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Exploring family emotions in do-not-resuscitate (DNR) decision-making for hospitalized patients: A systematic review

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Abstract

Background: End-of-life decision-making, particularly Do-Not-Resuscitate (DNR) decisions for critically ill patients in hospital care, is an extremely difficult and often traumatic issue. This process has a profound impact on the mental health of families, causing anxiety, depression, stress, and even post-traumatic stress disorder (PTSD). There is currently little literature that thoroughly explores the diverse and profound emotional landscape, such as fear, optimism, well-being, and challenges experienced by families during the DNR decision-making process.
Purpose: To examine the various emotions experienced by family members during the DNR decision-making process for patients hospitalised in hospital. Understanding these emotional experiences is crucial for improving support interventions, reducing conflict, and avoiding adverse psychological effects on families and healthcare providers.
Method: A systematic review (SR) design was used in this study to evaluate and synthesise existing qualitative evidence on the emotional experiences of families. This design was chosen because it provides a better understanding of the family situation. To ensure its relevance to current clinical practice, this review used the PRISMA guidelines and the PICO framework. The publications included were published between 2020 and 2025 and were retrieved from electronic databases such as PubMed, SAGE, and Clinicalkey Nursing. Nine studies in the qualitative synthesis included 28 primary studies that were evaluated, most of which were qualitative or used mixed methods, conducted in several countries (such as the US, Australia, Taiwan, and Chile). The focus of the analysis was to find patterns, similarities, and differences in emotional experiences.
Results: Families' experiences with DNR decisions are characterised by significant psychological stress. When families are faced with discussions about Goals of Care (GoC), they often feel unprepared, confused, and shocked. This situation is often exacerbated by time pressure. Families experience the deepest emotions, namely guilt and fear of making the wrong decision, with the family's main goal being to 'do everything right so there are no regrets'.
Conclusion: The DNR process is complex, dynamic, and emotional. This study shows that healthcare professionals must not only provide medical information but also acknowledge, validate, and assist families in coping with their emotional issues. To improve the quality of end-of-life care, clinical practice must shift to a more family-centred and friendly communication model that explicitly addresses the complex emotional dynamics that families face during difficult times in their lives.

Keywords: Critical Patients; Decision Making; DNR Decision; Family Emotions.

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INTRODUCTION

One of the most challenging issues in contemporary healthcare is end-of-life decision-making, where families are often asked to act as guardians or representatives for patients suffering from critical illnesses (Mehter, McCannon, Clark, & Wiener, 2018). This process, especially when it comes to Do-Not-Resuscitate (DNR) decisions, is often a traumatic event that impacts the psychological health of families, including stress, anxiety, depression, and even post-traumatic stress disorder (PTSD) (Palma, Aliaga-Castillo, Bascuñan, Rojas, Ihl, & Medel, 2022). Families and doctors often disagree about end-of-life care, which can cause emotional distress for everyone involved (Cavolo, de Casterlé, Naulaers, & Gastmans, 2021).

In the high-pressure environment of a hospital, families often feel unprepared, confused, and overwhelmed when suddenly faced with discussions about Goals of Care. This exacerbates the situation (Vivekananda, Jayawardene, O'Connor, Watts, Leonard, Keesing, & Johnson, 2023). Previous studies have examined various components of the decision-making process from different perspectives. Research has focused on how healthcare professionals handle conflicts and assist families in reaching agreements (Mehter et al., 2018). Additional research found that parents must be "good parents" to protect their children from suffering and act as their companions (Cavolo et al., 2021).

In addition, other studies have found that families make end-of-life decisions with the aim of reducing future regret, suggesting that anxiety and guilt are important emotional components in the process (Su, Yuki, & Hirayama, 2020). However, the current literature tends to focus more on how doctors communicate, procedural elements, or psychological impact as the end result. There is little research that comprehensively examines the changing emotional landscape, such as fear, hope, relief, and dilemmas experienced by families during the DNR decision-making process.

