

Partnership working between nurses and patients' families in the critical care environment

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Abstract

When an individual becomes critically ill, they may be admitted to a critical care environment, which can have significant effects on themselves and their family. There is a wealth of literature exploring the experiences and priorities of patients and their families in relation to critical care, but also a lack of research on practical interventions that can improve care delivery in this setting. This article explores partnership working between nurses and patients' families in the critical care environment and examines the barriers to, and facilitators of, family-centred care. The author draws on the literature to consider interventions that could enhance family-centred care in this setting, and make some recommendations for practice.

When a person becomes critically ill they may be admitted to a critical care environment, which can have a significant effect on themselves and their family. In the context of critical care, the term 'family' includes anyone the patient considers to be a family member and/or with whom they have a lasting and sustained relationship (Mitchell et al 2016). It can be challenging for the patient's family to adapt to the sudden and unwelcome experience of a loved one being admitted to critical care, and this can take over their life, particularly if they feel they need to be with the person throughout their hospital stay.

Admission to a critical care environment has been described as a 'time of crisis' for the whole family. This experience can result in a range of emotions such as fear, stress and anxiety, changes to their working life, relationships and responsibilities in the family, and behavioural responses such as alterations in eating and sleeping patterns (Cypriss 2011). In addition, some family members may experience postintensive care syndrome-family, a condition that refers to the acute and chronic psychological effects on the family of a critically ill patient during their admission and following their discharge from critical care or their death (Rawal et al 2017, Netzer 2018). Therefore, families require support from critical care nurses to minimise the effects of a loved one's admission and the risk of post-intensive care syndrome-family.

This article explores partnership working between nurses and patients' families in critical care, examines the barriers to, and facilitators of, family-centred care, and considers nursing interventions that could improve practice in this area.

Visiting in the critical care environment

The critical care environment can be a frightening place and families may require significant support when a loved one is admitted to this setting. Visiting a loved one with a critical illness and seeing them surrounded by complex technical equipment, such as tubes, drains and drips, can be a barrier to their relationship (Engström et al 2010). This could be not only a physical barrier presented by the equipment, but also a psychological barrier associated with seeing their loved one in a vulnerable position in an unfamiliar environment. The role of the family in supporting and caring for their loved one while in the critical care environment is often determined by healthcare staff. For example, in some critical care departments family members are asked to wait outside for long periods while certain procedures are undertaken. Additionally, visiting hours may be restricted in line with local trust policy, bedside visitor numbers may be limited for health and safety reasons, or there might be limited availability of overnight accommodation for visitors.

Family members are often told these regulations are to enable staff to deliver care, for example medical reviews, physiotherapy, nursing interventions and/or personal care (Gibson et al 2012). Critical care staff might also perceive that visitors by the bedside reduce the space available, which could compromise safety by delaying patient care, or that the presence of visitors may increase noise or infection levels (Gibson et al 2012). Furthermore, there are often limited opportunities for family members to participate in caregiving, for example feeding and washing, compared with other care settings such as medical wards or care homes (Kiwanuka et al 2019), regardless of the level of their involvement before the patient's admission to critical care. Such regulations and perceptions can restrict partnership working between critical care nurses and patients' families. Additionally the infection prevention and control measures introduced due to the coronavirus disease 2019 (COVID-19) pandemic have further restricted opportunities for partnership working.

The British Association of Critical Care Nurses position statement on visiting in adult critical care units (Gibson et al 2012) concluded that although some nurses may believe visitors are detrimental to their ability to deliver care, visitors can be a source of useful information that can assist with person-centred care and are often a positive psychological aid to patient recovery. The position statement also noted that concerns about infection control were unfounded and that even visits from children or pets can be beneficial because they can assist patients in maintaining their identity. The statement recommended that where possible patients should be allowed to decide if and when they want visitors (Gibson et al 2012). This recommendation is supported by Akbari et al (2019), who investigated the relationship between increasing visiting time and patients' physiological parameters in intensive care units (ICUs) in Iran, finding that increased and flexible visiting hours had a positive effect on these parameters.

There has been a subsequent call for flexibility around visiting by families and carers (Connelly et al 2019). However, there needs to be a balance between delivering patient care and enabling families to maintain their well-being through their direct involvement in their loved one's care while in the critical care environment.

