

Psychological consequences of critical illness: What is the long term impact on patients and how can nurses help?



Hanne Birgit Alfheim RN; BN, Grad. Dip. Nursing (Intensive Care), Rikshospitalet University Hospital, Intensive Care Unit, Oslo, Norway

Margaret Wheeler, RN; RM, BN (Hon), Grad. Dip. Adult Ed., Queensland University of Technology, Brisbane, Australia.

E-mail: hanne.alfheim@rikshospitalet.no

Key Words: amnesia ❖ follow-up services ❖ intensive care ❖ patient diary ❖ psychological consequences ❖ quality of life ❖ recollection

SUMMARY

- There is a plethora of psychological consequences of being critically ill and being admitted to an intensive care unit that affects the surviving patient.
- Many patients do not remember much from their time in the intensive care unit and this may complicate their recovery after a critical illness.
- The long term psychological consequences of being critically ill may have an adverse effect on the patient's quality of life.
- Follow-up services have been shown to be helpful in the patient's recovery after a critical illness.
- Patients' diaries, written for them while in the intensive care unit, have been positively evaluated as an important part of the follow-up service for critically ill patients.

INTRODUCTION

Being admitted to an intensive care unit (ICU) can have enormous long term consequences for patients, both physically and psychologically. The purpose of this paper is to critically examine and discuss the long term psychological impact that treatment in an ICU might have on patients. Additionally, different follow-up services offered to ICU patients will be reviewed. As evident in the literature, many surviving ICU patients will experience psychological problems after critical illness including amnesia, hallucinations or flashbacks, anxiety, depression, dreams, nightmares, delirium (Pattison, 2005), post traumatic stress disorder (PTSD) (Scragg et al., 2001), irritability and social withdrawal (Jones et al., 1998).

Several studies have investigated these factors and their implications for surviving ICU patients and the results from the literature are conflicting. Anxiety may or may not be related to ICU admission itself, however other factors may well have an impact (Rattray et al., 2005). Moreover, there is not a general agreement whether delirium is associated with increased mortality (Dubois et al., 2001; Ely et al. 2004). Patients' different memories after critical illness were evaluated in several studies, with findings indicating a significant impact on patients' psychological well being (Jones & Griffiths, 2002). However, it might be of significance what type of memories the patients have, whether memories are real or unreal after ICU stay, and how these affect patients psychologically (Jones et al., 2000). Furthermore, the link between PTSD and critical illness has been investigated and again there are conflicting results whether delusional

memories could be associated with PTSD (Capuzzo et al 2005; Jones et al., 2001).

The critical care environment has been shown to influence a patient's quality of life (QOL) (Cuthbertson et al., 2004). Over the past years, a number of studies has investigated QOL in patients discharged from ICU and concluded that it is lower than that of the general population (Flaaten & Kvåle, 2001; Dowdy et al. 2005). Furthermore, research has also suggested that this might lead to reduced patient satisfaction and high utilisation of health care resources (Cuthbertson et al., 2004).

In an attempt to assist ICU patients in their recovery phase different follow-up services have been investigated. Dedicated follow-up clinics have been shown to be beneficial as reported by patients (Hames et al., 2001). Furthermore, telephone follow-up (Moran et al., 2005), outpatient clinics (Jones et al., 1994) and rehabilitation programmes (Jones et al., 2003) have been shown to positively assist patients in their recovery. Interestingly, a small number of studies has investigated patient diaries written in the ICU for the purpose of helping patients in their recovery. The results to date indicate that these diaries are a positive and beneficial support to patients (Bergbom et al. 1999; Backman & Walter, 2001; Storli et al., 2003; Combe, 2005).

PSYCHOLOGICAL CONSEQUENCES OF ICU ADMISSION

Anxiety and depression

Anxiety and depression are prevalent among conscious ICU patients. A study conducted in Colombia assessed 96 patients on the first day of admission to the ICU and found that anxiety was present in 24% of patients and depression in 14% (Rincon et al., 2001). Research conducted by Pochard et al. (1995) demonstrated that 50% of patients (n = 43) experienced anxiety after mechanical ventilation and Daffun et al. (1994) found that depression was present in one third (n = 54) of ICU patients after discharge. These findings are supported by more recent studies (Eddelstone et al., 2000; Scragg et al. 2001). Eddelstone et al. (2000) prospectively assessed the prevalence of psychological distress three months after ICU discharge using the Hospital Anxiety and Depression Scale. Of 143 participants, anxiety was discovered in 12% and depression in 10%. This is lower than that found by Scragg et al. (2001) who found higher levels of psychological distress in former ICU patients when measuring depression, anxiety and post traumatic stress. Their findings were that 47 % (n = 80) of patients reported clinically significant anxiety and depression.

Delirium

Delirium is described as a disturbance in consciousness, decreased ability to focus, shift in attention or change in cognition. The causes of delirium are many, with delirium influencing the patient's episodic memory. Furthermore, it is thought that hallucinations and episodes of amnesia may be attributed to delirium (Jones et al., 2000). If anxiety in the critically ill patient remains high and is undetected and untreated it can negatively effect the patient's physical and psychological well being (Rincon et al., 2001) and delirium may result. Delirium can manifest as acute confusion, cognitive impairment (Marshall & Soucy, 2003), ICU psychosis, neurological impairment or encephalopathy of critical illness (Miller & Ely, 2006).

The exact pathophysiological mechanism causing delirium is not yet known (Truman & Ely, 2004). However, it is suggested that delirium might act directly as a promoter of other organ system dysfunctions and development of delirium is one of the strongest predictors of prolonged cognitive impairment in patients (Pandharipande et al., 2005). Delirium typically develops suddenly, usually within hours to days, is evident by changes in level of consciousness (Jones, 2002) and can manifest in a hypoactive state, a hyperactive state or a combination of the two. The hypoactive type is characterised by symptoms such as, slow speech, slow movements, apathy and depression. The hyperactive type is evident by the more active patient who speaks and moves rapidly, shows fear and an increased reaction to any stimuli (Marshall & Sourcy, 2003).

