

pp Family involvement in the intensive care unit in four Nordic countries

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Abstract

Background: Relevance to clinical practice The findings from the study highlighting family involvement, high-quality communication and flexible visiting policy as central aspects of family care may inspire clinicians to identify aspects of everyday family care in their ICUs calling for further improvement.

Aims and objectives: To describe family involvement, communication practices and visiting policies in adult ICUs.

Design: A cross-sectional survey.

Method: A questionnaire consisting of 11 sections was developed, pilot tested and e-mailed to 196 ICUs. The participants were intensive care nurses in adult ICUs in four Nordic countries.

Results: The survey was conducted in October to December 2019. The response rate was 81% (158/196) of the invited ICUs. Most of the units had fewer than 11 beds. Family participation in patient care, including involvement in ward rounds and presence during cardiopulmonary resuscitation, varied between the countries, whereas most families in all countries were involved in decision-making. Family conferences were generally initiated by staff or family members. Children under 18 did not always receive information directly from the staff, and parents were not advised about how to inform their children. Although most respondents described open visiting, restrictions were also mentioned in free-text comments.

Conclusions: The level of family care in ICUs in the four Nordic countries is generally based on nurses' discretion. Although most Nordic ICUs report having an open or flexible visiting policy, a wide range of potential restrictions still exists. Children and young relatives are not routinely followed up. Family members are included in communication and decision-making, whereas family involvement in daily care, ward rounds and family-witnessed resuscitation seem to be areas with a potential for improvement.

What is known about this topic:

- There is a need for a family-focused approach to patient care involving family members in the intensive care unit (ICU).
- Lack of care for family members might lead to long-term problems related to their own health.
- Despite decades of research of family members' needs for access to the patient, few studies address the exact nature of "open visiting" practice in the ICU settings, or how family participation is facilitated.

What this paper adds:

- Family members are involved as active partners in communication and decision-making processes but are excluded from ward rounds and witnessing cardiopulmonary resuscitation.
- A wide range of potential restrictions still exists related to involvement and visiting practices.
- Children and young relatives are less included and are not routinely followed up.
- Guidelines at the ICU level to further promote a culture of family involvement are needed to improve individual staff practices.

Background

In recent years, research has highlighted the need for a patient- and family-centred approach to patient care in the intensive care unit (ICU).¹⁻³ This is an approach based on mutual respect and partnership among patients, family caregivers and health care providers.^{2, 4}

During ICU admission and throughout post-ICU convalescence, family members play a vital role in patients' struggle to survive and recover from critical illness.⁵⁻⁸ In addition to being involved

in the patient's situation, families, including children, also need care themselves.⁹⁻¹¹

When patients are admitted to the ICU, their families must deal with the critical illness and fear of losing a loved one, which may lead to anxiety, depression, complicated grief or post-traumatic stress disorder, also known as post-intensive care syndrome-family.^{12, 13} In addition, family members describe changes in their social, financial, relationship and employment situation¹² and reduced quality of life.¹⁴ Family members' burden may be reduced by welcoming them in the ICU and involving them in patient care.¹⁵ Consequently, family presence in the ICU is fundamental to active family involvement.

Another vital element in ICU family involvement is communication between families and nurses,³ and the ability to build a trustful relationship based on appreciation of the role of the patient's family. Over the past decade, international research has shown that effective and efficient communication improves family satisfaction and psychological well-being.¹⁶⁻¹⁸

Research indicates variation in visiting policies from restricted to flexible.¹⁹ Restricted visiting may consist of, for example, 10 minutes every 2 hours or fixed periods of 1 to 3 hours during daytime. Flexible visiting policies indicate that family members can visit at any time if they do not interfere with patient rest, ward procedures or patient integrity.²⁰ A flexible visiting policy has the potential to improve family and patient satisfaction,^{21, 22} and reduce negative psychological symptoms.¹⁹⁻²² Despite considerable knowledge of family members' need for access to the patient, few studies address the exact nature of "open visiting" practice, or how family participation is facilitated in ICU settings.

