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Knowledge, attitudes, and preferences regarding End-of-Life Care among older adults in a tertiary care centre, Northern Sri Lanka

Pradeepan J[1,2], Kumanan T[1,2], Suganthan N[1,2], Selvaratnam G[1,2], Sujanitha V[1,2], Brammah R[1,2], Balendran K[1,2], Pathmanathan D[2], Rubakumar D[2], Mohanathas S[2]

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Abstract

Introduction: End-of-life (EOL) care is a vital component of healthcare that emphasises comfort, dignity, and quality of life during the terminal stages of illness. Although its significance is widely recognised, awareness and understanding of EOL care remain limited in many low- and middle-income countries, including Sri Lanka. Improving knowledge and aligning care with patient preferences can help clinicians deliver patient-centred, culturally sensitive, and cost-effective interventions and inform policy development for EOL care frameworks.

Objective: This study aimed to assess the knowledge, attitudes, and preferences regarding EOL care among older adults attending the medical outpatient department at the Teaching Hospital Jaffna, and to facilitate patient-centred, cost-effective care planning.

Methods: A descriptive cross-sectional study was conducted between November 2024 and January 2025 involving 510 patients aged 65 years and above. Data were collected using a pre-validated, self-administered questionnaire. Statistical analysis was performed using SPSS version 27.

Results: The majority of participants were female (65.7%), with the largest proportion aged 70-79 years (56.3%). In terms of education, 80% of patients had formal education. Multimorbidity was prevalent, with 84.9% reporting three or more chronic conditions, notably hypertension (72.9%), diabetes mellitus (54.7%), and dyslipidaemia (51.2%). A large majority (90%) lived with family, suggesting strong family support. While 77.3% acknowledged the irreversible nature of chronic disease and 97% preferred comfort-focused management at terminal stages, only 23.5% were aware of palliative or EOL care concepts. Paradoxically, 71.6% desired continuation of treatment even if futile, and 86% favoured resuscitation and intensive care during terminal illness. Clear communication on disease progression was valued by 76.5%. Decision-making responsibility was seen as shared among patients (34%), families (34%), and physicians (32%). Most respondents (86.3%) found EOL care meaningful, and 89.2% were open to discussing EOL care with healthcare providers.

Conclusion: Elderly patients with multimorbidity attending a tertiary care unit in the Northern region of Sri Lanka value communication and recognise the importance of EOL care but show limited awareness and mixed preferences, often favouring active medical interventions despite a desire for comfort. Better patient education and culturally sensitive dialogue are necessary to align EOL decisions with patient values and cultural context.

Introduction

End-of-life (EOL) care is increasingly recognised as an integral part of comprehensive healthcare. It seeks to enhance the quality of life and preserve the dignity of individuals with life-limiting illnesses by addressing not only medical needs, but also psychosocial and spiritual well-being. Globally, demand for EOL care is rising due to population ageing, the growing prevalence of chronic illnesses, and improved survival following acute disease. The World Health Organisation (WHO) emphasises that palliative and

[1]*University Medical Unit, Teaching Hospital, Jaffna, Sri Lanka,* [2]*Department of Medicine, Faculty of Medicine, University of Jaffna, Sri Lanka.*

Correspondence: JP, e-mail: jebananthy@yahoo.com

https://orcid.org/0000-0002-4124-0006

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EOL services must be accessible, affordable, and culturally relevant to ensure equitable care.

In Sri Lanka, free access to healthcare facilities has contributed to demographic transitions, resulting in an expanding older population, particularly those burdened by multimorbidity. Despite this shift, palliative care remains underdeveloped, and formal EOL care pathways are limited outside specialised cancer units. Furthermore, discussions about terminal illness and death are often culturally sensitive topics, with decisions frequently shaped by family members rather than patients themselves. Within such contexts, it becomes crucial to understand the knowledge, attitudes, and preferences of older adults to design appropriate, patient-centred, and cost-effective interventions.

This study, conducted at the Teaching Hospital Jaffna, addresses this gap by assessing older adults' awareness of EOL care, their preferences for treatment at terminal stages, and their attitudes toward decision-making and communication. The findings provide insight into cultural influences on healthcare choices and highlight areas that require improvement in policy and practice.

