff on diary content and style, and on how and when to take photographs. The diaries are not standardised and will depend on which staff are caring for the patient and the extent to which those staff and the patient's family engage with the diary concept. Clinical workload may also influence the quality of the diary.

As part of the evaluation of the use of diaries in the author's ICU it was felt to be important to explore patients' experiences of the diary in greater depth once they were at home and recovering, and up to two years after discharge. Thus, a two part study was designed involving a postal questionnaire and in depth taped interviews. The remainder of this paper will report on the questionnaire study.

The purpose of the questionnaire was to gather quantitative data about how many pages and photographs were in an average diary that was being produced, and how many times patients had read their diary. It was felt that this kind of specific information might not get mentioned as part of in depth interviews. The questionnaire also included questions about the patients' experience of the diary, and included free text responses to allow them to expand upon their answers.

Local research ethics committee approval and hospital trust research governance approval were obtained for the study

METHODS

A postal questionnaire was sent out in mid 2006 to all surviving patients who had received a diary in the first two years following their introduction. 36 questionnaires were posted and 20 (56%) were returned.

The questionnaire was designed to explore patients' experiences of having an ICU diary. In the accompanying letter and participant information that was posted with the questionnaire, the author explained that he also wanted to recruit volunteers to take part in taped interviews to explore their experiences of the diaries in more depth. A reply slip was included for interested participants to return.

RESULTS

All the respondents had been in possession of their diaries for longer than six months. 45% (n = 9) had their diaries for 12-18 months, and 40% (n = 8) had their diaries for 18-24 months. The diaries were variable in length ranging from as few as two pages to over 80 (mean = 27). Diaries contained between one to four photographs. All respondents reported that they had been able to read the handwriting of those who had made entries in their diaries

The majority of patients (n = 16) felt the diary was given to them at an appropriate time, with three patients feeling that it had been given too soon, and one that it was given too late. A slight majority found it distressing to be shown the diary for the first time (n = 11, 55%), and a number of comments were made in this respect:

- It made me realise just how ill I had been and what my family had been through.
- I had not realised how ill I had been.
- I still get emotional when I read it.
- Seeing things I couldn't remember anything about.
- It was shocking for me to know how bad things had been for me and my family.
- Photo was a little distressing (seeing it) for the first time.
- The comments in it seemed to refer to me as a child. It made me feel vulnerable. I don't like to think of myself as vulnerable.

All respondents agreed that the diary had helped them make sense of what happened and all had read their diary since going home between one to five times (n = 11), between five to ten times (n = 2) or more than ten times (n = 7). Most respondents (85%, n = 17) felt that the diary should have been continued after their discharge from ICU to the High Dependency Unit (HDU) but most respondents (70%, n = 14) reported that the diary had helped them understand what it was like for their family. However, two respondents stated that there were things in the diary that they were unhappy with, and they made the following comments:

- Some friends wrote things that I find hard.
- I personally thought the photographs were a little harrowing.
- A number of suggestions were made to improve the diaries:
- It would have been good if it continued throughout my stay in hospital.
- Where possible a happy ending photo.
- The writing in the diary stopped when I left ICU and moved to ICU at (another hospital), so that's where the continuity ended.
- Probably more photos for different stages on the road to recovery on different wards.
- Get relatives to write in it and continue it when moved to another ward.
- My diary only started after I had been in ITU for two weeks so it only lasted for one week, so a lot of my stay was undocumented, therefore it is still unclear what happened to me for most of my stay.
- When I was moved from ITU my family were not able to carry on with it. It ended abruptly without an ending.
- Having more people write in it, perhaps a little medical information?
- Personally, from my own perspective, there were some gaps, however my husband and family aided my understanding of these so that I had some idea of the chronological events of my experience.

DISCUSSION

All of the respondents said that the diary had helped them make sense of what had happened to them. This finding is in keeping with earlier studies (Bergbom et al., 1999; Backman & Walther, 2001; Storli et al., 2003; Combe 2005) and provides the main rationale for introducing diaries (Griffiths & Jones, 2001). Half of the respondents' diaries were less than twenty pages in length, with three of these being less than ten pages. Despite the variety in length all respondents appeared to value the diary and even those whose diaries were shorter still responded that the diary had helped them make sense of their experience.

