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# Patient and Family Partnerships in the ICU: History, Benefits, and Strategies for the Future

The seamless integration of patient- and family-centred care in the critical care setting remains elusive. This review discusses the history and benefits of patient- and family-centred care, plus strategies for partnering with patients and families in the critical care setting.

## Introduction

Patient and family partnerships in the intensive care unit (ICU) are an essential element of quality healthcare. Leading societies and organisations across the world have integrated families as key participants in shaping research priorities and improving hospital outcomes (Davidson et al. 2017; European Society of Intensive Care Medicine 2017; Feemster et al. 2018; Patient-Centered Outcomes Research Institute 2022). We define ‘family’ as a person or people identified by a patient as providing love, caregiving and/or support not necessarily related by blood or marriage. In this article, we 1) describe the history of patient- and family-centred care; 2) narrate the benefits of partnering with patients and families in the ICU; and 3) reflect on the COVID-19 pandemic’s impact on partnerships with patients and families. We conclude with recommendations and resources to support current ICU providers in their efforts to incorporate patients and families into their daily ICU practice.

## History of Patient- and Family-Centred Care

Patient- and family-centred care (PFCC) is a philosophy of care that is “grounded in mutually beneficial partnerships among healthcare providers, patients, and families” and supports patients and families in “determining how they will participate in care and decision-making”. It recognises patients and families as essential allies—not only in direct care and decision-making but also in quality improvement, safety initiatives, education of health

professionals, research, facility design, and policy development (Institute for Patient- and Family-Centered Care).

The family-centred care movement emerged as a major response to the widespread separation of children from their families during World War II (Isaacs 2019; Jolley and Shields 2009). Through the mid-20th century, it was common for children to be hospitalised for extended periods (Robertson 1970). Efforts to control disease spread led to restricting family visits to once a week, causing lasting psychological trauma to children (Robertson 1970). Until the 1960s, families were often kept out of the paediatric hospital care process. British researchers John Bowlby and James Robertson played pivotal roles in studying family separation during hospitalisation and advocating for the inclusion of parents in the care of hospitalised children (Alsop-Shields and Mohay 2001).

The evolution of U.S. healthcare to focus on patient-centred outcomes owes much to Avedis Donabedian’s influential work. In his landmark 1966 paper, “Evaluating the Quality of Medical Care”, Donabedian advocated for evaluating healthcare quality not only in disease management but also in care processes and patient-physician relationships (Donabedian 1966). His 1990 publication, “Seven Pillars of Quality”, identified key aspects of healthcare quality: efficacy, effectiveness, efficiency, optimality, acceptability, legitimacy, and equity (Donabedian 1990). He explicated the importance of care acceptability as including the patient-practitioner relationship, accessibility, amenities, and patient preferences regarding care effects and costs. The



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importance of patient and family engagement was echoed in the Institute of Medicine's 2001 report "Crossing the Quality Chasm", which outlined aims for 21st-century healthcare: safety, effectiveness, patient-centredness, timeliness, efficiency, and equity (Baker 2001). These factors helped shape PFCC, and from this, PFCC in ICUs took shape.

In 2004, the Institute for Healthcare Improvement called for open ICU visitation policies (Berwick and Kotagal 2004). Despite the acknowledged importance of family presence and partnership in the ICU, barriers to family engagement remain. For example, a study of family engagement in the ICU found while 97% of family members were willing to participate in patient care, only 13.8% spontaneously participated or asked the ICU staff to help them participate (Garrouste-Orgeas et al. 2010). The emphasis on quality has led to the development of quality assessment measures like the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), the Family Satisfaction in the ICU (FS-ICU), and the Critical Care Family Needs Inventory (CCFNI) (Giordano et al. 2010;

Molter 1979; Wall et al. 2007). More recent data shows families consider addressing patient psychosocial and spiritual needs as one of the most important ways they can participate in the ICU (Wong et al. 2019; Wong et al. 2020).