Families Experiences of the Critical Care Environment

One major theme in the literature on the experiences of families of patients in critical care is identifying families' needs. Research on this topic is often undertaken using the Critical Care Family Needs Inventory (CCFNI), a tool developed in the US by Molter (1979) and adapted for use in the emergency department by Redley and Beanland (2004). The inventory comprises 45 statements that family members can use to self-assess their needs. Hinkle and Fitzpatrick (2011) used the CCFNI to explore the perceptions of relatives' needs among relatives, nurses and doctors. They identified significant differences in perceptions between the three groups, as well as limited investigation by nurses and doctors regarding whether relatives' perceived needs were met and who was responsible for meeting these needs (Hinkle and Fitzpatrick 2011).

Other research has identified a gap between ICU staff perceptions about family members' satisfaction – that is, whether their needs were being met – and what family members believed was important (Padilla-Fortunatti et al 2019). Padilla-Fortunatti et al (2019) recommended a range of interventions to address this gap, including organising family meetings, involving family members in medical reviews, introducing a nurse family liaison role and resources for families, such as leaflets explaining the ICU environment and common procedures, as well as staff training in communicating with families. The researchers did not clarify whether the nurse family liaison role was required to implement these changes in practice or to act as a champion to support partnership working in the long term. Although a nurse champion role may assist in

sustaining changes in practice and should be explored further, it could be suggested that supporting patients' families is the responsibility of all critical care staff.

From 2020 onwards, the COVID-19 pandemic led to severe restrictions to visiting in many areas of health and social care. The author of this article has found no research on the needs of families of patients admitted to critical care during the pandemic. However, Yeh et al's (2020) study, undertaken during 2020 in a long-term care facility in China, found that patients' families were increasingly worried about the biopsychosocial care their loved one was receiving and had concerns about their mental health due to isolation measures. Families accepted the restricted visiting policies because of the pandemic, but found them a significant emotional burden, which led to increased conflict with staff. The researchers emphasised the need for staff to understand families' concerns to enable the development of strategies that could improve patients' mental health (Yeh et al 2020), and further work is required to explore this area in the context of critical care.

Nurses' perceptions of family involvement in care

Akroute and Bondas (2016) explored the perceptions of critical care nurses regarding the relatives of older patients in one ICU in Norway. They reported that many of these nurses acknowledged relatives as a source of support who understood the situation and were committed to supporting the patient's recovery. However, some nurses regarded relatives as a challenge and a burden who interrupted their work. They also perceived that relatives who were well-educated or who had a healthcare background could be critical and had high expectations of the support that should be given to their loved one. At times, some nurses interpreted relatives' sense of crisis as 'self-absorbed' or 'selfish' and found cultural differences and language barriers particularly challenging. As a result, they sometimes avoided interacting with relatives.

Akroute and Bondas (2016) concluded that lack of communication by healthcare professionals to relatives was the main source of conflict. They recommended that relatives should be involved in and kept updated about the patient's care and encouraged to share their feelings and concerns through regular meetings, for example formal multidisciplinary team meetings or informal conversations during visiting times.

A literature review by Adams et al (2015) found that nurses perceived communication with families in the ICU to be a vital aspect of their role. The reviewers reported that nurses were committed to developing a trusting relationship with the patient and their family, taking account of their spiritual needs, their need for hope and their need to be close to their loved one. However, the review also identified some non-supportive behaviours among nurses, such as suboptimal provision of information or support, which were attributed to nurses' lack of confidence, fear of burnout and emotional exhaustion (Adams et al 2015).

Cypress (2011) noted there was a lack of research on the 'triad' of nurses, patients and families in terms of examining their perspectives of each other in the context of critical illness. To address this, Cypress (2011) used a phenomenological approach to explore the lived experience of nurses, patients and families in an ICU. The author identified that nurses acknowledged that patients and their families were a part of a strong family unit, and that patients and families acknowledged the nurses' care of them as a unit. Cypress (2011) concluded that family-centred care can reduce anxiety and enhance confidence among patients and families, as well as improving patients' health outcomes, which illustrates the importance of involving the family in care interventions in the ICU setting. The study also emphasised the importance that families place on the nurse's role in supporting them and enabling familycentred care.

Engström and Söderberg (2007), who conducted four focus group discussions with 24 critical care nurses, reported that participants regarded relatives as a prerequisite for effective nursing care because they can assist with providing information and ensuring individualised care. However, some of the participants said they found it challenging to communicate with people from different cultural backgrounds to them. In their scoping review of patient and family involvement in adult critical and intensive care settings, Olding et al (2015) suggested that cultural differences between healthcare staff and families can result in misunderstanding or conflict. This indicates there is a need for education and training in family centred care which incorporates cultural diversity.

