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Research article

Recovery programme for ICU survivors has no effect on relatives' quality of life: Secondary analysis of the RAPIT-study

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ABSTRACT

Background: Relatives of intensive care patients are at risk of developing symptoms of anxiety, depression and posttraumatic stress resulting in reduced health-related quality of life. Recovery programmes for patients have been implemented, but their effect on relatives is uncertain.
Aim: To determine whether relatives benefit from a recovery programme intended for intensive care survivors.
Research design: A randomised controlled trial of 181 adult relatives: intervention group (n = 87), control group (n = 94).
Setting: Ten intensive care units in Denmark.
Main outcome measures: Primary outcome: health-related quality of life (HRQOL). Secondary outcomes: Sense of coherence (SOC), and symptoms of anxiety, depression and posttraumatic stress, compared to standard care at 12 months after intensive care discharge.
Results: No difference in HRQOL between groups was observed at 12 months (mean difference in mental component summary score, 1.35 [CI 95%: −3.13; 5.82], p = 0.55; and physical component summery score, 1.86 [CI 95%: −1.88; 5.59], p = 0.33). No differences were found in secondary outcomes.
Conclusion: The recovery programme intended for intensive care survivors did not have an effect on the relatives. Future recovery programmes should be targeted to help both patient and family, and future research should be conducted on a larger scale to make conclusions with higher probability.

Implications for Clinical Practice

- This study highlights the potential to improve health related quality of life sense of coherence, symptoms of anxiety, depression and posttraumatic stress disorder on relatives of intensive care unit survivors.
- The recovery programme intended for survivors indicated no effectiveness on relatives' health-related quality of life, sense of coherence and psychological health.
- Results generated from this study show that health-related quality of life, sense of coherence, and psychological health of relatives are better than found in previous studies.
- Future research should be conducted on a larger scale with intervention targeting patient and relatives based on their individual need during recovery of critical illness.

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Introduction

Relatives of intensive care patients are exposed to stress due to the critical and life-threatening condition of a loved one (Van Beusekom et al., 2016). In the intensive care unit (ICU) the relatives are faced with stressors such as feelings of helplessness, uncertainty regarding treatment and prognosis, lack of sleep and insufficient information (Frivold et al., 2016; Matt et al., 2017). Stressors may affect the relatives negatively and persist up to 12 months after ICU discharge (Ashby and Stoffell, 1995; Azoulay et al., 2005; Jones et al., 2004; Matt et al., 2017; van Beusekom et al., 2016).

It has been documented that relatives of ICU patients are at high risk of developing symptoms of anxiety, depression and post-traumatic stress (PTSD) during and after the ICU stay (Davidson et al., 2012; Frivold et al., 2016; McAdam et al., 2012; Pochard et al., 2005). This cluster of complications is known as "post-intensive care syndrome-family" (PICS-F) (Davidson et al., 2012). PICS-F is associated with reduced health-related quality of life (HRQOL) and the mental health component in particular is decreased compared to an age- and gender-matched population (Angus and Carlet, 2003; Matt et al., 2017; Rueckriegel et al., 2015; van Beusekom et al., 2016). A survey (n = 143) showed that nearly half of the relatives are affected by PICS-F at three months after ICU with outcomes reporting the prevalence of symptoms of anxiety (39%), depression (29%), and PTSD (47%), (Matt et al., 2017). Similar results were found at 6–12 months after ICU showing symptoms of anxiety (15–24%), depression (23–44%), and PTSD (32–80%), respectively (van Beusekom et al., 2016).

The quality of life of the relatives might be affected by the quality of life of the patients. A four-year cohort study (n = 57) showed that HRQOL of relatives was affected by patients' physical and mental problems (Rodriguez et al., 2005). Moreover, Matt et al. (2017) found a positive association between patients' HRQOL and the mental health of relatives after ICU (Matt et al., 2017).