### Benefits of Partnering With Patients and Families in the ICU

PFCC has gained prominence in critical care medicine and research in recent decades. For instance, a 2000 survey of U.K. clinicians ranked the impact of visitors on patient outcomes as one of the lowest priorities for ICU research (Goldfrad et al. 2000). However, by 2007, guidelines for PFCC in the ICU were introduced by the American College of Critical Care Medicine and updated in 2017 (Davidson et al. 2017; Davidson et al. 2007). These guidelines, along with the ABCDEF bundle—which integrates family involvement and improves patient survival and post-discharge disposition—underscore the importance of family engagement in care (Institute for Patient- and Family-Centered Care 2014; Marra et al. 2017; Pun et al. 2019). In a 2023 systematic review of randomised trials with family-centred interventions, 35 of 52 studies showed improvement in at least one family-centred outcome (Wang et al. 2023). (Tellingly, only 5 of the included studies occurred before 2010).

There is broad evidence for the benefit of using family caregivers to implement evidence-based interventions in the inpatient setting and a small but growing evidence base for their participation in direct ICU care (Dijkstra et al. 2023b; Fiest et al. 2018). Families want to participate in patient care, and ICU teams are generally supportive (Al-Mutair et al. 2013; Dijkstra et al. 2023a; Liput et al. 2016). Engaging family caregivers can improve hospital quality metrics vis-a-vis satisfaction ratings and implementation of best practices for reducing hospital-acquired weakness and delirium (Davidson et al. 2017; Fiest et al. 2018; Guerra-Martin and Gonzalez-Fernandez 2021; Rosgen et al. 2018; Rukstele and Gagnon 2013). Similarly, engaging caregivers in patient mobilisation in the hospital improves long-term patient mobility and home caregiver quality of life and reduces patient length of stay

(Yasmeen et al. 2020). While clinicians and families see value in forming partnerships, the seamless integration of PFCC into ICU practice remains elusive.

A 2017 systematic review of ICU PFCC interventions demonstrated that PFCC interventions were associated with reduced ICU costs, shortened ICU length of stay, improved family satisfaction, and improved patient and family mental health outcomes (Goldfarb et al. 2017). For example, multicomponent trials of ICU patients with high risk of death by White and Curtis used nurse communication facilitators to support families; both studies showed reduced ICU length of stay (Curtis et al. 2016; White et al. 2018). In general, there is no single "silver bullet" intervention that addresses all patient and family needs for partnership in the ICU; it is, therefore, recommended that interventions have multiple components and engage patients and families as partners in multiple aspects (Xyrichis et al. 2021).

The ICU experience can provoke significant emotional stress for patients and families (Gurbuz and Demir 2023; Kose et al. 2016; Pochard et al. 2001). Individual clinician, ICU culture, and geographic area differences all contribute to a lack of standard approach for discussions about value-based treatment plans and patient preference alignment (Turnbull et al. 2016). Surrogate decision-making around potentially medically non-beneficial treatments or end-of-life treatment thresholds burdens families and patients with guilt and confusion and is associated with poor psychological outcomes (Greenleaf et al. 2023; Wen et al. 2024). Symptoms of Post-Intensive Care Syndrome-Family (PICS-F), a constellation of psychological symptoms including anxiety, depression, post-traumatic stress, and complicated grief, can affect up to 73% of family caregivers (Davidson et al. 2012; Kentish-Barnes et al. 2015; Lautrette et al. 2007; Pochard et al. 2001; Pochard et al. 2005). Furthermore, patient and family employment absenteeism and hospital financial expenses accrue additional psychological strain and suffering (Khandelwal et al. 2020; Khandelwal et al. 2018; Stayt and Venes 2019). The intersection of these and other complex variables can result in depression, post-traumatic stress, anxiety, and care that is often inconsistent with the patient's previously expressed preferences

(Vrettou et al. 2022). Embracing PFCC in the ICU is one way clinicians can help to mitigate emotional stress and PICS-F (Love Rhoads et al. 2022).

