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IMPROVING PALLIATIVE CARE ACCESS IN RURAL MALAWI: INSIGHTS FROM A MIXED-METHODS EXPLORATION OF STRUCTURAL AND SOCIAL DETERMINANTS.

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Abstract

Introduction:

Globally, an estimated 56.8 million people require palliative care each year, with half in their final year of life. However, access appears to be scarce in the most impoverished settings, like rural sub-Saharan Africa. Africa is expected to experience a sharp rise in severe health-related suffering, underscoring the need to increase access to palliative care.

Methods:

A convergent parallel mixed-methods design was conducted to assess factors affecting palliative care access and utilisation in rural Malawi. Interviews using a question guide were conducted with patients, caregivers, and service providers to examine experiences in palliative care access and service utilisation, and the analysis used thematic content analysis. Electronic medical data were extracted, de-identified, and analysed using STATA software version 18.0 from nine palliative care implementing facilities using descriptive statistics.

Results:

Electronic medical records were analysed with 204 patients enrolled in the program. The mean age was 58.6 years, and 47% (n = 96) were aged 65+. Females predominated, comprising 65% (n = 132) of the enrollees. 72% (n = 139) of the patients lived more than five kilometres from the nearest clinic. Analysis of forty-four key informants' interviews highlighted the importance of health system and facility management, structural and contextual determinants of healthcare access, and community-based care and household health determinants, which play a central role in program management and coordination, community

health worker (CHW) engagement, and availability of essential supplies plays a central role in service accessibility and utilisation.

Conclusion:

The findings from the study highlight the importance of addressing social determinants of health, supporting community-based health workers, and strengthening local leadership to improve palliative care access. Provider support and locally adapted strategies can facilitate the delivery of palliative care services in hard-to-reach settings. While these insights are drawn from a single district and may not be broadly generalizable, they provide context-specific guidance for program managers and policymakers aiming to enhance palliative care access and utilisation in similar low-resource settings.

Key Terms: Community health worker, Health Service Accessibility, Malawi, Mixed-Method, Palliative care, Resource-limited setting.

Introduction

The World Health Organisation (WHO) describes palliative care as an essential component of comprehensive care for individuals facing serious illnesses [1]. Global estimates indicate that 56.8 million people annually need palliative care, with about half of them in their last year of life; two-thirds (78%) of these individuals reside in low- and middle-income countries, where few have access, especially in impoverished rural areas. [2–4]. In Africa alone, 700,000 cancer-related deaths and over one million cases were reported in 2020 [5], with steady growth in cases and mortality expected in the coming decades [6]. By 2060, it is estimated that Africa will have the second-greatest proportional regional rise in severe health-related suffering [7] as the age of the population and prevalence of cancers and other non-communicable diseases continue to rise [8, 9].

In an assessment of the palliative care landscape in 198 countries globally between 2006 and 2013, the speciality was noted to have developed and evolved in many countries [10]. In most countries, the services have remained at tertiary and secondary-level facilities [11]. However, efforts to decentralise services to rural areas have shown promise in improving access and utilisation of care. For example, decentralisation of palliative care in Neno District was perceived to improve local service access and reduce travel burdens [12]. Decentralised chronic disease care models yielded increased utilisation at primary care centres [13], and decentralised ART services reduced travel distances and enhanced access for poorer patients [14]. The Government of Malawi is one example of a low and middle-income country (LMIC) that has committed to extending palliative care services to health centres through service decentralisation [12].

Despite these achievements, there is patchy evidence on access to care and service utilisation in rural settings for both adults and, even worse, for children [15]. Therefore, research is needed to investigate strategies that improve palliative care service accessibility in rural areas in Malawi. In this study, we explored strategies that enhance palliative care access and utilisation in one hard-to-reach rural district of Malawi, Neno, a remote district located in the southern region of Malawi, known for its poor road network and limited healthcare infrastructure.

