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Bringing Back the Forgotten Puzzle Piece: Family Empowerment in the Care of the Critically Ill Patient

This article aims to address patient-family-centred care programmes, starting from their origins and discussing new protocols.

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Critically ill patients entail a great complexity of care. ICU staff has focused on their care, with family members and surrogates put aside for decades. In recent years, we are witnessing a paradigm shift led by nursing teams (Clark and Guzzetta 2017; Davidson 2009) and professionals dedicated to the paediatric patient (Griffin 2006; Lee et al. 2014; Wratney 2019): patient and family-centred care (PFCC) is here to stay.

The Dawning of PFCC

In 1993, the Picker Institute introduced the concept of "patient-centred care" as a response to growing concerns about disease-centred or clinician-centred care. Attempts to change this disease-focused care (and paternalistic model) earmarked six dimensions of healthcare improvement: (1) respect for patient's values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support; and (6) involvement of family and friends (Gerteis et al. 1993; Todres et al. 2009; Tzelepis et al. 2014). A respectful ICU requires recognition of fundamental human needs (physical, emotional, and psychological safety), acknowledgement of patients as unique individuals, and attention to the critical status and vulnerability of patients and families in the ICU (Azoulay and Sprung 2004; Bidabadi et al. 2019; Brown et al. 2018; Gazarian et al. 2021).

Critical illness of a loved one has enormous effects on family members, with approximately one-quarter to one-half of family members experiencing significant psychological symptoms, including acute stress, generalised anxiety, and depression both during and after the critical illness (impact termed as post-intensive care syndrome family; PICS-F) (Davidson et al. 2012; Lautrette et al. 2007; Needham et al. 2012). Families become essential caregivers, and we must support them: we must help mitigate the impact of the crisis of critical illness, prepare them for decision-making and caregiving demands, facilitate ethical shared decision-making, and promote their engagement during the ICU stay. High-quality family-centred care should be considered a fundamental skill for ICU clinicians (Gerritsen et al. 2017; Kang 2023). Increasing awareness of the vital role of family members in the ICU (and their continuous support) has shown improved outcomes for the family caregivers and patient outcomes (Adelman et al. 2014; Alonso-Ovies and Heras la Calle 2020; Lynn 2014). This trend has led to the "ICU humanisation movement" (de la Fuente-Martos et al. 2018; Nin Vaeza et al. 2020).

Starting Point: Guidelines 2007 and 2017

In 2007, the "Clinical practice guidelines for support of the family in the patient-centred intensive care unit" were published (Davidson et al. 2007). By 2017, the same group performed a new and more rigorous analysis, publishing new guidelines representing the current state of international science in family-centred care and family support for family members of critically ill patients across the lifespan (Davidson et al. 2017). Within the guidelines, patient- and family-centred care is a model of providing care in which the patient and family ally with the care team. **Table 1** summarises the most relevant points.

A little later, (Goldfarb et al. 2017) published a systematic review and meta-analysis assessing the outcomes of PFCC interventions. They found that over three-quarters of PFCC interventions were

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associated with improvements in at least one outcome measure (increased patient and family satisfaction, improved mental health status, and decreased resource use, including decreased ICU length-of-stay (LOS)). In contrast, by 2022 (Bohart et al. 2022) concluded that it was uncertain if PFCC, compared to usual care, reduced post-traumatic stress disorder (PTSD), delirium days, anxiety, and depression in patients due to limited and low certainty evidence. There is, therefore, a need for randomised controlled trials (RCT) on the effect of multi-component PFCC interventions on core outcomes for longer-term recovery in patients and families after ICU admission.

Barriers to Achieving PFCC

According to Kiwanuka et al. (2019), barriers to achieving PFCC across studies could be classified into four categories (**Figure 1**). For patient-centred care to become truly embedded in the healthcare system, it must depend on reliable systems rather than individuals. Organisational and teamwork factors profoundly impact quality and care outcomes, particularly in the ICU, where administrative and teamwork factors are central to daily operations (Long et al. 2016; Ludmir and Netzer 2019).

What is Brewing Within the ICU Programmes?

