

## Experiences of Patients with Advanced Chronic Disease Transitioning to Palliative Care in Low- and Middle-Income Countries: A Scoping Review

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**Cite as:** Nankundwa E, Mukeshimana M, Kanazayire C, Margaret F. Experiences of Patients with Advanced Chronic Disease Transitioning to Palliative Care in Low- and Middle-Income Countries: A Scoping Review. Rwanda J Med Health Sci. 2023;6(3): 411-422. <https://dx.doi.org/10.4314/rjmhs.v6i3.14>.

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### Abstract

#### Background

Palliative care is a holistic approach aimed at improving the quality of life for patients with advanced chronic diseases by providing physical, emotional, and spiritual support. communication is crucial during every stage of an illness to ensure that patients wishes are respected. This scoping review aimed to explore the literature on experiences of patients with advanced chronic disease transitioning to palliative care in low- and middle-income countries.

#### Methodology

This review was guided by Arksey and O'Malley's scoping review framework. A systematic search of the literature was conducted in MEDLINE, PubMed, Cochrane Library, PsycINFO, and Google Scholar from 2012 to 2022. thematic analysis was utilized to construct themes.

#### Results

The review identified key themes concerning the transition of people with advanced chronic diseases to palliative care in LMICs, including poor understanding, uncertainty, need for support, and poor communication.

#### conclusion

This review offers valuable insights into the experiences of patients transitioning to palliative care, aiding in the development of more effective interventions for researchers, clinicians, and policymakers.

*Rwanda J Med Health Sci 2023;6(3):411-422*

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**Keywords:** Transitions, End of life, Palliative care, Communication, Advanced chronic disease, Patient experiences

## Introduction

Palliative care is specialised medical care that focuses on improving the quality of life for people living with serious illnesses. It can be provided at any point during the course of an illness and assist patients in managing their symptoms, feeling more in control of their care, and making decisions regarding their care. It is based on the needs of the patient, not on the patient's prognosis, and it is appropriate at any age and at any stage in a serious illness.[1,2]

Palliative care is not about curing the chronic illness but about making the patient as comfortable as possible and helping them to live a full and meaningful life, while curative care focuses on eradicating the illness and restoring the patient to full health. [3] Palliative care (PC) is a crucial part of achieving universal health coverage. High-income countries offer effective palliative care interventions, allowing people with serious illnesses to live fully, while palliative care access is often limited in low-income and Middle countries due to a lack of awareness, cultural beliefs, limited services, and inadequate access to opioid pain relief. [1,4]

A person with an advanced chronic illness faces many obstacles, including the need to integrate the condition into their life, create coping mechanisms, and adopt good self-care practices. The ability to properly accomplish these tasks has a significant impact on the overall course of the illness. [5] Therefore, when a patient's illness progresses and curative treatments are no longer effective, it can be a so difficult time for everyone involved, including the patient and their family. Palliative care can guarantee that the patient's needs are satisfied while assisting them in adjusting to this change. [6] This specialized care can be a significant step for patients with chronic illnesses, as it helps them and their families navigate the challenges that come with the disease and improve the patient's overall well-being during their journey .

However, transition can be a challenging process and difficult time for patients, it indicates a personal sense of life, life/role changes, perceptions of the end of treatment, and death.[6,7] Adjusting to a chronic illness is a journey that requires time, effort, and patience, with ups and downs along the way. Patients need to keep a positive outlook and seek help from their families and healthcare professionals. The transition process involves adapting to change, coping with diagnoses, learning about illnesses, and changing one's lifestyle, often involving both medical and psychological aspects.[8,9]

Effective communication between patients and healthcare providers is crucial in palliative care to ensure that the patient's needs and preferences are addressed while also providing information and support to patients and their families about the illness, prognosis, and treatment options. [10] Maintaining ongoing communication is essential when moving to palliative care, it helps to ensure that patients and their families are informed about the patient's condition and that their wishes are respected. However, patients often feel left out of decision-making processes, and they don't feel valued or informed. [11] Involving patients in decision-making is crucial for tailoring care to their unique needs and aligning care with their values and preferences. Health providers should assess patients' preferences for involvement in decision-making, provide information about treatment options, and consider psychosocial factors that may affect decision-making.[12] Transitioning to palliative care is influenced by individual factors, including patient condition, support system, personal beliefs, and effective communication. To date, available literature on patients with advanced disease transitioning to palliative care has not been mapped yet, therefore this review aimed to map and synthesise the available evidence on the experiences of patients with advanced chronic illness during the transition to palliative care.