Recent years have witnessed an increase in research focusing on delirium within the ICU environment. A small study conducted by Ely et al. (2001) assessed patients to determine the relationship between delirium and patient outcome. 81% of their patients developed delirium, with a mean duration of 3.4 days. They found that where active delirium was present (the comatose days were excluded) the majority of patients were in a hypoactive or quiet state. Furthermore, the development of delirium in the ICU was the strongest independent determinant of length of stay in the hospital (Ely et al., 2001).

A prospective study by Dubois et al. (2001) investigated risk factors for the development of delirium in ICU patients and found a considerably lower incidence of delirium than Ely et al. (2001) at 19%. Additionally, Dubois et al. found a strong correlation with factors such as hypertension, smoking history, the use of epidural infusion and the use of morphine, and the development of delirium. Although delirium was not associated with increased mortality they found that morbidity (self extubation and removal of catheters) was increased in delirious patients.

A later study by Ely et al. (2004) focused on the development of delirium in 224 mechanically ventilated ICU patients. They found that 82% of patients developed delirium at some stage of their ICU stay. These patients had a higher six month mortality rate and had a longer stay in the hospital (median 10 days) compared to those who did not develop delirium. Thus, agreement exists about the presence and negative impact of delirium, though incidence varies across studies.

Despite the fact that delirium is highly prevalent in the ICU setting, it is a poorly recognised form of organ dysfunction (Miller & Ely, 2006). It is often misdiagnosed and mismanaged, which may be contributing factors to the disparity in documented incidence. Nevertheless, there is agreement that delirium complicates the patient's recovery from critical illness (Marshall & Soucy, 2003). Supporting this, a recent review of the literature (Pandharipande et al., 2005) found that acute confusional states (delirium) developed in 60-80% of patients in ICU. It was unrecognised by staff in as many as 66-84% of the cases, which may be related to incorrect assessment of delirium (described as dementia or depression) or the fact that many clinicians expect delirium to be evident as agitation or hallucination. Different risk factors for developing delirium are evident in the literature and can be divided into three main categories; baseline characteristics, such as cognitive impairment, co-morbidities and age; factors related to acute illness such as, sepsis, hypoxaemia, severity of illness; and environmental factors such as sedatives, analgesic drugs and sleep quality and quantity (Pandharipande et al., 2005).

Recollection and amnesia

Many patients admitted to an ICU do not remember anything from their time in the unit and hence, do not have any first hand information about what has happened to them (Jones, 2002). Recent studies have discovered that patients without memory of their time in the ICU were more heavily sedated (Samuelson et al., 2006). This conflicts with Capuzzo et al. (2001) who found that that memory loss in ICU patients was influenced more by length of stay than the sedation received. However, these two studies interviewed the patients at different stages after discharge.

Sedation and analgesia in the ICU setting are generally used to protect patients from traumatic and harmful stimuli such as providing relief from pain and anxiety, nocturnal sleep and sometimes to achieve amnesia (Rundshagen et al., 2002). There are numerous reasons why critically ill patients may suffer from memory loss and hallucinations. These include stress related to the severe illness, metabolic disturbances, the effects of drugs, delirium, drug withdrawal and sleep deprivation (Jones et al., 2000). It is thought that decreasing the potential for recall pharmacologically may influence and limit the patient's memory of distressing events from their time in the ICU and the possible influence on future adverse psychological problems (Cheng, 1996).

A number of studies has investigated ICU patients' recollection of experiences following discharge from ICU, finding that many remember little of this time. One study found that 34% of the patients had no recollection of their time in the ICU three months after discharge from the unit (Daffun et al., 1994). These findings are supported by those of Capuzzo et al. (2001) who interviewed patients six months after hospital discharge and concluded that one third of patients had a lack of memory from their time in the ICU. Similarly, another study found that six months after discharge 34% of patients had no memory of their time in the ICU, 42% had some memory and 24% had a clear memory (Russel, 1999). This is supported by a prospective study which found that 38% of patients stated that they did not remember anything from their stay in the ICU (Granja et al., 2005).

A recent prospective study found that 18% of patients reported having no recall from their time in the ICU. However, this study interviewed patients only five days after discharge from the ICU. Compared with patients who reported having memories from their time in the ICU, the patients with no memory were more heavily sedated. Thus, it was concluded that the depth of sedation may have contributed to the occurrence of amnesia (Samuelson et al., 2006).

Dreams, nightmares and hallucinations

Though some patients report having no recall of their time in the ICU others describe having vivid memories after discharge home. For example, research conducted by Granja et al. (2005) found that of 464 patients, 51% of the respondents experienced dreams and nightmares during their ICU stay. Of those experiencing dreams and nightmares, 14% reported being disturbed by the dreams for as long as six months after discharge from the ICU.

A recent descriptive study found that dreams were reported by 74% of patients interviewed twelve to eighteen months after ICU discharge and the majority of these patients also reported frightening hallucinations. However, 39% of these patients described their dreams as positive (Roberts & Chaboyer, 2004). A further study found a lower incidence of dreams and nightmares with 21% of patients reporting this occurrence after ICU stay. However, these patients were interviewed only days after discharge from the ICU (Rundshagen et al., 2002).

Patients' recollection of discomfort during their ICU stay has been reported in the literature and raises the question of whether the events are real or not. Recollection of ICU stay falls into two areas. There are those patients who have no factual recall; however they can remember paranoid delusions and nightmares. Also, there are patients who have fragmented factual memories plus recollections from delusions and nightmares. Patients' reports of hallucinations, nightmares and paranoid delusions are often vivid and difficult to separate from real experiences and it is stated that this may contribute to psychological morbidity throughout the recovery phase after critical illness (Jones et al., 2000).