Input from the Paediatric ICU (PICU)

Addressing children's social and emotional needs during hospitalisation was initially acknowledged in the 1920s and 1930s and formalised in the 1950s. Child life providers focus on helping

Domain	Item	GRADE *
Family presence in the ICU	Flexible family presence at the bedside, working in partnership with ICU staff	2D
	Participating in interdisciplinary team rounds	2C
	Present during resuscitation efforts (staff member assigned to support them)	2C
Family support	To be taught how to assist with care, improving confidence and competence (specific to neonates)	2B
	Family education programmes	2C
	Peer-to-peer support in NICUs	2D
	Leaflets with information about the ICU setting	2B
	ICU diaries	2C
	Validated decision support tools (optimising communication and medical comprehension): interactive movie regarding ICU environment and procedures, informative website, video-based education, etc.	2D
	Written bereavement brochure	2C
Communication with family members	Interdisciplinary family conferences	
	Structured approach (VALUE mnemonic)	2C
	ICU clinicians receive family-centred communication training	2D
Specific consultations and ICU team members	Proactive palliative care consultation	2C
	Ethics consultation for whom there is a value-related conflict between clinicians and family	2C
	Psychologist's intervention to incorporate a multimodal cognitive-behavioural technique-based approach (NICU)	2D
	Social workers as part of the interdisciplinary team	2D
	Family navigators (care coordinator or communication facilitator)	2C
	Spiritual support	2D
Operational and environmental issues	Protocols for standardised use of sedation and analgesia during withdrawal of life support	2C
	Nurses involved in decision-making about goals of care	2D
	Environmental hygiene practices (e.g. noise reduction)	2D
	Family-support zone: family lounge, family nourishment area, meditation area, and a family sleep area (whether it be inside the patient room or near the ICU)	2D

Table 1. PFCC recommendations
*GRADE = Grading of Recommendations, Assessment, Development, and Evaluations. VALUE = Value family statements, Acknowledge emotions, Listen, Understand the patient as a person, Elicit questions

both the child and family cope with illness through the following: (a) providing play experiences, (b) presenting developmentally appropriate information about events and procedures, and (c) establishing therapeutic relationships with children and parents to support family involvement in each child's care (Bruce and McCue 2018). Based on child life providers, adult life providers may provide family support based on an adaptation of the following three core child life principles (**Figure 2**).

Other developments coming from the PICU are the use of virtual family-centred rounds (Rosenthal et al. 2021), involving the family in the daily care of the patient (Verma et al. 2017; Zhang et al. 2018) and focusing efforts on family members with long-stay ICU patients (Erçin-Swearinger et al. 2022).

Strengthening communication

Many articles regarding PFCC stress the importance of information and communication. The lack of fluid communication between the two sides of the clinical relationship forces families to seek answers from unreliable sources. Without adequate communication, decision-making, so necessary for the critically ill patient, may be based on misunderstood or incomplete information. It is, therefore, indispensable to improve communication skills through training, identify possible barriers, create a calm environment that favours communication and dedicate the necessary time so that they can raise any doubts they may have (Azoulay and Sprung 2004).

As conceptualised by Seaman et al. (2017), effective communication requires multiple communication platforms. Optimal communication is enabled when family-centred rounds, daily updates, patient portals, and interdisciplinary family meetings are combined (Scheunemann et al. 2011; Valls-Matarín and Del Cotillo-Fuente 2022). This allows their strengths to complement and their weaknesses to offset each other. In a recent trial of a comprehensive family support intervention in the ICU, surrogate decision-makers in the intervention group reported a higher quality of communication and a degree of patient-centredness and family-centredness. However, there was no difference in surrogates' symptoms of anxiety or depression six months after ICU discharge (White et al. 2018). Additionally, protocolised family support interventions demonstrated improved communication, enhanced shared decision-making with family, and reduced ICU length of stay (Lee et al. 2019).