Objectives

The primary objective of this study was to assess knowledge, attitudes, and preferences regarding end-of-life (EOL) care among older adults attending the outpatient medical clinics of the Teaching Hospital, Jaffna. The specific objectives were to determine the level of awareness of palliative and EOL care among older adults; to evaluate their preferences for comfort-focused as opposed to active medical interventions during terminal stages of illness; to explore their attitudes towards communication, decision-making, and the perceived roles of patients, families, and physicians in EOL decisions; and to identify implications for strengthening patient-centred, culturally sensitive, and cost-effective EOL care services within the local healthcare setting.

Methodology

This was a descriptive cross-sectional study conducted at the Teaching Hospital Jaffna, a tertiary care institution serving the Northern Province of Sri Lanka, between November 2024 and January 2025.

The study population included older adults (≥65 years) attending the medical outpatient department. A total of 510 participants were enrolled using convenience sampling. Patients aged 65 years and above attending the medical outpatient services who provided informed consent were included in the study. Patients with severe cognitive impairment and those who were unable to complete the questionnaire were excluded.

Data were collected using a revalidated, structured, self-administered questionnaire developed through expert review and pilot testing to ensure content validity and reliability. To enhance data accuracy and inclusivity, trained data collectors assisted participants with limited literacy in completing the questionnaire, thereby reducing potential misunderstandings and improving reliability. The questionnaire addressed gaps identified in the regional and international literature, including limited awareness of EOL and palliative care, strong cultural and family influences on decision-making, and wide variation in preferences for life-sustaining treatments. Based on these findings, this study assessed the impact of sociodemographic factors, educational level, medical history, multimorbidity, and cultural and familial beliefs on patients' attitudes and preferences regarding EOL care. All questions were phrased with the understanding that participants were largely unfamiliar with palliative and end-of-life care, and were formulated in a culturally sensitive, non-directive manner to minimise anxiety and respect the emotional and cultural sensitivities surrounding discussions of terminal illness in this population.

Ethical clearance was obtained from the Institutional Ethics Review Committee of Teaching Hospital, Jaffna. Written informed consent was obtained from all participants. Confidentiality and voluntary participation were ensured.

Results

Demographic and clinical characteristics

Of the 510 participants, 65.7% were female. The largest proportion was aged 70-79 years (56.3%), followed by 65-69 years (24.1%). Multimorbidity was prevalent across all age groups, with 84.9% reporting three or more chronic conditions. Participants aged ≥80 consistently demonstrated a substantial disease burden. This pattern aligns with the high prevalence of chronic illnesses in the cohort, including hypertension (72.9%), diabetes mellitus (54.7%), and dyslipidaemia (51.2%). Most participants had been attending the clinic for more than 5 years, and 90% lived with family support.

Table 1. Sociodemographic and clinical profile of participants

Age	*Gender*	*One Comorbidity %*	*Two Comorbidities %*	*Three Comorbidities %*	*More than three Comorbidities %*
65-74	Male Female	5.0 7.25	8.82 7.64	6.07 17.45	2.54 8.62
75-79	Male Female	1.56 2.94	2.94 2.94	2.54 2.74	1.17 1.96
≥80	Male Female	3.13 0.78	0.98 1.56	0.58 1.17	0.39 0.39

Among participants, 5% reported having no formal education, 65% had completed formal schooling, and 15% had pursued higher-level education.

Table 2. Educational attainment of participants

Education Level	*Percentage (%)*
No formal education	5.0
Formal education	65.0
Higher-level education	15.0

Knowledge of EOL care

Although 77.3% recognised that chronic illnesses could become irreversible and not amenable to cure and 97% expressed a preference for comfort-focused care at the terminal stage, only 23.5% reported being aware of palliative or end-of-life care. Awareness levels differed across educational groups, with the majority of those who were aware having primary or secondary education; however, this association was not statistically significant (χ^2 test, p=0.069).

