

Discourse

Recovery After Critical Illness: The Role of Follow-up Services to Improve Psychological Well-Being

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Introduction

Intensive care units (ICUs) are one of the most expensive care settings (Flaatten & Kvale, 2003; McLaughlin, Hardt, Canavan, & Donnelly, 2009), with many patients receiving highly technological life-saving and complex clinical care of reasonably short duration. Internationally, ICUs maintain high standards of care, with specialized training comprising both clinical and theoretical content for critical care nurses (Williams et al., 2007). Family- and patient-centred care, which takes into consideration the patient's wishes and preferences and promotes the patient's involvement in care decisions, is a tenet of ICU care (Glimelius Petersson, Bergbom, Brodersen, & Ringdal, 2011). The overall goal of care in the ICU, as in other health-care settings, is for patients to regain their health and well-being. It is also important for individuals to return to work after critical illness and be part of society. These goals, however, are not achieved for all patients (Ringdal, 2008).

Physical and psychological problems often arise after discharge from the ICU. Health-related quality of life (HRQoL) for ICU patients 1 year after discharge is reported to be below that for the average population (Chaboyer & Elliott, 2000; Ringdal, Plos, Lundberg, Johansson, & Bergbom, 2009), and reduced HRQoL may persist for more than 5 years (Ringdal, Plos, Ortenwall, & Bergbom, 2010). Also, patients' ability to return to work after critical illness is decreased following ICU discharge, particularly within the first year (Myhren, Ekeberg, & Stokland, 2010; Ringdal et al., 2010), leading to increased societal burden.

What interventions currently are used to optimize psychological well-being and prevent long-term psychological problems for ICU patients and their families? The purpose of this Discourse is to highlight some of the issues that impact patient recovery after critical illness, current interventions, and justifications for ICU follow-up services.

The Stress of Intensive Care

For most patients, ICU admission is unexpected, with no time for preparation, and is a frightening experience that includes pain and anxiety (Ringdal, 2008). Interviews with ICU survivors tell us that they felt vulnerable during their ICU stay and did not know what was happening from day to day (McKinley, Nagy, Stein-Parbury, Bramwell, & Hudson, 2002). Anxiety may be worsened due to patients' reduced ability to communicate their fears because of intubation and mechanical ventilation, sedation, and decreased level of consciousness (Karlsson & Forsberg, 2008). For the same reasons, communication with the patient may be limited, with relatives/significant others receiving most of the information about the patient's status. Family members are forced to consider the impact of serious illness and deal with uncertainty about the outcome. For the family, nothing is more important during the patient's admission than what is happening in the ICU (Engstrom & Soderberg, 2004) and the need to keep hope alive (Engstrom & Soderberg, 2007).

Delusional Memories and Their Impact on Psychological Well-Being

Following ICU discharge, 30% to 70% of patients report unpleasant and sometimes delusional memories (Jones, Griffiths, Humphris, & Skirrow, 2001; Ringdal, Johansson, Lundberg, & Bergbom, 2006; Samuelson, Lundberg, & Fridlund, 2006). Development of delusional memories is multifactorial. Patients often require analgesia and sedation for pain and anxiety; however, over-sedation with benzodiazepines and opioids leads to decreased factual recall of the ICU stay (Samuelson et al., 2006). Insufficient treatment of pain is common (Arroyo-Novoa et al., 2008). Also, sleep is disrupted due to ongoing care needs and this can contribute to patients' anxiety and fear (McKinley et al., 2002). Sedation strategies that target light sedation, including daily interruption, facilitate patients' awareness of their environment and enable their participation in care, resulting in decreased duration of ventilation and of the ICU stay (Kress, Pohlman, O'Connor, & Hall, 2000). However, the impact of this wakefulness on the patient's psychological well-being remains uncertain. Facilitation of increased factual memories may decrease delusional memories and reduce psychological morbidity, including post-traumatic stress disorder (PTSD) (Jones et al., 2001).

Delusional memories also are suggestive of delirium, which increases morbidity and mortality among critically ill patients (Ely et al., 2004). Although the factors that precipitate ICU delirium are still not fully understood, patient characteristics, chronic pathology, acute illness, environmental factors, and medications such as benzodiazepines and anti-

cholinergic agents may contribute to the syndrome (Van Rompaey et al., 2009).

Decreased psychological well-being, including symptoms of anxiety, depression, and PTSD, after ICU discharge is common (Myhren, Ekeberg, Toien, Karlsson, & Stokland, 2010; Schandl et al., 2011). In fact, the psychological consequences of critical illness were first recognized in 1956, when a 3% incidence of psychosis following cardiac surgery was reported for a large cohort of patients (Bolton & Bailey, 1956). Even after 5 years, patients may experience anxiety and depression arising from delusional memories related to their ICU stay (Ringdal et al., 2010), which can have a lasting impact on HRQoL (Granja et al., 2005; Ringdal et al., 2010). It is imperative that ICU clinicians evaluate interventions aimed at reducing patients' delusional memories and associated psychological stress.

