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Use of patient diaries in critical care

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Abstract

The use of patient diaries in critical care in the UK is increasing, but there is little evidence-based research available to support this. The National Institute for Health and Clinical Excellence (NICE) has recommended that services should be developed to meet the psychological care needs of patients following critical illness. One response to this has been the introduction of patient diaries. To gain insight into the use of patient diaries in critical care, a literature review was conducted. This article provides an overview of the literature and suggests how it can inform clinical practice in relation to diary use in critical care and beyond.

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KEEPING A DIARY on behalf of a patient was first described in Denmark in the 1980s when brief notes were made about key events, the environment in the critical care unit and the world outside. Diary entries were made by nurses and relatives (Nortvedt 1987). The rationale for this note keeping was the loss of time and memories experienced by patients following a critical illness. Since then, the use of diaries has spread throughout critical care units in Scandinavia. In the 1990s, critical care units began to offer patients hand-written notes and photographs from their critical care admission (Bergbom *et al* 1999). Diaries have evolved to include nurse-led dialogue (Bäckman and Walther 2001, Egerod *et al* 2007, Storli *et al* 2008, Storli and Lind 2009). Indeed, nurses are perceived to be the inspiration for the adoption of diaries in critical care units (Egerod *et al* 2007, Åkerman *et al* 2010). More recently, the use of patient diaries has been adopted in the UK (Combe 2005, Robson 2008, Jones 2009, Hale *et al* 2010).

Support for patients following discharge from critical care is lacking (Rattray 2007, Rattray and Hull 2008). Part of the rehabilitation process after critical illness is for patients to understand what has happened, acknowledge the possible after-effects and set realistic goals for their recovery. Griffiths and Jones (2001) and Roulin *et al* (2007) identified that when patients' memory is poor, they are unable to relate to what they have been through during their critical illness, which can lead to unrealistic expectations of recovery or rehabilitation.

The psychological implications of admission to critical care have become a topic of interest in the past decade. Studies have linked memory disruption or delusional thoughts to the physical and psychological symptoms reported by survivors (Samuelson *et al* 2006, Storli *et al* 2008). This led to the introduction of patient

diaries as an aid to restoring memories, or at least to enable patients to read about key things that had happened during their admission to critical care and to help make sense of disrupted memories and deluded thoughts (Bergbom *et al* 1999, Egerod *et al* 2007).

There are two theories about the use of patient diaries in critical care. One theory is that the diary enables a void in the patient's memory to be filled by providing objective information and orientating the patient back to reality (Hupcey and Zimmerman 2000, Bäckman and Walther 2001, Combe 2005). Another theory is that the diary narrative, written to reflect patients' own experiences as closely as possible, gives meaning to potentially meaningless experiences during their time in critical care (Storli and Lind 2009, Egerod and Christensen 2009), as well as a belief that the diary helps to keep focus on the patient as a person (Gjengedal *et al* 2010).

The National Institute for Health and Clinical Excellence (NICE) (2009) recommends that services should be developed to meet the psychological care needs of patients following critical illness.

Patient diaries are portrayed in the literature as a resource to enable the patient to read about key things that happened during their critical illness. Research so far has been undertaken predominantly in Scandinavia, where diaries developed originally. However, there has been an increase in UK publications recently following a growth in the use of patient diaries in critical care units. The ensuing discussion explores some of the key issues identified in the research and clarifies the current knowledge base surrounding patient diaries in critical care. There is a lack of research related to diary use with a fundamental lack of focus on patient perceptions and what they want from a diary, if they want a diary at all and what contributes to this decision.

