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Research Article

Family Experiences with Patient Care Using Ventilators in the ICU

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ABSTRACT

Family members of patients receiving mechanical ventilation in the Intensive Care Unit (ICU) often experience significant emotional and psychological distress. The highly technological environment, limited patient access, and uncertainty regarding prognosis can profoundly affect family experiences and coping processes. This study aimed to explore family experiences during ICU care for patients receiving ventilator support. A qualitative descriptive study was conducted using Focus Group Discussions (FGDs) involving six family members of mechanically ventilated patients in the ICU of Welas Asih Regional General Hospital. Participants were selected using purposive sampling. Data were analyzed using thematic analysis to identify recurring patterns and meanings in family experiences. Five major themes emerged: (1) emotional shock at the initiation of ventilator use, characterized by fear, anxiety, sadness, and trauma; (2) uncertainty and psychological burden related to unclear diagnosis, limited patient interaction, and lack of regular information; (3) generally positive communication with healthcare professionals, though families desired more structured and routine updates; (4) firm hopes for patient recovery, rapid clinical response, and humane care; and (5) the need for comprehensive support, including emotional, informational, spiritual, social, and financial support. Family experiences during ventilator-assisted ICU care are complex and multidimensional. Implementing a comprehensive family-centred care approach, particularly through structured communication and holistic family support, is essential to improve family well-being and the quality of critical care services.

INTRODUCTION

The Intensive Care Unit (ICU) is a specialized care setting for critically ill patients who require continuous monitoring and intensive medical interventions. One of the primary interventions in ICU care is mechanical ventilation, which supports or replaces spontaneous breathing in patients with acute respiratory failure, including Acute Respiratory Distress Syndrome (ARDS), severe pneumonia, sepsis, and exacerbations of chronic lung disease (Acquisto et al., 2023). While mechanical ventilation plays a crucial role in sustaining life, its use is associated with significant physical and psychological consequences, not only for patients but also for their family members.

Families of ICU patients frequently experience high levels of psychological distress. Approximately 70% of family members report stress related to uncertainty about the patient's condition, complex medical decision-making, and limited interaction with the patient due to restrictive ICU policies (Davidson et al., 2017). Mechanical ventilation is often perceived as a "last line of defence," placing families in an emotional dilemma between hope for recovery and fear of poor outcomes, including patient death (Hutapea, 2024).

Previous studies have shown that family members of ICU patients commonly experience anxiety, sleep disturbances, emotional exhaustion, and depressive symptoms throughout the ICU stay (Choi et al., 2020; Nurjanah et al., 2022; Rahman et al., 2023). In addition to emotional distress, families often struggle to understand complex medical procedures. Research indicates that only 20–30% of families fully comprehend the function and purpose of mechanical ventilation, which may lead to misunderstandings, unrealistic expectations, and diminished trust in healthcare professionals (Isnaeni & Agustina, 2020; Schwarzkopf et al., 2013). Such challenges can complicate shared decision-making and exacerbate psychological burden.

Several interrelated factors shape family experiences in the ICU. First, limited knowledge of mechanical ventilation, patient prognosis, and potential complications may heighten anxiety and lead to resistance toward medical recommendations (Wendler & Rid, 2017). Second, the quality of communication between healthcare professionals and family members is critical. Clear, transparent, and consistent communication has been shown to increase trust, reduce uncertainty, and enhance emotional preparedness among families (White et al., 2018). Conversely, inadequate communication may intensify stress and foster conflict between families and healthcare providers. Third, family involvement in decision-making often places relatives in ethically challenging situations, particularly when decisions involve continuing aggressive treatment or transitioning to palliative care, which can impose substantial emotional strain without adequate professional support (Sprung et al., 2019). Finally, families may experience long-term psychological consequences, including anxiety, depression, and post-traumatic stress disorder (PTSD), especially following prolonged ICU stays or patient death (Amass et al., 2022), underscoring the importance of psychosocial support in critical care nursing.