## Methods

The methodology utilized in this review was based on the framework developed by Arksey and O'Malley [13] This framework allows to map the current literature and identify the nature and extent of research evidence related to transition into palliative care. the Preferred Reporting Item for Systematic Review and Meta-analysis for Scoping Review (PRISMA-ScR) methodology was used to report the outcome of this review and outline results.[14] It was well-suited for evaluating palliative care interventions available to patients with advanced chronic disease. The scoping review framework by Arksey and O'Malley which comprises five stages: identifying the research question; identifying relevant studies; study selection; charting the data and collating, summarizing, and reporting the results was used

### Identifying the research question

This stage involved identifying the research questions that would serve as a guide for the stages that follow: What are the experiences of patients with advanced chronic disease when transitioning to palliative care? What challenges do patients face when transitioning to palliative care?

### Identifying relevant studies

A literature search was conducted throughout MEDLINE, PubMed, Cochrane Library, PsycINFO, Hinari, and Google Scholar databases. Additionally, the reference lists of relevant review articles and identified studies were also searched by hand to identify any other studies that may have been appropriate for this review. The available scientific literature on palliative care in low- and middle-income countries (LMICs) from 2012 to 2022 has been reviewed to ensure representativeness of the current state of palliative care. A review from this period allows for a comprehensive analysis of the literature, which is valuable for identifying trends, gaps, and priorities in LMICs health care. The main keywords selected for the search were: palliative care,