Literature review

A literature search was carried out using the Cumulative Index to Nursing and Allied Health Literature, Medline, PubMed and Google Scholar. No date restriction was used for the search. Only studies that were specific to diary

TABLE 1

Literature related to diary use			
Type of study	Authors	Method	Notes
Survey	Egerod <i>et al</i> (2007) Åkerman <i>et al</i> (2010) Gjengedal <i>et al</i> (2010) Nydahl <i>et al</i> (2010)	Telephone survey	All Scandinavian studies, except Nydahl <i>et al</i> (2010), which was based on German intensive care units.
Controlled trial (two randomised, one non-randomised)	Knowles and Tarrrier (2009)	Longitudinal questionnaire	Anxiety and depression.
	Jones <i>et al</i> (2010)		Post-traumatic stress disorder.
	Bäckman <i>et al</i> (2010)		Health-related quality of life.
Narrative analysis	Roulin <i>et al</i> (2007) Egerod and Christensen (2009) Egerod and Christensen (2010)	Diaries and patient charts	Focus on diary narrative as opposed to patient views.
Interview	Engström <i>et al</i> (2008)	Interview at 12 months	Patients.
	Egerod <i>et al</i> (2011)	Interview at 6 months	Patients and relatives.
Pilot study	Bergbom <i>et al</i> (1999)	Questionnaire	Patients and relatives.
	Combe (2005)	Interviews at 2, 6 and 12 months	Prospective and retrospective diaries.
Focus group	Egerod and Bagger (2010)	Focus group	Patient and diary.
Observational questionnaire	Bäckman and Walther (2001)	Questionnaire 6 months after discharge	Patient and diary, diary structure, use of diaries as a debrief tool.
Evaluation or description	Robson (2008)	Questionnaire	Diary use.
	Storli <i>et al</i> (2003)	Diary	
	Jones (2009)	Diary	
	Hale <i>et al</i> (2010)	Diary	

use in critical care were included: studies on any other types of diary were excluded. Keywords used were diary, patient, critical care, intensive care, ITU, ICU, critical care survivors, psychological problems and coping. These keywords were used singularly and in combination, resulting in the identification of 20 articles written specifically about critical care patient diaries (Table 1).

Patient experience

Although the critical care unit can be a daunting place, it is essentially a continuously changing environment in which patients and their families are helped through the crisis of critical illness. Life-saving interventions continue to evolve, increasing the chance of recovery, but these interventions are not without potentially negative effects. Patient experiences and memories of critical care affect individuals' lives after discharge (Adamson *et al* 2004, Sheen and Oates 2005, Almerud *et al* 2007, Knowles and Tarrier 2009). Some patients remember and retain strong emotions and anxiety related to their experience, (Storli *et al* 2008). The emotions and anxiety felt by patients may relate to the critical care environment and the sensation of treatment; for example, patients may remember being unable to communicate because of endotracheal intubation. Storli and Lind (2009) advocated the use of patient diaries and suggested it is also beneficial for some patients to return to the critical care unit to help put these thoughts and feelings into context. There is a lack of research regarding the perceptions of patients who do not return to collect their diary.

Survivors of critical care may exhibit physical and psychological problems (Scragg *et al* 2001, Skirrow *et al* 2002, Adamson *et al* 2004). The incidence of anxiety and depression is increased, and in some patients this can lead to symptoms of post-traumatic stress disorder (Knowles and Tarrier 2009, Jones *et al* 2010). These psychological problems usually occur in patients who have been sedated and ventilated; as a consequence patients may be unable to recall events while they have been critically ill or may have a distorted perception of what happened (Storli *et al* 2003, Almerud *et al* 2007).

To enable critically ill patients to tolerate the often invasive interventions required to treat them, sedatives and analgesics are used to manage discomfort and pain and reduce anxiety (Sessler and Varney 2008). However, there is variation in sedation practices (Griffiths and Jones 2007, Fuchs and Von Rueden 2008). In the past, patients were heavily sedated in the belief that

amnesia was better for the patient (Ostermann *et al* 2000). However, studies of length of stay in critical care and time spent on a ventilator suggest that lighter sedation enables quicker patient recovery and discharge from critical care (Adamson *et al* 2004, Almerud *et al* 2007). The aim of lighter sedation is to provide a level of comfort at which the patient can tolerate the interventions required. 'Sedation breaks', 'sedation holds' or 'daily interruption of sedation' (Roberts *et al* 2010) are necessary to assess sedation score and to ensure patients are not over sedated; these breaks from sedation are also associated with earlier weaning from ventilator support (Kress *et al* 2000). However, the use of light sedation may lead to increased psychological problems (Kress *et al* 2000, Samuelson *et al* 2003).