Methods section

Study design

The study used a convergent parallel mixed-method approach to understand the palliative care service coordination and accessibility in rural Malawi [16, 17]. For the quantitative study, we collected retrospective data for palliative care from nine facilities providing palliative care from an electronic medical records database from January 1, 2022, to December 31, 2023. The qualitative component involved collecting primary data from service recipients and providers at three primary care facilities and two referral health facilities providing palliative care in rural Neno, Malawi, using an interview guide.

Study Setting

The study was conducted in Neno, Malawi, a rural district in southeastern Africa with an estimated population of 156,029 [18]. The majority of the population lives in the hardest-to-reach areas under abject poverty, with a poverty rate of approximately 75%, while barely surviving on subsistence agriculture as their primary source of income [19]. The district has two secondary-level facilities and 13 primary care facilities, of which nine provide palliative

care services.

Palliative care was introduced at Neno District Hospital, a referral hospital, in 2009 and expanded to Lisungwi Community Hospital, a referral hospital, in 2018. In 2022, services were further decentralised to seven health centres (see Figure 1). Health centres provide care for ambulatory patients in facility catchment areas at static clinics. Referral hospitals serve as central hubs, offering clinical oversight, direct care at static clinics within their catchment areas, and coordinating home visits for bedridden patients.

Patients are enrolled in the palliative care program based on clinical criteria, primarily those living with life-limiting illnesses such as advanced cancers, HIV/AIDS with complications, complicated non-communicable diseases, and progressive neurological conditions, as well as those with curable conditions who require complex clinical care. Eligibility is determined through clinical assessment by palliative care providers at the health facilities.

Patients through the palliative care program are regularly assessed across physical, psychosocial, spiritual, and socioeconomic domains. Those needing psychosocial, spiritual, and economic support are referred to appropriate programs based on their needs, including religious groups or the Program on Social and Economic Rights (POSER), a program by a local non-governmental organisation that offers socioeconomic assistance to patients.

Sampling and Recruitment

Quantitative: The quantitative study examined all electronic patient medical records enrolled in palliative care between January 1, 2022, and December 31, 2023, and, during data collection, had been entered in electronic medical records.

Qualitative: Purposive sampling was used to identify information-rich participants with deep

experience with the palliative care system. We sampled providers from healthcare centres and referral sites to ensure variation among healthcare workers. We included a range of professionals, including nurses, clinicians, community health workers (CHWs), CHW site supervisors, and POSER officers. Patients and caregivers were sampled in equal numbers from across three facilities to ensure a wide range of experiences with the program. The health centre supervisors identified providers, patients, and caregivers; the supervisor scheduled interviews with providers, and CHWs scheduled interviews with patients and families.

Data collection

Quantitative: The study extracted and de-identified all data from electronic medical records of patients enrolled in the palliative care program from nine health facilities in the district and entered the de-identified data into a Stata Software V.18 database.

Qualitative: Interviews were conducted using a self-developed semi-structured interview guide (Appendix A) that was informed by the Social Determinants of Health framework (SDH). The framework guided the formulation of interview domains and questions to examine how structural, social, and contextual factors influence access to and utilisation of palliative care in rural Malawi. Specifically, questions were mapped to key SDH domains, including socioeconomic conditions (e.g., livelihood constraints), physical environment (e.g., distance and transport), social context (e.g., family and community support), and health system factors (e.g., service availability and organisation). Guides were developed in English and translated into Chichewa by AP, a clinician experienced in palliative care service delivery in Neno district, with the assistance of a research assistant and a nurse coordinator for the palliative care program. All interviews were conducted in Chichewa by trained research assistants. Some participants were previously known to the research assistant, as were all health workers;

however, the research assistant did not know in advance who would be interviewed. For participants who were known, a brief standardised introduction was used to clarify roles and emphasise voluntariness. All participants were informed during the consent process that participation was voluntary and that confidentiality would be maintained, minimising potential coercion or bias. Patient and caregiver interviews took place at health centres, and service provider interviews were conducted in private offices at their places of work. All interviews were audio-recorded with permission from the participants and lasted between 45 and 90 minutes. The research assistant simultaneously transcribed and translated the audio recordings into English.

