Original Article

Perspectives of Patients on Communication and Involvement in Decision-Making during Palliative Care: A Qualitative Study in Rwanda

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Abstract

Background
In palliative care, communication is crucial for understanding and responding to patients' needs and preferences throughout their illness journey. It involves the clear exchange of information, supports active involvement in decision-making, and fosters an empathetic and trusting care relationship.

Aim
This review explored the perceptions of patients living with advanced illness regarding communication and their engagement in decision-making with healthcare providers during the course of palliative care.

Methods
A qualitative research design was employed, using semi-structured interviews to gather rich, personal insights from participants. Data were processed using Interpretative Phenomenological Analysis (IPA).

Results
Four main themes and eight corresponding subthemes were identified through the analysis: (1) Patients' perceptions of effective communication and information; (2) Perceived impact of conversations; (3) Challenges in patient–provider discussions; and (4) Engagement in decision-making processes. Each subtheme was analyzed within its respective main theme, providing concise yet meaningful insights into how participants experienced and understood communication and decision-making during palliative care.

Conclusion
Communication is fundamental to facilitating patient involvement in decision-making within palliative care. Despite patients' desire to engage actively, many experience unclear and insufficient information, particularly at critical points such as diagnosis and disease progression. To support meaningful engagement and align care with patient values and preferences, we need targeted, person-centred communication.

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Keywords: Communication, advanced chronic illness, end-of-life care, palliative care, decision-making, patient-provider communication

Introduction

Communication is a vital component of palliative care, enabling the exchange of information and supporting collaborative decision-making among patients, families, and healthcare providers. It is most effective when tailored to reflect each patient's unique values, goals, and preferences.[1] According to previous research, effective communication is foundational to delivering quality care, particularly in the context of serious illness. It enables clear and compassionate information exchange, helping patients and families understand the illness trajectory, prognosis, and available treatment options.[2,3] In palliative care settings, where curative treatment is no longer an option, decisions often involve interventions that may prolong life but also risk compromising the patient's comfort and overall well-being. In these circumstances, effective communication and collaborative decision-making are essential. Consequently, healthcare professionals must engage in open, empathetic, and timely conversations to help patients and their families understand the potential benefits, limitations, and burdens of the available treatment options.[4,5]

There is evidence that , implementing communication in practice is often challenging. Time constraints, emotional complexity, prognostic uncertainty, and varying levels of health literacy can all create barriers to effective dialogue. These challenges may limit patients' understanding, reduce their engagement in care decisions, and hinder the alignment of care with their values and preferences.[6,7] Timely and compassionate communication at the point of diagnosing a serious, progressive illness is a cornerstone of effective palliative care. It plays a crucial role in shaping how patients and families understand the nature of the illness, process emotional responses, and engage in meaningful care planning.[4,8,9] Previous studies among patients with cancer have highlighted the vital role of timely, clear, and honest communication throughout the illness journey. Access to accurate information early in the course of illness enables patients to better understand their condition, reduces uncertainty and emotional distress, and promotes active involvement in care planning. As a result, the care they receive is more likely to reflect their personal values, needs, and preferences.[10–12] Conversations in the context of advanced illness are frequently emotionally challenging for both patients and healthcare providers, as highlighted in previous literature. Patients may respond to distressing information with diverse emotions such as fear, denial, hope, or acceptance. Timely and empathetic communication plays a vital role in supporting shared decision-making and ensuring that care reflects the patient's values and preferences. Moreover, such communication helps patients and their families prepare for future care planning and end-of-life decisions.[13–15]

As palliative care expands into diverse cultural settings, culturally sensitive communication becomes essential. Effective care requires not only clinical skills but also respect for patients' values, beliefs, and traditions. Language differences and cultural norms can hinder understanding and limit patient involvement. This highlights the importance of communication approaches that build trust, respect local contexts, and promote meaningful engagement in care.[16]

In low-resource settings like Rwanda, illness is viewed through both biomedical and cultural lenses, which can shape how and when patients seek care. Additionally, cultural respect for medical authority may discourage patient involvement in decision-making. These factors together may create challenges for effective communication in palliative context.[17,18] In addition, Communication in palliative care is often challenged by provider training gaps, overcrowding, language barriers, and cultural beliefs. Understanding patients' experiences is essential for improving care, and promoting equity. This study examines how patients in Rwanda perceive and engage in communication and decision-making during their palliative care journey.