Sedation and analgesia may contribute to psychological problems after critical care admission (Sessler and Varney 2008). Patients who are heavily sedated may have no recall of their admission, and longer length of stay in critical care has been linked to increased delusional memories (Samuelson *et al* 2006). Fragmentation can occur, in which only part of a memory is recalled, leaving patients struggling to make sense of an event or communication (Granberg *et al* 1996).

Some studies have described patients' experiences of being unable to speak because of endotracheal intubation or tracheostomy insertion and the communication challenges this presents (Pathanassoglou and Patrarakis 2003, Sheen and Oates 2005, Roberts *et al* 2007, Meriläinen *et al* 2010). Patients have also described a loss of control over their body and feeling invisible to staff (Sheen and Oates 2005, Almerud *et al* 2007). In addition to this are concerns about communication with the patient and orientation in person, time and place. Patients can become confused about what year it is, what day it is and where they are; this can be related to their illness or the sedation and analgesia required to treat them (Stein-Parbury and McKinley 2000, Combe 2005). Some patients in critical care have a desire to know what is happening and what has happened to them. The use of a diary is seen as a means of supporting this process through reflection rather than just presenting the facts (Hupcey and Zimmerman 2000, Bäckman and Walther 2001, Egerod and Bagger 2010). The reasons why some patients do not collect their diary has not yet been examined.

The phrase 'ITU (intensive therapy unit) psychosis' is used in the literature to describe delirium, distortion of memory and hallucinations. ITU psychosis is described as an acute and fluctuating alteration in the mental status of the patient. This manifests as problems

with attention and altered levels of consciousness and comprehension of what is happening (Xie and Fang 2009). ITU psychosis may be a direct result of multiple and sometimes urgent interventions (such as insertion of invasive devices) or sensory deprivation such as lack of touch, communication and reassurance from staff (Roberts *et al* 2007). Alternatively, these psychological changes can be associated with the severity of illness and complications such as hypoxia, sepsis and altered electrolytes, which can make patients confused and disorientated (Stein-Parbury and McKinley 2000). According to Xie and Fang (2009), epidemiological studies in various countries have found that low severity critical care patients have a 20-50% chance of developing delirium whereas the risk increases to 60-80% in mechanically ventilated patients. In prospective cohort studies of mechanically ventilated patients, Ely *et al* (2004) and Lin *et al* (2004) found that delirium was associated with a 20% risk of longer length of stay in critical care and a 10% higher risk of mortality.

The challenge for critical care nurses is balancing humane, psychologically supportive and dignified care with the technological and pharmacological requirements of the critically ill patient (Almerud *et al* 2007). Little consideration has been given to meeting the ongoing needs of patients following admission to critical care and survival of life-threatening conditions. Critical care services need to develop patient support mechanisms beyond discharge, such as physical and psychological follow up and support; diaries could be used to aid this process (NICE 2009, Jones *et al* 2010).

Defining patient diaries

Patient diaries are prospective – they are written during the patient's stay in critical care for the patient to read in the future. The main author tends to be a nurse, although other members of the multidisciplinary team and relatives are invited to contribute (Bäckman and Walther 2001, Combe 2005, Jones 2009, Hale *et al* 2010). Retrospective diaries, based on clinical notes of events that occurred during the patient's stay in critical care, were trialled by Combe (2005), but this approach was found to be too impersonal and it was abandoned in favour of a prospective approach.