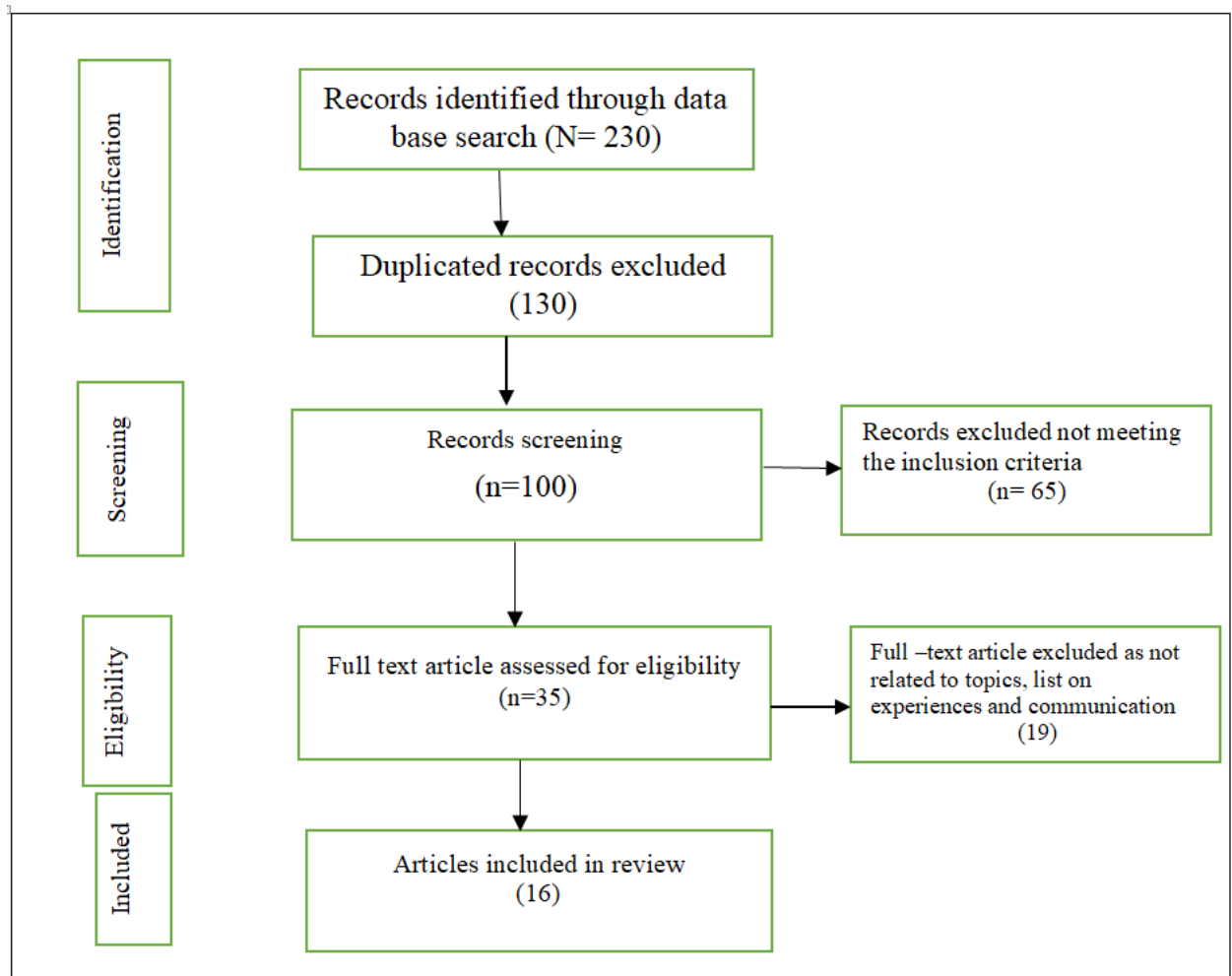
end-of-life care, low and middle countries, transition-related terms, including patient transfer, referral, transition, chronic illness, advanced disease, palliative communication, end-of-life care, curative care, comfort care, adult patients, patients' experiences, and hospice care. These concepts were combined using the Boolean (AND/OR). The literature search was conducted by the primary author; while the review and categorizing of the articles into themes took place separately by all of the authors, followed by a discussion, where a consensus was reached. Research papers were exported to Excel software.

### Inclusion and Exclusion criteria

Studies were considered if they focused on the experiences of patients with advanced chronic disease and/or palliative care in LMICs, Studies must have included adult patients (18 years of age or older) and were published in the period 2012 to 2022, the last ten years and in English languages. The following were excluded: Studies that do not focus on the experiences of patients with advanced chronic disease, studies that are not peer-reviewed, book chapters, opinion pieces, editorials, study protocols, systematic reviews, abstracts, and conference articles.

### Data extraction and charting

Two team members independently extracted studies selected based on the full-text articles that met the inclusion requirements. The wording and terminology in the papers were maintained to ensure that the data was accurately represented. The research results were imported into Excel software, and a duplicate analysis was run to identify and remove any duplicates. The remaining studies were then manually reviewed to ensure that no further duplicates were present. Data from the included articles were charted in relation to the author(s), publication year, country, study objective, study design, population and sample size, and relevant key findings. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow chart was used to outline results (Figure 1).



**Figure 1 Flow chart on study selection process according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)**

### **Collating, summarizing and reporting Result results**

In the process of collating and summarizing the results, the extracted evidence was repeatedly reviewed. Results were summarized to present an overview of the current evidence on the experiences of patients with advanced chronic illness transitioning to palliative care in low- and middle-income countries. The process involved consolidating research data, identifying key patterns, and presenting them concisely and informatively to the intended audience for clear, accurate, and accessible communication. Content analysis was used to identify and code broad thematic areas across the included studies. Themes were selected after reading each article and taking note of common results and research questions outlined in each paper. The research team identified four themes reflected across the selected studies through discussion and consensus based on the patients' experiences reported in the selected articles.