Methods

This study employed a qualitative approach using semi-structured interviews, grounded in hermeneutic phenomenology, to gain insight into how patients perceive and navigate communication and decision-making processes in palliative care. Given its emphasis on subjectivity and context, hermeneutic phenomenology was well-suited to this study, enabling a nuanced examination of patients' personal experiences with communication and shared decision-making.[25] It followed COREQ guidelines to ensure rigor and transparency.

Setting

This study was conducted at a teaching Hospital in Rwanda that has taken a leading role in integrating palliative care into its healthcare services. Palliative care services have been integrated into all hospital departments and expanded to home-based care through community health workers. Although the hospital is recognized for its role in providing palliative care services, it does not have a dedicated or separate palliative care unit. Instead, patients requiring palliative care are typically managed within various general wards alongside those being treated for other illnesses.

Participants and Sample Size

This study involved individuals living with chronic, progressive illnesses and receiving palliative care. These patients are characterized by serious, life-limiting conditions that require specialized care focused on enhancing comfort and quality of life.Recruitment was conducted within the medical department through close collaboration with the hospital's dedicated palliative care team. Head nurses played a pivotal role as gatekeepers, carefully identifying and introducing eligible patients to the study. Building on these introductions, the researcher met each participant individually, providing detailed written information, thoughtfully addressing their questions, and clearly outlining the study's purpose and procedures. Only after ensuring full understanding was informed consent obtained, allowing the researcher to proceed with in-depth, meaningful interviews.

Purposive sampling strategy was used to ensure the recruitment of a heterogeneous participant group, reflecting diversity in age, gender, and a range of complex health conditions. Eligible participants included adults aged 18 years and above, diagnosed with advanced chronic illnesses such as cancer, chronic obstructive pulmonary disease, HIV/AIDS, and other progressive life-limiting conditions. All participants were actively receiving palliative care services, were cognitively competent, and capable of providing informed consent, thereby ensuring the ethical integrity and relevance of the data collected. Exclusion criteria included individuals diagnosed with chronic conditions who were receiving exclusively curative (non-palliative) treatment interventions. Patients with cognitive impairment or altered mental status that prevented them from providing informed consent or meaningfully participating in interviews were also excluded. Additionally, family members, friends, were not included in the study.

The sample size was guided by the principle of data saturation, with interviews conducted until no new themes or insights emerged, ensuring thoroughness and depth in the findings. A total of twelve participants were included. Data collection was carefully monitored, with saturation reached by the tenth interview, followed by two additional interviews to confirm that no further new information emerged. These final interviews confirmed that data saturation had been achieved, as no new information or themes emerged.[20]

Interview guide

The interview guide was developed by two researchers (NE and KC) following an exhaustive review of palliative care literature, with a focus on communication, information provision, patient understanding, shared decision-making, and provider–patient interactions in serious illness, particularly in low-resource settings. To ensure its relevance, coherence, and alignment with the study objectives, the guide was reviewed by a multidisciplinary team of palliative care clinicians and researchers. Their expert feedback was incorporated to refine the tool, enhance its clarity, and ensure it remained focused on the research questions. The guide was then translated into Kinyarwanda and back-translated into English to ensure both linguistic and conceptual accuracy. It was pilot tested to assess clarity, cultural appropriateness, and ease of use. Feedback from the pilot informed final revisions, resulting in a contextually adapted tool capable of generating rich and meaningful data.

The main questions focused on patients' perceptions of communication and their engagement in decision-making within palliative care, including

Can you tell me how you came to understand your illness based on what healthcare providers have shared with you?

How would you describe the way information was communicated to you? Did it feel clear, supportive, or reassuring?

Have you had the opportunity to engage in discussions with your healthcare provider about your condition?

Data collection

A semi-structured interview guide with open-ended questions was used to initiate conversations, allowing for deeper exploration based on participants' responses. Interviews lasted between 40 and 60 minutes and were conducted by the principal investigator (NE), a PhD candidate with formal training in qualitative research and a professional background in nursing education and critical care nursing. Participants were asked to describe their perceptions of communication and involvement in decision-making throughout their illness journey. To ensure consistency, each interview began with the same core questions from the guide, providing all participants an equal opportunity to share their views on key topics. Probing questions were used to elicit more detailed and specific information. All interviews were conducted by NE, who had no prior relationship with the participants, were audio-recorded, and transcribed verbatim. At the start of each interview, NE introduced herself and explained the study's purpose. To maintain confidentiality, transcripts were anonymized, and pseudonyms were assigned to participants and used in all study documents. Participants were informed that they could withdraw from the interview at any time without giving a reason. Alongside the recordings, the principal investigator took field notes during interviews to capture contextual details and initial impressions that enriched data interpretation. Additional notes were made during data analysis, especially while reviewing transcripts, to deepen understanding and support theme development. Data collection continued until saturation was reached, that is, when no new themes or information emerged.

