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Group meetings after critical illness—Giving and receiving strength

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ABSTRACT

Introduction: An increasing number of intensive care patients are surviving critical illness, but many develop mental, cognitive and physical impairments after discharge. Adapting to a new life situation, often with major challenges, implies the need of support. Therefore, it is important to develop interventions aimed at promoting recovery.

Objective: The aim was to describe former intensive care patients' feelings of sharing their experience of critical illness with other former patients.

Method: Former intensive care patients (n = 17) participated in group meetings and wrote about their thoughts in a notebook after each group meeting. To deepen the understanding of the former patients' experience 11 of the former patients were interviewed. The notes in the notebooks and the interviews were analysed using qualitative content analysis.

Findings: Meeting others revealed to the former patients new dimensions of being critically ill, and they both gave and received strength from each other. The meetings were meaningful as they gained insight into other patients' lives, and realised what it meant to survive intensive care.

Conclusions: The group meetings meant sharing experiences and understanding the process of survival after critical illness. Giving and receiving strength from others helped the participants to go further.

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Implications for clinical practice

- Group meetings help former intensive care patients to understand what it means to survive intensive care.
- Sharing experiences with others is one way to both give and receive strength.
- Individuals felt aided in their battle to recover by the reactions of the other patients.

Introduction

After experiencing life-threatening illness or injury requiring a stay at an intensive care unit (ICU), life often changes dramatically during and after the period of illness. Health-related quality of life (HRQoL) is reported to be significantly lower for patients after critical illness compared with the general population (Davidson et al., 1999; Orwelius et al., 2005; Oeven et al., 2010). Many patients do not return to the same physical status as before their critical illness, which means that they need to adapt to a new life situation,

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often with major challenges. During the first year of convalescence, patients struggle for independence with their efforts focused on three domains; recovering physical strength, regaining functional capacity and resuming domestic roles (Ågård et al., 2012).

Furthermore, a substantial proportion of survivors experience cognitive impairment affecting memory and attention function (Desai et al., 2011). The fragmentary nature of memories from the patients' stay in the ICU and the delusional memories, such as hallucinations and nightmares, make it difficult for them to understand what really happened (Jones et al., 2000, 2007, 2010; Wade et al., 2015). Critical illness thus affects long-term health and well-being and consequently, it is important to develop interventions aimed at improving well-being, even after the patient has left the ICU (Angus and Carlet, 2002; Jensen et al., 2015). One form of intervention is writing diaries in order to fill memory gaps, and this has

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been well received by patients and their relatives (Bäckman and Walther, 2001; Engström et al., 2009; Bäckman et al., 2010; Egerod and Bagger, 2010; Jones et al., 2010, 2012; Garrouste-Orgeas et al., 2012), although Ullman et al. (2015) in their review suggest that clear evidence of the psychological effects of diaries still is limited.

Further interventions are ICU follow-up clinics, where former ICU-patients have a chance to discuss their ICU stay, and to be screened for complications and referred to specialist services, where necessary (Egerod et al., 2013). Organised by Milton Keynes Hospital, UK, meetings for former ICU patients and their relatives have been ongoing since 2005 (Peskett and Gibb, 2009). The ICU follow-up team and former patient and family volunteers hold drop-in sessions where recent patients and their relatives can meet and talk. In this report the participants of these meetings experienced them as giving positive support.

Follow-up clinics and drop-in sessions are often used to evaluate the patients' progress (Egerod et al., 2013). Former patients may attend with the intention of meeting each other and discussing their experience of being critically ill and consequently not further burdening their relatives. Thus, the aim of this study was to describe former intensive care patients' feelings of sharing their experiences of critical illness and recovery period with other former patients.

Method

As there is limited knowledge about former patients' feelings of sharing their experiences of critical illness with other former patients, a qualitative inductive descriptive design was chosen. A qualitative approach aims to deepen and broaden the knowledge about former patients' thoughts about sharing their experience of critical illness during group meetings (Krippendorff, 2013).