The emotional burden families carry can be exacerbated by communication breakdowns between physicians and surrogate decision-makers of critically ill patients (Connors et al. 1995; Ito et al. 2023). Provider disruption in the continuity of care, insufficient clinician training around palliative care, and difficult conversations are just a few of the barriers to successful communication with patients and families in the ICU and highlight the lack of consistent patient- and family-centred systems (Connors et al. 1995; Pochard et al. 2001; Schwartz et al. 2022). Recognising the essential role PFCC has in the care of critically ill patients is paramount to ensuring the successful transition of recovered critically ill patients and their families to healthy lives. Interventions to improve surrogate decision-making may reduce ICU length of stay without changing the mortality rate (Bibas et al. 2019). Overall, taking a proactive, structured approach to foster open communication, provide surrogate support, and engage families in treatment and medical decision-making is essential for PFCC (Azoulay and Sprung 2004; Lautrette et al. 2007; Schwartz et al. 2022).

### Learnings from COVID-19: Family Partnerships and Presence in the ICU

The Institute for Patient- and Family-Centered Care (IPFCC) is a non-profit organisation based in the United State providing leadership in understanding and advancing the practice of PFCC in all care settings. As part of its mission, IPFCC champions family presence and participation through its **Better Together** campaign (Institute for Patient- and Family-Centered Care 2014). The campaign embraces families as essential members of the healthcare team and reduces restrictions on their presence and participation (Dokken et al. 2020; Dokken et al. 2015).

In Spring 2020, faced with the tremendous uncertainty of the COVID-19 pandemic, severe restrictions on family pres-

ence were imposed by health systems globally. The sudden and widespread implementation of these restrictions led to serious consequences and harm to ICU patients, their families, clinicians, and staff. For example, a study of ICUs in 49 Michigan hospitals documented high rates of delirium and sedation requirements in patients with COVID-19, two conditions that are reduced by increased access to family members (Valley et al. 2020). Unable to visit loved ones in the hospital, family members had increased psychological distress (Heesakkers et al. 2022).

To better understand the impact of visitor restrictions, IPFCC partnered with health systems in an engagement project, *“Learning from Experience: Exploring the Impact of Approaches to Family Presence in Hospitals During COVID-19”* (Institute for Patient- and Family-Centered Care 2023a). The project’s purpose was to learn directly from patients, families, and healthcare workers about the impact of the restrictive family presence policies during the pandemic. Not surprisingly, the restrictive policies negatively impacted patient care, communication, information sharing, decision making and the emotional well-being of clinicians, families, and patients. Derived from participants who experienced hospital settings during COVID-19, these themes reinforce the benefits of family partnership (Institute for Patient- and Family-Centered Care 2023a). The IPFCC project

was able to capture quotes from participants that illustrate the helplessness felt by patients, families, and clinicians when families are not allowed to be present and participate in the care of their loved ones (**Table 1**).

Despite growing evidence about the negative consequences of restricting family presence, many hospitals have not returned to pre-pandemic levels of open visitation and welcoming family members as partners and allies (Fernández-Castillo et al. 2024; Marmo and Hirsch 2023; McTernan 2023). Emerging and anecdotal evidence suggests this is a global phenomenon (Fernández-Castillo et al. 2024).

### Strategies for Increasing Patient and Family Partnership

#### Involving Families in Care

Family members know the patient, their health history, and how care is managed at home—their deep understanding of their loved one provides a humanistic context for the patient’s care in the ICU. Clinicians should be prepared to use a consistent and standardised approach in partnering with patients and families. Useful guides for families about how they can be involved in care

| Stakeholder   | Quotation   |
|---|---|
| ICU patient with COVID-19                                 | <i>I had the shakes really bad ...all I wanted was to FaceTime my kids, my husband, and my friend. I couldn't communicate, and there was nobody there to help me communicate with my words.</i>   |
| Family member of a patient in the ICU during the pandemic | <i>It was devastating. Because, like I said, I could not be there for my mom... So [I] have to really trust these medical professionals to take care of her the way that I had always taken care of her... That was very, very hard.</i>  |
| ICU frontline healthcare clinician                        | <i>It was really, really, really hard to stand there as people would pass away or people would get sicker... standing with this iPad, showing this person their family member, and they're just devastated, and there's absolutely nothing I can do besides stand there with an iPad.</i> |