Despite the growing literature on mechanical ventilation and ICU care, significant gaps remain in understanding family members' subjective experiences during ventilator-assisted treatment. Existing research predominantly emphasizes clinical outcomes, ventilator management, or healthcare providers' perspectives, with family experiences often assessed quantitatively rather than explored in depth through qualitative methods (Davidson et al., 2017; Haines et al., 2018). Moreover, most studies originate from Western healthcare contexts, where cultural norms, family roles, and ICU policies differ substantially from those in low and middle-income countries. In Indonesia, family involvement, spiritual coping, and collective decision-making are integral to healthcare experiences; however, empirical qualitative evidence capturing these culturally embedded family experiences in ICU settings remains limited.

The novelty of this study lies in its qualitative exploration of family experiences with ventilator-assisted care in an ICU setting in Indonesia using Focus Group Discussions. By examining emotional responses, uncertainty, communication dynamics, expectations, and comprehensive family support needs, this study provides culturally contextualized insights that extend beyond existing literature. Understanding these experiences is essential to strengthening family-centred care approaches and improving communication, education, and psychosocial support in critical care nursing. Therefore, this study aims to explore family experiences of caring for patients receiving mechanical ventilation in the ICU.

METHOD

The research design used in this study was a qualitative descriptive design. The research was conducted in the intensive care unit (ICU) of a regional general hospital in the Bandung area of West Java Province.

The sampling technique used in this study was purposive sampling. The participants of this study were family members of patients who received mechanical ventilation in the Intensive Care Unit (ICU) for of least 48 hours. The 48-hour criterion was applied to ensure that family members had sufficient exposure to the ICU environment and the ventilator-assisted care process, allowing them to develop meaningful experiences related to patient care.

Inclusion criteria consisted of immediate family members, including parents, spouses, children, or siblings, who were actively involved in accompanying and supporting the patient during ICU hospitalization. Participants were required to be at least 18 years of age to ensure legal and cognitive capacity to provide informed consent and to articulate their experiences clearly. Only family members who were willing to participate and provided written informed consent were included in the study. The study included six participants.

Data collection was conducted using the focus group discussion (FGD) technique with a semi-structured interview format and field notes. Data were analyzed using Braun and Clarke's thematic analysis method, which includes the following steps: verbatim transcription of interview data; in-depth reading and understanding of the data; coding the data, identifying patterns and main themes; identifying core themes that describe family experiences; and interpreting the results by linking the findings to theory and previous research (Braun & V.Clarke, 2006; Nowell, 2017).

In this data analysis, the principle of trustworthiness was applied, encompassing aspects of credibility, transferability, dependability, and confirmability. This approach was adopted to ensure that research findings are reliable and accurately reflect the experiences of nurses. By adhering to these principles, qualitative data analysis was conducted in-depth and systematically, thereby identifying key themes in understanding family experiences of caring for patients receiving mechanical ventilation in the ICU.

Before conducting the research, the researcher obtained ethical approval from the Health Research Ethics Committee of the School of Nursing (STIKep) PPNI West Java, as indicated in letter number III/103/KEPK-SLE/STIKEP/PPNI/JABAR/IX/2025. The researchers then obtained research permission from the hospital.

RESULTS

This section presents the findings of the study obtained from Focus Group Discussions with family members of patients receiving mechanical ventilation in the Intensive Care Unit (ICU). Prior to describing the thematic findings related to family experiences, the characteristics of the study participants are presented to provide contextual understanding of the backgrounds of individuals who shared their experiences. Participant characteristics include age, gender, marital status, educational level, occupation, religious affiliation, and relationship to the patient. Understanding these characteristics is essential, as they may influence how family members perceive, interpret, and respond to the experience of accompanying patients during ventilator-assisted ICU care.

Table 1 Demographic Characteristics of Participants (n = 6)

No.	Characteristics of Participants	F	(%)
1.	Age		
	21-30 Years Old	3	50
	31-40 Years Old	1	16.67
	41-50 Years Old	1	16.67
	51-60 Years Old	1	16.67
2.	Gender		
	Male	2	33.33
	Female	4	66.67
3.	Marital Status		
	Not married	1	16.67
	Married	5	83.33
	Divorced/Widowed		
4.	Level of Education		
	Elementary School	1	16.67
	Junior High School	1	16.67
	Senior High School	3	50
	College	1	16.67
5.	Occupation		
	Labourer	2	33.33
	Housewife	3	50
	Private Employee	1	16.67
6.	Religion		
	Islam	6	100
7.	Relationship with Patient		
	Father	1	16.67
	Mother	2	33.33
	Wife	1	16.67
	Child	1	16.67
	Sibling	1	16.67