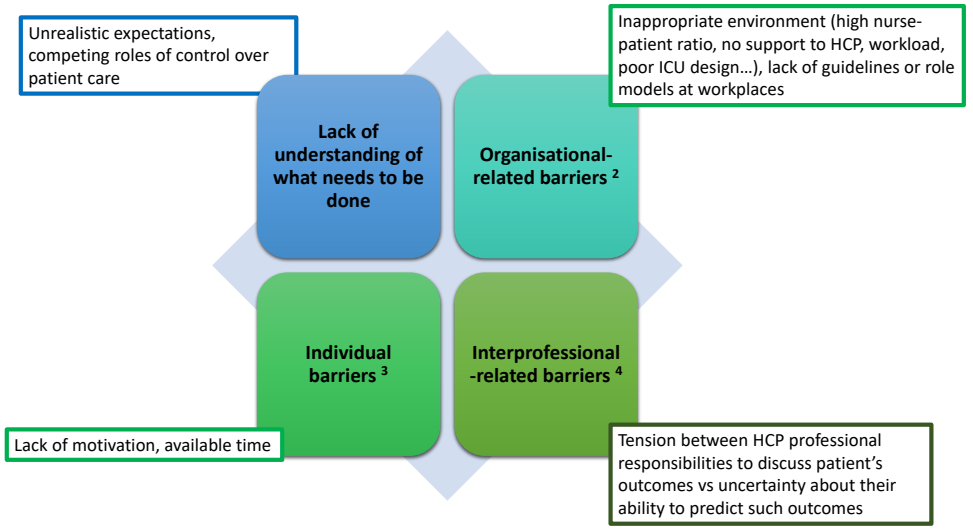

Figure 1. Barriers to achieving PFCC

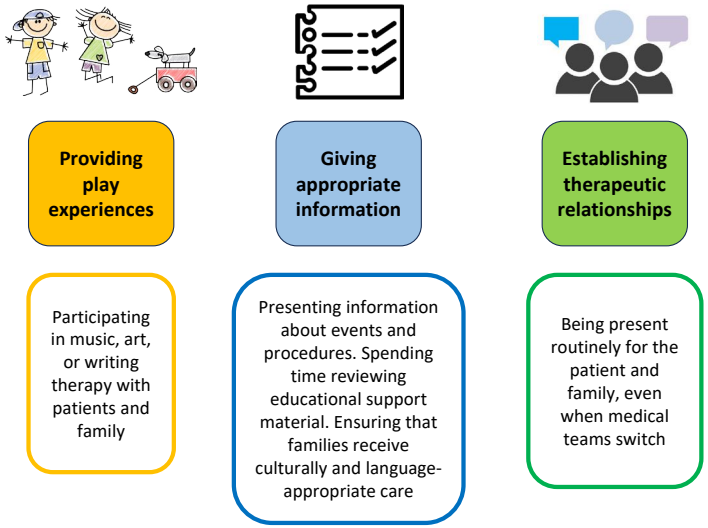

Figure 2. Adult life providers

Lastly, we must not forget that all communication must occur in an environment of respect and empathy. ICU-CORE (Beach et al. 2018) and EDMCQ (Ethical Decision-Making Climate Questionnaire) (Van den Bulcke et al. 2018) are self-assessment instruments used to measure the overall environment and climate of respect in the ICU. Ultimately, the DISPROPRICUS study group published a comprehensive multicentre study showing an independent association between clinicians' intent to leave and the quality of the ethical climate in the ICU (Van den Bulcke et al. 2020). Therefore, interventions to reduce the plan to leave may be most effective when they focus on improving mutual respect and interdisciplinary reflection.

Engaging families in patients' care

For relatives, the opportunity to actively participate in ICU care may diminish feelings of powerlessness and decrease the chance of developing PICS-F after discharge. A recent paper (Dijkstra et al. 2023) included studies on family participation in essential care activities during ICU stay (participation free of obligation and left to the relatives' discretion). Identified themes on needs and perceptions were relatives' desire to help the patient, a mostly positive attitude among all involved, stress regarding patient safety, perceived beneficial effects, and relatives feeling in control. Patient and family opinions have even been considered when designing and implementing a weaning trial (Burns et al. 2017).

Nonetheless, research on relatives actively participating in essential care is limited (Olding et al. 2016), and how family participation should be performed is unknown. Furthermore, identified factors influencing active family engagement in care among critical care nurses (Hetland et al. 2017) were age, degree earned, critical care experience, hospital location, unit type, and staffing ratios. In this case, nursing workflow partially mediated the relationships between the intensive care unit environment and nurses' attitudes and between patient understanding and nurses' perspectives.

Visitation policies

Visitation policies in ICUs have evolved from very restrictive in the 1960s to more open (Milner 2023). Visitation allows patients to stay in touch with their family members and friends and be aware of events outside the hospital, positively affecting their condition (Escudero et al. 2016). During the pandemic, we also learned that using new technologies within the ICU is possible, bringing the virtual visit to the daily ICU work (Rose et al. 2021). Video communication is also helpful for information sharing and brief updates, aligning clinician and family perspectives.