Van de Leur et al. (2004) used structured interviews and found that 54% of patients had memories of discomfort from their stay in the ICU and hallucinations were among the experiences that were reported most frequently. Furthermore, a prospective clinical study reported that nightmares were recalled in 9% of the patients while 7% reported hallucinations only days after discharge (Rundshagen et al., 2002). These findings are supported by a more recent but smaller study that found that patients' recollection of factual events and unreal experiences were quite similar at three and twelve months following discharge. However, at twelve months after discharge the unreal experiences could not be remembered with the same expressions and feelings. The authors concluded that this indicates that these memories have had, and continue to have, an enormous psychological impact (Löf et al., 2006).

From the above discussion, it can be seen that patients after ICU discharge experience dreams, nightmares and hallucinations and other psychological problems.

POST TRAUMATIC STRESS DISORDER

Psychological problems can arise after stressful or traumatic events and the symptoms are evident in a variety of ways. Patients might relive the trauma; have disturbing memories and vivid images of the event as well as nightmares. Another symptom is that patients avoid stimuli that remind them of the trauma. Additionally, patients may develop problems with sleeping, irritability and concentration. After hospital discharge they may experience anxiety and depression for example, as a result of the experience of critical illness and not necessarily the actual injury itself (Scragg et al., 2001). These are manifestations of PTSD.

The number of unpleasant memories experienced by ICU patients may be related to development of PTSD and recall of delusions alone may be related to the development of acute PTSD. However, recall of relatively unpleasant real events from ICU might protect patients against the development of anxiety and PTSD related symptoms after discharge (Jones et al., 2001).

The development of PTSD has been investigated in many studies. Scragg et al. (2001) found that 38% of the patients developed significant PTSD related symptoms and of these 15% demonstrated symptoms that met the criteria for the diagnosis of full PTSD. They found that part of the post traumatic stress reported by the patients could be related to the experience of treatment in the ICU. Their study used three established measurement tools of mental disorder amongst patients who have been critically ill and treated in an ICU. Furthermore, they developed a new tool for measuring PTSD directly related to the patients' experience of being admitted to and cared for in the ICU. Even though this new assessment tool requires more research to establish its reliability and validity, it indicates that being an ICU patient may be directly linked to PTSD. This correlates with the findings of a prospective study by Cuthbertson et al. (2004) which found an incidence of 14% among patients who met the full diagnostic criteria for the development of PTSD. However, a more recent study reported an incidence of PTSD to be as low as 5% (Capuzzo et al., 2005). At one week after ICU discharge, those patients presenting with symptoms of PTSD recalled less events than those without this condition. No differences were found in the two groups between feelings, memories and delusional memories, such as hallucinations, nightmares and dreams. The authors stated that the differences in findings between this study and that of Jones et al. (2001) might be related to differences in sedation practices and the population studied. Treatment in an ICU might leave the patients with long lasting psychological symptoms which might influence their QOL (Scragg et al., 2001).

QUALITY OF LIFE

Traditionally the focus of ICU management has been on decreasing short term mortality (Angus & Carlet, 2003) and improving survival rates. Over the past years there has been an increased attention on whether the service given to patients while in the ICU will have long term consequences on their health and well being (Chaboyer & Elliott, 2000). There is a rapidly growing body of literature focusing on QOL after ICU stay and it is becoming a research priority. When measuring QOL in

former ICU patients there are different measurement instruments which have been comprehensively tested (Chaboyer & Elliott 2000). These instruments include the Medical Outcomes Study 36-item Short Form General Health Survey (SF-36), the EuroQol-5D (EQ5D), the Sickness Impact Profile (SIP), and the Nottingham Health Profile (NHP). These tools assess QOL by focusing on certain domains such as physical problems, anxiety, depression and social functioning (Dowdy et al., 2005). Another measurement instrument frequently used is the McMaster Health Index Questionnaire.

In an attempt to summarise developments in this area, Chaboyer and Elliott (2000) examined health related quality of life (HRQOL) literature published from 1993 to 1998. The findings suggested that physical, psychological and social health dimensions affect patients after ICU discharge and that their HRQOL was poorer than in the general population. They also surmised that ICU survivors had generally poorer HRQOL after six to twelve months' recovery compared with their pre-admission period. Furthermore, these patients also had a lower HRQOL than the age adjusted general population. However, the review identified limitations in research focusing on HRQOL. These included small sample size, low response rate and use of non validated assessment tools and a lack in documentation of the instruments' validity and reliability. The findings of Chaboyer and Elliott (2000) are supported by other authors also investigating QOL in ICU patients.

A relatively recent systematic review of the literature with the objective of comparing QOL in ICU survivors and the general population included twenty-one independent studies with over 7000 patients (Dowdy et al., 2005). The included studies used measurement instruments such as, SF-36, EQ-5D, SIP or NHP. The follow up time of the patients had a median of seven months. Conclusions were that QOL in adult survivors of critical illness was poorer than the general population in each domain in the assessment tools, except from bodily pain at baseline, and at six months to fourteen years after discharge. After discharge from hospital, their QOL improved but still remained lower than in the general population. Furthermore, the improvement was not consistent across the domains. The ICU survivors reported generally lower QOL prior to ICU admission, and it appeared that patient gender, length of stay or medical or surgical diagnoses were not significant predictors of QOL. The research evaluated in this review also had methodological limitations. Studies were excluded to secure homogeneity which may influence the comprehensive picture of QOL in ICU survivors. The exclusion of certain QOL assessment tools limits a broad and comprehensive view, and some of the assessment tools used in the included research are more valid than others. In addition to these methodological issues, the authors reported inconsistencies in collection of data at baseline and report of the methods used. Consequently, it was difficult to conclude whether the lower QOL at follow-up reflected the impact of critical illness or the fact that these patients reported a lower baseline QOL.

