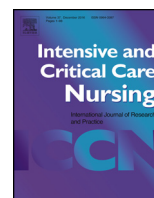




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Original article

# Family-centered bereavement practices in Danish intensive care units: a cross-sectional national survey

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### ABSTRACT

**Background:** Mortality in Danish intensive care units (ICUs) continues at 27%, resulting in a large number of bereaved family members being cared for in the ICU.

**Objectives:** To investigate the provision of bereavement care and follow-up services for bereaved families in Danish ICUs.

**Methodology:** Self-administered computerized cross-sectional nation-wide survey of Danish ICUs.

**Results:** Nurses at 46 of 48 (96%) ICUs in Denmark responded. Bereavement care at the time of patient death included viewing the patient in ICU (100%), and in the hospital mortuary (59%). Information about hospital-based follow-up for the family was provided in 72% of units, whereas only one unit provided information on community-based bereavement follow-up. Bereavement follow-up services after hospitalization were offered to families in 59% of ICUs and included an ICU visit, meeting with the staff present at the time of death, a letter of condolence, a phone call to the family, referral to a priest or clergyman, or referral to other counseling. Although many interventions were common, there were variations within the elements offered. Nurses and physicians were the most consistent health care staff involved in bereavement services.

**Conclusion:** Most ICUs in Denmark offered bereavement follow-up services, but these varied in their approach, were not evidence-based, and lacked formal evaluation. More systematic quality improvement of bereavement practices is required.

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### Implications for clinical practice

- Bereavement follow-up services in Danish intensive care units are variable
- General guidelines from the Danish Health Authority exist, but are not consistently followed
- We recommend systematic quality improvement of bereavement practices aimed at supporting the grief process of the patient's family

### Introduction

The aim of any intensive care unit (ICU) is the monitoring and support of patients with a life-threatening illness enabling diagnostic measures to be performed, appropriate interventions to be administered, and thereby improve patient outcome (Valentin and Ferdinande 2011). This is reflected in general recommendations for Danish ICUs where intensive therapy is provided for patients

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with potentially reversible conditions (Ilkjær et al., 2013). Nevertheless mortality within 30 days of ICU admission in Denmark remains high at 27% (Christensen and Faber 2014). This suggests that a large number of family caregivers are faced with the death of their relative in the ICU (Fridh et al., 2009; van der Klink et al., 2010). Some ICU patient deaths are unexpected and others are anticipated as the patient transitions from intervention to end-of-life care and controlled death (Coombs et al., 2012).

Resultant from these different trajectories of death, bereaved family members can experience different types of grief, such as uncomplicated or complicated grief, that can impact upon their mental and physical health outcomes (Aoun et al., 2015). Whereas uncomplicated grief is a normal, self-limiting reaction to bereavement, complicated grief is where intense, persistent grief lasts for more than six months after the loss, impairing normal psychological, social and daily functioning (Nielsen et al., 2017a; Shear et al., 2011; Zisook and Shear 2009). Given such impact, it is important to prevent, identify and treat complicated grief reactions to prevent prolonged suffering and dysfunction in family caregivers.

Family-centre care for relatives of patients dying in the ICU is not a new concept (Campbell and Thill 2000) and has indeed informed health policy. The Danish Health Authority has provided guidelines for the interaction between healthcare workers and relatives of patients with serious or life-threatening illness (SST, 2016), wherein it is recommended that the bereaved should always receive information on available support after the death of the patient. Further it is recommended that the bereaved should be offered a final consultation at the hospital and a follow-up phone call.

Whilst the profile of family-centered care in policy is clear, evidence of the impact of family-centered bereavement interventions in practice remains variable. A randomised clinical trial in 2007 compared the customary end-of-life family conference in ICU with a proactive intervention preparing the family for the patient's death (Lautrette et al., 2007). It was concluded that a brochure on bereavement and proactive communication reduces the burden on families at this time. Ten years later, a study tested the effect of a condolence letter on family members' grief symptoms and found that the letter failed to alleviate grief symptoms, and had potential to increase symptoms of post-traumatic stress and depression (Kentish-Barnes et al., 2017).

The most effective way to offer bereavement support has still not been determined internationally. A recent audit of ICUs in the United Kingdom concluded that bereavement care remains underdeveloped (Berry et al., 2017). An American survey showed that most ICUs did not provide bereavement follow-up services, but that hospitals with palliative care units were more likely to do so (McAdam and Erikson 2016). A survey of bereavement support in Australia and New Zealand reported that key components of family bereavement support have remained unchanged over the past decade, with little investment noted in this area (Mitchell et al., 2017).

To date, bereavement support in Danish ICUs has not been explored. The aim of this study was to investigate the provision of bereavement care and follow-up services for bereaved families in Danish ICUs. We wished to gain an overview of interventions offered to the family of deceased patients in ICUs, to describe characteristics of bereavement support, and to identify the role of ICU staff participating in these services.

## Methods

We conducted a self-administered computerised cross-sectional nation-wide survey of Danish ICUs. The survey was a collaborative replication of the 2016 study of bereavement

support in Australia and New Zealand (Coombs et al., 2017; Mitchell et al., 2017). By undertaking a replication study, we were able to accumulate evidence within this area of research and explore the comparability and generalisability of results. In this study "bereavement care" refers to interventions provided for the family caregivers at the time of death of the patient in ICU, and "bereavement follow-up services" refers to family support at a later time.

### Sample population

We compiled a list of the 48 ICUs in Denmark and contacted each unit to identify one or two nurses who were willing to respond to the survey. We specifically targeted nurse managers in the ICUs, but also approached other nurses with particular knowledge of bereavement services in that unit to improve the response rate and widen the scope of information. In each ICU we chose a primary respondent, preferably the nurse manager on site, to ensure equal representation at all participating units. If the manager recommended a secondary respondent, we only included free-text responses from that respondent. Invitations with a link to the survey were sent to the work emails of the potential respondents at each unit. Two reminders were sent to all respondents at three and four weeks.

### Data collection tool

The survey tool developed by Mitchell et al. (2017) was used and consisted of 30 items within four sections: I. Personal and unit demographics, II. Model of bereavement services, III. Workforce model, and IV. Service evaluation. The survey was translated from English to Danish (translation and back-translation by bi-lingual authors) and piloted by asking five experienced nurses at different ICUs to complete and comment on the survey. A few changes were made to the Danish version, for example, the title Clinical Nurse Consultant and the Post Graduate Certificate Diploma do not exist in Denmark and were omitted. Critical care nursing certification in Denmark is a non-academic program, which was added. The original survey in Australia and New Zealand was powered by SurveyMonkey<sup>®</sup>, but we chose SurveyXact in this study, as it is the leading web-based survey system in Scandinavia. The system is easy to use, providing a report of results and a database that exports to Excel and SPSS.

### Data analysis

Descriptive statistics were used to analyze the closed-ended items in the survey. Categorical variables were summarized as frequencies shown as numbers and percentages. Although SurveyXact provided a report of the results, we transferred data to IBM SPSS version 22 for calculations. The free text comments from all respondents were comprehensively summarized for each item in the sample.

### Ethical considerations

After consulting the Danish Data Protection Agency further approval was not required. Potential respondents were provided with information on the survey in the initial contact email. In this information, it was stated that consent was assumed by completion of the survey and that confidentiality would be assured as only aggregate data was to be reported.

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