Data Analysis

We analysed our data using Interpretative Phenomenological Analysis (IPA). IPA is a qualitative research approach that seeks to provide insights into how individuals interpret and understand their personal experiences.[20] Once transcribed, the interviews were analyzed. The Smith and Osborn's approach guided the data analysis through a systematic, multi-step process.[21] First, interviews were transcribed verbatim and read repeatedly to ensure deep familiarity, leading to the identification and organization of initial themes. Second, these themes were refined and grouped into broader categories. Third, connections among themes were explored to reveal overarching patterns. Fourth, each case was examined individually to retain its unique perspective.

Fifth, cross-case analysis was conducted to identify both shared and divergent experiences. Finally, a coherent narrative was developed, grounded in participants' lived experiences and integrating both individual and collective insights. ATLAS.ti 7.1 software was used to systematically organize, code, and categorise the data. The use of IPA gives voice to participants' own narratives, allowing their perspectives to guide the interpretation. NE began by reviewing a random sample of responses to become familiar with the content. Line-by-line coding was independently performed by two authors (NE, MF) to generate descriptive themes and interpretive categories. These were refined through collaborative discussion among the research team (MK, MF, MM, and NE), with any disagreements resolved through dialogue. A peer debriefing was conducted to ensure credibility and strengthen validity. The team developed operational definitions and mapped thematic relationships, supported by participant quotations. Transcripts were revisited to ensure accuracy and to remain true to participants' experiences. To maintain analytical rigour, transcripts were reviewed multiple times, and a qualitative memo kept by the first author documented the development of codes and interpretations as a reflective tool throughout the analysis. Transcripts were not returned to participants for comment or correction. All interviews were recorded digitally and safely stored on a computer.

Ethics approval

Ethical approval for this study was granted by three bodies: The Institutional Review Board (IRB) of the College of Medicine and Health Sciences at the University of Rwanda (reference number N° 047/CMHS IRB/2022), the Rwanda National Ethics Committee (RNEC) (reference number No. 107/RNEC/2022), and the relevant regulatory authorities. Participants were informed about confidentiality, with their identifying data pseudo-anonymized, and were assured of voluntary participation and the right to withdraw without impacting their treatment.

They were also informed that they could pause or end the interview at any time, although none did. Participants provided both oral and written consent, ensuring their rights were protected throughout the study.

Result

Characteristics of the Participants

The sample consisted of twelve participants six women and six men, ranging in age from 31 to 72 years, with a mean age of 51.2 years. Participants included four married individuals, one widowed, three single, and four divorced. Most had multiple comorbidities, reflecting the complex health challenges they experienced alongside their primary illness.

Table 1. Patient's characteristics (n = 12) at the time of the interview

Participant ID	Age Range	Gender	Marital Status	Diagnosis
PTO1	40-49	M	Divorced	HIV,Post-TB Complications, Lung fibrosis
PTO2	40-49	F	Married	Post-TB Complications, Lung fibrosis
PTO3	30-39	M	Single	Advanced Cirrhosis
PTO4	40-49	M	Divorced	Advanced HIV- Lung Fibrosis post- TB
PTO5	40-49	M	Divorced	HIV and Opportunistic Infections
PTO6	50-60	M	Married	Advanced kidney disease
PTO7	30-39	F	Married	Advanced Cancer of the knee
PTO8	70-79	M	married	Advanced prostate cancer and diabetes
PTO9	50-59	F	widowed	Advance HIV, heart disease lungs fibrosis
PTO10	30-39	F	Single	Myasthenia gravis
PTO11	40-49	F	Divorced	Advanced cancer and HIV
PTO12	40-49	F	Single	Hepatic-Pulmonary Failure, Lung Fibrosis

Table 2. Emergent Themes and Subthemes from the Data

Themes	Subthemes
1.Patients' views on effective Communication	1.Open and honest information 2.Clarity and Understandable Language
2. Perceived conversation impact	1. Emotional Responses to Difficult information 2 Compassionate Communication
3.Challenges in patient-provider discussion	1.Time Constraints Limiting Difficult Conversations 2.Lack of Privacy in Communication
4. Engagement in Decision Processes	1.Being Part of the Decision 2.Family members support in decision making

Theme 1: Patients' views on effective communication.