An important issue regarding visitation is that the ICU is an emotionally taxing environment. Family members experience difficult emotions alongside their ill loved ones due to the intimidating and complex nature of the ICU, its restricted access, and the limited ability to interact with patients. Patient care is challenging, and the added demand to attend to the social needs of patients and their families may contribute to staff burnout (Ning and Cope 2020). For these reasons, facilitating the paramount role of visitation while simultaneously minimising any added burden on healthcare workers is crucial. An excellent example in this regard is the ICU bridge programme (Petrecca et al. 2022), which assigns volunteers (university students) to families. Volunteers acted as the bridge between families, staff, and patients, supporting both ends by representing the hospital staff (within the realms of their training) while keeping the non-medical needs of the patients and families.

Multi-component family support interventions

One of the main problems of PFCC is its implementation. PFCC programmes require multidisciplinary coordination beyond health professionals and must involve the hospital organisation and social policies at local and national levels. Recent studies (Wang et al. 2023; White et al. 2018) have assessed interventions delivered by the interprofessional ICU team that address both the affective and cognitive challenges that surrogate decision-makers experience. In the multicentre PARTNER trial, a low-cost intervention did not significantly affect the surrogates' burden of psychological symptoms at six months. Still, the surrogates' ratings of the quality of communication and the patient- and family-centredness of care were better, and the ICU LOS was shorter with the intervention than with usual care. Wang et al. (2023) systematically reviewed randomised family-centred interventions with family-centred outcomes in the adult intensive care unit (ICU). 67.3% of studies found improvements in at least one family-centred outcome, and 60% showed improvement when assessing the impact on mental health outcomes.

Currently underway, the FICUS trial (NCT05280691 (Naef et al. 2022) will test the clinical effectiveness and explore the implementation of a multi-component, nurse-led family support intervention in ICUs. The primary study endpoint is quality of family care, operationalised as family members' satisfaction with ICU care at discharge. Secondary endpoints will include quality of communication and nurse support, family management of critical illness (functioning, resilience), and family members' mental health (well-being, psychological distress) measured at admission, discharge, and after 3, 6, and 12 months.

Within multi-component family support interventions, we may also find strategies to mitigate PICS-F, especially on the caregiver burden (Torres et al. 2017). Family caregivers report impairments in quality of life during the first year after the patient's admission to the ICU (Alfheim et al. 2019; Milton et al. 2022). Moreover, greater severity of PTSD symptoms, explicitly numbing and re-experiencing symptoms experienced by patients and caregivers during neuro-ICU admission, was predictive of worse 3-month quality of life (Presciutti et al. 2021). It is imperative to consider screening and follow-up of caregivers for mental health problems, especially within the post-ICU programmes. Examples of studies focused on decreasing PICS-F are the assessment of psychological interventions on the mental health of ICU caregivers (Cairns et al. 2019; Ricou et al. 2020), the feasibility of implementing an app-based delivery of cognitive behavioural therapy to family members (Petrinec et al. 2021) or the devel-

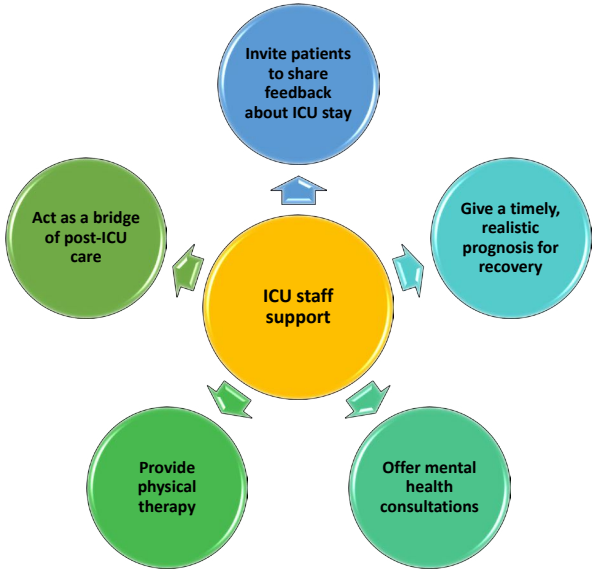

Figure 3. ICU staff responsibilities within PFCC

opment of a nurse-led intervention to support bereavement in relatives (van Mol et al. 2020).

What About Once Discharged?