**Table 1.** Representative quotations from hospital visitation restrictions during the COVID-19 pandemic. Source: *Learning from Experience: Exploring the Impact of Approaches to Family Presence in Hospitals During COVID-19* (Institute for Patient- and Family-Centered Care 2023a)

| Role  | Description   |
|---|---|
| <b>Preserve patient individuality</b>               | Create a story board that shows the patient's humanity and supports physicians and staff to see the patient holistically (Ahmad et al. 2023).   |
| <b>Comfort the patient</b>                          | Families can comfort the patient through gentle touch, applying lotion, light massage, being bedside, reminiscing, reading aloud or playing games (Dijkstra et al. 2023a; Momeni et al. 2020).  |
| <b>Provide care</b>                                 | Based on personal preferences and in consultation with ICU staff, families can help with care activities such as personal hygiene (e.g. combing hair, applying lip balm, bathing) and range of motion for mobility (Amass et al. 2020; Dijkstra et al. 2023a; Wyskiel et al. 2015). |
| <b>Assist with communication</b>                    | Serve as healthcare proxies and advocates by adding information to whiteboards and patient portals and assisting with technology or writing what the patient wants to say (Seaman et al. 2017).   |
| <b>Share clinical observations</b>                  | Families observe subtle changes in patients (e.g. pain, altered mentation, and other concerns) and should be encouraged to bring them to the attention of the clinical team (Schwartz et al. 2022).   |
| <b>Keep an ICU diary</b>                            | A log of the ICU experience written either by the family or in collaboration with ICU staff can help patients process their time in the ICU (Davidson et al. 2017; Mcilroy et al. 2019).  |
| <b>Participate in planning and decision-making.</b> | Include families in rounds, change of shift, and other care planning meetings where important information is shared and decisions are made (Calderone et al. 2022; Davidson et al. 2017).   |
| <b>Support ongoing healing and recovery.</b>        | This is important when patients are transitioning to a different level of care (Ghorbanzadeh et al. 2022).  |

Table 2. Partnership roles for families in the ICU

| Role  | Description   |
|---|---|
| <b>Invite families to participate in daily rounds and shift change</b>                    | Include in and educate about the purpose of rounds and change of shift invite observations, concerns, and questions (Calderone et al. 2022; Davidson et al. 2017).  |
| <b>Enable flexible, multicultural family participation.</b>                               | In some cultures it may be preferable to engage a larger group of family in decision-making rather than one or two key individuals. In-person interpreter services or telehealth alternatives are essential (Jones 2023). Facilitate expanded in-person visiting hours as well as video visits. |
| <b>Support a culture shift that relies on families being involved in care activities.</b> | Families can assist with care according to their own preferences and patient appropriateness. Identify appropriate care activities and coach families to safely provide care (Amass et al. 2020; Momeni et al. 2020).   |
| <b>Participate in internal education and training.</b>                                    | Training workshops on relationship building, communication, shared decision-making, and minimising bias promote family-clinician partnerships in care (Dijkstra et al. 2023a).  |
| <b>Provide feedback systems</b>   | Implement systems that enable families to follow up if care is discriminatory. Enable systems that allow families to provide feedback anonymously.  |
| <b>Provide robust support for spiritual care, especially at end-of-life</b>               | Inquire about and respect spiritual beliefs such as the inclusion of church leaders and end-of-life practices such as deathbed vigils, last rites, and handing of body.   |

Table 3. Partnership roles for ICU clinicians

and decision-making are available online (European Society of Intensive Care Medicine 2017; Institute for Patient- and Family-Centered Care 2014; Minniti and Abraham 2013).

Involving families in care requires commitment from both families and healthcare professionals. To effectively integrate families as care partners, it is critical to provide families with clear expectations of their roles. These include: 1) maintaining the patient's identity, i.e., enabling clinicians to understand the patient within their life's context; 2) assisting with communication between the patient and healthcare team, including

shared medical decision-making; and 3) acting as advocates for the patient (Ahmad et al. 2023; Calderone et al. 2022). Families can collaborate with staff to keep a diary to help patients process their time in the ICU. These diaries are associated with improved patient quality of life, decrease depression and anxiety, and may also reduce family caregiver post-traumatic distress (Mcilroy et al. 2019). A more detailed list of family roles can be found in **Table 2**.