Participant

The Ethical board approved using data from the ICU follow-up clinic to get in contact with former ICU patients. The first author, working as an ICU nurse on the ICU and at the ICU follow-up clinic, completed the data selection out of patients that had visited the ICU follow-up clinic. All patients who had been treated in a general ICU at a regional Hospital, in the previous 3–18 months were invited to participate if they met the following inclusion criteria: Adults over 18 years old, an ICU stay more than 96 hours had visited the follow-up clinic at least one time, able to attend both group meetings, ability to speak and write in Swedish. Twenty five former patients reached the inclusion criteria and were invited to participate of whom seventeen agreed to participate in the study. Those who declined participation claimed that they were busy and couldn't attend to both meetings or had problem with hearing during group sessions.

Intervention

The former ICU patients participated in two group meetings, one month apart, with three to six patients in each group. An experienced ICU nurse (the first author) facilitated the group discussion and made sure that everyone was given time to speak and that the participants kept to the topic. At the first session all the patients talked about why they had been admitted to the ICU and their experiences of their stay until discharge to a general ward. They discussed what they could remember and what they had been told by relatives or read in their ICU diary. Subsequently, time was allocated for the other patients to ask questions. During the second meeting, the focus of the discussion was on the experience of leaving the ICU, the time on the general ward, and the recovery at home.

Data collection

An invitation to participate in group meetings was sent by mail and the patients were then contacted by phone. The postal invitation included information about the study, the group meetings and the confidential and voluntary nature of the study. An informed consent form was provided to sign and send back.

Four group meetings were held, with three to six former ICU patients in each, for a duration of two hours on two occasions at monthly intervals. The first meeting opened with an introduction of the participants themselves. The topic of this meeting was the critical illness and their experience of the ICU care. The second meeting dealt with the recovery period after ICU care until this meeting. Thereafter, the group discussed freely. To protect everyone's privacy it was emphasised that what was discussed in the meeting should not be shared outside the group.

After each session, the participants wrote down their feelings in a notebook that they were given at the first meeting. According to Polit and Beck, (2008), notebooks are used to collect data related to specific aspects of experiences. These questions were posed to guide the patients' comments in the notebooks:

- Do you feel that you have been affected in some way by the meeting? If so, how? Why?
- Has it brought up feelings for you? Which? Why?
- Did today's meeting give you something? If so, what?

All participants sent their notebooks back within 14 days of the meeting. As the content of the notebooks was sparse, all participants were asked to consent to an interview in order to deepen the understanding of the meaning of the group meeting.

Two to three months later, a semi-structured interview was conducted to obtain further insight. Eleven of the 17 former patients who participated in the group meetings, seven men and four women, gave their informed consent to be interviewed. All interviews were tape-recorded and performed at the hospital in a room next to the ICU, except one which was performed in the patient's home. The questions from the notebook were used to guide the interviews and the interviews lasted between 30 and 60 min. All interviews were conducted by the first author, who also transcribed the interviews verbatim.

Data analysis

Qualitative inductive content analysis was used to deepen and broaden the insight and understanding of former patients' feelings of sharing their experiences of critical illness with other former patients. This was completed by analysing the contents of the comments in the notebooks and the transcribed interviews (Krippendorff, 2004, 2013). The text was read several times by the first, second and the last authors, and meaningful units, relevant to the purpose of the study, were identified individually. Similar meaningful units were then given the same code and sorted into subcategories and categories. To ensure credibility, all the authors discussed similarities and differences during the analysis until consensus was reached. The meaningful units, subcategories and categories were read over and over again and the analysis steps were processed back and forth to validate identified codes. Verbatim quotes have been used in this paper to give the reader an opportunity to evaluate the conformance between the interviews and the categories. This increases the credibility of the findings (Krippendorff, 2013; Patton, 2002).

To ensure dependability and to verify that the findings were understood and interpreted correctly, a third session was organised when eleven participants from the first two group meetings were presented with a summary of the data analysed from the notebooks.

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