Data analysis

Quantitative: The study used descriptive statistics to analyse participants' demographics to develop descriptive reports using Stata Software V.18, reported frequency tables, and distribution between variables.

Qualitative: Analysis of interview data used an inductive, thematic, content analytic approach to develop conceptual categories representing service providers' and recipients' experience in palliative care service utilisation [17]. AP -coded a subset of interviews to identify key concepts related to palliative care access and utilisation. Open codes were reviewed with HG, an expert in qualitative research, and used to formulate a draft codebook, which was piloted by AP and the research assistant. The codebook was revised by AP and HG based on feedback from the pilot. All transcripts were coded with Dedoose qualitative data management software version 9.2.22. Following an inductive, thematic approach, the coded data were analysed to formulate an initial set of descriptive categories that represent respondents' experiences with care delivery [20]. HG and EW, global and public health specialists with five years of

experience working in Neno, reviewed the initial categories. Any discordant views were resolved through discussion. Using an iterative approach, AP returned to the coded data to revise the initial set of categories, using an iterative review approach to develop a series of overarching themes and subthemes (Appendix B) that are presented in the results section below [17, 21]. EW provided continuous oversight to ensure rigour and quality. In the final report, the study adhered to the guidelines provided by the "Consolidated Criteria for Reporting Qualitative Research" (COREQ) [22].

Integration of results

Using a convergent parallel mixed-methods design, qualitative and quantitative data were analysed concurrently, with each dataset analysed independently. Integration occurred at the interpretation stage through triangulation, consistent with COREQ guidance on qualitative rigour and transparency.

The quantitative component provided descriptive insights into service access and utilisation; however, missing data limited multivariable analysis and statistical inference. Convergence was therefore not based on statistical corroboration but on interpretive complementarity. Quantitative descriptive trends related to geographic access, clinical encounters, and patient characteristics were examined alongside qualitative findings.

The qualitative data, reported in accordance with COREQ criteria, offered an in-depth understanding of lived experiences and contextual factors influencing palliative care delivery, including caregiver burden, health worker motivation, and informal social support systems. These findings contextualised and expanded the quantitative results, strengthening the credibility and explanatory depth of the integrated analysis despite limitations in the

quantitative dataset.

Results

Quantitative results

204 palliative care patients were enrolled between January 2022 and December 2023. The mean age was 58.6 years (SD = 23.20), with nearly half (47%, n = 96) aged 65+. Females predominated at 65% (n = 132). Approximately 72% (139/194) of patients lived more than 5km from the nearest healthcare facility. Enrolment was higher in 2022 (n = 117/203), and around 20% (31/151) of enrollees had multimorbidity (Table 1).

Table 1. *Sociodemographic characteristic information for new enrollments in palliative care programs between 2022 and 2023 (N = 204)*

Variable	**n**	**%**
Age		
< 18 years	15	7
18-64 years	93	46
65+ years	96	47
Sex*		
Males	71	35
Females	132	65
Nearest referral facility		
Neno District Hospital	85	42
Lisungwi Community Hospital	119	58
Distance to the nearest clinic in kilometres[1] (km)*		
> 5 km	139	72
≤ 5 km	55	28
Number of clinical palliative care encounters per year*		
> 4 visits	36	22

[1] Maximum walking distance of 5 km to a health facility is recommended by the World Health Organisation [WHO]. Accessibility of healthcare in rural Zimbabwe: The perspective of nurses and healthcare users - PMC.