Therefore, knowledge about the deep and diverse emotional experiences that families undergo during the complex and ethically charged process of DNR decision-making is insufficient. It is crucial to fully understand these emotions as they can impact the psychological well-being of families, relationships with the medical team, and the quality of end-of-life care for patients (Mehter et al., 2018). Filling this gap can foster better supportive interventions, reduce the likelihood of conflict, and prevent adverse psychological effects for families and healthcare providers. Therefore, the purpose of this study is to examine the various emotions experienced by family members during the DNR decision-making process for patients hospitalized in a hospital.

RESEARCH METHOD

A systematic review (SR) combining narratives aims to evaluate and synthesize existing qualitative evidence. This design was chosen because it allows for the integration of data from various types of qualitative research to gain a broader understanding of the emotional experiences of families. This method is reported in accordance with PRISMA guidelines and follows the PICO framework.

This systematic review will only include publications published between 2020 and 2025 taken from electronic databases such as PubMed, SAGE, and Clinicalkey Nursing. The purpose of this restriction is to ensure that the synthesized results are consistent with current clinical practice, DNR policies, and palliative care situations.

In the primary studies analyzed, data collection times varied greatly depending on the method used. The duration of semi-structured interviews ranged from 13 to 186 minutes. The average duration of interviews reported varied from study to study, but was typically around 22 minutes, 37.5 minutes, and 115 minutes. Focus group discussions averaged 90 minutes.

Both methods were used to collect data for the primary study. Most studies used semi-structured individual interviews conducted face-to-face or via telephone or video call with one family member at a time. However, to discuss perspectives collectively, several other studies used a focus group approach involving six to twelve people in one session. Both approaches allowed for a thorough exploration of individual experiences as well as group dynamics.

In the primary study, various data collection locations covered a range of clinical and non-clinical settings. Most of the research was conducted in hospitals or general medical wards. Medical school offices, high-complexity urban academic hospitals, community hospitals, and long-term care facilities

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were some of the other places where interviews and discussions were conducted to maintain the privacy and comfort of the participants. Additionally, some interviews were conducted remotely via telephone or online platforms such as Zoom, allowing participants to conduct interviews at locations of their own choosing.

Primary studies use tools to collect and analyze data, including: **Interview Guide:** Most studies use a semi-structured interview guide that uses open-ended questions to guide the discussion. These questions are often tested beforehand to ensure that they are clear and relevant. **Audio Recording:** To ensure that all conversations were accurately recorded, interviews and group discussions were recorded using tools such as Olympus digital voice recorders. **Transcription:** After that, the audio recording is transcribed verbatim into text for analysis. **Qualitative Analysis Software:** Researchers use specialized software such as NVivo (various versions) to manage and analyze transcript data; this software assists in the process of coding, categorizing, and developing themes from textual data. **Field Notes:** To record nonverbal observations and initial reflections, some researchers also take field notes during and after data collection.

There was no control group in this study because it was a qualitative systematic review. The focus was on a narrative synthesis of emotional experiences reported in primary qualitative studies. There was no comparison between intervention and control groups; instead, the themes were drawn from the various contexts, populations, and designs of the qualitative studies included. This question is unreasonable because there is no control group. To gain a better understanding of the phenomenon under study, the analysis will concentrate on finding patterns, similarities, and differences in the emotional experiences of families across the included studies. In this systematic review, uncontrolled components are a source of heterogeneity and potential bias in the primary studies analyzed.

Recall Bias: Many studies are retrospective, in which subjects talk about their past events. Their memories and interpretations of events may be influenced by the time that has passed between the event and the interview, such as six to eight months of mourning. Selection bias, also known as selection bias, occurs when participants are recruited voluntarily or through referrals from healthcare professionals. The latter may result in a sample of participants with a particular interest in the subject or specific experience, which may have a significant positive or negative impact. Many studies involve predominantly women (mothers or daughters), so the experiences of fathers or male family members are not fully represented.

Cultural and Geographical Context: This study originates from various countries (such as the United States, Chile, Taiwan, and Australia) with different legal systems, cultural values, and social norms regarding death and decision-making, which cannot be controlled by SR researchers. Influence of Primary Researchers: The background of primary researchers, such as psychologists or palliative nurses, and their relationship with participants, such as clinical colleagues, can influence how data is collected and interpreted.