Based on Table 1, the characteristics of the participants in this study were mainly in the 21–30 age range (3 people, 50%), while the 31–40, 41–50, and 51–60 age groups each had one person (16.67%). In terms of gender, the majority of participants were female (4; 66.67%), while two were male (33.33%). Based on marital status, most participants were married (5; 83.33%), and 1 (16.67%) was unmarried. The participants' educational levels were dominated by high school graduates (50%), with three people, while elementary school, junior high school, and college graduates numbered one each (16.67%). In terms of occupation, most participants were housewives (3 people, 50%), followed by labourers (2 people, 33.33%) and private employees (1 person, 16.67%). All participants were Muslim (100%). Based on their relationship with the patient, the participants consisted of 2 mothers (33.33%). At the same time, fathers, wives, children, and siblings each numbered 1 (16.67%), indicating that the majority of participants were members of the patient's immediate family.

The Focus Group Discussion (FGD) involving six participants yielded five main themes. Each theme was further elaborated through sub-themes and supported by participants' verbatim statements to strengthen the interpretation of family experiences.

Theme 1. Emotional Turmoil Experienced by Families When Accompanying Ventilated Patients

Families reported intense emotional reactions upon learning that their family members were being treated in the ICU with mechanical ventilation. Feelings of shock, fear, anxiety, and sadness emerged simultaneously, primarily due to a lack of psychological preparedness for critical illness.

Participant statements:

"The first time I saw the breathing machine, I felt very nervous and afraid that something might happen. I was shocked because I had never experienced this before." (P2)

"I felt confused, anxious, and sad… my mind was not at ease, especially because this was my first experience." (P4)

Some participants also described feelings of trauma and diminishing hope as the patient's condition worsened.

"I was traumatized and afraid of hearing bad news. My hope felt very limited, and I was not ready for anything to happen." (P1)

Over time, however, families attempted to accept the patient's condition with resignation and spiritual surrender.

"Now I try to be more accepting and take things as they are. Hopefully, this is the best outcome." (P6)

Theme 2. Uncertainty About the Patient's Condition as a Psychological Burden

Uncertainty regarding diagnosis and patient condition emerged as a significant challenge for families throughout the treatment process. This uncertainty placed families in a prolonged state of anxiety.

Participant statements:

"We try to be patient, but honestly, it is challenging. Especially since there is no clear diagnosis, all we can do is pray." (P3)

Limited access to visiting the patient further intensified emotional distress.

"Not being able to see the patient at any time makes me constantly worried. If only the ICU had a glass window so we could see their condition." (P5)

This situation also disrupted families' daily activities.

"I am afraid to do anything. I worry that something might happen to the patient if I leave." (P2)

Theme 3. Good but Inconsistent Communication With Healthcare Professionals

Most participants perceived communication with nurses and physicians as generally good and easy to understand. Families felt included in medical decision-making processes.

Participant statements:

"The nurses and doctors are communicative, and their explanations are easy to understand." (P1)

"We were involved in decision-making, so we felt respected as a family." (P4)

However, families expressed a strong need for more consistent and structured communication.

"Information is usually only given when a procedure is about to be done or when the condition worsens. We want regular updates every day." (P6)

Theme 4. Families' Expectations for Recovery and Rapid Healthcare Response

Families expressed high expectations for patient recovery and the quality of care provided. Beyond physical recovery, families also desired emotional closeness with the patient.

Participant statements:

"My only hope is that the patient recovers quickly and their condition improves." (P3)

"I really want to be able to hold their hand, hug them, and know their condition at all times." (P5)

Rapid response from healthcare professionals was perceived as an important source of reassurance.

"When the staff act quickly and respond promptly, we feel more at ease." (P2)

Theme 5. The Need for Comprehensive Support for Families of ICU Patients

Families emphasized the importance of support that addresses not only the patient's needs but also the well-being of the family as primary caregivers.