Our search retrieved 230 articles. After de-duplication and title/abstract screening, 35 full-text articles were retrieved for further appraisal, of which 16 separate articles were eligible (Figure 1). Of the 16 selected studies, 13 used a qualitative design with semi-structured interviews as the primary data collection method. Two studies were quantitative, and one was a mixed-method study. Nine of the studies were done in sub-Saharan Africa, South Asia (n = 6), and South America (n = 1). The research team identified four themes from the extracted data: poor understanding of the palliative care concept, uncertainty about life with an incurable disease, feeling supported, and poor communication and information. Characteristics of the included articles like country, setting and sample, focus of interest, applied method and analysis were extracted and summarized in Table 1.



**Poor understanding palliative care concept**

From this review, it was evident that palliative care was poorly understood by patients with chronic advanced disease. The lack of awareness about palliative care among patients entails not knowing its benefits and when it's appropriate. Two studies from India and Ghana show that even educated patients lacked a comprehensive understanding of palliative care. When asked about palliative care, patients valued medication changes that alleviate suffering, even if the medications did not lead to a cure. [15,16] Two studies from Bangladesh and Kenya showed that patients' knowledge of their cancer condition and its causes was

incomplete, contributing to misconceptions about the illness. Patients' lack of awareness of their own condition contributed to delays in diagnosis, treatment, and access to vital palliative care. Patients also had uncontrolled symptoms, including pain, worry, and despair, which prolonged physical and mental suffering and put a strain on careers. [17–20] A study conducted in Uganda and Zimbabwe showed that community members and families stigmatize patients with cancer disease, often stemming from misunderstanding, misconception, and fear. Such stigma can lead to social isolation for people with cancer.

**Table 1. Characteristics of studies identified in scoping review in Low and Middle countries**

Author (year)	Country	Objective	Study design	Population & sample size	Key findings
1. Prado et al., (2022)	Brazil	To explore the meanings and experiences of patients with terminal chronic diseases and their caregivers, who face the imminence of death in the home environment after hospital discharge	A qualitative study	11 patients and 10 family caregivers (n=21)	In the transition between hospital and home, terminally ill individuals experience the process of the uniqueness of emotions, feelings of hopelessness, loss of control and uncertainty around death can have a detrimental impact
2. Ngwenya et al., (2021)	South Africa	To identify factors that impact communication and support and recommend ways to improve patients' understanding of living with life-threatening illness	A qualitative study	Patients with LC (n = 22) and advanced COPD (n = 18), their informal caregivers (39) and HCPs (n = 51)	Patients reported that information was mostly obtained after a crisis and focused on what they themselves could do for their illness. A more indirect and uncertain approach was identified into the finitude of life reflects an individual's social environment and how they interact with those participants.
3. Shen et al., (2018)	South Africa	Examined patients' terminal illness awareness, their preferences for the type of care received at End of Life	longitudinal study / cohort studies	221 patients	Most patients indicated that they did not want to know how long they had left to live, even if their physician knew.  Resource constraints and a lack of awareness of options may also factor into this preference for comfort care
4. Vasileiou & Smith, (2020)	South Africa	To explore the lived experience of attending hospice care facilities  to develop a bottom-up understanding from the perspectives of patients themselves	A qualitative study	12 patients	The findings suggest strong stigma attached to palliative care and associated with diminished hope choice and death. Receiving hospice care sensitively improve patients' psychosocial and physical needs.
5. Dandadzi et al., (2022)	Zimbabwe	To explore the experience of patients with cancer from the point of initially experiencing symptoms, through to access to palliative care services	a cross-sectional, multi-country qualitative study	20 patients	Participants' experiences gaps, breaks and discontinuity across each stage of the illness courses from accessing medical assistance, obtaining a diagnosis, plan and accessing palliative care