Participants highlighted an absence of open and honest information about their medical condition. Additionally, language barriers complicated communication, which led to confusion and a limited understanding of the participants' illness.

Subtheme 1: Open and honest information

Some participants reported that the information they received about their condition was often unclear or not detailed enough. As they expressed in their own words:

> *…I found out I had HIV during my pregnancy, which was already difficult to accept. After giving birth, my health began to deteriorate, and I was referred to a larger hospital. There, the doctors told me I had serious heart and lung complications and that I needed a breathing machine. I couldn't understand how things had become so severe. I kept worrying about my child and what the future would hold for us (POT9).*

> *… It started when I felt like I couldn't stand or walk like I used to my legs just felt weak, like they were giving up on me. I went from one hospital to another, and after many tests, they said I had a strange illness. But they didn't explain it well, and I didn't really understand what was going on. I felt scared and confused. I had so many questions, but I stayed silent (POT10).*

Some participants looked for help outside the hospital to better understand their illness and get extra support. As participant said:

> *… We kept going from one hospital to another. At first, they told me it was just a small infection. But after many tests, I was told I had HIV and that there was some swelling in my private parts. We felt lost and overwhelmed, so we decided to see a traditional healer to try to understand where all of this was coming from (PO8).*
>
> *After a while, I no longer understood exactly what was wrong. I thought perhaps my previous tuberculosis was coming back, but the healthcare providers didn't explain much; they just referred me to another place. Feeling lost, I turned to a prayer group and placed my trust in God for healing (POT12).*

Subtheme 2: Clarity and Understandable Language

Participants noted that the explanations provided by healthcare professionals were often difficult to understand, leading to confusion and anxiety about their diagnosis and treatment goals." participants shared:

> *They did a scan of my leg, and later the doctor showed me the picture. He pointed at one area and said something wasn't right. He explained a bit, but I didn't really understand what he meant. I just kept nodding, but inside I was really worried. I left feeling confused, wondering if it could be something severe like cancer (POT7).*

> *I had TB many years ago. After some time, I started feeling weak, and it became harder to breathe. When I went back to t*

> *he clinic, they did some tests and took an X-ray. Then the doctor said there was something dark in my lungs. I didn't really understand what that meant or what would happen next (POT1).*

Theme two: Perceived conversation impact

Participants felt that conversations with healthcare providers shaped how they understood their illness. The way discussions began, how clearly things were explained, and whether providers showed empathy made a big difference. These factors influenced how informed, supported, and emotionally prepared patients felt.

Subtheme 1: Emotional Responses to Difficult Information

Participants described a range of emotional reactions after receiving distressing or complex information about their illness, often leading to feelings of fear, confusion.
Patients expressed:

> *… After receiving my test results, the doctor simply told me, "You will not be able to breathe on your own; your lungs were destroyed by the old disease tuberculosis." I was shocked. I was shocked. Hearing that I would have to remain in the hospital because I couldn't get this breathing machine at home was devastating, everything changed in that moment. I lost the hope of ever returning home (POT4).*

> *When they gave me the results, it felt like my world stopped. "When they said it was cancer", I felt like I'd already been told I was going to die. It was too heavy " (POT8).*

Subtheme 2: Compassionate Communication

Participants highlighted the great importance of healthcare providers speaking with kindness and understanding. As participants shared:

> *When I first heard that my liver was destroyed, I was really scared. But they sat by my bed, looked me in the eyes, and gently said, "Ihagane," which means "be strong." They explained that I needed to stop drinking beer and promised to help me manage my illness (POT3).*

> *…He told me that my illness had become very serious, and it was hard to take in. Then he explained they would transfer me to a place where I could get free medicine and proper care. He also said there would be a preacher and other people like me. Knowing I wouldn't be alone brought me some peace (POT11).*

Themes 3: challenges in patient-provider discussion

Participants experienced barriers to meaningful communication, often due to the brevity of clinical interactions and the lack of privacy in hospital settings, which led to many of their informational needs remaining unaddressed.