Table 3. Knowledge of EOL care

Variable	*Percentage (%)*
Awareness of palliative/ EOL care	23.5
Recognized chronic illness as irreversible	77.3
Preferred comfort-focused care at terminal	97.0

Table 4. Educational level and knowledge on End-of-Life and palliative care

Awareness of Level	*Education EOL care %*	*Awareness of palliative care %*
No Education	5.1	3.5
Primary	76.9	79.1
Secondary	14.0	13.9
Higher Education	4.1	3.5

P-value (χ^2 test) 0.069

Attitudes and preferences towards treatment at the EOL

Despite 97% of participants indicating a preference for comfort-focused care at the terminal stage, notable contradictions were observed in their treatment preferences. A majority (71.6%) still wished to continue active medical treatment even when considered futile, and 86% preferred active resuscitation and intensive care at the end of life. Additionally, 76.5% were willing to discuss EOL care options. When treatment preferences were compared across educational levels, most responses-whether favouring comfort care, ICU-based treatment, or engagement in EOL discussions-were observed among participants with primary education, who comprised the most significant proportion of the study population. However, no statistically significant asso-ciation was found between educational level and EOL care options (χ^2 test, p=0.074).

Table 5. Treatment preferences at EOL

Preference	*Percentage (%)*
Continue treatment even if futile	71.6
Prefer resuscitation and intensive care	86.0
Willing to discuss EOL care options	76.5

Table 6. Educational level and EOL care options

Education Level	Comfort Care %	ICU Care %	EOLC %
No education	4.7	3.3	6.7
Primary	76.1	73.5	72.5
Secondary	12.7	7.1	13.3
Higher education	3.5	2.3	7.5

P-value (χ^2 test) 0.074

Communication and decision-making preferences

Although 86.3% viewed EOL decision-making as an important part of their treatment plan, 80% valued clear communication with their treating physician about their illness, treatment options, and prognosis before making decisions and were willing to engage in such discussions. An almost equal proportion of participants believed that EOL decision-making should be made by patients themselves (34%), family members (34%), or treating physicians (32%). A statistically significant association was found between participants who were already aware of end-of-life care and palliative care and their decision-making preferences (χ^2 test, p<0.001)

Table 7. Attitudes and preferences toward EOL decision-making

Attitude / Preference	*Percentage (%)*
Patient as primary decision-maker	34.0
Family members as the primary decision-maker	34.0
Physicians as primary decision-makers	32.0
View EOL decision-making as important	86.3
Willing to discuss illness and treatment with a doctor	88.0

P-value (χ^2 test) < 0.001

Influence of comorbidities and duration of illness

The influence of the number of comorbidities and the duration of illness on patients' attitudes and preferences toward end-of-life care and palliative care options was also analysed; however, no statistically significant associations were observed in our study. (χ^2 test, p=0.5; p=0.082)

Discussion

This study provides important insights into the knowledge, attitudes, and preferences regarding EOL care among older adults with multimorbidity in the Northern region of Sri Lanka. Although participants carried a high burden of chronic illness, awareness of EOL and palliative care remained low, with only one quarter reporting familiarity with these concepts. Despite this limited knowledge, many recognised the irreversible nature of advanced disease and preferred comfort-focused care at the terminal stage. However, strong preferences for active resuscitation, intensive care, and continuation of treatment even when futile revealed an apparent contradiction between the desire for comfort and the inclination toward active interventions. The majority were willing to engage in EOL dis-cussions, indicating a significant unmet need for improved communication and shared decision-making.

These findings highlight the complexity of EOL decision-making, which is influenced not only by knowledge but also by cultural norms, family expectations, emotional factors, and perceived obligations to "do everything possible." In addition, decision-making in older adults with multimorbidity is influenced by clinical factors – such as illness stage, frailty, functional dependence, and symptom burden – which were not assessed in this study but are well-established determinants of preferences in global literature.[2] When viewed through the WHO palliative care model, the present findings indicate gaps across key domains, including limited understanding of illness progression, inadequate communication between patients and healthcare providers, and delayed integration of palliative care services.[1]

Findings from Sri Lankan studies demonstrate similar patterns. Local research has shown that healthcare professionals often have limited knowledge of palliative care, despite generally positive attitudes.[8,5] The contradictions observed in our patient population – valuing comfort while simultaneously favouring active medical interventions – align with evidence that Sri Lankan clinicians frequently experience discomfort when limiting or withdrawing life-sustaining treatments.[4,12] Together, these studies indicate that both patients and providers are influenced by shared cultural norms, gaps in palliative care training, and a health system environment that continues to prioritise curative treatment over supportive care.