**Table 1. Continued**

Author (year)	Country	Objective	Study design	Population & sample size	Key findings
6. Nair et al., (2020)	India	To assess the lived experiences of palliative care among critically unwell people living with HIV/AIDS (PLHA), caregivers and relatives of deceased patients	Exploratory, qualitative study design	20 patients	Very poor understanding of the concept of palliative care among PLHA and their caregivers.
7. Ozdemir et al., (2021)	South Asia	To assess patient reported perceived roles in decision-making	Multicounty cross-sectional survey.	200 participants were recruited from five country	Participant more likely to report less participation in decision making.  knowledge of cancer diagnosis may be associated with higher levels of patient involvement in decision-making
8. Ofosu-poku et al., (2020)	Ghana	Identification and comprehension of the factors influencing the decision to refer patients for specialist palliative care	A qualitative exploratory study design	12 participants	Unavailability of provider as well as to meet the specialist palliative care needs of patients in the hospital may affect referrals. poor understanding of palliative care” and thus had difficulties identifying palliative care needs or initiating a conversation about palliative care
9. Doherty et al., (2019)	Bangladesh	To understand the psychological, spiritual, and social needs and experiences of patients with advanced, incurable illness	28 participants	A qualitative study	Patients and their families had a strong perception that some professionals did not listen and were not perceived to be caring in their attitude.  Poor communication may be a factor contributing to this perception.
10. Zafar et al., (2016)	Pakistan	To survey preferences of adult cancer patients regarding disclosure of prognosis and end-of-life care	Mixed method quantitative and qualitative	40 participants	They do not discuss prognosis and life expectancy because they hesitate to deliver overwhelming news to patients.
11. Sarfo-Walters & Boateng, (2020)	Ghana	Explored the perceptions of individuals with ESKD and their in-formal caregivers on palliative care as a treatment option of the disease in Ghana	Qualitative study	15 participants	It was shown that individuals with ESKD would consider palliative care services, if available. Late presentation, poor functional status imply that many could benefit from palliative care services if this choice was to be available.
12. Kaba et al., (2021)	Bangladesh	To explore palliative care needs and preferences of female patients with breast and cervical cancer or other life-threatening chronic illnesses, and their primary and voluntary caregivers	Qualitative study	77 participants: 34 patients, 12 caregivers, 15 voluntary caregivers and 16 with stakeholders.	Patients and caregivers positively experienced the care and support provided, The majority of patients still suffered from moderate to severe pain and there was an unmet need in psychosocial, spiritual, economic and emotional support.

**Table 1. Continued**

<b>Author (year)</b>	<b>Country</b>	<b>Objective</b>	<b>Study design</b>	<b>Population &amp; sample size</b>	<b>Key findings</b>
13. Namukwaya et al., (2022)	Nigeria / Uganda	To explore the experiences and expectations of palliative care for people living with advanced cancer in Nigeria, Uganda, and Zimbabwe.	A secondary qualitative analysis of in-depth interviews	62 people	Participants expressed multidimensional needs whenever they interacted with palliative care services. The wider impact of stigmatization within their local communities and families was not addressed.
14. Dehghan et al.,( 2012)	Bangladesh	To describe the needs, experiences and care of patients and families in receipt of palliative care in Bangladesh,	Qualitative study	20 participants	Suggests that patients and their families in our sample had a strong perception that some professionals did not listen and were not perceived to be caring in their attitude. Poor communication may be a factor contributing to this perception
15. Ntuzimira, Christian R.,2019	Rwanda	To explore and to examine end-of-life care experiences of oncology patients in end-of life care in Rwanda rural and urban area	Qualitative study	29 participants	The end-of-life care is challenging due to the stigma surrounding the disease but also the difficulty from patients, family caregivers, and healthcare providers to start talking about end-of-life care. There is no clear advanced care plan when patients are discharged from hospital.
16. (Natuhwera et al., 2022).	Uganda	To examine health care professionals' (HCPs) lived experiences of cancer and generate evidence to inform policy and clinical practice for cancer care.	Qualitative study	8 participants	Participants identified how they experienced a healthcare system which was costly and staffed by unmotivated staff with limited access to resources, which resulted in many unmet needs and an overall poor experience