Subtheme 1: Time Constraints Limiting Difficult Conversations

Participants shared that limited time during medical visits made it hard to have meaningful conversations with healthcare providers. As participants expressed:

> *Most of the time, we only see the doctor briefly during morning rounds. When we come from home, we go to the medical office, but even then, the time for discussion is very limited. They move quickly from one patient to the next, look at the papers, and maybe ask a quick question. It feels rushed; I wish there was more time to really talk and understand what's going on (POT10).*

> *You know… I don't really get much time or chance to talk with the doctor. I understand they have many patients to see, so most of the time, we end up sharing our problem with the nurses or even with other persons instead (POT1).*

Subtheme 2: Lack of Privacy in Communication

Many participants described difficulties sharing sensitive information due to a lack of privacy during consultations or hospital stays, noting that conversations often took place in crowded wards or shared spaces. as participant expressed:

> *This hospital has become like a second home to me, as I have been here for many years. My bed is in the corner, which offers some comfort, but we are all crowded into one noisy room. It is difficult to have serious conversations because others nearby also want to hear your history and ask questions (PTO9).*

> *At home, we usually keep our health problems private and don't talk much about them. But here, it's different. There's very little privacy because other patients and staff are always nearby. Because of that, I don't feel comfortable asking all my questions or sharing my worries. It's hard to speak openly when I'm afraid others might hear our discussion (PTO4).*

Theme 4: Engagement in Decision Processes

Being involved in decision-making and having family present are important factors that enhance patients' active participation in healthcare decisions. While family members often provide essential support during the illness journey, many patients view healthcare providers as the primary experts responsible for guiding decisions about their treatment and care.

Subtheme 1: Being Part of the Decision

Several participants said they were not included in important decisions about their health condition. As participants expressed:

> *One day, the doctors told me my only chance was to get a new kidney. It shocked me. I just sat there, speechless. It's a big decision, not something you can accept right away. I didn't fully understand everything and wanted more information about any other options. I asked to speak with another doctor. I also needed time to talk with my family …(POT6).*

Some participants expressed strong trust in their doctors as experts who know what's best for their health:

> *This illness has been with me for a long time. Honestly, I don't really know what's best anymore. I just trust the doctors now because they are the ones who understand what is happening. At this point, I feel like getting better is not in my hands anymore (PTO4).*
>
> *"Right now, getting better isn't really in my hands anymore. The doctor knows what's best for me, so I just have to trust them and wait" (PTO8)*

Subtheme 2: Family members support in decision making

Many participants highlighted the vital role of family presence during the illness journey, providing not only emotional and practical support but also assisting in understanding their health condition.

> *I'm really grateful to have my family with me during this time. My sister never left my side. She spoke with the doctors and did her best to understand everything. I didn't have the strength to ask questions or even think clearly, so I just trusted her. Knowing she's there makes me feel safe and cared for (POT2).*

However, some participants reported having little or no family support during their illness journey due to various circumstances. As one participant explained…:"

> *It's been really hard. I'm the only one left from my family after the genocide. When this illness began, my wife left with our two sons. In times like this, you hope your family will be there for you but I didn't have that chance (POT9).*

> *"After the genocide, I was left with only my mother, and I think this illness is too much for her to handle" (PO10).*

Discussion

The aim of this review was to explore the perceptions of patients living with advanced illness regarding communication and their engagement in decision-making with healthcare providers during the course of palliative care. The review was conducted in a context where palliative care services are often limited, and where cultural beliefs and healthcare system constraints significantly shape patient experiences. Within this setting, patient-centred communication and shared decision-making remain emerging practices.

Findings from this study revealed that several participants felt the information they received about their illness was unclear or incomplete. This made it hard for them to understand what healthcare professionals were saying, causing confusion and anxiety about their diagnosis and treatment plans. Because of this lack of clear communication, some patients sought help outside the hospital from traditional healers and religious leaders to better understand their condition and receive emotional and spiritual support.