≤ 4 visits	129	78
Year of enrolment in palliative care program*		
2022 enrollees	117	58
2023 enrollees	86	42
Diagnosis by disease category*		
Cancer	30	16
Cardiovascular Condition[2]	74	41
Gastro-Intestinal[3]	12	7
Neurological Condition[4]	25	14
Chronic Respiratory	6	3
Non-Specific conditions[5]	35	19
More than one multimorbidity*		
Yes	31	17
No	151	83
Clinical outcome documented		
Lost to follow-up	10	5
On treatment	46	23
Died	30	13
Missing data	118	58
Mean duration in care, months (SD)	median	25th -75th IR
Alive	14.7	1.0 - 24.1
Deaths	2.4	1.0 - 6.7

Qualitative Results

Participant Characteristics

The study included 44 participants: nine patients, nine caregivers, one program coordinator,

[2] These are all conditions that are related to heart problems, and these include hypertension without complications and heart disease.

[3] These are conditions that affect the gastrointestinal organs, such as liver cirrhosis, hepatocellular carcinoma, etc.

[4] Neurological conditions impair normal nervous system function and include disorders such as cerebral palsy and stroke.

[5] These conditions did not have a code in the palliative care program and were registered as "Others." The conditions included Arthritis, Fractures, Sickle cell disease, etc.

* Numbers not adding up to 204 reflect missing data.

seven nurses, five clinicians (referral and health centre), two POSER officers, eight CHWs, and three CHW site supervisors. Patients were the oldest group, averaging 67.8 years, with most having primary or no formal education and 6.3 years of illness. Caregivers were younger (32.9 years on average), primarily female (78%), with primary education, and had an average of six years of caregiving experience. Nurses and clinicians had an average age of 34.5 years, all received tertiary education, and had an average of 4.9 years of experience. Other program staff were on average 43.4 years old, and nearly 62% (n = 8) were males, with varied education levels and over 10 years of experience. For more information, please see Table 2.

Table 2 Sociodemographic characteristic information of Palliative Care Study Key Informant Interviews (n = 44)

Category	Summary statistics			
Variable	Patients (n = 9)	Guardians (n = 9)	Other program staff[6] (n = 13)	Nurses and Clinicians (n = 13)
Age				
Mean	67.8	32.9	43.4	34.5
Range	47 - 92	23 - 46	30 - 56	28 - 47
Sex				
Male	5	2	9	8
Female	4	7	4	5
Education				
Never	3	-	-	-
Primary	4	8	2	-
Secondary	2	1	10	-
Tertiary	-	-	1	13
Experience in years of providing care	-	6.00	10.23	4.85
Range	-	1-13	2-16	0.08 - 16
Experience of Suffering	6.33	-	-	-

[6] These included community health workers (CHW), CHW site supervisors, and POSER officers.

Range	1-13	-	-	-

The inductive analysis yielded three key themes: Facility Leadership and Operational Management, structural and contextual determinants of healthcare access, and community-based care and household health determinants, as further presented in sections A, B, and C below.

Presentation of Themes

A. Facility Leadership and Operational Management

Leadership and facility management: Participants described the importance of a designated focal person who combined *leadership* (providing strategic direction and prioritising palliative care within the facility) with day-to-day management responsibilities. These individuals acted as a link between referral sites and facility teams, facilitating communication, coordinating service delivery, and supporting access to care. Their managerial roles included coordinating CHWs, ensuring the availability of medicines and supplies, scheduling clinic staff, submitting reports, and resolving operational challenges. Participants noted that where focal persons were proactive in both leadership and management functions, services were more accessible and better coordinated. Conversely, limited engagement in these roles was perceived to contribute to lower enrolment and reduced service availability.

> *"Yes, but basically, the challenge we face is the coordination among the facility members. You will find that providers are helping one another in other facilities, but in some, they are not. I would give an example of the Health Centre [name withheld], where a lack of coordination affects enrolment and service delivery."* Service provider, male, 29 years.

Communication: Participants highlighted that inter-departmental communication and referrals play a crucial role in facilitating good clinical decision-making and effective service delivery within the continuum of care. Regular communication channels include phone calls (though costly), text messages, physical engagement (one-on-one), or documentation through referral forms.

