The changing dynamics of community care and support in rural Malawi: The impact on Women's health and wellbeing at end of life

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Highlights

- Malawi is one of few countries in the world with a national palliative care policy.
- Examined women's experiences receiving end of life care and their caregivers in Malawi.
- Community care affected women's health and wellbeing at end of life.

Abstract

In this critical ethnographic study, we examined women's end of life experiences in Malawi, one of the few countries in the world with a national palliative care policy. Specifically, we explored how women's and their caregivers' experiences were shaped by family and community care, and material needs. Interviews and observations with female clients of a non-governmental organization in rural Central Malawi, and with their caregivers, revealed that community-level support was both precarious and critical. We found three main themes: (1) *I stay with them well*, (2) *we eat together*, and (3) *everyone is for themselves*. The analysis illustrates the centrality of community care, social in/exclusion, and availability of stable food, shelter, medical, and caregiving resources on health and wellbeing at end of life. We provide recommendations to strengthen community care opportunities and women's resource bases.

Keywords: Malawi; Palliative care; End of life care; Community care; Qualitative research; Critical ethnography

1. Introduction

Similar to its neighbors in sub-Saharan Africa, Malawi faces several intersecting transnational crises, including widespread food insecurity, agricultural precarity worsened by climate change, the impacts of structural adjustment, and multiple pandemics (e.g., HIV/AIDS, malaria, and presently COVID-19). These crises injure people directly. They also affect health services, health policies, and patterns of care upon which people rely. As communities face increasing stresses, how do their multiple burdens affect care for the vulnerable at life's end?

Scholarship on palliative care in African contexts initially focused on inpatient services. The HIV/AIDS epidemic produced a rapid increase in numbers of people in need of end of life care, and a simultaneous severe strain on health-care facilities. Inpatient wards could not keep up; and outpatient clinics could not provide all needed services (Lamas and Rosenbaum, 2012). Policymakers increasingly recognized that home- and community-based care, which had always been important, were key to managing overwhelming demand for palliative care (Court and Olivier, 2020).

Yet, care, perhaps especially as life's end nears, is often provided by unpaid family members (see e.g. Dilger, 2012). Women and children provide most bodily care, while men are often important financial resources. Literature shows some ambivalence about the work of end of life care. Care can be a tremendous strain on financial, emotional, and labor resources, and when resources are severely limited, families are sometimes forced into difficult triage decisions (Dilger, 2005; Herce et al., 2014). However, care is also an expression of love and of interdependence. It can be a pathway to belonging for people who are otherwise in marginal positions (Brown, 2014).

This robust body of scholarship has tended to explore the impact of end of life care on families. A separate literature has explored the socio-cultural patterns of care. Much of this literature views care as the product of human rationalism driving cooperative and/or competitive relations amongst different groups of people. Townsend, Aktipis, and Cronk (2021) review the anthropological literature on care, scarcity, and patterns of sharing behaviors and conclude that across societies and cultures, when people live under conditions of cyclical, short-term scarcity, they often develop redistributive practices that help assure access to needed resources for all; however, under conditions of extreme hunger and physical precarity, mutual aid practices may disappear as people fight for their own survival, in competition with those around them for limited resources.

Here we strive to situate the labor of palliative care in the community context, bringing together these diverse literatures on care-in-practice. We show how women's relationships and material realities intersect with communities' attitudes and practices to shape the experiences of women at the end of life, and to increase or decrease strain on caregivers.

Additionally, we describe how community care (or its lack) mattered to the health and wellbeing of women at end of life and their caregivers. The purpose of the larger critical ethnographic study, informed by feminist epistemology, was to analyze the physical, spiritual, and mental health needs of female palliative care patients in rural Malawi at end of life. In this article we describe the important role played by communities in meeting these needs—or exacerbating them. The lived experiences of the most vulnerable patients and their caregivers reveal both the strengths and increasing tensions that underscore questions of who cares for whom, where, and to what end, in countries affected by multiple predicaments like Malawi.

The article begins by describing Malawi's palliative-care situation and other important context. We then move to analyzing the lived experiences of female palliative-care patients and their caregivers and explaining four ways that community-level care mattered for their wellbeing.

2. Background

2.1. Palliative care in Malawi

Malawi is one of the few countries with a national palliative care policy (*Palliative Care*, 2014). The palliative care policy mirrors the World Health Organization (WHO) definition, which indicates the use of palliative care in patients with “life-threatening illness, through the prevention and relief of suffering applicable early in the course of illness, from the time of diagnosis, in conjunction with other therapies that are intended to prolong life and should not be associated with end-of-life-care” (Republic of Malawi, 2014, p. 10). Through the palliative care policy, the government of Malawi articulates a commitment to systematically providing palliative care to all its citizens in need of such care. While this definition of palliative care clearly articulates that palliative care should not be associated with only end of life care, the limited human and material resources in the healthcare system often results in patients being admitted to palliative care at the end of life (Mkandawire-Valhmu et al., 2020), and almost always in a home-based context.