As the hospital where the study was conducted does not have an ICU follow up clinic, the respondents had their diary handed over to them whilst they were recovering on a general ward, prior to their discharge from hospital. Over half of the respondents (55%) said that they had found it distressing being shown the diary for the first time. The distress appears to result from the shock and realisation of how ill the patients were and what their families had been through. One respondent had found it distressing, feeling that the entries referred to him as a child, which made him feel vulnerable. Although over half found it distressing seeing the diary for the first time, this did not appear to be because of them being shown the diary before they were ready. Sixteen respondents (80%) felt that the diary had been handed over to them at the right time, and only three patients felt that their diary had been handed over to them too soon.

Seven of the respondents (35%) had read their diary more than ten times since going home, suggesting that the diary might be a valuable tool in helping patients understand their critical illness experience as their recovery progressed. Two of the respondents (10%) had read their diary between five to ten times and the majority of respondents (55%, n = 11) had read their diary one to five times since going home. These results are similar to an earlier study Backman and Walther (2001) in which 51% of respondents had read their diary more than ten times.

Many respondents (70%) stated that the diary had helped them understand what it was like for their family whilst they were ill in ICU. This may serve a valuable function as Young et al. (2005) argue that when patients have amnesia about their ICU experience this contrasts with relatives' memories, which are often complete and vivid, and the lack of a shared memory/ understanding between them might be a psychological burden to relatives. Young et al. (2005) argue that this might explain why relatives report more symptoms of anxiety than patients.

Almost half of the patients (45%) suggested ways in which patient diaries could be improved. Many of the comments referred to ensuring the diaries gave a comprehensive account of their experience with fewer gaps in their story, and more photographs. This might reflect the strong need for this group of patients to make sense of, or find meaning, in what happened to them. Respondents felt strongly (85%) that it would have been a good idea if the diary had been continued after they were discharged from ICU.

CONCLUSIONS

The results only represent 56% of the population addressed, and so must be interpreted with caution. However, they do suggest however that patient diaries may be a worthwhile tool to help recovering ICU patients understand what has happened to them. The results from this study are consistent with those carried out in Sweden, Norway, and UK.

There is a need for further research to explore patients' experiences of the ICU diaries in more depth. The second part of this study addressed this, and is reported elsewhere. ICUs that do not provide a follow up clinic or rehabilitation service may wish to consider implementing patient diaries into practice to help patients avoid post-ICU problems. In comparison with formal outpatient follow up, patient diaries are a low cost alternative means of helping patients in their recovery.

There is a need for further research to explore how to improve the standard of diaries that are produced, to ensure that all diaries give a comprehensive record of the patient's stay in ICU, with no gaps in their critical illness journey, and include several photographs at various stages of their stay. Respondents felt overwhelmingly that the diary should not end upon discharge from ICU. This might suggest that patients experience some amnesia not only about their stay on ICU, but also about their immediate recovery period in the HDU and the general ward. Future research could explore the continuation of diaries when patients are transferred to the HDU or a general ward, and nurses' experiences of trying to provide a patient diary service in an environment were occupancy levels and clinical workload within critical care units, and general wards are often very high.

Limitations

The questionnaire was not piloted, and it did not incorporate methods to establish reliability and validity (Rattray & Jones, 2007). The results of this study are based on a small sample of patients from one ICU in England. Although the response rate of 56% is reasonable for a postal questionnaire caution must be taken in interpreting the results and making generalisations to other ICUs. However this response rate does not appear to be unusual for health-related research. Badger and Werrett (2005) report that there is a lack of consensus in the literature about what is a desirable response rate with suggestions for postal surveys ranging from 20-60%. This group of patients was recovering from critical illness and some may have chosen not to complete the questionnaire because they found it distressing to revisit their ICU experience.

Implications

Patients who are recovering from critical illness do not seem to have

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access to the same standards of rehabilitation services that are routinely available for patients recovering from other diseases such as myocardial infarction or cardiac surgery. Levels of PTSD in post-ICU patients has been reported to be as high as 27.5% (Schelling et al., 1998), but despite this, follow up clinics are the exception rather than the norm. Griffiths et al. (2006) reported that only 30% of ICUs in the United Kingdom provide a follow up clinic. Patient diaries may offer an inexpensive and effective method of helping patients make sense of their critical illness experience and may help to reduce the incidence of PTSD-related symptoms in this group of patients.

Nurses should strive to ensure that diaries offer a comprehensive record of the patient's stay with a number of photographs that show the patient's journey from admission to ICU discharge. Diaries are photocopied and placed into the patient's medical notes with copies of the photographs on discharge from hospital. In the future it may be possible to include a copy of the diary in the patient's electronic personal health record. If diaries could be continued onto general wards, then patients could be given the opportunity to make entries in their diary.