> *"Okay, for health centres, we have been using phone calls where I communicate with patients or fellow healthcare workers in the health centres. This cost me a lot; as usual, the patients would flash you so that you could give them a call. This is a challenge since I do not get airtime to call patients or fellow providers and coordinate patient care."* Service provider, female, 29 years.

Participants recognised that these forms of communication facilitated both bottom-up and top-down communication. They noted that communication along these referral pathways was essential throughout service delivery. Providers, particularly those close to the patient, are perceived as untrustworthy or dishonest when these pathways break. This tension was considered a challenge in palliative care delivery, as some participants explained that it took them more time to build trust with fragile patients than to lose it.

> *"Sometimes I know the clinical team fails to come and conduct home visits, as it is due to the bad weather conditions on this side, but other times, the reasons are unclear. These [trip postponement] affects the trust that we build with our clients because if the clinical team fails to show up, we are seen by the clients as liars."* Service provider, female, 47 years.

Supply management and continuity: The availability of essential supplies, including

medications, was fundamental to ensuring uninterrupted healthcare, promoting drug adherence, and achieving symptom control in palliative care patients. Providers used various strategies to ensure that medicine and supplies did not run low. They used home visits as an opportunity to monitor supplies and partnered with caregivers to report potential stock-outs. When providers anticipate a delay between appointments, they provide patients with additional supplies to carry them over until their next appointment.

> *"So, we have been using community health workers close to their communities, or encouraging* caregivers *to come to collect supplies when they notice that the supplies are about to finish. We have also been giving [patients] more supplies than the scheduled time for the following review as a cover-up."* Service provider, male, 47 years.

Development of Workforce Capacity: Participants noted that mentorship, supervision, and training ensure continuous skill transfer and capacity building among healthcare providers, strengthening service delivery. Mentorship and supervision took place through field visits, where mentors engaged health workers in supervisory exercises and refresher training using formal materials such as training manuals, posters, and other IEC materials. Through these site visits, supervisors could identify areas for improvement and devise follow-up plans. Health workers noted that in addition to regular supervisory field visits, they appreciated that mentors made themselves available via phone calls or WhatsApp groups. The availability of supervisors helped healthcare workers feel confident in their skills, which they describe as "helpful" and "motivating."

> *"With the [the district team], whenever we need something, we always call them. Besides that, they sometimes come for supervision and data assessment when free. So,*

that is how we work with them. Sometimes, we do interact through WhatsApp forums, but they are always there for us." Service provider, male, 37 years.

B. Structural and Contextual Determinants of Healthcare Access

Home visits: Within this theme, home visits are discussed as a formal, provider-led service delivery mechanism, shaped primarily by health system capacity, logistics, and inter-facility coordination. Participants agreed that regular appointments for patients with life-limiting conditions were essential for symptom management and treatment adherence. However, provider availability, transport challenges, and system inefficiencies hindered successful regular clinical reviews. Home visits were often conducted by providers working at the referral facilities, who were already overstretched with facility-based responsibilities. Poor road conditions, challenging topography, and insufficient funds for fuel made it difficult for them to travel to patients' homes. A lack of coordination between referral site teams and health centre teams exacerbated the problem of missed appointments, leaving some patients with no supplies. Participants suggested empowering health centres to conduct home visits, improving coordination and patient care for the home-bound population.

"*If we look at palliative care in Neno, statistically comparing the numbers, we will realise that the number of patients has increased, especially those home-bound. So, conducting home visits is becoming a challenge for us. We can have about 14 to 16 patients scheduled for home visits daily, which is not feasible. So, sometimes, we fail to review all of them. In the future, if there is a consideration [for health centres] to provide home-based care in transport and other logistics, that would be better."* Service provider, female, 40 years.