There is limited knowledge about interventions to promote families' involvement in the ICU setting. ICU visiting policies and communication practices differ between countries; this also includes the Nordic countries, even though ICU practices there appear to be quite similar. This study may provide new insights into how to enhance patient- and family-centred care and reveal areas for further research. The aim of the study was to describe family involvement, communication practices and visiting policies in adult ICUs.

Methods

Design and setting

The design was a cross-sectional survey involving adult ICUs in Norway, Denmark, Sweden and Finland. The ICUs in these countries are at three levels of care: university medical centres (level 1), large community hospitals (level 2) and smaller hospitals with limited critical care capabilities (level 3).²³

Survey development

The literature was searched to identify instruments for surveying family members' involvement, communication practices and visiting policies in adult ICUs. The search revealed a lack of tested and validated survey instruments. To answer the aim of the study, the lead investigators of each country designed a survey containing questions inspired by recent research about the involvement of family members of adult ICU patients.

Initially, the survey questionnaire was written in Norwegian. Subsequently, the survey, the information sheet and the invitation to participate were translated into Danish, Finnish and Swedish by the country lead investigators. The Danish and Swedish versions were translated back into Norwegian and validated by an independent researcher. The Finnish version (Uralic family of languages) was validated by an independent Finnish- and Norwegian-speaking researcher. The survey was pilot tested by 10 ICU nurses from five ICUs in Norway and Denmark who were similar to the intended end users, to ensure face and content validity. The pilot test feedback led to minor changes to the wording. The final survey consisted of the following 11 sections: Type of ICU, visiting policies, admission to the ICU, information and conferences with family members about the patient, general guidelines for family members, treatment of children under 18 as family members, facilities for family members, care initiatives targeting family members, follow-up initiatives in the ICU, ICU personnel and additional comments. The sections had one to nine questions with Likert scales or specific ICU response options, and each section had free-text fields. In addition, at the end of the questionnaire, the responders were encouraged to add further comments about families in the ICU.

Data collection and data management

The contact details of all adult ICUs in each country were provided by the national ICU registers or through professional networks. The country lead investigators asked the ICUs by telephone or e-mail to provide the name of one ICU nurse or nurse coordinator. These nurses were then e-mailed the information about the study and the online survey. The survey was distributed by SurveyXact to the participants' work e-mail address and was administered from a secure university platform. All participants received one reminder by e-mail. The survey data were checked and cleaned in the SurveyXact platform and analysed using the Stata 15 statistical software. The STROBE Statement, a checklist of items that should be included in reports of cross-sectional studies, was used.²⁴

Data analysis

Results from all the four countries were managed and analysed as one survey by the Norwegian research team. Categorical variables were described using frequencies and percentages. Continuous variables were presented using mean and SD if normally distributed, otherwise using median and range. Qualitative data in the form of free-text comments on specific questions in the survey were analysed using content analysis,²⁵ with the aim of elaborating the quantitative results. The comments were retained in their original languages for the analysis except for the Finnish comments, which were translated into English by the Finnish lead investigator. This was done to make the Finnish comments accessible to the other investigators, and to avoid double translation first into Norwegian and then into English for publication.

Using content analysis, the set of comments from each country was analysed by a national qualitative co-researcher. Each set of comments on a specific question was a unit of analysis, and each comment (1-5 lines of text) was a meaning unit. To gain an overall understanding of the manifest content of the comments, each set of comments was first read several times. Next,

to support the analysis process across the four countries, a matrix of analysis was created that asked questions of the data, such as: What are the comments about? Which topics are mentioned? How do the comments elaborate on the quantitative responses in the questionnaire? Later, the preliminary national findings were shared in several meetings during the analysis to reach a consensus on how to most accurately summarize the qualitative findings to include central elements from all four countries elaborating the quantitative findings, presented below in Tables 2-4.

Ethical considerations

The Norwegian Centre for Research Data approved the study. Research ethics approval was obtained according to the requirements of each country. Consent was obtained when the participants returned the questionnaire. The data were stored in a secure university platform.

