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A Qualitative Exploration of Palliative Care Experiences among Javanese Patients and Families

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ABSTRACT

Background: Cultural aspects play a crucial role in providing nursing care, particularly for patients and families with terminal or chronic illnesses undergoing palliative care. Understanding patients' and families' cultural aspects is essential to provide empathetic, effective, and culturally respectful palliative care.
Method: This qualitative phenomenological study involved in-depth interviews with 10 participants (5 patients and 5 family members) selected through purposive sampling. Data were analyzed using Colaizzi's method.
Result: Five main themes emerged reflecting the cultural perceptions of palliative care among Javanese patients and families: (1) Hope for recovery and a better life-serving as a spiritual and emotional anchor held by patients and families; (2) Family roles and responsibilities-encompassing caregiving duties, emotional support, and efforts to maintain family harmony and dignity; (3) Anxiety about the future-including concerns about dependency, financial burden, and the impact of loss, felt by both patients and families; (4) Life as a test and trial from God-a strong spiritual belief that illness is part of destiny, collectively accepted; (5) Surrender and acceptance (nrimo)-a characteristic Javanese attitude practiced by patients and families as a coping mechanism to find peace amidst uncertainty.
Conclusion: Nrimo, sincere acceptance of illness as divine will, functions as an active, value-based coping mechanism that enhances resilience and spiritual well-being, differing from Western concepts of passive resignation. Healthcare professionals must validate nrimo as adaptive coping, not fatalism. Family-centered, indirect communication with early engagement of decision-makers is recommended. Spiritual care integration through religious leaders is essential for meaning-making.

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INTRODUCTION

Palliative care interventions have increased significantly worldwide. Studies predict that the future global burden associated with serious health suffering will substantially increase (Sleeman et al., 2019; Wantonoro et al., 2022), with 87% of patients expected to require palliative care interventions by 2060 (Clark et al., 2020). Palliative care plays a vital role in improving the quality of life for all populations worldwide, particularly for patients with terminal or chronic illnesses. Palliative care can help alleviate symptoms and pain, promote advances in healthcare technology (Cruz-Oliver, 2017), and is predicted to become an option for approximately 20 million people annually, with around 69% aged over 60 and 6% children.

To maximize the benefits of palliative care, three strategic times for implementation have been recommended: at the early stage of illness, upon diagnosis, and when symptoms appear (Yeo et al., 2023). Various studies have shown that nurses, as members of the healthcare team, have the most intensive and sustained interactions with palliative care patients, enabling them to play a crucial role in providing holistic support and care to these patients (Sekse et al., 2018). Palliative care is a subspecialty in nursing practice that continues to evolve and advance with developments in nursing science and technology, as well as an evolving understanding of the needs of patients with terminal or chronic illnesses (Dobrina et al., 2014). Palliative care is a comprehensive and holistic approach to improving the quality of life for patients with terminal or chronic illnesses. However, palliative care is not only influenced by medical factors but also by cultural factors, including in Indonesia (Monette, 2021; Rochmawati et al., 2016, 2018).

Cultural and spiritual beliefs fundamentally influence end-of-life care decisions worldwide. In many Asian, Middle Eastern, and Southern European contexts, nondisclosure of terminal prognoses is common to shield patients from distress and honor family elders. These regions also emphasize family-centered decision-making and hold diverse spiritual interpretations of death and dying (Hira et al., 2025). The misconception that palliative care signifies "giving up" or is limited to terminal care constitutes a major barrier to timely referral. Compounding this issue are cultural constraints, including aversions to discussing prognosis and mortality and the predominance of family-centered decision-making, which mandate a high level of sensitivity and skill in the palliative team's communication (Prima et al., 2025). Culture plays a significant role in palliative care as it can influence how patients and families understand and experience the illness and dying process (Cain et al., 2018). Culture can also influence patients' and families' decisions about end-of-life care and how they interact with the healthcare team (Koenig & Gates-Williams, 1995; Putranto et al., 2017). Indonesia's cultural diversity affects how patients and families understand and experience the illness and dying process, including in Javanese culture. Leininger's Transcultural Nursing Theory (1978) is used as the foundation for this research. The theory explains the importance of understanding patients' cultures in providing effective nursing care (Hidayat & Uliyah, 2019). Leininger defines transcultural nursing as an approach that focuses on understanding patients' cultures and using that knowledge to provide nursing care (McFarland & Wehbe-Alamah, 2019).