Benefits of family presence in critical care

There are various benefits to patients' families being present in the critical care environment. Netzer (2018) suggested that the presence of families can support patients to mobilise increasingly quickly, decrease the time patients spend on a ventilator and their overall length of ICU stay, and reduce delirium and anxiety, which are common among patients in critical care. The researcher also suggested that families can keep a diary, which can reduce patients' risk of posttraumatic stress disorder, recognise changes in the patient's condition and identify omissions in care such as healthcare staff forgetting to turn the patient or change their dressings, all of which can improve patient safety (Netzer 2018).

Families can be a crucial source of support for patients and critical care nurses because they may be able to provide assistance when the patient is unable to communicate their needs and can explain what the patient is usually able to do when they are well. They can also enable the patient to feel safe, supported and orientated, and may assist with simple activities of daily living, such as eating, drinking and personal care, where possible (Williams 2005). This type of family involvement can be supported by the 'what matters to you?' approach (Kebede 2016), which encourages practitioners to explore the priorities of critically ill patients.

In a quality improvement project that aimed to understand what patients in a critical care environment needed to improve their experience, Connelly et al (2019) asked patients 'what matters to you?' during daily ward rounds. Consistent themes identified were the need for family presence, since this made the patient feel safe, and the need for normal routines, such as eating food from home or watching television with their family to humanise the critical care environment (Connelly et al 2019).

Family-centred care

A family-centred approach to care emphasises that each patient is embedded within a family system. Mitchell et al (2016) stated that it is essential to include the patient and their family in planning, delivering and evaluating care to empower them and to ensure a mutually beneficial relationship with healthcare professionals. They defined this as patient-familycentred care. Critical care nurses should adopt a family-centred and partnership approach to enhance care delivery. However, there is limited understanding among critical care staff of how to do this and how to make family members partners in patient care (Mitchell et al 2016).

Some authors have suggested that critical care nurses can be inconsistent in their support of patients' families (Williams 2005, Adams et al 2015). This may be due to lack of time, nurses' focus on providing patient care and regarding families as a lower priority, or if receiving information from families is regarded as more important than enabling them to access patients and become actively involved in their care (Williams 2005, Adams et al 2015). This issue could occur due to critical care nurses' lack of knowledge of and education in family-centred care; for example, Buckley and

Andrews (2011) found that although ICU nurses perceived they had the required knowledge to care for families, this did not always translate into practice.

Barriers to family-centred care

Adams et al (2015) found potential barriers to communication between nurses and patients' families in the ICU, including insufficient education and training on the topic, a perceived lack of support leading to emotional exhaustion and moral fatigue, and uncertainty about their roles and responsibilities. The authors identified the need for a designated role such as a 'communication facilitator', changes to the daily routines and culture of ICUs to increase opportunities for information sharing, and potentially changes to the infrastructure to provide a dedicated space in which staff could communicate with families. In the context of the COVID-19 pandemic this could be a virtual space. Adams et al (2015) also recognised the need for clear, consistent and honest information, and giving families 'room for hope' where appropriate. They emphasised the role of the nurse in holistic communication – that is, not only discussing the patient's medical diagnosis, but also providing ongoing support.

Kiwanuka et al (2019) found that common barriers to family-centred care in adult ICUs included: a lack of understanding among healthcare professionals of how to demonstrate this approach; individual barriers such as staff lack of motivation or time; organisational barriers such as lack of a role model or champion and staffing issues; and interprofessional-related barriers such as tensions between different professional groups.

It is important to address the needs of patients' families and consider how to support a partnership between them and healthcare professionals in critical care, for example through communication and information sharing or by actively involving them in care interventions. A study by Mitchell and Chaboyer (2010) used telephone interviews to explore families' experiences of providing care to their loved ones in critical care. Common themes included: families' ability to enact physical care and thus demonstrate their love and care; supporting an emotional connection between families and the patient; and partnering with nurses, without whom participants believed they could not undertake care. Participants welcomed nurses' support and felt able to do as much or as little as they were comfortable with under their guidance (Mitchell and Chaboyer 2010).

Latour and Coombes (2017) identified that family-centred care is a research priority and that there has been a lack of systematic testing of interventions, such as providing physical care or involvement in patient reviews, in terms of how these facilitate a partnership between nurses and patients' families. This was also noted by Davidson et al (2017), who concluded that further research was needed to determine the effectiveness of family-centred care interventions in the critical care environment.