Results

The survey was conducted in October to December 2019. The response rate was 81%, with 158 of the 196 adult ICUs participating: Norway 79% (44/56), Denmark 93% (39/42), Sweden 86% (56/65) and Finland 57% (19/33). The majority of the ICUs were at levels 1 and 2, and most of the nurses had an ICU qualification. All ICUs had some nurses with master's degrees, but not all had nurses with PhDs (Table 1). In Norway, Denmark and Sweden, in addition to a three- to four-year nursing programme, certified ICU nurses (75%-100% of nurses in the ICUs) have taken a one- to two-year postgraduate course in intensive care nursing that includes both theoretical and practical training. In Finland, nurses working in ICUs have completed 3.5 years of nursing education supplemented with local ICU training courses.

TABLE 1. Intensive care unit (ICU) characteristics

Family involvement, including participation in patient care and ward rounds and presence during cardiopulmonary resuscitation (CPR), varied between the countries, whereas more than 80% of families in all countries were always or often involved in decision-making (83% in Norway, 89% in Denmark, 97% in Sweden and 88% in Finland) (Table 2).

TABLE 2. Family involvement

Additional comments on the responses regarding family involvement also seemed to reflect variations in nursing practices within each country. Some nurses argued that experience directed their practice, while others referred to guidelines or scientific evidence. When inviting family members to participate in patient care, nurses would consider beforehand if this would compromise patient integrity or safety. Data describing family participation during ward rounds presented an even more diverse picture. Nurses needed to reflect on confidentiality, patient consent and integrity, especially in rooms with more than one patient. Although family members were often not present at the resuscitation of adults, nurses from all countries described in several comments how they made special efforts to have the parents present if a child needed CPR.

Communication practices varied according to the individual situation. Family conferences were generally initiated by both staff (72%) and family members (86%). They were mostly conducted as required (71%) without a fixed schedule and mainly took place in the patient's room, with the patient if the patient was alert and cooperative (78%), or in designated meeting rooms (89%) (Table 3).

TABLE 3. Communication practices in the intensive care unit (ICU)

The free-text comments revealed that a few ICUs practised inviting the families of long-term patients to weekly conferences. Some ICUs invited families to evening telephone calls, while others informed families that they could ring whenever they needed information. The written information (leaflets, web pages or apps) varied between the countries in terms of quantity and content. Sixty-eight percent of ICUs always or almost always prepared families for patient transfer out of the ICU, ensuring them that good patient care would be continued. Fifty-eight percent of families were always or almost always offered written information about practical issues regarding the ICU, whereas written information about possible reactions and consequences of being a close relative of an ICU patient was less common (Table 3). In the free-text comments, nurses from all four countries noted that they rarely had children as family visitors in the ICU. When there were children, this was documented in 88% of the cases, but only 25% of the children always or almost always received information directly from the staff, and 29% of the parents were always or almost always advised about how to inform their children (Table 3). As for family conferences with doctors, staff at 28 (64%) ICUs from Norway, 30 (77%) from Denmark, 23 (40%) from Sweden and 8 (44%) from Finland stated that nurses always or almost always took part in these.

As shown in Table 4, 85% of all ICUs had access 24/7 or 24/7 < 2 hours. In many ICUs, a maximum of two visitors at a time could stay in the patient room. The response option "Other" was due to the number of visitors being agreed on individually. In the free-text comments, family members were often described as a resource for the patient. By sharing their knowledge of the patient's needs and preferences, they helped the nurses individualize patient care. Although the majority of respondents reported that their unit practised open visiting, respondents described general restrictions related to, for example, ward rounds, shifts, patient rest or the size and arrangement of the patient room, including the number of beds. When inviting the family to the patient room, the nurses would consider potential threats to patient integrity, confidentiality or the patient's condition. One-bed patient rooms were described as facilitating family presence, while rooms with two or more beds limited family presence. The nurses described how family members often had to wait in the waiting room. Even with an open visiting policy, the actual time spent with the patient could be limited.