Incentives: Participants noted that programs that provided financial rewards in health centres were attracting providers' attention more than those without incentives. Allowances were the main reward these providers would get after working away from their duty station. While healthcare workers were obligated to work according to their standard salary and attend all facility-level services, healthcare staff preferred paid program activities over others that do not have financial incentives, such as palliative care.

> *"We also need motivation to do home visits. If we can have enough allowances and refreshments when doing home visits, that can help a lot. So, we ask for consideration on that from the Coordinator."* Service provider, female, 28 years.

C. Community-Based Care and Household Health Determinants

Social and household-level support: This refers to the broader network of formal and informal support within patients' households and communities, extending beyond clinical encounters to address social, psychological, and material needs. Social support was seen as a crucial service for patients at the terminal stage of life. As patients were becoming more fragile in their disease trajectory, they became increasingly dependent on others for their social and daily life needs, including food, shelter, clothing, and companionship. When these needs were unmet, their quality of life was compromised, leading to what participants described as "stress" for patients. Participants noted that failure to address these basic needs impacted the delivery of holistic care at the end of life. Some patients turned to informal community support to address the burden, including church members, who provided clothes, food, blankets, and other essentials.

> *"In addition [to physical support], we have some clients who can barely do anything to earn a living. I would love to see such clients being helped with enough*

socioeconomic support to sustain patients' lives." Service provider, female, 30 years.

Support system: Participants noted that palliative care patients required a sound support system at home for better psychological, social, and coordinated care. These support systems were viewed as either formal, where providers receive training on delivering the service regarding palliative care principles, or informal, where providers provide services to patients without formal palliative care training. This informal care was seen as vital for patients. However, participants were concerned that informal supporters lacked the training to equip them with the necessary skills to appropriately manage patients in the community.

> *"Most of our faith organisations are unaware of the palliative care concept; all they know is that they preach to their congregants. These leaders need to understand these concepts to serve their communities better. They need orientation training in palliative care."* Service provider, male, 32 years.

The informal support system played a significant role in helping the patient navigate their disease trajectory within the community. Their support was particularly valued when they faced discrimination or bullying in their communities. Some patients faced "trauma and were dehumanised," and informal providers were crucial in providing psychosocial first aid to the patients.

> *"It hurts me, so I even called the village Chief and told him to talk to these people who were saying bad things about me. The words they said to me made me overthink, and I want to commit suicide by hanging myself or taking a particular medication. So, the chief came and talked to the people, and things changed after he talked to them. Now, they have started showing me some love. They can chat with me now despite*

everything they had said previously." Patient, female, 71 years.

Services closer to home: Services closer to home describe how decentralised care delivery, particularly through CHWs and locally accessible providers, enhanced continuity, trust, and culturally responsive care from the patient and caregiver perspective. Home visits by healthcare providers and CHWs within the patient's local setting facilitated service accessibility, fostering trust and enabling more personalised, culturally appropriate care. During home visits, CHWs reminded patients of their next appointment date, assessed compliance with treatment, and checked for remaining supplies. In addition to assessing living conditions, they also identified patients who needed further assistance. Nurses and clinicians assessed patients' living conditions, reviewed patients' conditions, changed prescriptions, and provided medical supplies, recognising that these issues were crucial for enhancing the quality of care to patients.

"In 2007, she began coughing, had diarrhoea, and faced other health issues. That was around the same time as I was dealing with my health problems. Thankfully, a community health worker played a huge role in helping us. She called an ambulance and accompanied us to the hospital, even though people mocked her for helping someone [my mother, whom] they thought would not survive." Caregiver, female, 37 years.

Discussion

The findings from the study highlight the importance of addressing social determinants of health, supporting community-based health workers, and strengthening local leadership to improve palliative care access in rural Malawi. The results highlight the important role of social support networks, program management and coordination, provider motivation,

community health worker engagement, and availability of essential supplies as key to service access and utilisation in rural areas. Lack of transportation, challenging terrain, and distance to health facilities hindered access and utilisation. The analysis underscores the impact of social, structural, and geographic factors on care access and utilisation. These interconnected elements reflect the need for a holistic, patient-centred approach to improve decentralised, highly coordinated, equitable access and enhance service utilisation in low-resource contexts.