Regionally, the findings align with studies from India, Pakistan, and Bangladesh, which consistently report limited EOL literacy, family-centred decision-making, and strong expectations to continue active medical treatment irrespective of prognosis.[9] The tension between comfort-focused and treatment-focused preferences is therefore a broader South Asian phenomenon shaped by cultural, religious, and familial values.

In contrast, evidence from high-income countries reports earlier integration of palliative care, stronger emphasis on patient autonomy, and more structured communication pathways.[7,6] But even in these contexts, multimorbidity often exhibits similar contradictions to those observed in this study. International research consistently demonstrates that early, honest, and culturally sensitive communication improves alignment between patient values and clinical decisions.[10] The willingness of most participants in this study to engage in EOL discussions suggests a significant opportunity for clinicians to initiate such conversations earlier. The lack of association between educational level and treatment preferences in our findings also mirrors evidence from other low- and middle-income contexts, where family influence and cultural norms often outweigh individual health literacy. This underscores the importance of system-level interventions rather than relying solely on patient education.

This study contributes original evidence by focusing specifically on older adults with multimorbidity – an understudied and vulnerable population in Sri Lanka. The findings highlight the need for healthcare providers to initiate culturally sensitive EOL conversations earlier in the disease trajectory, while strengthening the national framework for palliative care development.[3,11] Enhancing clinician training, expanding community-based palliative services, and improving public awareness may help align care decisions with patients' values and reduce unnecessary, aggressive interventions toward the end of life.

Conclusions

This study highlights that older adults with multimorbidity, attending a tertiary care hospital in Northern Sri Lanka, value comfort, dignity, and communication in end-of-life care, yet overall awareness of palliative and EOL care remains limited. The coexistence of preferences for both comfort-oriented and active medical treatment reflects profound cultural influences, emotional factors, and gaps in understanding of illness progression. Family involvement and physician guidance emerged as central influences on decision-making, underscoring the importance of shared, culturally attuned approaches to EOL discussions. Moving forward, healthcare systems must prioritise public and family education, strengthen awareness, enhance provider training in culturally sensitive communication, and promote earlier integration of palliative care within routine services. Addressing these gaps will help ensure that EOL care in Sri Lanka becomes more compassionate, culturally appropriate, and aligned with the values and preferences of its ageing population.

Limitations

Several limitations must be acknowledged. The use of convenience sampling and recruitment from a single tertiary hospital limits the generalisability of the findings to other regions, particularly rural settings. The cross-sectional design prevents understanding how preferences change over the illness trajectory. Self-reported responses may be influenced by social desirability and cultural expectations, especially when it comes to decisions about life-sustaining treatments. Additionally, preferences were recorded among clinically stable participants attending routine follow-up, which may differ from decisions made during acute clinical deterioration, when emotions and urgency play a stronger role, and choices are more complex and emotionally driven. Significantly, the strong preference for family involvement and reliance on physician guidance observed in this study may influence patients' autonomy in decision-making-particularly within Sri Lanka's culturally bonded family structure, where collective decision-making often supersedes individual choice. Despite these limitations, the study establishes an essential foundation for improving EOL care for older adults with multimorbidity in Sri Lanka.

Recommendation and advocacy

Based on the findings of this study, strengthening EOL care in Sri Lanka requires action across community, clinical, and system levels. First, improving public awareness through community-based education is essential, as limited understanding of palliative and EOL care remains a significant barrier to informed decision-making. Second, healthcare providers need focused training in culturally sensitive communication and shared decision-making, given that patients in this study relied heavily on physicians and family members when navigating complex choices. Third, integrating structured EOL care pathways into routine practice – particularly within secondary and tertiary hospitals – alongside providing family counselling and support will help ensure consistent, patient-centred, and culturally appropriate care. Further research, particularly in rural and underserved regions, is necessary to inform equitable national-level strategies for the development of EOL care.

Author declaration

Ethics approval

The Ethics Review Committee of the Teaching Hospital, Jaffna, approved the study protocol.

Conflict of interests

The authors declare no conflict of interests related to this study.

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Availability of data and material

The dataset used and analysed during the current study is available from the corresponding author on reasonable request.

Criteria for authorship

All authors have met the established criteria for authorship. Each contributed substantially to the conception and design of the study, data collection, analysis, and interpretation. All authors participated in drafting or critically revising the manuscript and approved the final version for publication.

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