The findings of Dowdy et al. (2005) are supported by a Norwegian study conducted by Flatten and Kvåle (2001). They studied survival and QOL in former ICU patients twelve years after ICU stay and compared this to the general Norwegian population. A total of 106 (48%) of the patients were still alive twelve years after their ICU admission. These patients were mailed a SF-36 questionnaire. The results indicated that the QOL scores of long term survivors' scores were significantly lower in six out of eight dimensions in SF-36. It is suggested that this might be because ICU patients as a group are different from the general population from the beginning. A limitation of this study is that the patients included were from 1987 only, which may influence the result as they may not be representative of the rest of the ICU patients admitted to this unit. Furthermore, twelve years is a long time concerning treatment in the ICU and therefore these results may not be equivalent to results achieved years later (Flaaten & Kvåle, 2001).

Lower QOL before ICU admission has been reported in other studies as associated with increased in-hospital mortality and decreased QOL one year after discharge from the ICU (Capuzzo et al., 2000). Hence, the assessment of baseline QOL is important and essential to be able to control for pre-existing impairments (Dowdy et al., 2005) and can provide health care workers with valuable information which could influence decisions

regarding management of patients (Hofhuis et al., 2003). However, this information can be difficult to obtain due to the fact that these patients are often sedated, fatigued, their concentration is poor, and they may suffer from cognitive impairment or physical disability (Adamson & Elliott, 2005). To obtain this information data must be collected from the ICU survivor retrospectively, which is a source of recall bias. For this reason, data may be collected from proxies, which is a source of measurement error (Dowdy et al., 2005). However, use of proxies or relatives in QOL evaluation has been found to give a good assessment of the patient's QOL (Rogers et al., 1997; Hofhuis et al., 2003).

Even though HRQOL has been investigated using different questionnaires there are aspects of patients' problems after ICU stay that these questionnaires can not reveal. Follow-up consultations might give a better understanding of these problems, and the information received from the patients could be used to improve intensive care management and support a QOL service for patients and relatives (Kvåle et al., 2003).

FOLLOW-UP SERVICES

It is evident from the above discussion that problems related to experiences from a patient's ICU stay are not always addressed (Glendinning, 2001). On the other hand, there is a growing body of literature that indicates that this may be addressed through follow-up services (Daffurn et al., 1994; Jones & O'Donnell, 1994; Glendinning, 2001). These services are needed so that common physical and psychological problems experienced by surviving ICU patients are recognised early and acted upon (Glendinning, 2001). Follow-up services can typically be set up as follow-up clinics where the patients receive direct consultation with nurses and/or doctors in an attempt to review their admission, assess their overall physical and psychological well being, summarise their medical stay and explain progression and, if needed, referrals to other specialists can be arranged (Crocker, 2003). Follow-up clinics may be doctor-led, nurse-led, or collaborative (Waldmann, 2002).

When setting up a follow-up clinic, surviving patients can provide valuable information (Kvåle et al., 2003). It is evident in the literature that surviving ICU patients often return to the ICU to visit and hopefully meet someone who knows them. Furthermore, they have the opportunity to talk about their experiences from this time in their life. This highlights the importance of including these patients in the process, as they express a need to be seen after their critical illness by coming back to the unit during their recovery (Glendinning, 2001). Furthermore, these consultations will over time provide a better understanding of patients' problems and the information gained can be used in further development of the service (Kvåle et al., 2003).

Several years ago a UK national review by the Audit Commission recommended aftercare following admission and stay in ICUs. *Critical to Success* (Audit Commission, 1999) indicated that only 7% of ICUs in England and Wales had established follow-up clinics for patients who survived intensive care. Furthermore, the report suggested that more research should focus on both survival and long term effects of being an ICU patient. The work of the Audit Commission was reinforced by The Department of Health (2000) document *Comprehensive Critical Care* which recommended that National Health Service hospitals should review the provision of follow-up care with a view to providing appropriate services.

Evaluation of follow-up clinics is evident in the literature and a follow-up clinic in England interviewed 26 patients three months after discharge from hospital (Hall-Smith et al., 1997). They found that psychological problems after discharge were major problems experienced by patients. Approximately half of the patients recalled unpleasant dreams and many of the patients were unwilling to share these experiences with staff and were struggling to cope at home with their memories, dreams and nightmares. Moreover, almost half the patients reported having no memory of their time in the ICU. Many patients also reported anxiety or frustration, expressing an unrealistic view in their ability to return to normal life at home. These findings are supported by another study which found that some patients had problems with memory from their time in the ICU (Cutler et al., 2003). Recollections ranged from no memory through

to others having fragments of memory that distressed them or made no sense. The authors indicated that there is a great potential for nurses in the clinic to answer questions, provide information and make sense of the memory gap.

Crocker (2003) evaluated a multidisciplinary follow-up clinic in England and found that a common complaint after discharge from ICU was amnesia. Some patients reported patchy or delusional memories whereas others did not remember their stay in the ICU at all. For some patients, having a memory gap does not seem to matter, particularly if relatives are able to help them fill in the missing time. However, other patients require help to put their missing time in context (Crocker, 2003).

Although a number of studies has indicated that follow-up clinics address problems that are experienced by surviving ICU patients, limited research has assessed patient satisfaction with the follow-up service offered to them. Hames et al. (2001) published an abstract from a conference proceeding on patients' satisfaction with follow-up clinics. They found that 99% of patients gained some benefit from the clinic, 77% of these reported that they gained a great deal of benefit and 22% minor benefit. The majority of patients answered that they benefited from having questions answered and an opportunity to discuss their problems (Hames et al., 2001).