One of the most critical limitations of the PARTNER trial was that it did not address events after discharge from the ICU that may have contributed to psychological distress, such as grief, financial strain, and the demands of caregiving. While family engagement throughout an ICU stay is central for patient healing, family members must also prepare to transition to post-discharge care. Caregivers face significant challenges, including the need to quit or change jobs and substantial economic hardships. Around 50-60% of caregivers of critically ill patients show depressive symptoms on patients' hospital discharge, and 43% reported symptoms one-year post-discharge (Cameron et al. 2016; Griffiths et al. 2013; Lobo-Valbuena et al. 2021). While many communication techniques mentioned above may mitigate the risk of developing PICS-F, families still need the emotional strength and skillset to care for their loved ones.

Active participation in care during the ICU admission may ease the transition home and make it less stressful for family members acting as the primary caregivers. Future interventions should be developed with much closer family member input, designed by considering key features such as involvement outcomes (communication, decision-making and satisfaction), health outcomes (family trauma and family well-being) and patient outcomes (**Figure 3**). The choice of intervention should be informed by a baseline diagnostic of family members' needs, readiness, and preparedness for involvement (Xyrichis et al. 2021).

What Remains to be Done?

Healthcare systems must engage patients and families primarily through patient and family advisory councils. We must foster a humanised environment for patients and families and value and respect our healthcare workers, addressing the burnout syndrome in ICU clinicians. Further attention is needed in three areas:

- Disparities in healthcare delivery: By being responsive to the preferences, needs, values, and cultural traditions of patients and families, PFCC may reduce inequities in critical care. We must study how healthcare disparities influence PFCC and explore how PFCC can promote health equity.
- Patient and family engagement: We must consider engagement as a continuum, occurring at different levels and influenced by multiple factors that affect the willingness and ability of patients and families to engage.
- Intentional efforts to humanise the ICU workplace environment for the betterment of patients, families, and staff.

The ICU environment of the future will be designed to support the needs of patients and family members and mitigate their risks for PICS and PICS-F. Wearable technologies and home-based rehabilitation programmes will identify and alleviate these syndromes better. Future ICU design will distinguish between clinical and non-clinical areas to better integrate humanistic objects; the utmost setting will optimise physical, emotional, and mental well-being for the patient, family, and critical care team, shifting from a hostile environment into a home-like environment through architectural and interior design modifications. Mapping the impact of ICU design on patients, families, and the ICU team will be a challenge for future generations (Kesecioglu et al. 2012; Kotfis et al. 2022; Saha et al. 2022; Thompson et al. 2012; Vincent et al. 2017).

Finally, data regarding the experience of critically ill patients at high risk of death are scant. In a recent multiple-source multicentre study (Kentish-Barnes et al. 2023), a list of fifteen concerns was identified, encompassed in seven domains: worries about loved ones; symptom management and care (including team competence, goals of care discussions); spiritual, religious, and existential preoccupations (including regrets, meaning, hope and trust); being oneself (including fear of isolation and of being a burden, absence of hope, and personhood); the need for comforting experiences and pleasure; dying and death (covering emotional and practical concerns); and after death preoccupations. Identifying problems could allow clinicians to meet their needs better and align their end-of-life trajectory with their preferences and values.

Final Thoughts

The COVID-19 pandemic has once again highlighted the need for multidimensional care for the patient and the family and essential support for the healthcare professional.

PFCC is integral to high-quality health care and benefits patients, families, and clinicians. The highly technical nature of critical care puts patients and families at risk of dehumanisation and renders the delivery of PFCC challenging. Deliberate attention to respectful and humanising interactions with patients, families, and clinicians is essential. Optimal PFCC requires authentic engagement with patients and families of diverse backgrounds and experiences to inform quality improvement and research initiatives.

A better understanding of (1) the patient's needs and perceptions regarding family participation in essential care and (2) barriers that hinder a patient- and family-centred environment can help. Insights into these aspects can guide interventions to implement or improve PFCC in the ICU. Besides, education and training of relatives and ICU healthcare providers are necessary to address safety and quality of care concerns, though most studies lack further specification. In addition, randomised controlled studies are needed to improve our understanding of the impact of PFCC in the intensive care setting.

We must work together to create a humanistic ICU environment for our patients and ourselves. It is time to include bioethics in our daily practice. It is time to transform the ICU into a friendly and respectful environment.

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Our work as professionals dedicated to critically ill patients would not be what it is without the unconditional support of relatives and patients. They are why we wake up daily ready to care, learn and improve (albeit in tiny steps).

Conflict of Interest

F Gordo has performed consultancy work and formation for Medtronic. The other authors have no competing interests.

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