Clinicians and healthcare staff can: 1) offer options for communication, including personalised technology and translation services; 2) encourage patients and families

| Role  | Description  |
|---|--|
| <b>Form patient and family advisory councils (PFACs)</b>        | PFACs can help improve bedside care and communication, contribute to PFCC environmental design and participate in quality improvement (QI) and research (Minniti and Abraham 2013). Engage patient and family partners in all phases of QI initiatives, from needs assessment to intervention development, implementation, and outcome evaluation. |
| <b>Be inclusive</b>   | Ensure that councils, committees, and work groups are representative of the population served and include members who have been historically under-represented or marginalised (Institute for Patient- and Family-Centered Care 2023b).  |
| <b>Engage in narrative medicine through sharing experiences</b> | Patients and families can provide constructive feedback: what went well, what could have gone better, and ideas for improvement (Minniti and Abraham 2013). Ask patients and families to share their experience and educate ICU health professionals, students, or trainees (Loy and Kowalsky 2024).   |
| <b>Collaborate</b>  | Collaboration among patients, families, and clinicians is nuanced, requires navigating power dynamics, and may be more successful using mentors and training sessions (Minniti and Abraham 2013; Patient-Centered Outcomes Research Institute 2021).   |
| <b>Prepare for specific initiatives.</b>                        | Projects should centre on a specific topic and/or methodology. This allows for training that is relevant to the topic and explains models, methods, or processes that support effective participation (Minniti and Abraham 2013).  |
| <b>Evaluate collaboration</b>                                   | It is essential for sustainability to regularly assess the collaboration by capturing informal and formal candid feedback (Hamilton et al. 2021; Minniti and Abraham 2013). Outcomes of QI should be stratified by marginalised groups (i.e., race and ethnicity at minimum). This data can inform training and programme development.             |
| <b>Provide compensation</b>                                     | Patients and families should be appropriately compensated at a level that matches their time and effort. Compensation can be offered in various ways, and out-of-pocket expenses such as transportation or parking should be covered by the organisation (Dhamanaskar et al. 2024).  |

**Table 4.** Partnership roles for former patients and clinician leaders in improvement and change

to participate in rounds and change of shift, and educate them about the ICU environment, the purpose of rounds and shift change sign out; and 3) encourage families to ask questions, provide observations and assist with care activities according to the family's preferences (Calderone et al. 2022). Ultimately, ICU clinicians should strive to engage families in caring for patients and shared medical decision-making (**Table 3**) (Dijkstra et al.

2023a). A useful guide for clinicians and staff is available online (Institute for Patient- and Family-Centered Care 2014).

### **Involving Patients and Families in Improvement and Change**

Former ICU patients and family caregivers have insight into the needs, values, and experiences of patients and families. Close

partnerships—through collaborative committees, patient and family advisory councils, formal evaluations, and feedback systems—ensure patient and family voices are represented in organisational change (Schwartz et al. 2022). Partnership with patients and families is facilitated by identifying barriers, exploiting facilitators, and achieving buy-in at each level of engagement (Kiwanuka et al. 2019). An important consideration is ensuring that patients and family partners represent diverse perspectives and backgrounds, including diversity of race, ethnicity, religion, gender, education, socioeconomic, and disability status. Information about engaging former patients and families in change can be found in the resource, *Essential Allies: Patient, Resident, and Family Advisors* (Minniti and Abraham 2013). Additional strategies for improvement and change can be found in **Table 4**.

### **Conclusion**

We discussed the importance of PFCC and patient and family partnership in the ICU for achieving high-quality healthcare. Organisational leaders, clinicians, and community members recognise the value of these partnerships for inpatient and outpatient care and the improvement of health systems. Buy-in and conscious integration of family partnerships in the ICU are required from clinicians, policymakers, and other non-clinical staff to achieve the desired cultural shift. The tables offer resources and recommendations that we hope will serve as a starting point to help interested parties implement PFCC worldwide.

### **Conflict of Interest**

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