In addition to follow-up clinics, other approaches towards follow-up services are evident in the literature. One Australian hospital developed a telephone follow-up service in an attempt to meet the patients' needs after ICU admission. They offered surviving ICU patients the opportunity to explore their experience of being critically ill and provided support during the recovery phase. The telephone service evolved because patients who lived some distance from the hospital had difficulty accessing follow-up services. Approximately 300 patients received one phone call around two months after discharge. The experiences most commonly reported by the patients were muscle weakness, fatigue, disturbed sleep and financial difficulties. Furthermore, many patients experienced having no memory of the ICU stay and a few recalled unreal dreams (Moran et al., 2005).

The experiences of operating an outpatient clinic in England led to the development of an ICU staff-led support group (Jones et al., 1994). It was discovered that some patients needed extra support after their critical illness and it was felt that ICU staff who had knowledge of the patients' medical history and of problems that are common during recovery after critical illness were in a unique position to meet their needs. The beneficial impact of this was demonstrated by the enthusiasm the patients expressed while encouraging other patients to attend the group. Furthermore, some patients indicated that it was beneficial to share experiences with those who had experienced similar situations.

In the UK, a randomised controlled trial involving 126 patients was performed to evaluate the effectiveness of a rehabilitation program following critical illness to support physical and psychological recovery (Jones et al., 2003). All patients received the same follow-up services; however, the intervention group also received a rehabilitation manual. Findings suggested that patients who received the rehabilitation manual had a reduced rate of depression at eight weeks follow-up, however, this did not reach statistical significance. Anxiety was documented as being present in greater than 30% of patients in the study and high levels were observed in patients recalling delusional memories. Furthermore, 51% of patients documented PTSD related symptoms. The highest PTSD related symptom scores were seen in patients who experienced delusional memories.

The above findings strongly suggest that there is a need for follow-up services after ICU admission so that the problems commonly found in former ICU patients are detected at an early stage and interventions can be initiated (Glendinning, 2001). In addition, there are some interesting studies performed in Europe using patient diaries as a part of the follow-up care of ICU patients, which may have a complementary effect.

PATIENT DIARIES

There is limited research available in the literature on patient diaries. However, over several years a small number of articles focusing on patient diaries written by ICU staff and given to patients after discharge

from the ICU has been published.

In Sweden, a pilot study reviewed patients' and relatives' opinions and feelings about written diaries from the patients' time in the ICU (Bergbom et al., 1999). The diary was given to the patient on discharge from the unit and approximately one week after discharge the patient's nurse visited the patient on the ward to talk about the diary and discuss recollections from their time in the ICU. If the patient died the diary was given to the patient's relatives. After discharge from the ICU a questionnaire was sent to ten patients and four relatives, with a 100% response rate from patients. All the patients had read the diary and seven of them stated that it had helped them remember the ICU period. Three patients stated that they had no recall of the ICU stay and that the diary helped them make sense of the lost time. Many patients indicated that reading the diary helped them to gain insight and answered some of their questions. Patients felt that they had a better understanding as to why recovery was prolonged. Some patients also stated that it gave them a feeling of security and helped them to carry on with their lives after a period of critical illness. In contrast, some patients stated that they were afraid that when reading the diary it would trigger unpleasant memories such as, horror, nightmares and frightening occasions. No photographs were incorporated into the diaries, however some patients expressed a desire to see photographs taken during their admission. Because this study was small and context-specific, no generalisations can be made. Nevertheless, a written personal diary may prove to be helpful to former ICU patients in their recovery (Bergbom et al., 1999).

The above findings are supported by an evaluation report of utilising patient diaries in the ICU setting as a tool to help patients understand their experiences of being admitted to an ICU (Storli et al., 2003). Patients evaluated the diaries as being a positive part in their recovery. Furthermore, it was seen as a valuable tool for staff in learning from the patients' experiences.

An observational study investigated the use of diaries in patient and relative debriefing following critical care (Backman & Walter, 2001). The diary was provided to patients or, in the case of patient death, to relatives at a follow-up visit two to four weeks after discharge from the ICU. The diary was used as a guide to explain the experience of critical illness. The writing and photographs provided in the diary were explained thoroughly at the follow-up visit. In this study no negative outcomes were reported regarding the photographs. The receiver of the diary was mailed a questionnaire six months later. This revealed that the diaries had been read by all 51 recipients and the feelings and thoughts about the diary were expressed as very positive by 39%, positive by 28% and 33% had neutral feelings. As in the study by Bergbom et al. (1999) this was a small single centre study.

The above findings are supported by a recent study evaluating patients' diaries. Some of the main findings were that the diary helped the patients re-orientate more easily to a normal life, moreover the photographs were found helpful by expressing in a visual way exactly how ill they had been. The diary was also helpful in expressing exactly what happened in the ICU and allowed different perceptions of the stay to be grounded in facts (Combe, 2005).

DISCUSSION

Patients admitted to an ICU have usually experienced a life threatening illness which often results in short and long term psychological consequences (Ratray et al., 2005). A proportion of these patients will have the opportunity to prepare for admission to an ICU, for example after elective surgery, however, others will be emergency admissions with no preparation time. These patients often have a prolonged stay in ICU during which time they will most likely receive sedatives and analgesics (Jones et al., 1998).

The immediate psychological effects of being admitted to an ICU, such as anxiety and depression are well recognised (Rincon et al. 2001). Over recent years, there has been an increased interest in the long term consequences of critical illness and treatment in an ICU. Anxiety and depression have been documented to be as high as 47% in patients experiencing ICU admission (Scragg et al., 2001). However, it is not yet

clear how much can be attributed to reaction to the ICU experience itself, or whether other individual factors, such as previous anxiety, depression or lack of factual events from the time in the ICU play a role (Ratray et al., 2005).