REFERENCES

American Psychiatric Association (1994). Diagnostic and Statistical Manual of Mental Disorders, 4th edition. Washington, USA.

Backman CG, Walther SM (2001). Use of a personal diary written on the ICU during critical illness. Intensive Care Medicine 27 (2), 426-429.

Badger F, Werrett J (2005). Room for improvement? Reporting response rates and recruitment in nursing research in the past decade. Journal of Advanced Nursing 51 (5), 502-510.

British Council (2007). Digital Therapy [Online]. Available at: http://www.britishcouncil.org/ca/science-cubed-digital-therapy.htm Accessed 13 June 2007.

Bergbom I, Svensson C, Berggen E, Kamsula M (1999). Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit: pilot study. Intensive and Critical Care Nursing 15 (4), 185-191.

Brewin CR, Joseph S, Dalgleish T (1996). A Dual Representation Theory of Posttraumatic Stress Disorder. Psychological Review 103 (4), 670-686.

Combe D (2005). The use of patient Diaries in an intensive care unit. Nursing in Critical Care 10 (1), 31-34.

Compton P (1991). Critical illness and intensive care: what it means to the client. Critical Care Nurse 11 (1), 50-56.

Dahlin V, Grahn A (1999). The meaning of a photo – diary for intensive care recipients. Essay (Level C), Dept. of Medicine and Care, Nursing Science within the Faculty of Health Sciences, Linkoping University, Sweden.

Griffiths RD, Jones C (2001). Filling the intensive care memory gap? Intensive Care Medicine 27 (2), 344-346.

Griffiths JA, Barber VA, Cuthbertson BH, Young JD (2006). A national survey of intensive care follow up clinics. Anaesthesia 61 (10), 950-955.

Hupcey JE, Zimmerman HE (2000). The need to know: Experiences of critically ill patients. American Journal of Critical Care 9 (3), 192-198.

Jones C, Humphris GM, Griffiths RD (1998). Psychological morbidity following critical illness-the rationale for care after intensive care. Clinical Intensive Care 9 (5), 199-205.

Jones C, O'Donnell C (1994). After intensive care – what then? Intensive & Critical Care Nursing 10(2), 89-92.

Jones C, Griffiths RD, Humphris G, Skirrow PM (2001). Memory, delusions, and the development of acute post traumatic stress disorder-related symptoms after intensive care. Critical Care Medicine 29 (3), 573-580.

McKinney AA, Deeny P (2002). Leaving the intensive care unit: a phenomenological study of the patients' experience. Intensive and Critical Care Nursing 18 (6), 320-331.

Morse JM, O'Brien B (1995). Preserving self: from victim, to patient, to disabled person. Journal of Advanced Nursing 21 (5), 886-896.

Perrins J, King N, Collings J (1998). Assessment of long term psychological well-being following intensive care. Intensive and Critical Care Nursing 14 (3),108-116.

Rattray J, Jones MC (2007). Essential elements of questionnaire design and development. Journal of Clinical Nursing 16 (2), 234-243.

Robson WP, Wheeldon G, Penney D (2006). Patient Diaries. In: Cutler L, Robson WP (eds.) Critical Care Outreach. Chichester: Wiley.

Schelling G, Stoll C, Haller M, Briegel J, Manert W, Hummel T, Lenhart A, Heyduck M, Polasek J, Meier M, Preuss U, Bullinger M, Schüffel W, Peter K (1998). Health-related quality of life and post traumatic stress disorder in survivors of acute respiratory distress syndrome. Critical Care Medicine 26 (4), 651-659.

Schou I, Nordvik M, Torseth AM, Fet U, Thon I, Mokkelgard M (1993). Dagbok til intensiv patienter [Diary for intensive care patients]. Nye Fagoscopet 4, 7-10.

Storli SL, Lind R, Viotti I (2003). Using diaries in intensive care: a method for following up patients. Connect: The World of Critical Care Nursing 2 (4), 103-108.

Weinert CR, Sprenkle M (2007). Post ICU consequences of patient wakefulness and sedative exposure during mechanical ventilation. Intensive Care Medicine [Online]. Available at: http://www.springerlink.com/content/b260j766331v8866/ Accessed 20 September 2007.

Young E, Eddleston J, Ingleby S, Streets J, McJanet L, Wang M, Glover L (2005). Returning home after intensive care: A comparison of symptoms of anxiety and depression in ICU and elective cardiac surgery patients and their relatives. Intensive Care Medicine 31 (1), 86-91.