Javanese culture has a significant influence on the understanding and experience of Javanese people in facing the illness process. In the context of palliative care, Javanese culture has several important implications, including: a more positive view of death and the illness process, emphasizing the importance of family and community roles in caring for the sick, and emphasizing the importance of patience and surrender in facing illness and death. Therefore, exploring the concept and practice of palliative care from a Javanese cultural perspective is necessary to improve the achievement of nursing care goals. The objective of this study is to explore the lived experiences of Javanese patients and families undergoing palliative care, focusing on their cultural values and perceptions

METHODS

Study Design

This study employs a qualitative phenomenology research method with in-depth interview techniques for data collection. The main questions were designed to explore the experiences, feelings, and situations of patients in palliative conditions; How do you experience living with a palliative condition, how do you perceive the meaning of your current illness, how do you view other individuals living with chronic illness, how has your illness affected your family and social life?

Partisipants

Participants were recruited through Purposive Sampling, with data collection continuing until saturation is achieved. Eligibility criteria include: (1) Being a spouse or family member of a patient with a chronic or palliative condition (e.g., cancer, chronic kidney disease, chronic obstructive pulmonary disease). (2) Having a Javanese cultural background and being from Yogyakarta. (3) Currently residing in Yogyakarta. (4) Not having any cognitive impairment that could impact their ability to participate in the study.

Procedure

Data collection was involved semi-structured in-depth interviews lasting 20-40 minutes to explore the experiences of patients and families with palliative care in the hospital private room. To establish credibility, the researcher will engage in prolonged involvement with participants, building trust and rapport over 1-2 months. Data triangulation will be achieved through multiple sources, including interview transcripts, observational notes, and patient medical records. To ensure transferability, experienced interviewers who can communicate in Indonesian or Javanese will conduct the interviews, and participants will be selected based on their ability to converse in these languages. This approach will facilitate the collection of rich, descriptive information about the experiences of patients and families with chronic/palliative illnesses.

To enhance trustworthiness, several strategies were employed. Methodological triangulation was achieved using multiple data collection methods. (Carter et al., 2014; Xu et al., 2024). Credibility was further strengthened through prolonged engagement with participants, which involved repeated home visits and observations. This process facilitated the comparison of self-reported data with observed behaviors and reinforced confidence in the authenticity of the findings. Dependability and confirmability were ensured through peer review and auditing by colleagues and the ethics committee at the research site. These auditors will verify that research procedures, data collection, analysis, and logical reasoning are accurate and appropriately applied. An audit trail will be maintained to document the research process and determine the reliability of the findings.

Ethical Clearance: This study has obtained ethical approval from the Research Ethics Committee with No. 00228/KT.7.4/VI/2025 and Research Permit with No. 1397/PI.24.2/VI/2025. The researcher ensures that participants agree to participate in this study without any coercion or pressure from any party and guarantees that all acknowledgments or data provided will be kept confidential. Informed consent forms have been provided to participants, outlining the study's purpose and requirements, and participants have signed the forms indicating their willingness to participate and provide information as needed.