Participant statements:

"The ICU waiting room is uncomfortable at night; we need a special place where we can rest." (P1)

"Listening to murotal (Qur'an recitation) makes us feel calmer and helps soothe our hearts." (P4)

Ongoing informational and emotional support from healthcare professionals was highly valued to reduce anxiety.

"We need support from nurses and doctors, especially regular updates, so we are not constantly anxious." (P6)

Additionally, support from extended family members and financial assistance were identified as essential.

"Fortunately, we have family members who support each other, because the financial burden and worries are very heavy." (P3)

DISCUSSION

The results of this study indicate that most participants were young adults (21–30 years), predominantly female, married, with a secondary level of education, and were members of the patients' immediate family. These characteristics influenced how families interpreted and experienced accompanying patients receiving mechanical ventilation in the ICU. Young adulthood is generally associated with high social and family responsibilities; therefore, having a family member hospitalised in the ICU may trigger significant emotional stress (Stuart, 2016). The predominance of female participants is consistent with previous studies indicating that women, particularly mothers or spouses, are more likely to assume the role of primary caregivers and demonstrate greater emotional involvement in the care of critically ill patients (Al-Mutair et al., 2013).

Most participants were married and had close familial relationships with the patients (parents, spouses, or children), indicating strong emotional bonds. Such bonds may intensify anxiety, fear of loss, and the need for clear and continuous information regarding the patient's condition (Davidson et al., 2017). In addition, variations in educational backgrounds may affect families' ability to understand medical information provided by healthcare professionals, underscoring the importance of simple, clear, and repetitive communication in the ICU. Overall, family experiences of accompanying ventilated patients in the ICU were characterised by emotional turmoil, uncertainty regarding patient condition, the need for ongoing communication, hope for recovery, and the need for physical, emotional, spiritual, and financial support. These findings highlight the importance of implementing family-centred care in ICU services.

Emotional Turmoil Experienced by Families

FGD findings revealed that families experienced intense emotional turmoil, including anxiety, fear, sadness, confusion, and trauma when first accompanying patients receiving mechanical ventilation in the ICU. These reactions emerged as responses to the sudden onset of a critical situation, the highly technological ICU environment, and the perception that mechanical ventilation signifies a life-threatening condition. Rose et al. (2019) reported that the early phase of ICU admission is the most emotionally challenging period for families, marked by heightened anxiety and fear due to uncertainty surrounding the patient's condition.

Furthermore, emotional distress was exacerbated by families' limited involvement in direct patient care. Families often felt a loss of control and helplessness when unable to assist patients directly, intensifying negative emotional responses. Iokasti et al. (2019) emphasised that exposure to the ICU environment and restricted patient interaction can trigger significant psychological distress among family members. Therefore, emotional turmoil represents an adaptive response to critical illness but may evolve into psychological problems if not adequately addressed (Cristobal, 2021; Naef et al., 2021).

Uncertainty and Psychological Burden

Uncertainty related to diagnosis, prognosis, and limited access to patients emerged as primary sources of psychological burden for families during ICU care. This situation placed families in a prolonged state of waiting characterised by anxiety and fluctuating hope. Several studies have identified informational uncertainty as a significant risk factor for the development of Post-Intensive Care Syndrome–Family (PICS-F), which includes anxiety, depression, and post-traumatic stress symptoms among family members of ICU patients (Davidson & Harvey, 2016; Inoue et al., 2024; Naef et al., 2021; Saeid et al., 2020; Zante et al., 2020).

The psychological burden intensified when families received information only during clinical deterioration or when consent for medical procedures was required. Haines et al. (2018) noted that the lack of continuous information impedes family coping processes and prolongs emotional distress. Limited interaction with patients also reduces opportunities for emotional closeness, which is an important adaptive mechanism for families facing critical situations (Liu et al., 2025; Wang et al., 2023).

Communication With Healthcare Professionals

The findings indicate that communication with nurses and physicians was generally perceived as clear, understandable, and inclusive of families in decision-making. Clear and empathetic communication fostered a sense of respect and enhanced trust in healthcare professionals. Previous studies have emphasised that effective communication is a key element of ICU care, as it can reduce family anxiety and improve satisfaction with care (Briggs, 2017; Edward et al., 2020).