Delirium has been found to be highly prevalent in ICU patients (Miller & Ely, 2006) and complicates the patient's recovery from critical illness (Marshall & Soucy, 2003). Different risk factors for delirium have been described in the literature and it is rare that ICU patients are not in the high risk group for developing delirium (Pandharipande et al., 2005). Furthermore, delirium is often misdiagnosed and mistreated and may represent a significant long lasting burden for patients and their families (Miller & Ely, 2006). Conflicting results arise from various studies, ranging from delirium being a strong predictor of six months mortality in ventilated patients in one study (Ely et al., 2004), to another study that suggested that delirium was not associated with increased mortality (Dubois et al., 2001). Despite this, it is clear that delirium has a negative impact on patients and is associated with increased length of stay in hospital (Ely et al., 2001). Benefits could be gained from future studies to clarify the risk factors for delirium and develop prevention and treatment options for patients (Miller & Ely, 2006).

Delirium has been found to be one of several factors linked to patients' memory loss after ICU admission (Jones et al., 2000). The evidence is contradictory regarding the occurrence of memory loss and what influences this loss. Some studies have revealed that memory loss in ICU patients was influenced by length of stay, and to a lesser extent the amount of sedation received (Capuzzo et al., 2001). However, other studies have indicated that degree of sedation was a strong predictor in recollection of ICU stay (Samuelson et al., 2006). Other studies have indicated that up to one third of patients has no recollection of their ICU stay (Daffun et al., 1994; Russel, 1999; Samuelson et al., 2006).

Patients' memories after discharge from the ICU seem to have a significant impact on their psychological well being (Jones & Griffiths, 2002), with reports ranging from frightening hallucinations to positive dreams (Roberts & Chaboyer, 2004). In addition, patients who remember delusional memories but no factual events from their stay in the ICU experienced higher levels of anxiety and depression (Jones et al., 2001). Again, research has demonstrated inconsistent findings. One study showed that delusional memories were clearly related to PTSD symptoms (Jones et al., 2001) whilst other studies indicated that links between delusional memories and PTSD can not be made (Capuzzo et al., 2005). Furthermore, findings have demonstrated that patients' recollection of unreal experiences and factual events remained for a long time after discharge, reducing after twelve months (Lof et al., 2006). This would indicate there is a strong need for more research to investigate ways of reducing delusional memories and reveal the link, if any, to PTSD and whether an increase in patients' factual recall from this time will have an impact on long term psychological distress after a critical illness.

As discussed above, many patients who survive critical illness are left with long lasting psychological consequences. Furthermore, research has demonstrated that former ICU patients generally have a lower QOL than the general population. Though this improves over time, it remains lower than in the general population (Dowdy et al., 2005). In an attempt to predict patient outcome after critical illness there has been an increased interest in assessing their pre admission QOL. This information may be difficult to obtain due to the fact that ICU patients often are unable to provide this information themselves (Adamson & Elliott, 2005). The use of proxy assessment has been evaluated (Dowdy et al., 2005) and has been shown to give adequate results, though methodological limitations exist in this research (Rogers et al., 1997; Hofhuis et al., 2003). Possible future research should focus on QOL research using more rigorous study designs.

In an attempt to help surviving patients with the psychological distress they are experiencing after discharge home, a variety of different follow-up services have been evaluated. The English Department of Health recommended that National Health Service hospitals should provide appropriate follow-up services for surviving critically ill patients (Department of Health, 2000). An increased interest in follow-up services has been evident in the literature over recent years.

❖ Psychological consequences of critical illness: What is the long term impact on patients and how can nurses help? ❖

Follow-up services have been provided in several different ways. Follow-up clinics have been organised so that patients were offered a meeting after discharge home, providing an opportunity to discuss problems and were offered support with an opportunity to be referred for further treatment if needed (Sharland, 2002). Feedback from patients attending this type of clinic was mostly positive, with patients indicating that it was beneficial to have questions answered and an opportunity to discuss the problems they experienced after critical illness (Hames et al., 2001). Furthermore, outpatient clinics and rehabilitation programmes have been shown to be beneficial for patients (Jones et al., 2003). However, there is not sufficient evaluation of these services and a number of questions regarding benefits and costs are still unanswered, which indicates that there is a need for further research in this area.

The focus on after care in surviving ICU patients has revealed that patient diaries might have a beneficial effect on patient recovery from critical illness. Though limited studies have been published, they do indicate that patients with no recall from their time in the ICU felt that the diaries helped them make sense of the lost time. Furthermore, patients realised how ill they had been and that this would possibly prolong their recovery (Bergholm et al., 1999). The use of photographs in diaries has not been rigorously evaluated. However, those diaries which included photographs did not have a negative impact on patients (Backman & Walter, 2001). Overall the experience of using diaries was positive and they were also seen as valuable tools for staff in learning from patients' experiences (Storli et al., 2003). The use of patient diaries in the ICU setting requires further research to determine how it may best be organised as well as its potential benefits.

CONCLUSIONS

The psychological consequences of being critically ill and admitted to an ICU can be profound and long lasting. Episodes of amnesia, hallucinations, delirium and post traumatic stress disorder are not uncommon amongst these patients. The net effect is that surviving patients' quality of life will be poor. Hence, the focus of care for intensive care patients should extend to the management of long term psychological consequences, utilising follow-up clinics and diaries. Nurses are in a pivotal role to prevent the development of such negative events and the introduction of certain interventions may positively help to modify the recovery of patients.

IMPLICATIONS FOR PRACTICE

As evident from the above discussion there are enormous psychological consequences of surviving ICU treatment and implications for practice. These are summarised in Table 1.