Data Analysis

The data analysis technique employed in this study is Colaizzi's method (Wirihana et al., 2018). The steps involved in Colaizzi's data analysis are as follows: 1) Reading interview transcripts: The researcher thoroughly reads the interview transcripts to gain a deep understanding of the participants' experiences. 2) Identifying significant statements: The researcher identifies significant

and relevant statements related to the phenomenon being studied. 3) Formulating meanings: The researcher formulates meanings from the significant statements. 4) Clustering meanings: The researcher clusters similar meanings into categories. 5) Developing a structure of experience: The researcher develops a structure of experience based on the categories formed. 6) Integrating results: The researcher integrates the analysis results to gain a deeper understanding of the phenomenon being studied. 7) Returning results to participants: The researcher returns the analysis results to the participants to validate the findings and ensure the accuracy and relevance of the analysis. To establish credibility, data or results are shared with participants for confirmation of accuracy and congruence with their lived experiences, followed by final interpretation conducted by the entire research team.

RESULTS AND DISCUSSION

RESULTS

This qualitative phenomenological study involved 10 participants (5 patients and 5 family members), sumarized in table 1 who were selected purposively based on specific inclusion criteria and data saturation. The data analysis yielded five main themes (table 2):

Table 1. Participant Characteristics

Participant	Patients (5 participants)	Family (5 participants)
Gender		
Male	2 participant	1 participant
Felame	3 participant	4 participant
Mean Age	57.72 year	48.70 year
Diagnosis		
Cancer	2 participant	-
End Stage Renal Disease (ESRD	2 participant	-
Chronic Obstructive Pulmonary Disease	1 participant	-
Role		
As a participant's spouse	-	2 participant
As a participant's child	-	3 participant

Table 2: summarizing the themes and sub-themes

Sub-themes	Themes
To be able to return to the previous condition To remain healthy and be able to contribute through work To not burden the family To achieve an improved health condition To be free from pain	Hope for recovery and a better life
Responsibilities for children's Maintaining employment in the role of a husband To fulfill the role as a spouse	Family roles and responsibilities
Experiencing uncertainty about the future Expressing concerns regarding the family's well-being Perceiving life as uncertain and lacking purpose	Anxiety about the future
Perceiving the illness as a test of life the illness as a trial to be endured it as one's destiny in life	Life as a test/trial
I have surrendered to the situation Accepting it as the will of the Almighty Awaiting the divine call, as all will return to the Creator Believing that everything is divinely ordained Believing there is wisdom behind every occurrence	Surrender and acceptance (nrimo).

Hope for recovery and a better life; such as participant explain;

"....I hope the pain isn't too bad, as prolonged suffering would affect my muscles, nerves, and bones. I'm hoping I'll be strong enough to cope....)(P1)[".....harapannya ya pengennya sakitnya ini gak terlalu sakit, karena kalau sudah lama kan otot, saraf, tulang itu sakit semua. Jadi berharapnya saya masih kuat untuk menahan sakitnya" (P1)]

[I've lived my life, got my money, don't need much anymore. Just give me health, and my kids are doing okay, that's all I care about...(P4) [.....Sudah gak ada, umur sudah tua, uang sudah punya uang, ndak minta apa apa yang penting sehat, anak anak saya juga sehat sudah...(P4)]

".....He's a stoic one, Doc. When I ask him to do something, he just does it without mentioning any discomfort, Ma'am. There's never any "Dad, Mom says you're not feeling well" kind of thing. He just keeps quiet about it, Doc....(P10)." [".....Bapak ini minim keluhan, Dok. Kadang-kadang kalau disuruh sekali, dia langsung gajadi, gak pernah protes atau bilang sakit, Mba. Gak pernah ada yang bilang "Pak, Mbok bilang to nek sakit" gitu. Kadang-kadang gak pernah bilang, Dok..."(P10)].