TABLE 4. Family visiting policies

Discussion

Family involvement

This study of ICU practices in the Nordic countries revealed variation between countries in the involvement of family members in care activities and ward rounds. Participation in patient care and ward rounds has been described as central to family members' ability to make sense of what has happened. Family involvement is about engaging families to partner with the nursing staff. Nurses must actively explore how family members can participate, while also keeping the patient's preferences in mind.^{2, 3, 9} In the free-text comments, patient safety, confidentiality and integrity were mentioned as essential aspects to be considered when deciding whether to invite family members to participate in patient care and ward rounds. However, the finding that some nurses from all four countries stated that family members rarely or never participated in patient care or ward rounds could reflect a different practice of family participation in some ICUs. Negative effects of family involvement such as staff burnout and decreased work satisfaction have been reported.²⁶ These factors may also influence the approach of some ICU nurses in the Nordic countries. Furthermore, both family- and ICU-related barriers to family caregiver involvement have been identified: for example, a lack of family resources to participate in patient care and the professional practice environment.²⁷

As shown in Table 2, 82% to 97% of the participating nurses stated that family members were often included in decision-making when the patient was unable to give consent to decisions: for example, about the level of medical treatment. This finding identifies decision-making as a highly prioritized area of family involvement.

The results from our study raise the question of whether ICU nurses' level of knowledge of evidence supporting active family involvement in the ICU transforms into their actual practice. ICU nurses in the Nordic countries have generally had a very good clinical education (Table 1), and in some of the countries, family care is part of the national ICU nursing curriculum. However, the number of nurses with additional academic education varied substantially, which may influence the implementation of evidence-based practice. Also, differences could exist between what nurses would prefer to do and what they are able to achieve.²⁸

Communication practices

As recommended in the framework of patient- and family-centred care,² high-quality communication and information are essential to family satisfaction and engagement. In the current study, few ICUs had fixed plans for family conferences. Instead, these were reported to take place when requested by the family members or the staff. Family engagement may be enhanced using different methods, and a structured plan for daily communication involving doctors may improve trust in the family-staff relationship.²⁹

Using leaflets and diaries can help reduce family anxiety and stress,³⁰ and video-based information can support the existing formats and may appeal to families with reduced reading ability. In this study, the ICUs provided family members with written information about ICU practicalities and treatment, but less about being a family member of a critically ill patient. To relieve family anxiety or stress, it might be beneficial to provide written or video-based information focusing on family experiences and coping.

Family involvement presupposes a relationship based on mutual respect and trust between family members and staff. A trusting relationship can be built through inclusive dialogue and information.³¹ The results of our study showed that family members were reported as being involved as active partners in communication processes, including decision-making discussions.

There seems to be a potential for improvement in the inclusion of child family members through active communication and information suitable to their age and level of understanding. The study findings show that there are seldom child visitors in many of the ICUs, children are not always given information directly by staff and parents are not advised about how to include their children. According to Knutsson et al,¹¹ parents often instinctively seek to protect their children by keeping them away from the ICU. To overcome this well-intentioned barrier, three elements are needed. First, nurses must be motivated to engage with the parents to meet the needs of a child visitor. Second, the parents should receive advice on how to best include children in the ICU family situation. Thirdly, children need individual support and guidance. When one of the parents is the patient, supporting both child and parents is of particular importance.

Visiting policies and practices

In a Canadian study of how ICU families work to get through the situation, the authors state: "It starts with access!" highlighting access to the ICU as fundamental for families.³² In line with current international recommendations, most of the ICUs in the Nordic countries report having open or almost open access for family members.^{2, 26, 33}

In combination with liberal visiting practices, including family members in the ICU is to acknowledge the concept of patient- and family-centred care.⁴ However, an international study has shown that even in ICUs with a liberal visiting policy, family members still spend time waiting outside the patient's room during examinations or treatment.³⁴ This might also be the case in the Nordic countries. In ICUs with restricted access for families, time spent waiting outside the patient's room has a greater impact on family members' actual time with the patient.

