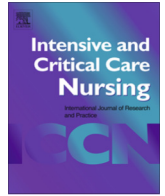




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## Research article

## Picking up the pieces: Qualitative evaluation of follow-up consultations post intensive care admission

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## ABSTRACT

**Objectives:** On an intensive care unit at a university hospital in Denmark patients are offered a nurse-led consultation three months post intensive care unit admission, to help them cope with Post Intensive Care Syndrome and identify opportunities for further intervention. The aim of the study was:

1) To describe former intensive care patients' experiences of the consultation, specifically regarding content and setting.

2) To explore the benefits of the consultation in regard to the individual patients' symptoms of Post Intensive Care Syndrome.

**Methods:** Focused ethnography was chosen as methodology combining observations and interviews.

Ten patients participated in a two-part qualitative study: 1) an observational study of the current follow-up consultation; 2) a semi-structured interview based upon observations and statements arising during the initial consultation.

The data was analysed using a hermeneutic-phenomenological approach.

**Findings:** Content and setting of the consultation were of upmost importance. Revisiting the unit and experiencing the setting in person played a huge role in coping with Post Intensive Care Syndrome. Involving relatives was essential as they were an important part of the patient's rehabilitation.

**Conclusions:** Participating in the consultation and revisiting the unit proved important. It helped patients understand their symptoms and make sense of what had happened during their stay in intensive care unit.

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## Implications for clinical practice

## Post-ICU follow-up:

- Gives patients an understanding of their Post Intensive Care Syndrome symptoms.
- Seeing the patient room with all of its technical equipment and hearing the sounds gives the patients explanations of some of their thoughts and nightmares.
- Gives the patients a feeling of belonging to a group of normal post-intensive care patients, which is an important element of further processing and coping with the intensive care unit stay.
- Relatives play a major role and should participate in follow-up.

## Introduction

In recent years, rehabilitation after critical illness and admission to an intensive care unit (ICU) has been increasingly addressed worldwide (Egerod et al., 2013). The number of patients admitted for intensive care treatment and surviving critical illness is rising

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(Elliott et al., 2014). Traditionally, focus has been on mortality rates; however, the long-term consequences for ICU survivors are not being taken into account (Angus and Carlet, 2002). Many patients suffer from complications after their admission. These complications are identified as post-intensive care syndrome (PICS). PICS is defined as new or worsening problems in physical, cognitive or mental health status that arise after critical illness and persist beyond acute care hospitalisation (Needham et al., 2012). PICS, which affects both survivors and relatives, reduces quality of life and increases the overall cost of care (Jensen et al., 2015; Davydow et al., 2008; Cameroun et al., 2016).

Post-ICU follow-up varies both nationally and internationally. Some hospitals offer no follow-up, while others have defined rehabilitation programs and designated outpatient clinics (Egerod et al., 2013). Qualitative studies indicate that patients benefit from follow-up by receiving continuity, information, coherence and feedback; patients who are offered follow-up have a significantly reduced risk of developing post-traumatic stress disorder (PTSD) (Jensen et al., 2015). In Scandinavia, the purpose of follow-up is to identify patients who are in need of additional intervention and to promote their recovery by filling in the gaps in their memory, as well as information and advice to help them come to terms with their ICU experiences and memories (Egerod et al., 2013).

Follow-up in the form of nurse-led consultations have emerged because of experimental initiatives in clinical practice. As a result, the current evidence available is generally of a low quality, no gold standard exists for rehabilitation programs for patients after ICU treatment (Jensen et al., 2015). Based on recent knowledge, a more systematic approach to follow-up is recommended as an integral component of intensive care therapy with clearly defined goals and assessment programs (Egerod et al., 2013).