Family roles and responsibilities;

"....It's hard to bear, leaving my toddler behind, they're only 3, and now I'm stuck in hospital...."(P3) ["...mesti mikirnya karena masih punya anak kecil, masih 3 tahunan sudah ditinggal ke rumah sakit...." (P3)]

"....I'm really worried, I've got a little one at home, just 8 years old, in 2nd grade. I wonder who's gonna be there for him if something happens to me. It's tough to even think about not being around for him (P9) [.....saya sangat khawatir, saya punya anak kecil di rumah, baru 8 tahun, kelas 2 SD. saya pikir siapa yang akan menjaganya kalau aku ada apa-apa. Susah rasanya membayangkan tidak bisa ada untuknya] (P9)

Anxiety about the future;

"....I was anxious about it because a neighbor had dialysis and it was on my mind. But at Bethesda, they explained this treatment isn't like regular dialysis; it's just to remove excess fluid. That put my mind at ease. And they said if things get better, I won't need it anymore, unlike others who have it ongoing...(P6)"

['....takutnya itu karena di tetangga juga ada yang cuci darah, terus terbayang-bayang nanti gimana. Tapi kemarin saat di bethesda itu dijelaskan kalau cuci darahnya ibu ini tidak seperti cuci darah yang lain, tapi cuma untuk menarik airnya itu, terus ini jadi lebih ayem. tapi nanti kalau sudah membaik, itu katanya sudah enggak cuci darah, kalau yang lain kan masih terus-terusan...(P6)]

Life as a test/trial;

"...I see it as a test from God, a trial. Trials can be about wealth, illness, or other things..." [".....ya saya berpikir ini sudah dari Yang Kuasa, ini sudah ujian. Jadi kalau ujian itu kan memang dari harta, sakit, dan sebagainya..." (P2)]

"....I'm not asking for much now, just good health. My kids are healthy, that's all that matters. I've lived my life, I've had my share..." [".....Sudah gak ada, umur sudah tua, uang sudah punya uang, ndak minta apa apa yang penting sehat, anak anak saya juga sehat sudah..."(P7)]

Surrender and acceptance (nrimo).

"I've thought about it, it's like weighing the options. I'm not saying I don't love my kids, but I'd rather go first, you know? My wife says 'if one of us has to go, I'll go first, okay?' Not sure my kids would feel the same. I just think it's better if the one who's struggling goes first..." (P8). [".....ya kalau itu, saya hitung-hitungan. Bukan saya tidak sayang kepada anak, siapa yang menderita dulu, kelihatan itu yang lebih baik. Gitu saja. Seperti saya dengan istri saya, dia bilang 'pak kalau tidak

ada, saya duluan ya'. Entah kalau anak saya nggak tau. Jadi kalau dia hitung-hitungannya biar yang menderita yang duluan...(P8)]"

"I didn't really think about it, I knew it was out of my hands. God has a reason for everything. And it's true, when you're healthy, people are always asking 'when are you graduating?', 'when are you getting married?', 'when are you having kids?' Now, nobody asks me that stuff...(P5)" ["....enggak, karena dari awal itu memang sudah nggak mungkin, Allah memang ngasih ini itu pasti ada hikmahnya. Dan memang iya. Kalau orang sehat kan pasti ditanyain kapan lulus, kapan nikah, kapan punya anak, gitu-gitu. Nah itu nggak ada yang nanyain saya kaya gitu...(P5)]

DISCUSSION:

These study findings are consistent with previous studies conducted in Indonesia (Martina et al., 2022; Effendy et al., 2022), highlighting the significance of cultural and contextual factors in shaping patients' and families' experiences with palliative care. The themes that emerged from this study provide valuable insights into the complex needs and concerns of patients and families navigating serious illnesses, and underscore the importance of holistic and culturally sensitive care.

Hope for recovery and a better life; In the context of palliative care, hope is conceptualized not merely as the possibility of complete recovery but also encompasses efforts to maintain a meaningful quality of life. For patients with a Javanese cultural background, the notion of hope is intricately linked with fundamental religious values, specifically ikhtiar (effort), ikhlas (sincere acceptance), and pasrah (surrender). These concepts shape patients' cognitive frameworks and attitudes toward life when facing chronic or terminal illnesses. As noted by oleh (Wicaksono et al., 2024), framing symptom control as a form of ikhtiar provides spiritual legitimacy and enhances patients' acceptance of palliative care at home. This is particularly significant given that many patients still perceive palliative care as "end-of-life care." By approaching palliative care through the lens of ikhtiar, interventions can be viewed as a legitimate effort to maintain quality of life, rather than solely a terminal care approach.