Current Interventions for Improving Psychological Well-Being After Critical Illness

Diaries as a Recovery Tool Following Critical Illness

The primary aim of patient diaries, kept during ICU admission, is to facilitate understanding of the ICU course of events for the patient and family (Bäckman & Walther, 2001). Diaries are a low-cost potentially rehabilitative intervention that promotes psychological recovery (Egerod, Christensen, Schwartz-Nielsen, & Agard, 2011). Over the last decade, research on patient diaries has been conducted in Scandinavia and other European countries, with a focus on patient, family, and nurse perspectives (Egerod, Storli, & Akerman, 2011; Knowles & TARRIER, 2009; Roulin, Hurst, & Spirig, 2007). Diaries, written in the ICU in everyday language by both nurses and patients' family members, are an important tool for initiating a conversation about the ICU experience. Also, they may contribute to the patient's recollection of events (factual memories) and are a useful debriefing tool following ICU admission (Bäckman & Walther, 2001). Diaries facilitate sharing of the patient's story and family members' feelings during the ICU stay and provide support to patients as they piece together fragmentary memories after ICU discharge (Bergbom, Svensson, Berggren, & Kamsula, 1999; Roulin et al., 2007). Diaries that contain photographs can provide strong visual images to give friends and relatives a better understanding of the individual's experience with critical illness. The benefits of diaries as identified by family members include the opportunity to put into writing the sadness and hope they experienced as well as to read about the patient's daily life in the ICU (Bäckman & Walther, 2001). For nurses, writing in the diary can be a way of forming a relationship with the patient as a person and focusing on

the patient's everyday life (Gjengedal, Storli, Holme, & Eskerud, 2010). Through these mechanisms, diaries can facilitate the patient's psychological recovery (Jones et al., 2010).

There are different methods for writing diaries. For example, in some ICUs only nurses write the diary (Knowles & Tarrier, 2009) whereas in other ICUs relatives and all ICU team members are encouraged to make entries (Bäckman & Walther, 2001; Bergbom et al., 1999; Egerod, Schwartz-Nielsen, Hansen, & Laerkner, 2007). Since diaries are moderately resource-intensive, generally they are used only if it is clear that the patient will be in the ICU for more than 3 days. Patients or their relatives must consent to the keeping of a diary and the taking of any photographs. Generally, diaries begin with a case summary, including the reason for ICU admission and the current status of the patient. Content and writing style should be in lay language. Diary entries on issues important to the patient should be included. For example, events outside the ICU normally of interest to the patient, such as sporting events or relevant news items, can be included. It is important to describe the seriousness of the patient's condition and any significant progress, such as sitting up in a chair for the first time (Bäckman, 2011).

Follow-up Services

A statement in a Brussels Roundtable report in 2002 proposed that ICUs take increased responsibility for long-term outcomes of ICU survivors, including provision of ICU follow-up services (Angus & Carlet, 2003). It is important that follow-up services be patient- and family-centred. In Sweden, most follow-up services are led by ICU nurses and comprise patient diaries with photographs, patient consultation at a nurse-led clinic (NLC), and feedback about ICU survivors to ICU staff (Glimelius Petersson et al., 2011). Similar models are reported for other European countries (Cutler, Brightmore, Colqhoun, Dunstan, & Gay, 2003; Jones et al., 2010). The primary aim of NLCs is to meet the information needs of patients and family members and give them an opportunity to ask questions about the ICU stay (Glimelius Petersson et al., 2011). Diaries are handed over to the patient either upon ICU discharge or at the first follow-up visit to the NLC. Some follow-up services include a ward visit by the NLC nurse after ICU discharge but prior to hospital discharge.

Patients are generally offered up to three follow-up visits — soon after ICU discharge and subsequently at 3 and 6 months. Accompaniment by family members is encouraged. Feedback to ICU staff is facilitated via a patient follow-up book that includes a brief description of the patient's ICU stay and recovery experience as well as photographs (Glimelius Petersson et al., 2011; Samuelson & Corrigan, 2009). The

NLC model is perceived as requiring only modest resources (Glimelius Pettersson et al., 2011; Samuelson & Corrigan, 2009), as the service generally entails one to four experienced ICU nurses working part-time and consultation with the multidisciplinary team only as needed. More resource-intensive approaches include follow-up led by a physician or provided by a multidisciplinary team (Schandl et al., 2011).

ICU follow-up clinics are not a new phenomenon. In the United Kingdom, ICU follow-up clinics have existed since 1990. In a national survey of UK ICUs conducted in 2006, 30% had follow-up clinics, 55% of which were nurse-led (Griffiths, Barber, Cuthbertson, & Young, 2006). Nurse leadership of follow-up services seems to be the most prevalent model in the United Kingdom, with various methods for negotiating additional multidisciplinary services as required by individual patients. No data are available on the number of ICUs with follow-up clinics in Sweden and other countries, including Canada. The Swedish national intensive care registry (SIR) provides guidelines stipulating that follow-up services be available for all patients with an ICU stay exceeding 4 days (<http://www.icuregswe.org/sv>).