This study revealed that social support influenced patients' quality of life during advanced illness. Qualitative results highlighted that the patient needed food, shelter, and companionship most. This study's findings align with previous studies on cancer patients receiving palliative care in Bangladesh, showing strong correlations between perceived social support and improved mental health outcomes, reduced symptom burden, and enhanced coping among palliative care patients [23]. Addressing these social determinants is thus compassionate and essential to delivering equitable, holistic palliative care in resource-limited settings. Therefore, there is a need for program managers and policymakers to consider allocating adequate resources for the improved mental well-being of palliative care patients.

The study highlighted the critical gap in enhancing symptom control, drug adherence, and addressing daily needs among palliative care patients. It reinforced these results by revealing that proximity fostered trust between patients and providers who resided closer to them. Community health workers (CHWs) played a critical role in bridging the gap by offering timely interventions and prompt communication to the next level of care, especially where transport and staffing limitations hindered routine patient reviews. The qualitative results demonstrated how using CHWs ensured patients have enough drugs for symptom control and other challenges patients face daily by reminding patients of their subsequent appointments

and reporting challenges to health centre providers. These results are consistent with the literature showing that CHWs effectively provide healthcare services in rural settings with limited resources [24, 25] and improve patient treatment outcomes [26]. However, to ensure consistency and maximise their use, CHWs need capacity building, as most of them lack fundamental knowledge and channels for communication and coordination with the palliative care team.

Facility-level leadership emerged as an important *enabling factor* influencing access to palliative care services rather than a direct indicator of service effectiveness. Qualitative findings showed that designated focal persons supported access by coordinating referrals, facilitating communication between referral sites and peripheral facilities, and ensuring continuity of services, thereby shaping how patients navigated the health system. Consistent with findings from a study in Kenya by Seims *et al*, which suggests that effective local leadership strengthens coordination, supervision, and provider support, which may indirectly improve service accessibility in resource-limited settings [27–29]. Within this study's scope, leadership functioned as a contextual determinant of access by influencing organisational processes, suggesting that strengthening facility-level management through clear role definition, mentorship, and supportive accountability may help reduce operational barriers to palliative care access in rural settings [30–32].

These findings from the qualitative results suggest that lack of transport, home visits conducted by overstretched staff, harsh weather in some parts of the district, and poor topography are major contributing factors making it hard for patients to have access and improve utilisation. This finding is consistent with existing evidence indicating that geographic barriers adversely affect health service utilisation, particularly for patients

requiring regular follow-up care [33, 34]. As suggested by one of the participants, a potential strategy in addressing these spatial challenges is to decentralise home visits to health centres so that the nurses and clinicians in the peripheral facilities could take charge. These innovative solutions can help provide equitable access to care, mitigate the impact of distance [35, 36] and improve access and service utilisation.

The study revealed that nurses and clinicians in the health centre need motivation to remain engaged in programming activities, including home visits. Highlighting that motivation is key in influencing palliative care accessibility and utilisation, as providers are willing to go out for home visits and reach out to home-bound patients. These findings align with another study that reported intrinsic and extrinsic rewards, such as salary increases, training and allowances, boost healthcare workers' morale and engagement [37, 38]. According to qualitative results, there is a need for the program to have a constant provision of essential medicines and supplies, on-the-job training, staff recognition, and supervision, and Reid *et al.* further point out that this boosts motivation [39]. Therefore, program managers need to incorporate intrinsic (non-financial) factors besides the financial incentives in palliative care programming, such as training, staff recognition, etc., to improve and sustain providers engaged in service delivery, which would improve access and utilisation of care.