Variations in Patient Clinical Conditions: Although all patients are in critical or terminal condition, specific diagnoses (cancer vs. non-cancer), disease trajectories, and levels of physical suffering vary, which can significantly affect the emotional experience of families.

Internal Family Dynamics: Highly variable and uncontrollable factors include the level of conflict or cohesion within the family, prior relationships with the patient, and existing caregiving burdens prior to the DNR decision.

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RESEARCH RESULTS

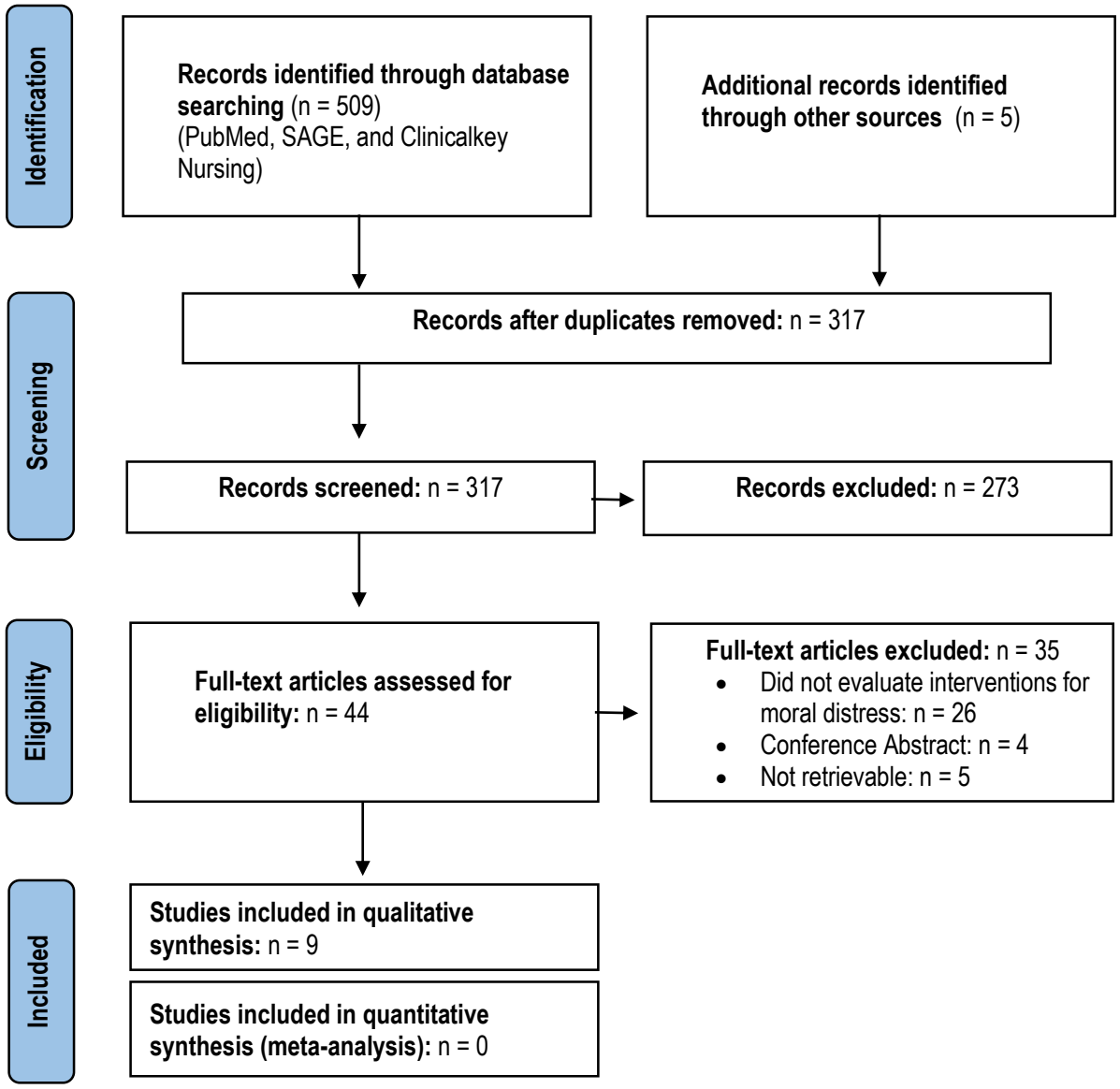


Fig. 1. PRISMA Flow Diagram

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Table Summary of the Reviewed Articles