Supporting family involvement in patient care

Olding et al (2015) identified four components of family involvement in patient care:

- » The ability to be present.
- » Receiving care and having their own needs met.
- » Contributing to decision-making.
- » Contributing to care.

Xyrichis et al (2019) called for a standardised, international, evidence-based approach to partnership working with families in critical care and recommended the prioritisation of communication aids, caring skills such as massage, and decision-making abilities such as collaborative medical reviews. However, Wong et al (2021) favoured tailored interventions based on families' preferences. The researchers explored the preferences of 30 family members in an Australian critical care environment and found that just under half (47%) wanted to share decisionmaking about care for their loved one with healthcare professionals. Around 60% of families preferred a passive role in the physical care of their loved one, 33% preferred shared participation with staff and 3% preferred active participation with little staff involvement (Wong et al 2021). These findings illustrate the need for individualised familycentred care interventions.

The infection prevention and control measures that have been introduced due to the COVID-19 pandemic have removed or restricted the presence of families in critical care and other clinical environments. An additional challenge is the use of personal protective equipment such as face masks, which can reduce the ability to hear and speak on the phone (Baker et al 2020) and to convey empathy and nonverbal communication (Azoulay and Kentish Barnes 2020). Furthermore, some staff have been redeployed during the pandemic and bed capacity has increased, so in some areas critical care may have extended to other clinical environments, such as theatres, which can result in phone calls being misdirected (Azoulay and Kentish Barnes 2020).

To address these issues, some healthcare organisations have implemented family liaison teams and virtual video links to support communication with families (Gabbie et al 2020). Newcombe et al (2020) asserted that during the COVID-19 pandemic, alternative approaches to communicating with families of patients in critical care – such as written information, smartphones and computer tablets – might have mitigated their distress but were an 'imperfect solution' because the absence of family can be distressing for patients and healthcare professionals. The authors also emphasised that the benefits of having a physical waiting area, in which families might offer peer support, cannot be replicated in a virtual environment (Newcombe et al 2020). Despite this, videocalls, photos, music playlists and family voicemails have been valuable approaches to providing a sense of 'presence' for families and patients (Baker et al 2020).

Sasangohar et al (2020) reported that, among 230 respondents, there was an 86% satisfaction rate with the use of telecritical care for ICU family visits during the pandemic. However, issues regarding the use of this technology included technical issues, inability of the patient to communicate, lack of physical touch, frequency and clarity of the communication, and the desire of some respondents to contact the critical care environment on demand. However, the researchers also found that these virtual communications resulted in feelings of joy, gratitude, relief and happiness and a sense of closure at the end of life (Sasangohar et al 2020).

Azoulay and Kentish Barnes (2020) suggested a five-point strategy to foster a positive connection between patients, relatives and healthcare professionals, which included allowing some restricted visiting, providing standard written information, making scheduled routine telephone calls, encouraging families to stay in touch through the use of diaries, drawings and text messages, and organising a family conference or visit at the end of life.

Recommendations for practice

To enhance family-centred care in the critical care environment, the author of this article has identified the following recommendations for practice, which are aligned with the five categories in the CCFNI (Molter 1979):

» Information – dedicate time for in-person and/or virtual family meetings with critical care staff; enhance families' contribution to care planning; involve families in ward rounds; and ensure families receive regular updates via a family liaison nurse or team.

» Support – provide staff education and training on family-centred care and cultural awareness.

» Assurance – supply families with resources, for example information leaflets that introduce them to the critical care environment and explain some of what they will experience there; implement a nurse champion role; and encourage families to keep a diary.

» Proximity (the ability to be close to a loved one) – introduce flexible visiting hours that work for individual families; support normal routines such as activities of daily living and well-being activities such as music or reading, as well as cultural and religious requirements; and assist family members in providing hands-on care where appropriate.

» Comfort – provide a nearby waiting room, access to food and drink, access to overnight accommodation and the ability to sit by the patient's bedside. During the COVID-19 pandemic some of these recommendations may be challenging to enact and will require creative solutions, such as technology-enhanced communication. The risks of allowing family visits should be measured against the benefits to patients and their families.

Conclusion

There are various benefits of family presence in the critical care environment, and it is important for nurses to consider the needs of patients' families and work in partnership with them. There is a need for nursing interventions to be implemented to support familycentred care in the critical care environment, such as providing information, enhancing cultural awareness, introducing flexible visiting hours and ensuring access to food and drink. At present there is limited UK-based evidence on family-centred care in this environment, however some international research could be applied to the NHS context. Further research is required to assess the effectiveness of interventions and optimise practice.

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