Diary structure

Although diary content is broadly consistent, diary structure varies. Diaries can be loose leaf or bound; an advantage of loose-leaf diaries is that entries can be edited to ensure they are

appropriate for patients to read, the language used is easily understood and the content will not cause distress to the patient (Egerod and Christensen 2009, Gjengedal *et al* 2010). A loose-leaf format can also avoid the risk of relatives reading diary entries that contain potentially confidential information relating to the patient. However, it could be argued that confidential material not meant to be shared with the relatives should not be included in the diary. Diaries can be placed in a protective plastic cover so that they remain in good condition and a notebook size format is advocated (Bäckman and Walther 2001, Jones 2009). A summary of events before admission can be provided with the help of relatives to provide the context of and background to the critical illness (Åkerman *et al* 2010, Gjengedal *et al* 2010). Patients may have little or no recall of their stay in critical care and the aim of the diary is to provide a chronological record of events (Bäckman 2002)

Diaries can include descriptions of the weather, news and personal events such as family and friends visiting, a picture drawn by a grandchild or a flower picked by a nurse on his or her way to work (Egerod and Christensen 2009, Jones 2009). Key milestones for patients are detailed such as intubation, extubation and sitting out at the bedside. Diaries are jargon-free so that the patient can easily understand what is written. Some diaries mix comments from nurses, other members of the multidisciplinary team and relatives, whereas others have two separate versions to protect the patient's privacy and confidentiality (Jones 2009).

Egerod *et al* (2007) studied the use of patient diaries in Denmark in 2006. The diaries had been implemented as a means addressing periods of amnesia in patients who had been critically ill. The authors found that diaries can be ambiguous and vary in structure, and they were concerned about the lack of information available regarding diary use and evaluation. Diaries were being introduced in an experimental manner rather than as part of a therapeutic approach and their effects were not being evaluated. Egerod *et al* (2007) proposed that national clinical guidelines on diary use should be developed, and these have now been introduced in Denmark (Egerod *et al* 2011). However, the development of guidelines remains a contentious issue. Complaints and litigation could constrain what the writer is willing to say and how they say it. The general consensus from studies in Scandinavia is that the appearance, content, language used and handing over of patient diaries varies between units and there are no standard criteria for selection or diary compilation (Egerod *et al* 2007, Åkerman *et al* 2010, Gjengedal *et al* 2010).

Jones (2009) described the introduction of patient diaries in a specific hospital and outlined some of the issues they had considered during the process. A diary group was established to enable the process and guidelines were produced regarding how and when to write in the diary, about including photographs and how the diary would be stored. Concerns were raised about the ethics, legality and confidentiality regarding diary writing and use of photographs and, therefore, the hospital legal team provided advice and support. This is a complex consideration for any critical care unit or ward implementing patient diaries; authors need to exercise an element of self-governance in case of complaint or litigation, and consideration needs to be given to how this may affect the quality of the diary.

Patient diaries have been developed and constructed by healthcare professionals based on assumptions about what the patient wants. The diary may or may not capture information that the patient can use to gain clarification of events at a later date. This approach could be described as paternalistic in that patients do not have central control over a diary which is intended for their use.

Storage

Diaries can be photocopied and filed in the patient's medical notes for future access by the patient; some critical care units destroy diaries 12 months after the patient is discharged. However, some patients who do not collect their diary initially do make contact with the unit around the first anniversary of their illness and may wish to collect it at this stage (Jones 2009). People have different needs and ways of coping at different times in their lives and it is difficult to predict when the critical care diary may or may not be of use to the patient. There is therefore disparity in the manner in which diaries are stored and for how long. To ensure some patients are not disadvantaged, Hale *et al* (2010) suggested filing a copy of the diary in the medical notes rather than risk destruction of what could be construed as a record of patient care. However, diaries should not be confused with medical notes as the diary essentially belongs to the patient.

Use of photographs

Photographs can be taken as soon as possible after admission and more photographs can be taken of key events, for example insertion of a tracheostomy or sitting the patient out of bed for the first time (Jones 2009, Gjengedal *et al* 2010). Patients can sign a retrospective consent form for the photographs. In some cases, permission from

a relative of the patient can be sought, but some patients felt the wrong decision had been made on their behalf and they did not have a photograph when they wanted one (Jones 2009, Egerod and Bagger 2010).