(Authors, Year) (Country)	Purpose	Method	Description of Intervention	Outcomes	Limitations	Result
(Su et al., 2020) (USA)	As surrogate decision-makers play an increasingly vital role for older adults with impaired decisional capacity, there remains a critical deficit in evidence-based frameworks to support family surrogates across diverse decision-making contexts. Furthermore, a comprehensive understanding of family caregivers' lived experiences and perspectives regarding the surrogate decision-making process is currently lacking.	Systematic review of qualitative studies. Thematic synthesis (Joanna Briggs Institute & Thomas & Harden). 637 family surrogate decision-makers (more than 50% were female)	No intervention; systematic review of surrogates' experiences and perspectives	Six main themes: . Struggle and reluctance . Struggle and reluctance . Communication with HCP . Family support . Older adults' wishes . Negative impact	. Most studies did not mention researcher influence . Only English-language studies were included (20/24 from the US) . Quantitative studies were not included	Surrogates are often unprepared, experience negative effects, and require clear communication and support from healthcare providers and family members.
(Cavolo et al., 2021) (Belgium)	To understand neonatologists' clinical–ethical decision-making for resuscitation of EPIs.	Qualitative study with a constructivist Grounded Theory approach. Data collection: 20 semi-structured face-to-face interviews (average duration of 60 minutes) Data analysis: Qualitative	No clinical intervention. The study explored the ethical-clinical decision-making process through interviews about real cases.	Key ethical principles: Best interests of the infant and parental autonomy Ethical challenges: Conflicting principles, limited guidelines, clinical uncertainty Strategy: Setting limits and	Homogeneous sample (gender, religion) Underrepresentation of large NICUs English not native language A posteriori case reports	Neonatologists balance the best interests of the EPI and parental autonomy. Conflicts in the gray zone (24-25 weeks) pose a major challenge. Moral distress arises when it is impossible to limit parental demands

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(Authors, Year) (Country)	Purpose	Method	Description of Intervention	Outcomes	Limitations	Result
		Analysis Guide of Leuven (QUAGOL) Inclusion criteria: Involved in EPI resuscitation decisions, willing to be interviewed in English. Participants: 20 neonatologists from 10 NICUs in Belgium Age: 34–63 years old Experience: 2–30 years Gender: 15 women, 5 men Religious affiliation: 75% Catholic Region: Flanders (50%), Wallonia (30%), Brussels (20%)		trial of treatment Impact: Moral distress when conflicts remain unresolved		that conflict with the interests of the infant.
(Mehter et al., 2018 (USA)	To characterize how ICU physicians approach and manage conflict with surrogates regarding end-of-life decision-making.	Qualitative Study. Semistructured interviews analyzed using grounded theory. 18 critical care physicians from four academically affiliated hospitals.	No intervention; the study observed the natural approach of doctors in handling conflicts with families in the ICU.	Physicians use strategies such as “assessing” the family, “completing the narrative,” offering opinions, and choosing between accommodating or persuading. The approach is modulated by the quality of “substituted judgment” and perceptions of patient suffering. Emotional impact on families and physicians is reported.	Small sample from one geographic area. Potential participant bias (selected based on interest in the topic). Interviewer's relationship with participants. Same researcher as interviewer and data analyst.	ICU doctors use complex multidimensional approaches to handle conflicts, with the aim of achieving the best outcomes for patients while minimizing emotional impact. Some reported strategies are potentially counterproductive.