Nevertheless, families expressed a need for more routine, structured communication regarding patient progress (Frivold et al., 2018; Klaas & Baliki, 2024). Moale et al. (2025) argued that communication quality is determined not only by content but also by frequency and continuity. Inconsistent updates may leave families in a persistent state of anxiety, even when communication is generally perceived as good. This finding highlights the importance of scheduled communication systems as part of family-centred care in the ICU (Abukari & Schmollgruber, 2025; Schwartz et al., 2022).

Expectations for Care and Recovery

Families expressed firm hopes for patient recovery, prompt medical interventions, and optimal use of ICU technology. These expectations served as a source of psychological strength in coping with critical illness (Rückholdt et al., 2019). Valle and Lohne (2021) explained that hope functions as an adaptive coping strategy, enabling families to maintain emotional stability despite ongoing uncertainty.

Beyond expectations for recovery, families also expressed a need for emotional closeness with patients, including the desire to touch or see them directly. Schwarzkopf et al. (2013) emphasised that emotional closeness helps families preserve relational meaning and strengthen psychological resilience. Thus, family expectations extend beyond clinical outcomes to include humane interactions and compassionate care.

Need for Comprehensive Support

This study found that families require comprehensive support encompassing physical, emotional, spiritual, informational, social, and financial dimensions (Checa-Checa et al., 2025). A supportive physical environment, such as a comfortable waiting area, along with spiritual support, was shown to reduce anxiety and promote emotional calmness. A systematic review by Bohart et al. (2022) demonstrated that family support interventions in the ICU significantly improve family well-being and satisfaction with care.

Within cultural and religious contexts, spiritual support emerged as a critical need for families of ICU patients (Badanta et al., 2022). Torke et al. (2025) emphasised that holistic nursing approaches integrating spiritual and family aspects can strengthen family coping mechanisms. Therefore, meeting families’ comprehensive support needs is an integral component of high-quality ICU care.

Nursing Implications

The findings underscore the strategic role of ICU nurses not only as providers of clinical care but also as primary supporters of families. Nurses play a crucial role in facilitating communication, providing education, and offering emotional and spiritual support. Naef et al. (2025) reported that consistent implementation of family-centred care can reduce families’ psychological burden and enhance the quality of critical care nursing.

Moreover, integrating family-centred care aligns with the people-centred healthcare framework recommended by the World Health Organisation (World Health Organization, 2021). Developing ICU policies that support routine communication, family involvement, and holistic support represents a strategic approach to improving service quality and enhancing family experiences during ventilator-assisted ICU care.

CONCLUSIONS AND RECOMMENDATION

This study demonstrates that family experiences of accompanying patients receiving mechanical ventilation in the ICU are complex and characterised by substantial emotional burden. Families experience intense emotional distress from the early stages of care, including anxiety, fear, sadness, confusion, and trauma, which are exacerbated by uncertainty regarding the patient's condition and limited access to the patient. Communication with healthcare professionals was generally perceived as clear and understandable; however, families expressed a need for more regular and continuous updates to reduce anxiety. In addition, families held strong expectations for patient recovery, rapid responses from healthcare professionals, and compassionate, humane care. Family support needs encompassed physical, emotional, spiritual, informational, social, and financial dimensions. These findings underscore the importance of comprehensively implementing a family-centred care approach in ICU services, particularly for patients receiving mechanical ventilation.

Based on the findings of this study, ICU nurses are encouraged to strengthen their professional roles not only in delivering clinical care to patients but also in supporting family members. Nurses should implement structured, routine therapeutic communication, such as providing daily updates on the patient's condition in clear, easily understood language. Furthermore, nurses are encouraged to integrate psychosocial and spiritual support into nursing practice by demonstrating empathy, actively listening to family concerns, and facilitating spiritual care in accordance with families' cultural values and beliefs. Advocating for supportive environments, including more comfortable, family-friendly waiting areas, is also an important nursing responsibility to communicate to hospital management. At the managerial and educational levels, the findings of this study may serve as a foundation for developing ICU family-centred care guidelines and for guiding future research on nursing interventions to improve service quality and family satisfaction in critical care settings.

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