In one unit photographs were taken and kept in locked storage with the patient's name, date of birth, date the photograph was taken and patient identification number written on the back (Jones 2009). The diary itself can be kept at the bedside for daily updates to be entered and gaps can be left for the potential insertion of photographs. When patients are well enough, it is up to them to decide if they want their diary with photographs, their diary without photographs or neither. The completed diary and photographs can be safely stored in a locked fire-proof cupboard in an alarmed office. They will either be given to the patient or bereaved relative, or destroyed on the patient's request. Although this is how one unit deals with patient diaries, variation in diary practice continues to be a matter of contention (Åkerman *et al* 2010, Gjengedal 2010).

According to Storli and Lind (2009), photographs enabled patients to 'visualise how it really was' in critical care, and even aided in understanding bodily sensations, such as having an endotracheal tube in the mouth. It is important that photographs are appropriate and that patients are given a choice to see them.

Allocation criteria

There is variation between critical care units in how diaries are allocated to patients. Usually diaries are started for any patient who is expected to stay more than two or three days in the critical care unit, and for any patients who require sedation and mechanical ventilation because they are more likely to experience memory distortion or amnesia (Egerod *et al* 2007, Åkerman *et al* 2010, Gjengedal *et al* 2010).

Diary writing

Diaries are written for patients so entries need to be clear and jargon free to help individuals make sense of their admission to critical care (Bäckman and Walther 2001, Combe 2005). Some diaries include a glossary of terms and labelled photographs of equipment with the aim of enhancing the descriptions provided in the diary (Jones 2009). Entries should be provided for every day of the patient's stay in critical care and reflect patient milestones and progress (Bergbom *et al* 1999, Bäckman and Walther 2001, Jones *et al* 2010).

There will inevitably be discrepancies in the way individual authors write and how much time they are willing or able to allocate to the diary. It is important that diary entries are monitored and the content scrutinised before handover to the patient. It is important that the content is appropriate for the patient to read and any writing that may be misunderstood is clarified or edited appropriately. Usually critical care units allocate a specific team of nurses or diary team who are interested in diary use. They tend to adopt a role that oversees the process and ensures the standard or quality of the diary is acceptable before handover to the patient; aspects can be edited to ensure the patient can understand what the writer is trying to say (Jones 2009). Diary contributors should be encouraged to develop the skill of diary writing, balancing the legal and ethical considerations without compromising authenticity. Relatives of the patient can be given an information sheet and encouraged to write about key events at home. If the relative wants to write a private note to the patient, it can be sealed and taped into the diary (Gjengedal *et al* 2010).

Capturing good practice in diary authorship is difficult, although there are a few studies that have looked at diary narrative in particular (Roulin *et al* 2007, Egerod and Christensen 2009, Egerod and Bagger 2010). Egerod and Christensen (2009) highlighted that diary narrative provides new insight into patient experiences and the role that nurses may play. One criticism is that the narrative tends to focus on the nurse's actions rather than the patient's reactions: diaries often fail to note the patient's reactions or behaviour, particularly when describing what the individual felt was a significant event (Egerod and Bagger 2010). This highlights the challenge of writing on behalf of a patient and that the level of skill involved will vary significantly.

Storli and Lind (2009) stated that diary writing goes beyond the expected role of the nurse and that patients view the diary as a 'symbol of staff wishing them well in their recovery'. The diary narrative can show that the nurse has been respectful and provided dignified care (Gjengedal *et al* 2010).

Choosing to use a patient diary

According to Nydahl *et al* (2010), patients who have spent time sedated and ventilated in a critical care unit often want to reflect on their experience. A way of making this reflection possible is to have a chronological record of events in the form of a diary, with a follow-up appointment to enable the patient to ask questions.

Hupcey and Zimmerman (2000) found that memory varied between patients, with some individuals recalling nothing at all and others very little about their admission to critical care. In critical care units today, patients are often more lightly sedated than in the past, when amnesia was seen as a desirable effect. According to Ulvik *et al* (2008), memories, dreams and nightmares can reduce the quality of life of critical care survivors. The diary aims to restore reality and dismiss any misinterpretations or confusion (Nydahl *et al* 2010).