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(Authors, Year) (Country)	Purpose	Method	Description of Intervention	Outcomes	Limitations	Result
(Gardiner et al., 2024) (UK)	To explore the experiences and perspectives of UK paramedics responding to specific OHCA events, focusing on the decision whether or not to terminate resuscitation	Qualitative Interview Study. Semi-structured interviews analyzed using thematic analysis and an empirical ethics approach. 31 paramedics and 14 relatives of non-survivors of Out-of-Hospital Cardiac Arrest (OHCA).	No intervention; the study observed the natural experiences and perceptions of paramedics and families in making decisions to discontinue resuscitation.	Four main themes: . Preventing harm to patients: including saving lives and preventing undignified deaths. . The patient's best interests: influenced by values such as dignity, age, and quality of life. . Caring for the patient's family: clear communication and emotional support are essential. . Moral pressure: arises when clinical guidelines conflict with the personal beliefs of paramedics.	No OHCA survivors participated. Some paramedics did not remember the specific cases planned. It was difficult to recruit paramedics and families from the same cases for triangulation. There were no direct observations during OHCA events.	Paramedics use clinical guidelines but also consider non-protocol ethical factors such as patient dignity and the impact on families. They experience moral pressure when they have to follow protocols that conflict with their beliefs. Ethics training and a support framework are needed to reduce moral pressure and improve decision consistency.
(Lundgren et al., 2025) (Sweden)	To describe coping strategies used by parents who seek psychological support after end of treatment to cope with cancer-related distress and concerns and; To consider these coping strategies to inform ongoing adaptations to the EJDeR intervention, taking potential gender	Qualitative Embedded Interview Study. 73 semi-structured interviews analyzed using a two-step process: 1) inductive manifest content analysis, and 2) theory-driven analysis guided by the control-based model of coping. 73 parents (26 fathers, 47 mothers) of children who had completed cancer treatment (3 months to 5 years prior) and	No interventions were tested. This study describes coping strategies used naturally by parents. The findings were used to inform future adaptations of existing psychological interventions (EJDeR).	Three main categories of coping strategies were identified: Primary Control Coping: Using tools/techniques, pursuing a healthy lifestyle, seeking support. Secondary Control Coping: Accepting and diverting attention, adapting with the help of others, temporarily diverting attention.	The sample consisted mostly of mothers born in Sweden with higher education, limiting generalizability. Interviews varied in length, affecting the depth of data. Analysis of large amounts of data risks missing nuances. Control-based coping models are not always	Parents seeking psychological support use various coping strategies in line with the control-based model. Engagement strategies (primary and secondary) are considered helpful, while disengagement strategies (avoidance) are recognized as not helpful in the long term. Findings support the

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	differences in coping and subsequent support needs into consideration.	were seeking psychological support.		Disengagement Coping: Avoiding and distancing oneself. Gender differences were seen in the frequency of use of some strategies.	easy to apply (e.g., classification of distractions). Deductive approaches risk forcing data to fit the model.	use of cognitive behavioral therapy (CBT) techniques in EJDeR interventions to target behavioral and experiential avoidance.
(Vivekananda et al., 2023) (Australia)	To examine family carers' perspectives on GoC within acute Australian hospital settings.	Exploratory qualitative. Semi-structured interviews, reflective thematic analysis. 25 family caregivers of elderly patients in 6 acute care hospitals	No intervention; the study observed the experiences of caregivers in Goals of Care (GoC) discussions conducted by healthcare professionals.	Three main themes: . Carers' experiences in GoC discussions . Carers' need for time, privacy, empathy . Carers' desire to become patient advocates	Sampling bias (recruitment via HCP) Participants mainly from metropolitan areas Only 2 participants from non-English backgrounds Short interviews (average 22 minutes) Retrospective data (recall bias)	Caregivers are often unprepared, confused, and need more communication support from HCPs. They want GoC discussions to be conducted earlier, more empathetically, and with patient involvement.
(Liang et al., 2023) (Taiwan)	To explore family caregivers' experiences in preparing for a relative's death in specialist palliative care in Taiwan.	Qualitative. Semi-structured interviews, reflective thematic analysis. 22 primary family caregivers of patients who received specialized palliative care before passing away	No intervention; the study explores the natural experiences of caregivers in preparing for the death of a family member.	Two main themes: . Making the right end-of-life decisions . Becoming a competent carer . The aim is to reduce regret and influence the grieving process.	Participants were mainly adult children of deceased patients The majority were female and cancer patients Did not represent non-primary caregivers or non-palliative settings Interviews were conducted 6–18 months after death (recall bias).	Caregivers strive to minimise regret by involving the family, building consensus, and ensuring patient comfort. Patient involvement in decisions is often limited in order to protect them.