Participants experienced gaps, breakdowns, and discontinuities throughout each stage of the illness, from getting medical help to getting a diagnosis, making a plan, and getting access to palliative care because they were unaware of palliative care.[21]

### **Uncertainty about life with an incurable disease**

Living with an incurable disease can be a challenging and uncertain experience, and uncertainty may occur not just during the diagnostic period but also at any stage of the medical process. Knowing that the disease is incurable can cause patients to have a variety of negative emotions, including stress, fear, a sense of powerlessness, or false expectations of a cure.[22] Studies conducted in Nigeria, Uganda, and Zimbabwe have shown that a cancer diagnosis can significantly impact personal self and role identity, leading to feelings of worry, anxiety, and uncertainty. The diagnosis is often seen as an irreversible event that worsens the discomfort and pain symptoms in patients' illness trajectory.[18,21] Another study reported that people with incurable diseases often worry about what will happen to them in the future, as it is difficult to predict how the disease will affect them. This can lead to stress and anxiety, as they may feel uncertain about their prognosis.[18] Studies conducted in Zimbabwe and Bangladesh, reported that when people received a diagnosis of an incurable disease, they would experience a range of emotions, including fear, worry, sadness, despair, and grief.[17,21] Another study from Brazil explored the meanings and experiences of patients with terminal chronic diseases and recognized that patients who are experiencing the end of their lives go through a unique emotional transition as they move from the hospital to their homes. These feelings, together with powerlessness, losing control, and uncertainty about death, can be harmful.[22]

### **Need of Social and psychological support**

Reaching a point of needing palliative care can be accompanied by critical psychological impacts on the patients and their caregivers.

Two papers highlight the significant psychological challenges experienced by individuals living with advanced illnesses, including loss of control, dependence, loneliness, and feelings of abandonment. [21–23] Unmet psychosocial needs can have a significant impact on the well-being of both patients and their families, as reported in three studies. Unmet psychological needs lead to increased emotional distress as the condition worsens. Loneliness and isolation, exacerbated by the feeling of being a burden to loved ones, were common. Additionally, patients still suffered from moderate to severe pain and had an unmet need for psychosocial, spiritual, and emotional support.[12,19,24] Two studies from India and Ghana showed Patients needed social support when illnesses got worse, as they experienced anxiety, depression, decreased quality of life, and social isolation. Patients who were confined to hospital rooms for a number of days while waiting a family member's visit reported having limited opportunities for social interaction and social engagement, feeling lonely and isolated.[13,21]

### **Poor Communication and information**

Palliative care offers patients the chance to express their fears and concerns, fostering a sense of control and informed decision-making in their care. Study done in Asia, showed that, regardless of their poor prognoses, patients with serious illnesses often do not discuss prognosis with their health professionals. Health professionals fear that patients will lose hope and abandon treatment or experience anxiety or depression upon learning their prognosis. [25] Disclosing a poor prognosis was also discussed by one author, who reported that most patients wanted their family members to be told about their prognosis, even if it was poor, as family members want to be involved in the patient's care decisions and prepare for the patient's death. [26] A study conducted in Asia revealed that the patient was not involved in the decision-making process. Patients with advanced cancer commonly have a passive role in decision-making.



The study revealed that 22.8% of patients are not actively involved in decision-making about their care, largely due to a lack of patient education and understaffing, which hinders effective communication. [26] The lack of appropriate space and privacy was reported in many studies. Not having a private room for discussion when delivering bad news and discussing the disease and the changes that would result from it was seen as a significant barrier that made both patients and health providers uncomfortable.