Good communication and clear information in palliative care are essential for addressing patients' needs, supporting shared decision-making, and building trust. However, despite its importance, studies have shown that communication in palliative care remains challenging. Some healthcare providers worry that sharing difficult information might emotionally distress patients, while others are unsure about how to communicate effectively in these sensitive situations.[14,21]

The findings of this study, consistent with previous research, revealed that unclear and inconsistent communication caused confusion and uncertainty among patients, particularly when diagnoses were delayed and information about treatment options, prognosis, and care planning was lacking. This breakdown in communication left many patients with unmet informational needs, heightened emotional distress, and limited involvement in decision-making during a critical and vulnerable stage of their illness.[5,14] As revealed in this study, the absence of clear and sensitive communication prompted many patients to seek guidance and understanding from traditional healers or religious leaders. This highlights the strong influence of cultural values and beliefs in shaping how information about illness and end-of-life care is interpreted and communicated in settings like Rwanda. The findings emphasize that, in such contexts, patients often turn to alternative sources of support to make sense of their condition and navigate care-related decisions. Traditional healers and spiritual practices play a significant role in offering emotional and cultural support, particularly as illness is commonly understood as a disruption of spiritual or social harmony. However, the absence of formal recognition and integration of these practices into the healthcare system may contribute to delays in seeking medical care and limit timely access to appropriate palliative services.[7,22]

This study highlighted the key role of physician–patient communication in shaping patients' emotions and understanding of their illness. Patients' reactions to serious news depended on how, when, and how sensitively the information was delivered. Compassionate, culturally appropriate communication improved patients' understanding and emotional resilience. These findings align with previous research showing that patients respond differently to serious diagnoses. Some feel relief, while others experience fear, denial, or distress based largely on how the information is presented and their emotional readiness. This underscores the need for clear, compassionate, and patient-centred communication to build trust, reduce anxiety, and help patients cope with complex and often difficult information.[14,23–25] Our study found that most patients had limited interactions with physicians, primarily due to the short amount of time allocated for conversations during clinical encounters.

This lack of time made it difficult for patients to express their concerns, ask questions, or participate meaningfully in decisions. These findings are consistent with broader research that identifies time constraints, high patient volumes, and lack of privacy as key barriers to effective communication in palliative care settings. Addressing these challenges is crucial for strengthening patient-centered care, building trust between patients and providers, and ensuring that care decisions reflect patients' values, goals, and preferences.[1,13,26]

In addition, the absence of dedicated palliative care services, combined with overcrowded hospital wards and shared patient rooms, significantly compromised patient privacy. These communication challenges are further intensified in many low-resource settings, where the absence of dedicated palliative care services, inadequate infrastructure, overcrowded hospital wards, and insufficient staff training collectively compromise patient privacy and hinder open, honest discussions between patients and healthcare providers.[13,15,17,26] Although many patients expressed a desire to be involved in decision-making within palliative care contexts, this review found that limited opportunities for participation often led them to place trust in physicians to make decisions on their behalf, particularly as their illness progressed. Several studies further suggest that when patients lack a clear understanding of their illness or available treatment options, they frequently defer decision-making to healthcare providers. This deference functions as a coping mechanism to alleviate the emotional burden associated with making complex and challenging healthcare decisions.[24]

Cultural beliefs significantly impact the dynamics of communication in healthcare settings, particularly in palliative care. In many societies, including those in low-resource contexts, doctors are traditionally viewed as the ultimate authority figures whose decisions are rarely questioned. This deep-rooted respect can lead patients and their families to adopt a passive role during consultations, limiting open dialogue and active participation in decision-making.[2,7,27]

Family members contribute significantly by delivering emotional, physical, and practical care in palliative settings. This study reinforces existing literature by highlighting how participants deeply recognize and appreciate the multifaceted role their families play. Emotional support from family provides comfort and helps patients cope with the psychological challenges of advanced illness. Family members also assist with daily care and decision-making. Their involvement improves patient well-being and quality of life.[13,28]

Strengths and limitations

This study's strength lies in the in-depth interviews conducted with 12 individuals living with advanced illness receiving palliative care, offering rich and personal insights into their experiences with healthcare communication and involvement in decision-making. Their accounts highlight the crucial role of clear and comprehensive information, supporting approaches that aim to empower patients through improved education and access to relevant knowledge. These findings provide valuable guidance for enhancing patient-provider relationships and increasing patient agency in palliative care. However, the study has limitations. Participants were recruited from a single hospital, which may affect the generalizability of the results to other settings or healthcare systems. Additionally, the absence of family members' perspectives may have limited a fuller understanding of the decision-making dynamics and communication processes. The findings may also be less applicable to patients with cognitive impairments, who may have difficulty expressing their preferences or participating fully in their care decisions.