Diaries have also been described as a debriefing tool for patients: diaries can alleviate memory deficits and psychological symptoms by ensuring that patients understand the implications of their critical illness and allowing realistic goals for recovery to be set (Bäckman and Walther 2001, Combe 2005, Robson 2008). However, debriefing requires appropriate support as a diary has the potential to cause harm if the patient is not provided with suitable psychological support in a structured manner, for example cognitive behavioural therapy. In a randomised controlled trial of diary use in patients with post-traumatic stress, Jones *et al* (2010) found that concerns about debriefing and the manner in which this occurred were not supported by their findings. In fact, the authors likened the patient reading and re-reading the diary narrative to cognitive behavioural therapy. However, not enough research has been carried out to establish if there are any risks associated specifically with use of patient diaries.

The main focus of research appears to be on anxiety, depression and post-traumatic stress disorder (Knowles and Tarrrier 2009, Jones *et al* 2010) and audit of diary use in terms of allocation, guidelines and structure (Åkerman *et al* 2010, Gjengeda *et al* 2010, Nydhal *et al* 2010). Knowles and Tarrrier (2009) found that the use of a patient diary significantly reduced anxiety and depression scores at two months after discharge from critical care. In a non-randomised prospective study of patients, Bäckman *et al* (2010) compared patients who had diaries kept on their behalf ($n=38$) with patients who did not have a diary ($n=224$). The authors found that diaries enabled patients to re-orientate themselves to normal life after their critical illness and that more realistic goal setting had a positive influence on physical recovery (Bäckman *et al* 2010). However, there were disparities between the two groups in age and severity of illness, which brings the reliability and validity of these findings into question. The authors themselves note that a larger, randomised study is required.

In a randomised controlled trial of 322 patients, Jones *et al* (2010) found that the use of a diary kept by nurses and/or the multidisciplinary team reduced symptoms of post-traumatic stress disorder associated with critical care admission. The incidence of the disorder was 5% in the diary group compared with 13% in the control group. The authors suggested that the use of diaries in critical care is associated with reduced psychological consequences for patients (Jones *et al* 2010). However, several means of assessing post-traumatic stress disorder were used in the study, which may have increased the likelihood of finding a difference between the diary and the control groups.

To date, little attention has been given to the interaction of the patient with the diary. The author argues that it is important to ascertain patients' perceptions of their diary, without any preconceived assumptions or associations, to gain insight into the role of the diary in their recovery process.

Diary handover and follow up

Patient diaries have been described as a low cost means of providing psychological support that can improve quality of life for patients (Combe 2005, Egerod *et al* 2007). Patients gain understanding of their experience through diary content, such as dialogue and photos (Bäckman and Walther 2001, Robson 2008). Recovery is purported to be aided by realistic goal setting and improved communication with relatives about the critical care experience (Roulin *et al* 2007, Engström *et al* 2008).

Jones (2009) noted that patients ask their relatives many questions as they try to understand what has happened: a diary may constitute a source of information that may be perceived by the patient as more concrete. Jones (2009) and Storli *et al* (2008) suggested that relatives also find the critical illness journey difficult and that the diary might alleviate the pressure on them once the patient is discharged home. However, the diary may cause anxiety as a result of misunderstood comments or may unleash memories that the patient finds difficult to cope with. A diary may describe the patient's struggle to survive: reading it will be emotional for the patient and, therefore, suitable support processes should be in place before the diary is given to the patient (Engström *et al* 2008).

Diary handover requires careful consideration to ensure patients do not feel forced to participate in the process, and if they do participate they will need guidance and support. Jones (2009) noted that reading the diary or seeing the photographs

for the first time is often an emotional experience for the patient, so careful consideration should be given to when and how the diary is handed over. Patients should determine when the time is right for them to be given their diary and the speed at which the information is provided. As this process requires sensitivity and perception of patient distress, the diary should be handed over by an experienced nurse so that content can be clarified with the individual and questions answered. There is no training or education available for this process, although some units have developed their own educational processes (Hale *et al* 2010).