Different types of family-centred interventions have been tested in ICU and found to improve the level of satisfaction in patients and relatives (Goldfarb et al., 2017). It has been recommended to involve relatives as an integrated part of patients' admission (Goldfarb et al., 2017).

Qualitative studies have indicated that post-ICU follow-up interventions might strengthen relatives' sense of coherence (SOC) related to the management of ongoing challenges (Frivold et al., 2016; Long et al., 2016). Post-ICU follow-up is valued and beneficial for patients and relatives alike (Frivold et al., 2016). Interventions specifically targeting the relatives of ICU survivors are lacking (Jones et al., 2004; Svenningsen et al., 2017). To address this gap, we developed a nurse-led individualised recovery programme aimed at ICU survivors to improve HRQOL, SOC, and psychological health in patient and relatives after intensive care (Jensen et al., 2016). The Recovery and Aftercare in Post-Intensive Care Therapy patients (RAPIT) study investigated the effect of the recovery programme on patients and their relatives (Jensen et al., 2016).

Study aim and objectives

The aim of the study was to determine whether relatives benefit from a recovery programme intended for intensive care survivors.

The objectives of the study were to evaluate:

1. Primary objective: The mental component score from The Medical Health Survey Short-Form 36 (SF-36) after a recovery programme compared to standard care (SC) at 12 months after ICU discharge.
2. Secondary objectives: The level of SOC and symptoms of anxiety, depression and PTSD after a recovery programme compared to SC at 3 and 12 months after ICU discharge.

Methods

The present study is a secondary analysis of the RAPIT-study treating data from relatives (Jensen et al., 2016). Analyses of patient data are detailed in previous publication (Jensen et al., 2016). The CONsolidated Standards of Reporting Trials (CONSORT) guideline was followed when reporting the study (Boutron, 2008).

Study design

The study was a multicentre, non-blinded, two-armed, pragmatic randomised controlled trial (RCT). Enrolment of relatives was made on the basis of patients from the RAPIT-study who were randomly assigned in a 1:1 ratio to receive the recovery programme or SC. Treatment allocation was concealed by random selection of opaque sealed envelopes in permuted blocks. The data analysis was blinded, but the recovery programme could not be blinded.

Setting and participants

The study was conducted in 2012–2015 in 10 ICUs (level II-III) in four out of five regions in Denmark. Participants were relatives of intensive care patients recruited through the RAPIT-study (Fig. 1). Relatives were invited to participate up to one month after ICU, by patient consent. Self-reported postal questionnaires were sent at three and 12 months after ICU. Participants were Danish-speaking adults (>18 years) that were relatives of ICU patients who participated in the RAPIT-study. Relatives of patients who died during the study were registered as non-responders.

Intervention and standard care

The intervention was a recovery programme consisting of three consultations conducted by specially trained study nurses. The first consultation was conducted at the hospital with the patient and relatives at one to three months post-ICU. The dialogue focused on supporting the patient in constructing an illness narrative aided by photographs of the patient during the ICU-stay and revisiting ICU. The second and third consultations were conducted by telephone with patients at five and 10 months post-ICU. The dialogue focused on issues of importance to the patients. Standard care included informational needs of patients and relatives and patient care including light sedation, early mobilisation, physical rehabilitation and ICU discharge without follow-up.

Outcome measures

The primary outcome was HRQOL at 12 months post-ICU. Secondary outcomes were HRQOL at three months, and SOC, anxiety, depression, PTSD at three and 12 months post-ICU.

HRQOL was assessed by SF-36, a validated and reliable questionnaire that summarises self-evaluated health in 36 items (Bjørner et al., 1997). The questionnaire is designed to represent the most important health profile from eight multi-items scales or two aggregated summary scores: Physical Component Score (PCS) and Mental Component Score (MCS) (Bjørner et al., 1997). The scores range from 0 to 100 with higher scores reflecting better health. MCS was the primary outcome in this study.

SOC was measured by 13 questions from Sense of Coherence Scale (SOC-13) (Eriksson and Lindstrom, 2005). The scale has

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