A literature review revealed that in eight of nine studies, family satisfaction increased with liberal visiting policies,³⁵ which might reduce not only family distress and anxiety but also the patient's suffering.^{22, 26, 33, 36} However, even though open access was common practice in the current study, several barriers to family presence were described, such as patient safety, integrity, tiredness, stress and environmental factors while the nurses tried to balance the needs of the family, patient and staff. Similar barriers have been identified in other studies.^{20, 37, 38} In the current study, the final decision on family bedside presence was made at the discretion of the ICU nurse.

Family presence during CPR of adults in the ICU is not common practice in the Nordic countries, even though some nurses reported experiences of this (Table 2). There is strong evidence to support family presence during CPR.³⁵ It has therefore been suggested to allow family presence by default.³⁵ Further, over the past two decades, international professional organizations, including ICU nursing organizations,³⁹ have recommended allowing family presence during

CPR. Although they did not allow family presence during the resuscitation of adults, several nurses in our study commented on how they made efforts to allow parents to be present during the resuscitation of a child. This distinction in the attitude towards the resuscitation of adult and child patients is also reflected in other countries.⁴⁰ However, medical ethicists have argued that from an ethical perspective excluding family members from the resuscitation of an adult patient can be more ethically challenging than excluding the parents of a child.⁴¹ Consequently, allowing family presence during the resuscitation of adult patients in the ICU seems to be an aspect of family presence and involvement where evidence and practice are still not aligned.

The nurses in this study reported that their family-centred care approaches were influenced by tradition, experience and scientific evidence. The shift from seeing the patient as their main priority towards active involvement of the family can be challenging for ICU nurses to adopt and implement.²⁷ In the present study, none of the nurses referred to ICU guidelines or formal unit policies on family-centred care. Lack of organizational policies has been found to hinder nurse-promoted family engagement and involvement,^{22, 26, 33, 36} pointing to a need to develop guidelines for ICU staff interaction with family members.

Also, organizational responsiveness factors are essential to change family care in the ICU.⁴² A healthy work environment with sufficient qualified staff is fundamental, as are patient room facilities that are welcoming for families.³² Furthermore, well-functioning systems of recording information on families in the ICU to ensure continuity in all aspects of family care are needed in the Nordic countries.⁴²

Methodological considerations and limitations

The survey instrument was pilot tested in the population before data collection to improve the validity and reliability of the study. However, the instrument was specifically developed for the study and was not further psychometrically tested. The study was multi-national and thus provides an insight into both similarities and differences between the participating Nordic countries. Differences between what ICU nurses do and what they say they do may be present in the data. In addition, patients and family members were not included in this study and should be the subject of future research. The overall response rate was 81%, minimizing the risk of non-responder bias. Thus, the survey provides a useful overview of the involvement practices, information and visiting practices of family members in adult ICUs. Observations of nurse-family interaction in ICU settings have the potential to further advance our knowledge about family involvement.^{42, 43} The implications of ICU and hospital exclusion of families and the consequences for patients, families and staff should be explored in future studies. The data of the current study were collected before the COVID-19 pandemic. Consequently, several factors related to family involvement, communication practices and visiting policies in the ICU have since changed significantly. This needs further exploration.

Conclusions

The level of family care in ICUs in the four Nordic countries is generally based on nurses' discretion. Although most Nordic ICUs report having an open or flexible visiting policy, a wide range of potential restrictions exists. Children and young relatives are not routinely followed up. Family members are included in communication and decision-making processes, whereas involvement in daily care, ward rounds and resuscitation seems to be areas with a potential for improvement.

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Author contributions

Gro Frivold: Project administration; designed the study; substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Anne Sophie Ågård:** Substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Hanne Irene Jensen:** Substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Eva Åkerman:** Substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Mariann Fossum:** Designed the study; substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Hanne Birgit Alfheim:** Substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Matias Rasi:** Substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript. **Ranveig Lind:** Designed the study; substantially contributed to the development of the survey instrument; data collection; data analysis/interpret data; manuscript writing and read; approved the final manuscript.



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