Family roles and responsibilities; In Javanese culture, the family is positioned as central in decision-making regarding care, serving not only as companions but also as key actors involved in formulating care choices and coping strategies. In this context, decisions are rarely made individually but rather collectively to maintain harmony and communal values. This study's findings illustrate a pattern in which families engage in internal discussions to determine the next steps in care. Advance care planning (ACP) in Indonesia is more effective when based on the exploration of values and family communication, rather than merely being an administrative document (Martina et al., 2022). This highlights the importance of prioritizing family-based interventions in the design of palliative care services.

Anxiety About the Future; Patients and families in palliative care often experience anxiety about the future, including fears of dependency, financial burden, and loss of loved ones. This anxiety is complex, involving not only medical but also social and economic aspects. Families of palliative patients in Indonesia face significant economic pressure and require support in the form of information and financial assistance (Effendy et al., 2022). In this qualitative framework, anxiety is viewed as a form of anticipatory grief that requires intensive psychosocial support. Nurses play a crucial role as mediators, not only focusing on clinical aspects but also helping families access relevant social support.

Life as a test/trial; Spirituality plays a central role in how Javanese patients and families make sense of illness. Illness is often viewed as a test or trial from God, which must be accepted with sincerity and surrender. In this context, practices such as prayer, rituals, and seeking religious meaning become significant coping mechanisms. According to Pratiwi et al. (2024), the concept of nrimo represents active acceptance, rather than mere resignation without effort. This active acceptance enables patients and families to continue treatment and maintain quality of life while

finding inner peace within their spiritual framework. This highlights the importance of integrating spiritual support into palliative care services

Surrender and acceptance (nrimo); The concept of acceptance (nrimo) in Javanese culture is often misunderstood as a form of fatalism. However, this study reveals that nrimo is actually a form of active acceptance, where patients and families continue to make efforts (ikhtiar) while accepting existing limitations. A challenge that arises is the presence of implicit communication within the family, which is a tendency to convey messages indirectly to maintain harmony. According to Wicaksono et al. (2025), implicitness can help preserve relationships but also risks delaying the expression of patients' real needs. Therefore, nurses are required to develop culturally sensitive communication skills to balance respecting family communication styles while ensuring patients' clinical needs are articulated.

Implications for nursing practice; The findings of this study make a significant contribution to Leininger's Transcultural Nursing Theory. This theory emphasizes the importance of culturally congruent care, which is care that is tailored to the values, beliefs, and cultural practices of patients. Nurses need to be trained in empathetic communication and to respect the implicit communication style typical of Javanese families. And also, the development of standard operating procedures (SOPs) for palliative care must accommodate collective decision-making within the family."

CONCLUSION

This study clarifies how Javanese cultural values shape meaning-making, coping, and care expectations in palliative care. Nrimo, sincere acceptance of illness as divine will, functions as an active, value-based coping mechanism that enhances resilience and spiritual well-being, differing from Western concepts of passive resignation. Families adopt collectivistic, protective roles as primary decision-makers who filter information to maintain rukun or social harmony. Communication is indirect and high-context, relying on non-verbal cues, euphemisms, and third-party mediation to preserve emotional stability and family dignity. Clinicians should acknowledge nrimo as a culturally adaptive coping strategy rather than misinterpreting it as fatalism or depression. Family-centered communication should be prioritized by involving key decision-makers early and utilizing indirect, empathic approaches for prognostic disclosure. Collaboration with religious leaders is necessary to support spiritual care and facilitate patients' meaning-making processes.

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AUTHOR CONTRIBUTION STATEMENT

R; designed the study, conceptualized the methodology, monitored data collection, carried out data analysis and interpretation as well as being primarily responsible for manuscript writing and critical revision. W contributed to data analysis, and manuscript writing.

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