Table 1 *Potential Psychological Benefits of Follow-up Clinics*

- Enhanced person-centred care to help patients move on with their life after critical illness
- Opportunity for patients and relatives to ask questions after ICU discharge
- More thorough information and explanation about the ICU stay
- Referral mechanisms for patients and relatives in serious psychological distress
- Increased feedback to staff about the long-term consequences of critical illness

Theoretical Considerations Regarding the Recovery Process

From a philosophical point of view, experiences and memories are a person's life history. They bring meaning to events and have an influence on a person's present and future life (Gadamer, 1989). When something happens that makes individuals forget parts of their own history or leaves them with memories that are bizarre or unbelievable, it may affect their everyday functioning (Ringdal, 2008). Morse's (1997) Responding to Threats to Integrity of Self theory can be used as a framework during follow-up care to understand a patient's situation after ICU discharge. This theory concerns the process of recovery from serious illness, includ-

ing the meaning of the illness experience and changes experienced by the individual. It has five phases: *vigilance*, *disruption*, *enduring*, *suffering*, and *learning to live with the altered self*. The *vigilance* phase marks the start of the illness, when the patient suspects something is wrong; for ICU patients, this phase may begin when they regain consciousness in the ICU. With *disruption*, the patient has to hold on to life and survive. In the *enduring* phase, the patient strives to regain self; the most acute phase of critical illness is over and the patient focuses on recovery. In the *suffering* phase, the patient struggles with grief concerning his or her altered future. Finally, in *learning to live with the altered self*, the patient tries to accept the consequences of critical illness and to put the suffering aside.

Ringdal, Plos, and Bergbom (2008), in an interview study with ICU survivors, found that patients had bad and good memories in accordance with the different phases in Morse's (1997) theory. In the *vigilance* phase, bad memories, experienced early in the ICU stay, arose from feelings of anxiety and fear, disbelief about what was happening, and changing plans for the future due to the critical illness. Bad memories related to the *disruption* phase arose from their injured body and delusional memories that did not make sense to them. In the later phases, after ICU discharge, bad memories resulted from inconsistent information, a feeling of not recognizing oneself, and the perception that life was forever changed.

At the same time, patients had good memories arising from attention received when the injury occurred and the initial care (*vigilance* phase). Good memories also arose from the physical comfort provided by ICU nurses, support by family, and information about the world outside the ICU (*disruption* phase). After ICU discharge, good memories were related to gratitude for life and wanting to win life back again when returning home (*enduring* and *suffering*). In the final stage, *learning to live with the altered self*, patients needed to balance bad memories with good ones in order to get on with life and to be accepting of their situation (Ringdal et al., 2008). This is where diaries and ICU follow-up services can play an important role.

Future Directions

Patients need to know what happened during their ICU stay, to facilitate psychological well-being (Hupcey & Zimmerman, 2000), and for this reason follow-up services play a vital role in the continuum of ICU care. Research shows that, in general, patients are very satisfied with ICU follow-up care (Engstrom, Andersson, & Soderberg, 2008; Glimelius Petersson et al., 2011; Prinjha, Field, & Rowan, 2009; Samuelson & Corrigan, 2009). However, we lack empirical evidence of its beneficial effect on psychological well-being. The largest randomized controlled

trial of ICU follow-up clinics conducted to date, comprising structured case review, discussion of ICU experiences, assessment of the need for specialist medical referral, and screening for psychological morbidity, failed to detect an improvement in psychological HRQoL (Cuthbertson et al., 2009). It may be that current tools for measuring psychological HRQoL are insensitive to the subtle changes that occur over time and that further work is required to develop and validate appropriate measures.

Another important question for future research is which patients are most likely to benefit from follow-up services. An ICU length of stay of 3 to 4 days is generally used as an indication for commencing a diary or making a referral to follow-up services. In Sweden, this is stipulated by the SIR. Yet we do not know if this is the best criterion for commencing a diary and prescribing follow-up care. Some patients with shorter ICU stays may experience psychological morbidity but be ineligible for follow-up services, while patients with longer ICU stays may not always need this potentially resource-intensive intervention. Screening of patients' psychological well-being upon ICU discharge may be an alternative. However, no existing psychological measures have been validated for this purpose.

Another aspect of follow-up interventions designed to improve psychological well-being that requires further investigation is the structure and content of clinic visits. We do not know the optimal number, timing, or structure of follow-up visits. There also is a need for discussion about the most cost-effective approach for follow-up services that enable physical, psychological, and social rehabilitation using an individualized approach.

Conclusion

There is substantial evidence that many patients experience stressful, frightening, and delusional memories as a result of their ICU stay and that these memories last for many years. Some patients have impaired psychological health after critical illness, which may be associated with these memories. Diaries and follow-up services are two interventions that can mediate the psychological impact of critical illness. It is useful if follow-up services employ a relevant theory, such as that proposed by Morse (1997), as a framework to situate patient memories. Existing evidence indicates that follow-up services require modest resources and are viewed as valuable by patients and their family members. However, there are still limited data on the impact of follow-up services on psychological well-being in the long term. Promoting quality of life as well as saving lives is now firmly on the ICU agenda. Therefore, we need to continue

to investigate interventions that are deliverable both within the ICU and after ICU discharge and that prevent or ameliorate psychological morbidity.

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