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(Authors, Year) (Country)	Purpose	Method	Description of Intervention	Outcomes	Limitations	Result
(White et al., 2022) (USA)	To describe how an intervention to teach family caregivers of persons living with dementia to provide complex care tasks contributes to their self-efficacy.	Descriptive qualitative study embedded in the pilot clinical trial. Semi-structured interviews, content analysis. 15 family carers of people with moderate dementia	Learning Skills Together (LST): A four-session online psychoeducational intervention designed by an interprofessional team. Focuses on teaching complex care tasks (behaviour, communication, safety, transfers, nutrition, incontinence, etc.) to improve caregiver self-efficacy based on Bandura's theory.	Three main themes: . Helpfulness of the content . If they can do it, so can I . Applying what I am learning . Interventions increase caregivers' confidence in providing complex care.	Small sample size (15 participants) Only caregivers who are confident and tech-savvy Does not represent caregivers who do not have access to or technological capabilities Potential selection bias from trial participants	Caregivers reported increased self-efficacy after the intervention. They appreciated the relevant content, learning from experts and fellow caregivers, and the opportunity to apply skills. The online group format was rated as effective and supportive.
(Palma et al., 2022) (Chile)	To explore the experiences and perspectives of the various members of an ICU care team in Chile regarding the EOL care of their patients.	Exploratory-descriptive qualitative study. Separate focus groups based on discipline, narrative analysis based on grounded theory. 28 ICU professionals (8 nurses, 6 nursing assistants, 8 junior doctors, 6 senior doctors) from one urban academic hospital	No intervention - the study explores the experiences of existing ICU teams in providing end-of-life (EOL) care.	Four main themes: Roles based on discipline Barriers to EOL decision-making Communication difficulties Emotional impact on the team	Sample from a single ICU in an urban academic hospital Potential for participation bias (special interest in EOL topics) Translation from Spanish to English may lose nuance Does not represent all clinical settings.	ICU professionals experience significant emotional impact and face cultural, communication, and interprofessional practice barriers in EOL care. Communication with families is a major challenge due to workload and lack of self-efficacy.

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DISCUSSION

The goals of end-of-life care, also known as Goals of Care (GoC), are intended to support care that is consistent with the patient's preferences and values (Bone, Gomes, Etkind, Verne, Murtagh, Evans, & Higginson, 2018; Brimblecombe, Crosbie, Lim, & Hayes, 2014). Using social constructivist epistemology, this exploratory qualitative study examined how nursing families perceive GoC in Australian acute hospitals (Creswell, 2013). Using a semi-structured approach, 25 nursing families of elderly patients treated in six Australian hospitals were interviewed (O'Connor, Watts, Kilburn, Vivekananda, Johnson, Keesing, & Leonard, 2020). Reflective thematic analysis was used to analyse the data and identify three main themes (Braun & Clarke, 2006).

Theme 1: Family Experiences in GoC (General Opinion) Discussions. When GoC discussions began, families reported varying levels of preparedness; some felt unprepared, confused, and stressed (Vivekananda et al., 2023). Prior knowledge of the patient's wishes greatly influenced the dynamics of the discussion (Shaw, Hewson, Hogan, Bouchal, & Simon, 2018). The sudden and direct delivery of the news shocked some families, while others regretted never having discussed their end-of-life preferences with their family members beforehand (Vivekananda et al., 2023). Patients with cognitive decline made the discussion particularly difficult (Ma, Kiekhofer, Hooper, Dulaney, Possin, & Chiong, 2021). However, some families are happy to make predictions based on what they know about the patient's values (Vivekananda et al., 2023). Although many agree that there is no ideal time, it is better to start the conversation earlier (O'Connor et al., 2020).