- It is essential that ICU staff recognise that the ICU environment is distressing and that psychological reactions are normal. Support from staff and management is vital, and information that focuses on these consequences should be available, and easily accessible.
- ICU staff should be educated regarding early detection of the psychological consequences of being an ICU patient, focusing especially on delirium, which is highly prevalent, and may be misdiagnosed and untreated.
- Patients, their family and staff should be informed that psychological problems are issues that may arise and that it is important to seek support early.
- It is important that there is knowledge among patients, their families and staff that help and support is available, for example psychotherapists.
- The use of written patient diaries should be considered to help the patients in their psychological recovery.
- Consideration should be given to the development of guidelines, standards or protocols regarding discharge and follow-up services provided for ICU patients.
- It is essential to collect data and information about the type of follow-up service that is provided and to what extent it is meeting patients' needs. Thus, by identifying gaps in service provision, future development in this area may be initiated.
- Further research on minimising the psychological consequences of surviving ICU treatment is needed. In addition, further work is needed to identify specific patients' needs following hospital discharge.

Table 1. Implications For Practice

REFERENCES

- Adamson H, Elliott D. (2005). Quality of life after a critical illness: a review of general ICU studies. *Australian Critical Care* 18(2), 50-60.
- Angus DC, Carlet J, on behalf of the 2002 Brussels Roundtable Participants. (2003). Surviving Intensive Care. *Intensive Care Medicine* 29, 368-377.
- Audit Commission. (1999). *Critical to Success: The Place of Efficient and Effective Critical Care Services Within the Acute Hospital*. London: Audit Commission.
- Backman CG, Walter SM. (2001). Use of a personal written diary on the ICU during critical illness. *Intensive Care Medicine* 27, 426-429.
- Bergbom I, Svensson C, Berggren E, Kamsula M. (1999). Patients and relatives opinions and feelings about diaries kept by the nurses in an intensive care unit: pilot study. *Intensive and Critical Care Nursing* 15, 185-191.
- Capuzzo M, Grasselli C, Carrer S, Gritti G, Alvisi R. (2000). Quality of life before intensive care admission: agreement between patient and relative assessment. *Intensive Care Medicine* 26, 1288-1295.
- Capuzzo M, Pinamonti A, Cingolani E, Grassi L, Bianconi M, Contu P, Gritti G, Alvisi R. (2001). Analgesia, Sedation, and Memory of Intensive Care. *Journal of Critical Care* 16(3), 83-89.
- Capuzzo M, Valponti V, Cingolani E, Gianstefani G, De Luca S, Grassi L, Alvisi R. (2005). Post-traumatic related symptoms after intensive care. *Minerva Anestesiol* 71, 167-179.
- Chaboyer W, Elliott D. (2000). Health-related quality of life of ICU survivors: review of the literature. *Intensive and Critical Care Nursing* 16, 88-97.
- Cheng EY. (1996). Recall in the Sedated ICU Patient. *Journal of Clinical Anesthesia* 8, 675-678.
- Combe D. (2005). The use of patient diaries in an intensive care unit. *Nursing in Critical Care* 10(1), 31-34.
- Crocker C. (2003). A multidisciplinary follow-up clinic after patients discharge from ITU. *Critical Care* 12(15), 910-914.
- Cuthbertson BH, Hull A, Strachan M, Scott J. (2004). Post-traumatic stress disorder after critical illness requiring general intensive care. *Intensive Care Medicine* 30, 450-455.
- Cutler L, Brightmore K, Colqhoun V, Dunstar J, Gay M. (2003). Developing and evaluating critical care follow-up. *Nursing in Critical Care* 8(3), 116-125.
- Daffun K, Bishop GF, Hillman KM, Bauman A. (1994). Problems following discharge after intensive care. *Intensive and Critical Care Nursing* 10, 244-251.

❖ Psychological consequences of critical illness: What is the long term impact on patients and how can nurses help? ❖