On an ICU at a university hospital in Denmark, patients are offered a nurse-led follow-up consultation three months post ICU admission. This provides patients with an opportunity to discuss their ICU experiences and receive an explanation of the physical, mental and social symptoms that can occur after critical illness' it provides a setting in which these often traumatic experiences can be addressed (Fonsmark and Rosendahl-Nielsen, 2015). On this specific ICU, patients and their relatives are invited to a follow-up consultation and a reunion with the ICU and the staff. The nurse's role is to listen, provide mental support and identify whether there is a need for further follow-up. The visit is scheduled for one hour. This approach is used in other hospitals (Egerod et al., 2013; Samuelson and Corrigan, 2009). A local guideline for use in individual consultations was developed and the inspiration for the structure and content of the consultation was derived from experiences of practice and the latest research (Angus and Carlet, 2002; Egerod et al., 2013; Fonsmark and Rosendahl-Nielsen, 2015; Jones, 2014; Elliott et al., 2014; Rattray, 2014; Samuelson and Corrigan, 2009).

During the consultation, the patient sees a patient room to enable them to once again experience the light and sounds of the monitoring and treatment equipment. At present, an ICU follow-up consultation includes the possibility of referring patients to the department's senior physicians, relevant specialist physicians within the hospital or the patient's own general practitioner (GP). A Danish survey shows that almost half of the patients seen in an interdisciplinary intensive care centre are referred for further treatment (Fonsmark and Rosendahl-Nielsen, 2015); it is known that interdisciplinary collaboration is necessary for optimal patient care (Rattray, 2014).

The aim of this study was to generate knowledge about how patients experience follow-up consultation in terms of form, content and importance for their life situation. This knowledge facilitates the evaluation and further development of a structured interdisciplinary follow-up offer for patients who were previously admitted to the ICU. More specifically, the following aims were established:

- To describe former ICU patients' consultation experiences, specifically regarding content and setting.
- To explore the benefits of the consultation in regard to individual patients' symptoms of PICS.

## Methods

Focused ethnography was chosen as methodology because the purpose of this study was to explore a specific clinical setting of follow-up consultations and the patient's experiences of the consultations in regard to the content and setting and the individual patient's symptoms of Post Intensive Care Syndrome. Focused ethnography in health care research can be applied when the research concerns a context-specific and problem-focused framework. The research motive of this method are to develop nursing knowledge and practice (Knoblauch, 2005).

The patients were informed about the follow-up consultation prior to discharge from ICU. Two months later, they received a written invitation, followed by a telephone call to agree on a time for the consultation as is normal procedure for follow-up in the ICU. During the call patients were informed about the possibility to participate in a study. For patients not interested in taking part, the consultation was held by colleagues. Patients interested in taking part were scheduled for a consultation held by the authors (ALBH and AOG). The patients were recruited randomly from already existing lists of patients being invited for a consultation. Recruitment ended when we reached data saturation.

## Objectives

Eighteen patients were invited to take part in the study. Eight patients declined: Two were still too sick to attend, three did not want to attend, two wanted to participate in the follow up consultation, but not the study and one patient did not show up.

A total of three men and seven women aged between 32 and 84 years and admitted with common ICU diagnoses participated in the study based on the following inclusion criteria:

- Interested in participating in a follow-up consultation
- Hospitalised in the ICU for at least five days
- Mechanically ventilated for at least 24 h during hospitalisation
- Residents in the university hospital region

These criteria are in accordance with criteria for all patients attending follow-up consultations in this ICU.

Patients were included from December 2015 to May 2016 (Table 1).

## Data collection

When the patients attended the follow-up consultation both authors ALBH and AOG were present. One held the consultation and the other made handwritten field notes following each observation. Each patient observation was followed by an interview two to four weeks after the follow-up consultation. Both authors (ALBH and AOG) were present at the interviews and the author who held the consultation also conducted the interview. The authors ALBH and AOG did five consultations and interviews each. The interviews were based on semi-structured interview guides individually created on the previous observations and statements from the consultations as well as relevant literature. Table 2 is an example of one of the interview guides. The duration of the interviews was from 35 to 90 minutes, they were audio recorded and transcribed verbatim immediately after being recorded. The authors (ALBH and AOG) whom made both the interviews and observations had attended

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