Theme 2: The Need for Empathy, Time, and Family Privacy. During GoC discussions, families reported unmet needs (Vivekananda et al., 2023). They needed sufficient time to process information, ask questions, and communicate with other family members. Those working as healthcare professionals (HCPs) often experience time constraints, which can cause them to feel overwhelmed and rushed (Waldron, Johnson, Saul, Waldron, Chong, Hill, & Hayes, 2016). In addition, physical privacy is very important. Many people argue in uncomfortable public spaces, while others prefer the privacy of a private room (Vivekananda et al., 2023).

HCPs are highly valued for communicating with others in a friendly, honest, and empathetic manner. This communication can also help reduce the burden of decision-making (Riedl & Schüßler, 2017). The opportunity to follow up on questions and a two-way communication style that is not rigid is very helpful (Stephens, William, Lim, Allen, Zappa, Newnham, & Vivekananda, 2021). Doctors are considered less empathetic, even though they have the medical authority to lead discussions. Because they better understand the patient's condition and have a more empathetic approach, the role of nurses or other professionals such as social workers and chaplains is recommended (Wittenberg, Ferrell, Goldsmith, Buller, & Neiman, 2016).

Theme 3: The desire to defend patients' interests. Families want to speak up for patients when clinical teams ignore their needs (Vivekananda et al., 2023). Patients with cognitive decline or diverse cultural and linguistic backgrounds need this attention even more because their wishes may be misunderstood (Miyashita, Kohno, Yamamoto, Shimizu, Azuma, Takada, & Fukuhara, 2021; Wang, Sun, Liu, Kong, & De Fries, 2022). Families feel the need to ensure that the patient's preferences and dignity are respected, sometimes even having to defend the patient's interests in front of other family members who may have different opinions (Cresp, Lee, & Moss, 2020).

This study reveals the following discussions and implications: Confusion about the purpose of GoC, family discomfort, difficulties when the patient's wishes have never been discussed before, and barriers and support for better GoC discussions (Vivekananda et al., 2023). Promoting death literacy, or knowledge about death, can help people talk about advance care planning (Noonan, Horsfall, Leonard, & Rosenberg, 2016). Preparing families and normalising GoC conversations will be the best way to achieve the greatest benefits for all parties (Vermorgen, Vandenbogaerde, Van Audenhove, Hudson, Deliens, Cohen, & De Vleminck, 2021). Medical communication that is jargon-free, empathetic, and open is essential (You, Downar, Fowler, Lamontagne, Ma, Jayaraman, & Carenet,

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2015). Although rules and guidelines have been established, their implementation still needs improvement (Shaw, et al., 2018). In acute care hospitals, time and hierarchy can be barriers; however, effective multidisciplinary team communication can help families and HCPs.

This study has limitations because it relies on retrospective reports. Therefore, additional research is needed to address memory bias by analysing actual GoC discussion recordings (Vivekananda et al., 2023). The one-time interview method and short interview duration allow for broader exploration. Sampling bias may occur due to HCP recruitment. Additional research is needed to adapt the GoC framework to diverse cultural needs as the majority of participants reside in metropolitan areas and only a few are from non-English backgrounds (Coogan, Kimpel, Jones, Barroso, Frechman, & Maxwell, 2022).

CONCLUSION

For families of critically ill patients, making a Do-Not-Resuscitate (DNR) decision is a difficult and emotional task. Families often experience uncertainty, confusion, and time pressure. However, their greatest responsibility is the guilt and intense fear of making the wrong decision, which could harm the patient and leave them with irreparable regret. The quality of communication from healthcare professionals greatly influences this emotional experience. Poor communication only exacerbates confusion and mistrust, but clear, honest, and empathetic communication can ease the burden. Knowing the patient's prior wishes and obtaining support from the immediate family are also crucial. Therefore, clinical practice must shift to a supportive, family-centred approach to communication, which not only conveys medical facts but also acknowledges and validates the emotional difficulties families face during these most difficult times.

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