Conclusion

This review highlights the central role of communication in supporting patient engagement in decision-making within palliative care. Participants emphasized the value of being actively involved in care decisions but reported significant gaps in the clarity and adequacy of information provided, particularly at the time of diagnosis and throughout the palliative care journey. Addressing these deficiencies through targeted communication strategies is essential for fostering meaningful patient engagement and ensuring that decisions align with individual values and preferences. These findings have important implications for healthcare professionals, policymakers, and stakeholders committed to improving the quality, responsiveness, and person-centered nature of palliative

Authors' contributions

Each author E.N., M.M., C.K., and F.M. made significant contributions to the research, including developing the concept, design, and analysis. E.N. and F.M. were responsible for writing the main manuscript, while C.K. and M.M. reviewed the text and table. All authors have reviewed the manuscript and approved the final version for publication.

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Competing interests

The authors declare no competing interests.

References

1. Back AL. Patient-clinician communication issues in palliative care for patients with advanced cancer. *J Clin Oncol.* 2020;38:866-76. https://doi.org/10.1200/JCO.19.00128
2. Care P, Svendsen SJ, Grov EK, Staats K. Patients ' experiences with shared decision making in home based palliative care - navigation through major life decisions. *BMC Palliat Care* . 2024;1-10. https://doi.org/10.1186/s12904-024-01434-2
3. Österlind J, Henoch I. The 6S-model for person-centred palliative care: A theoretical framework. *Nurs Philos.* 2021;22:1-10. https://doi.org/10.1111/nup.12334
4. 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 Heal Sci.* 2023;6:411-22. https://doi.org/10.4314/rjmhs.v6i3.14
5. Silva JLR da, Cardozo IR, Souza SR de, Alcântara LFFL de, Silva CMC da, Santo FH do E, et al. Transição para os cuidados paliativos: ações facilitadoras para uma comunicação centrada no cliente oncológico. *Reme Rev Min Enferm.* 2020;24:1-8. https://doi.org/10.5935/1415.2762.20200070
6. Ngwenya N, Crang C, Farquhar M, Rintoul RC, Mahadeva R, Calvert LD, et al. Communicating uncertainty: Contrasting the communication experiences of patients with advanced COPD and incurable lung cancer. *Fam Pract.* 2021;38:637-43. https://doi.org/10.1093/fampra/cmab024
7. Paladino J, Sanders JJ, Fromme EK, Block S, Jacobsen JC, Jackson VA, et al. Improving serious illness communication: a qualitative study of clinical culture. *BMC Palliat Care.* 2023;22:1-11. Available from: https://doi.org/10.1186/s12904-023-01229-x
8. Roodbeen R, Vreke A, Boland G, Rademakers J, van den Muijsenbergh M, Noordman J, et al. Communication and shared decision-making with patients with limited health literacy; helpful strategies, barriers and suggestions for improvement reported by hospital-based palliative care providers. *PLoS One.* 2020;15:1-20. http://dx.doi.org/10.1371/journal.pone.0234926