## Discussion

Palliative care helps patients with advanced chronic diseases manage pain, emotional and psychological challenges, make informed decisions about their care and treatment, and live well, regardless of their prognosis. Research findings from this review reveal that little is known about this potentially complex process of patients with advanced chronic disease transitioning to palliative care within the LMIC context. The majority of the studies that have been done on this transition process have been in high-income settings, which may not be very relevant to low- and middle-income countries. This review revealed some significant issues within LMIC settings that require further research and discussion. This review highlights a poor understanding of palliative care. Many patients miss out on the benefits of palliative care because they are not aware of it or what it can offer to improve their quality of life. [15,20]

This review has also shown that many people have misconceptions about palliative care, believing that palliative care is only for use in the final stages of life and discouraging early access. As a result, patients are missing out on potentially helpful therapies and causing unnecessary suffering. Due to misunderstandings, people in need may receive insufficient palliative care, make uninformed decisions, and experience unnecessary suffering. [18–20]

Uncertainty is a common and challenging experience for people with advanced illnesses, as they often face unpredictable health outcomes. It can be related to the disease itself, the prognosis, the course of treatment, the impact on daily life, and the future. [27] This review shows that uncertainty can occur during diagnosis or when learning about a poor prognosis. It causes great anxiety for people who are trying to understand their diagnosis and how their disease will progress. This uncertainty can make it difficult for patients to plan for the future, as they may not know the full extent of their condition, its long-term outcome, or the effectiveness of available treatments. [18,22,23] Given that many chronic diseases are incurable, requiring lifelong management, this review found that they are also unpredictable, leading to overwhelming fear and a loss of control. False hopes of a cure can lead to disappointment and disillusionment if the disease does not improve. [18] It was also shown that advanced chronic disease impairs daily functioning as it can cause a number of health issues, such as fatigue, pain, and difficulty moving, as well as emotional distress. People with advanced chronic diseases need significant social and psychological support from family and health care providers. [5,23] The progression of illness greatly affects a person's physical, mental, and social health, disrupting family life, causing emotional stress for carers, and causing social disengagement. Patients require help managing their illness, including medical care and social support. [19,21,26,28]

Communication is a crucial tool for patients with advanced chronic diseases transitioning to palliative care. Patients in the studies reviewed wanted to know their prognosis, even if it was poor, while providers were less likely to discuss it. This lack of communication can lead to poorer-quality decisions and a failure to manage care effectively. Our scoping research revealed that, due to low patient literacy, people may have difficulty understanding complex medical information and misconceptions

about palliative care, making it difficult to make informed care decisions and cope with illness.[21,28] The review also shows that patients face challenges in accessing information from healthcare professionals, which reduces their acceptance of palliative care and involvement in decision-making. Healthcare providers may feel distress when giving bad news about incurable diseases, and they may worry about how the patient will react. This may be due to a lack of training in how to start sensitive conversations. [12,21,28] To help patients understand their condition, make informed decisions about their care, and prepare for end-of-life care, healthcare practitioners working in low- and middle-income countries must engage and involve patients in difficult conversations about their illness journey. Engaging and involving patients in difficult conversations is an essential part of providing high-quality healthcare.[18,19,21] It is apparent from the review that discussing illness or death is still taboo in many cultures, which can make it challenging for patients to obtain the information they need on their diagnosis and prospective therapies in the future. This can lead to a lack of awareness and common misconceptions about palliative care.[5,17,29]

## Conclusion

Understanding the experiences of patients with chronic disease when transitioning to palliative care in low and middle countries (LMICs) can significantly improve patients' quality of life. However, more needs to be done to improve communication, providing patient support, and raising awareness about palliative. This review will have relevance to a variety of audiences, including researchers, clinicians, and policymakers interested in developing new interventions for patients that can offer patient support, access to palliative care, and improve the quality of life of patients with chronic diseases.

## Authors' Contribution

NE, MM and MF conceived the review; KC and NE designed the search strategy; NE and MF conducted literature searching, screening, and quality assessment. All authors had interpreted data, revised manuscript, and approved the version for publication.

## Competing interests

The authors report no conflicts of interest.

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