Patients may value the fact that a nurse has taken the time to keep a diary for them while they have been critically ill. Engström *et al* (2008) reported that patients felt touched by their diary. A diary can give coherence to events during patients' illness and recovery, but it can be painful for patients to realise how ill they have been and how this may have affected their family, their own mortality and the length of time to recover. In support of this, Roulin *et al* (2007) described the patient diary as more complex than just a means of filling in gaps in memory; it is a means of conveying the commitment and care provided by the nursing team. Some diaries contain personal touches, for example the author may provide art for the diary cover or as page border. Likewise, some authors use poetry that they feel sums up events and that the patient may value. Writing the diary for the patient may also be cathartic for the nurse as it acts as a demonstration of care provided. Furthermore, diaries may allude to acts, intentions, goals or even emotions of the nurse. Patient diaries can be powerful tools for judging performance and quality of nursing care.

Van der Kolk and Fisler (1995) wrote that 'trauma arises from an inescapable stressful event that overwhelms people's coping mechanisms'. Patient diaries could assist patients in accessing a personal narrative or 'explicit memory', and continued use of the diary as a form of reflection after discharge from critical care may also be useful. Bäckman and Walther (2001) noted that patients wanted the diary to continue beyond critical care because they felt the story was incomplete, and that a change in emphasis from the critical care diary to the patient's own journal may be beneficial. However, this does not appear to feature in practice according to the literature reviewed. What may be preventing this is the explanation of the diary content to the patient and how and when it would be best to introduce the patient to this.

Discussion

Although diary use is being widely adopted, it is occurring in an *ad hoc* fashion and consensus is needed on the approach to diary use to ensure the structure, process and support mechanisms are appropriate and consistent (Åkerman *et al* 2010). The nature of patient diaries requires guidelines for development, based on patient feedback, to ensure those who write on the patient's behalf are clear about what to include and what not to include. There remains disparity in the criteria for allocation of a diary and, indeed, diary structure (Egerod *et al* 2007, Åkerman *et al* 2010, Gjengedal *et al* 2010).

The literature reviewed tends to focus on the diary as an aid to reconciling memory with reality. However, this has resulted in studies that explore

memory and the critical illness experience at the expense of ascertaining what patients really think about the diary, its structure, the dialogue and content. It remains to be established how patients feel about the diaries and whether improvements are possible.

Some authors describe patient diaries as a debriefing tool (Bäckman and Walther 2001, Combe 2005). Patients who show signs of avoidance or denial in relation to their critical illness may or may not benefit from the option to collect and read their diary. The diary can be perceived as a form of confrontation as reading and re-reading the diary is seen as therapeutic and may help recovery by enabling patients to make sense of their experience (Storli *et al* 2003, Storli *et al* 2008). Equally,

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for others, not accessing their diary may be part of a self-protective mechanism and further research is needed in this area.

Conclusion

There are several viewpoints about patient diary use. One is that the diary is therapeutic and acts as a debriefing tool by filling in gaps in memory so patients can make sense of the situation and be realistic about goals for recovery. Another viewpoint is that the diary captures a human element of caring and shows the patient has been treated as a real person with respect and dignity. The diary not only fills gaps in the patient's memory, but also conveys nursing care through its dialogue.

Another consideration is diary symbolism and what it represents to the nurse, the patient and relatives. Patients do not contribute to their diary and, although guidelines and best practice in relation to diary use are under discussion, diary use is arguably based on paternalistic assumptions made by nurses. In the author's opinion, nurses can only assume they know what patients want and it is vital that they not only ask patients, but also listen to what they have to say. As use of patient diaries in critical care increases, it is fundamental to establish patient perceptions of their diaries to inform future direction and development of this tool in clinical practice and what effect the diary may have on care delivery **NS**

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