Limitations

We examined 204 patient databases from electronic medical records, which had much missing data on variables of interest. This compromised the extent to which quantitative analysis was done and may have affected the reliability of quantitative findings, as we could not do stepwise logistic regression analysis to predict the outcome. However, using a mixed method, particularly interviewing service recipients (patients and caregivers) and service providers, our

data captured various experiences at the community, local facility, and district levels.

The study was conducted in a single and one of the poorest districts in the country, which limits generalisability; however, it provides insights that could be replicated in similar rural settings. We also acknowledge the potential for selection bias in the qualitative sample, as facility in-charges were involved in identifying and recruiting participants. Their choices may have shaped the perspectives represented in the interviews. To mitigate this, we used purposive sampling across different cadres and sites to ensure diversity in views.

We acknowledge that the positionality of the principal investigator, as both a clinician and researcher in Neno, may have influenced the interpretation of findings. To minimise this, the study team incorporated multiple perspectives during coding and analysis, engaged in reflexive discussions, and documented analytic decisions to ensure transparency and rigour.

We also acknowledge that patients, family caregivers, and healthcare workers could have brought distinct perspectives to issues of palliative care access and utilisation if their views were seen separately. But our decision to report their narratives together was guided by the use of inductive content analysis allowed us to identify cross-cutting themes and subthemes that reflected systemic and multi-level determinants of access.

Conclusion

This study highlights critical insights into facility-level leadership, social support, community health worker engagement, motivated providers, and essential supplies in promoting palliative care access and utilisation in rural Malawi. The evidence underscores that geographic and structural barriers, including poor terrain and long distances, limit equitable access. Notably,

the analysis advocates for a holistic and integrated approach that addresses social determinants, invests in community-based human resources, strengthens local leadership, and ensures consistent provider support. Program managers and policymakers must embed these strategies into programs to improve palliative care access and utilisation in low-resource settings. Future researchers should, however, consider employing longitudinal prospective design studies to evaluate factors that affect service utilisation in palliative care and guide policy reforms for optimised palliative care in low-resource settings.

List of abbreviations

CHW – Community Health Worker

COREQ – Consolidated Criteria for Reporting Qualitative Research

HIV/AIDS – Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome

IEC – Information, Education, and Communication

IRB – Institutional Review Board

LMIC – Low- and Middle-Income Countries

MMSc-GHD – Master of Medical Science in Global Health Delivery

NHSRC – National Health Sciences Research Committee (Malawi)

PIH/APZU – Partners In Health / Abwenzi Pa Za Umoyo

POSER – Program on Social Economic Rights

RA – Research Assistant

WHO – World Health Organisation

Declarations

Ethics approval and consent to participate.

The study received ethical approval from the Harvard IRB protocol # IRB24-0272, dated April 5, 2024; the Neno District Health Office, letter dated May 6, 2024, to conduct the study in the Neno District, and the NHSRC protocol # 04/07/4455, dated August 23, 2024. Furthermore, the ethical principles in the Declaration of Helsinki [40] were followed so that all participants were informed about the study's aim and objectives through the RA, who shared the information sheet by reading aloud in the presence of the witness. Participants were then provided with their consent to participate by signing or providing a thumbprint on the consent form, which the witnesses were also asked to sign. The witnesses were present only during the consent signing process and were asked to move during interviews to maximise participant confidentiality. The participants were given a unique identifier to protect their identity, and the study team conducted themselves with good clinical practice training.

Consent for publication

Not applicable

Availability of data and materials.

The data supporting the conclusions of this article are provided as additional files. Documents required to replicate this study are available from the corresponding author upon reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

AP was involved in conceptualisation, study design, and analysis, and drafted the manuscript. AP and HG developed the codebook (Appendix B), and AP, HG, EK, MH, and CM provided guidance and feedback during data collection, analysis, and manuscript writing. EW supervised the whole project from conceptualisation to report and manuscript writing. All authors read and approved the final manuscript.

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