9. Moreland PJ, Rosa WE, Uwimana P, Male MA, Sego R, Nankundwa E, et al. Palliative and End-of-Life Care Self-perceived Educational Needs of Physicians and Nurses in Rwanda. *Journal of Hospice & Palliative Nursing.* 2021;23:557-63.https://doi.org/10.1097/NJH.0000000000000794
10. Dandadzi A, Chapman E, Chirenje ZM, Namukwaya E, Pini S, Nkhoma K, et al. Patient experiences of living with cancer before interaction with palliative care services in Zimbabwe: A qualitative secondary data analysis. *Eur J Cancer Care (Engl).* 2022;31:1-16. https://doi.org/10.1111/ecc.13632
11. Lubuzo B, Ginindza T, Hlongwana K. Exploring barriers to lung cancer patient access, diagnosis, referral and treatment in Kwazulu-Natal, South Africa: The health providers' perspectives. *Transl Lung Cancer Res.* 2019;8:380-91.https://doi.org/10.21037/tlcr.2019.08.17
12. Li J, Luo X, Cao Q, Lin Y, Xu Y, Li Q. Communication Needs of Cancer Patients and/or Caregivers: A Critical Literature Review. *J Oncol.* 2020;2020. https://doi.org/10.1155/2020/7432849
13. Engel M, Kars MC, Teunissen SCCM, Van Der Heide A. Effective communication in palliative care from the perspectives of patients and relatives: A systematic review. *Palliat Support Care.* 2023;https://doi.org/10.1017/S1478951523001165
14. Collins A, Gurren L, McLachlan SA, Wawryk O, Philip J. Communication about early palliative care: A qualitative study of oncology providers' perspectives of navigating the artful introduction to the palliative care team. *Front Oncol.* 2022;12:1-11.https://doi.org/10.3389/fonc.2022.1003357
15. Namukwaya E, Nabirye E, Dandadzi A, Akeju D, Adejoh S, Namisango E, et al. "From the Time You Start With them Until the Lord Calls You": A Qualitative Study on the Experiences and Expectations of People Living with Advanced Cancer Interacting With Palliative Care Services in Uganda, Nigeria and Zimbabwe. *J Pain Symptom Manage.* 2022;64:588-601.https://doi.org/10.1016/j.jpainsymman.2022.08.022
16. Nassif R. Navigating cultural diversity and conversation barriers in palliative care: a mini review. *Hosp Palliat Med Int J.* 2023;6:74-9. https://doi.org/10.15406/hpmij.2023.06.00220
17. Wabl CA, Athanas R, Cubaka V, Mushi B, Ngoma M, Nsabimana N, et al. Serious Illness Communication in Cancer Care in Africa: A Scoping Review of Empirical Research. *JCO Glob Oncol.* 2022;8:47-47. https://doi.org/10.1200/GO.22.53000
18. Ntizimira C, Deo MS, Dunne M, Krakauer E. Decolonizing end-of-life care : lessons and opportunities. *ecancermedicalscience.* 2022;6-8. https://doi.org/10.3332/ecancer.2022.ed121
19. Ector GICG, Hermens RPMG, Blijlevens NMA. Filling the gaps of patient information and comprehension. *Curr Opin Oncol.* 2020;32:262-8. https://doi.org/10.1097/CCO.0000000000000633
20. Hossain MS, Alam MK, Ali MS. Phenomenological Approach in the Qualitative Study: Data Collection and Saturation. *ICRRD Qual Index Res J.* 2024;5:148-72. https://doi.org/10.53272/icrrd.v5i2.4
21. Gerwing J, White AEC, Henry SG. Communicative Practices Clinicians Use to Correct Patient Misconceptions in Primary Care Visits. *Health Commun.* 2023;00:1-16. Available from: https://doi.org/10.1080/10410236.2023.2283658
22. Tan M, Otake Y, Tamming T, Akuredusenge V, Uwinama B, Hagenimana F. Local experience of using traditional medicine in northern Rwanda : a qualitative study. *BMC Complementary Medicine and Therapies.* 2021;5:1-11. https://doi.org/10.1186/s12906-021-03380-5
23. Swenne J, Nissen RD, Hansen TF, Jensen LH, Søndergaard J, Stie M. Lived experiences of life with newly diagnosed advanced cancer-a qualitative interview study. *Int. J. Qual. Stud. Health Well-being.* 2025. https://doi.org/10.1080/17482631.2025.2453296

24. Stephens E, William L, Lim LL, Allen J, Zappa B, Newnham E, et al. Complex conversations in a healthcare setting: experiences from an interprofessional workshop on clinician-patient communication skills. *BMC Med Educ.* 2021;21:1-8. https://doi.org/10.1186/s12909-021-02785-7
25. Cerqueira P, Pereira S, Costa R. Unlocking Team Potential : Mastering Communication in Palliative Care. *cureus* .2024;16. https://doi.org/10.7759/cureus.74417
26. Stenman T, Rönngren Y, Näppä U. " Unless someone sees and hears you , how do you know you exist ?" Meanings of confidential conversations - a hermeneutic study of the experiences of patients with palliative care needs. *BMC Nursing.* 2024;1-12. https://doi.org/10.1186/s12912-024-01988-9
27. Rn LK, Hupli CM. Patient participation in shared decision-making in palliative care -an integrative review. *wiley.* 2021;3415-28. https://doi.org/10.1111/jocn.15866
28. Kusi G, Boamah Mensah AB, Boamah Mensah K, Dzomeku VM, Apiribu F, Duodu PA, et al. The experiences of family caregivers living with breast cancer patients in low-and middle-income countries: A systematic review. *Syst. Rev. BioMed Central*; 2020. https://doi.org/10.1186/s13643-020-01408-4