- Department of Health. (2000). *Comprehensive Critical Care: A Review of Adult Critical Care Services*. London, HMSO.
- Dowdy DW, Eid MP, Sedrakyan A, Mendez-Tellez PA, Pronovost PJ, Herridge MS, Needham DM. (2005). Quality of life in adult survivors of critical illness: A systematic review of the literature. *Intensive Care Medicine* 31, 611-620.
- Dubois M-J, Bergeron N, Dumont M, Dial S, Skrobik Y. (2001). Delirium in an intensive care unit: a study of risk factors. *Intensive Care Medicine* 27, 1297-1304.
- Eddlestone JM, White P, Guthrie E. (2000). Survival, morbidity and quality of life after discharge from intensive care. *Critical Care Medicine* 28(7), 2293-2299.
- Ely EW, Gautam S, Margolin R, Francis J, May L, Speroff T, Truman B, Dittus R, Bernard GR, Inouye SK. (2001). The impact of delirium in the intensive care unit on hospital length of stay. *Intensive Care Medicine* 27, 1892-1900.
- Ely EW, Shintani A, Truman B, Speroff T, Gordon SM, Harrell Jr FE, Inouye SK, Bernard GR, Dittus RS. (2004). Delirium as a Predictor of Mortality in Mechanically Ventilated Patients in the Intensive Care Unit. *JAMA* 291 (14), 1753-1762.
- Flaaten H, Kvåle R. (2001). Survival and quality of life 12 years after ICU. A comparison with the general Norwegian population. *Intensive Care Medicine* 27, 1005-1011.
- Glendinning A. (2001). Intensive care follow-up: setting up a new practice area. *Nursing in Critical Care* 6(3), 128-132.
- Granja C, Lopes A, Moreira S, Dias C, Costa-Pereira A, Carneiro A. (2005). Patient's recollections of experiences in the intensive care unit may affect their quality of life. *Critical Care* 9(2), 96-109.
- Hall-Smith J, Ball C, Coakley J. (1997). Follow-up services and the development of a clinical nurse specialist in intensive care. *Intensive and Critical Care Nursing* 13, 243-248.
- Hames KC, Gager M, Waldmann CS. (2001). Patient satisfaction with specialist ICU follow-up. *British Journal of Anaesthesia-Conference Proceedings*, 372-373. South Bank Centre, London: Intensive Care Society and Riverside Group.
- Hofhuis J, Hautvast JLA, Schrijvers AJP, Bakker J. (2003). Quality of life an admission to the intensive care: can we query the relatives? *Intensive Care Medicine* 29, 974-979.
- Jones C. (2002). Acute psychological problems. In: Griffiths RD, Jones C, (Eds.), *Intensive Care Aftercare*, 19-22. Oxford: A division of Reed Educational and Professional Publishing Ltd.
- Jones C, Griffiths RD. (2002). Physical and psychological recovery. In: Griffiths RD, Jones C. (Eds.), *Intensive Care Aftercare*, 54-65. Oxford: A division of Reed Educational and Professional Publishing Ltd.
- Jones C, Griffiths R, Humphris G. (2000). Disturbed memory and amnesia related to intensive care. *Memory* 8(2), 79-94.
- Jones C, Griffiths RD, Humphris G. (2001). Memory, delusions, and the development of acute posttraumatic stress disorder-related symptoms after intensive care. *Critical Care Medicine* 29(3), 573-580.
- Jones C, Humphris G, Griffiths R. (1998). Psychological morbidity following critical illness-the rationale for care after intensive care. *Clinical Intensive Care* 9, 199-205.
- Jones C, Macmillan RR, Griffiths RD. (1994). Providing psychological support for patients after critical illness. *Clinical Intensive Care* 5, 176-179.
- Jones C, O'Donnell. (1994). After intensive care- What then? *Intensive and Critical Care Nursing* 10, 89-92.
- Jones C, Skirrow P, Griffiths RD, Humphris GH, Ingleby S, Eddelston J, Waldmann C, Gager M. (2003). Rehabilitation after critical illness: A randomized controlled trial. *Critical Care Medicine* 31(10), 2456-2467.
- Kvåle R, Ulvik A, Flaatten H. (2003). Follow-up after intensive care: a single center study. *Intensive Care Medicine* 29, 2149-2156.
- Löf L, Berggren L, Ahlström G. (2006). Severely ill ICU patients recall of factual events and unreal experiences of hospital admission and ICU stay-3 and 12 months after discharge. *Intensive and Critical Care* 22, 154-166.
- Marshall MC, Soucy MD. (2003). Delirium in the Intensive Care Unit. *Critical Care Nursing Quarterly* 26(3), 172-178.
- Miller RR, Ely EW. (2006). Delirium and Cognitive Dysfunction in the Intensive Care Unit. *Seminars in Respiratory and Critical Care Medicine* 27(3), 210-220.
- Moran D, Elliott R, McKinley S. (2005). The Royal North Shore Hospital ICU nurse initiated telephone follow-up service. *Intensive Critical and Care Nursing* 21(1), 47-84.
- Pandharipande P, Jackson J, Ely EW. (2005). Delirium: acute cognitive dysfunction in the critically ill. *Current Opinion in Critical Care* 11, 360-368.
- Pattison N. (2005). Psychological implications of admission to critical care. *British Journal of Nursing* 14(13), 708-714.
- Pochard F, Lanore JJ, Bellivier F, Ferrand I, Mira JP, Belghith M, Brunet F, Dhainaut JF. (1995). Subjective psychological status of severely ill patients discharged from mechanical ventilation. *Clinical Intensive Care* 6, 57-61.
- Ratray JE, Johnston M, Wildsmith AW. (2005). Predictors of emotional outcomes of intensive care. *Anaesthesia* 60, 1085-1092.
- Roberts B, Chaboyer W (2004). Patients dreams and unreal experiences following intensive care unit admission. *Nursing in Critical Care* 9(4), 173-177.
- Rogers J, Ridley PC, Chrispin P, Scotton H, Lloyd D. (1997). Reliability of the next of kins estimates of critically ill patients quality of life. *Anaesthesia* 52, 1137-1143.
- Rincon HG, Granados M, Unutzer J, Gomez M, Duran R, Badiel M, Salas C et.al. (2001). Prevalence, Detection and Treatment of Anxiety, Depression, and Delirium in the Adult Critical Care Unit. *Psychosomatics* 42(5), 391-396.
- Rundshagen I, Schnabel K, Wegner C, Schulte am Esch J. (2002). Incidence of recall, nightmares, and hallucinations during analgesedation in intensive care. *Intensive Care Medicine* 28, 38-43.
- Russel S. (1999). An exploratory study of patients' perceptions, memories and experiences of an intensive care unit. *Journal of Advanced Nursing* 29(4), 783-791.
- Samuelson K, Lundberg D, Fridlund B. (2006). Memory in relation to depth of sedation in adult mechanically ventilated intensive care patients. *Intensive Care Medicine* 32, 660-667.
- Scragg P, Jones A, Fauvel N. (2001). Psychological problems following ICU treatment. *Anaesthesia* 56, 9-14.
- Sharland C. (2002). Setting up a nurse-led clinic. In: Griffiths RD, Jones C. (Eds.), *Intensive Care Aftercare*, 96-113. Oxford: A division of Reed Educational and Professional Publishing Ltd.
- Storli SL, Lind R, Viotti I-L. (2003). Using diaries in intensive care: A method for following up patients. *Connect: The World of Critical Care Nursing* 2(4), 103-108.
- Truman B, Ely EW. (2004). The delirium Dilemma in the Intensive Care Unit: Current Concepts in Monitoring and Management. *Primary Psychiatry* 11(11), 59-64.
- Van de Leuar JP, Van der Schans C, Loef BG, Deelman BG, Geertzen JHB, Zwaveling JH. (2004). Discomfort and factual recollection in the intensive care unit patients. *Critical Care* 8, R467-R473.
- Waldmann C. (2002). Setting up a doctor-led clinic. In: Griffiths RD, Jones C. (Eds.), *Intensive Care Aftercare*, 89-95. Oxford: A division of Reed Educational and Professional Publishing Ltd.