Furthermore, in terms of mainstream palliative care services, as articulated in the palliative care policy, each district hospital in the country is required to have a designated officer who monitors how palliative care services are implemented. Malawi is divided into 28 districts for a population of 18 million people (Republic of Malawi, 2014). A district hospital thus serves thousands of patients, many of whom are attempting to access care from very remote communities, often by foot or by bicycle given resource limitations to access motor vehicle transportation. In Sub-Saharan Africa, it is currently estimated that less than 5% of the population in need of palliative care actually receive it (Downing et al., 2015). In Malawi, this 5% is partly covered through a few non-governmental agencies in the country that provide palliative care on a limited scale to patients within a specific geographic area, including the agency from which we recruited participants.

Moreover, as Malawi is at the epicenter of the HIV epidemic, the prevalence of HIV among those aged 15–49 is 8.1% (UNAIDS, 2020), characteristics of palliative care and how services have developed is mostly in response to the needs of patients living with HIV and AIDS-related illnesses. This includes the development of community home-based care which involves community health volunteers functioning under the auspices of faith-based or community organizations. The availability of such agencies and health volunteers varies and is also dependent on the communities and the strength of community leadership.

Furthermore, given limited resources and the strains on the healthcare system, the context of palliative care access in Malawi is one in which healthcare facilities often lack basic resources such as medications. As such, while morphine was readily available for the study participants who accessed the non-governmental agency where recruitment took place, morphine is not always available for all or at the recommended doses for patients at end of life across the nation (Tapsfield and Bates, 2011). Additionally, in the home-based context of palliative care in Malawi, this care often requires an unpaid caregiver, almost always female and usually a relative. Both caregivers and women at end of life are often strained due to a lack of resources to meet their needs (Mkandawire-Valhmu et al., 2020). Moreover, the literature also indicates that poverty and limited access to resources such as psychosocial support exacerbates not only patient suffering but also caregiver anxiety (Herce et al., 2014).

In terms of informal care, patients admitted to hospital are cared for by what is commonly known as a guardian, who is a family member present by the patient's bedside throughout the admission. Given the limitations in human resources within the healthcare facilities and the inability of nurses and nurses' aides to meet all patient care needs, the guardian provides the patient with basic care including toileting, bathing, and feeding. For patients at end of life, family members similarly provide the necessary care at home, bringing the patient to the health facility as they deem necessary. The agency where we recruited participants sometimes visited palliative care patients in their homes, particularly those who were bedridden. However, this was often limited by lack of human resources as the same staff who were to visit patients at home were also responsible for providing care to patients at the clinic.

2.2. Community cohesion and community care

Core to the definition of community are social interactions, collective identity, and “meeting basic needs for sustenance” (Wallerstein et al., 2015, p. 278); which all are affected by broader ecological and political systems. Furthermore, community care can have multiple meanings, including but not limited to, “a desirable objective for service users” (Means et al., 2008, p. 2), an integration between daily life and service provision (Twigg, 2002), and community care workers as liaisons between individuals and the healthcare system, with some community health workers trained only on one or two diseases (Uwimana et al., 2012). Here, we use the term community care to mean material, social, financial, and psychological support provided to an individual by members of a community, in order to fill gaps in that individual's needed support. In essence, we use community care to mean care that which is provided by community members to help fulfill their health care needs.

Notably, community care is linked with community cohesion, as less cohesive communities may be less likely to provide care. There is no single widely accepted definition of community cohesion. Following Beider (2012), we suggest that community cohesion may be defined as a shared sense of belonging in the community, strong relationships, a sense of one's rights and responsibilities in a community, institutional trust, fair opportunities for community members, valuing diversity, and a concentration on what community members have in common. Relationships are critical to community cohesion. Importantly, community cohesion influences “access to knowledge and cooperation in natural resource management” (Nunan et al., 2018), which may be especially important for people dependent on subsistence agriculture and on food sharing. Thus, it is concerning that community cohesiveness has begun shifting in recent years due to deepening poverty in Sub-Saharan African countries due, in part, to climate change (Connolly-Boutin and Smit, 2016; Maingo, 2015), which may in turn impact a community's ability to care for its members needing palliative care.

Community cohesion is linked to community care, and additional factors influence that cohesion and care. For example, religious leaders and traditional authorities may play vital roles in establishing and maintaining community cohesion and care in Malawi. While many

African religious leaders have an interest in maintaining their status as a privileged social class (VonDoepp, 2002), they nevertheless also “leverage their authority in ways that reinforce social cohesion in times of hardship” (Trinitapoli, 2015, p.247). This is especially true in Malawi's context. Consequently, Malawian pastors and imams have demonstrated a willingness to publicly reinterpret scriptural and doctrinal teachings regarding marriage and divorce in order to address this health concern in their communities (Trinitapoli, 2015). Additionally, local chiefs and *ankhoswe*, or traditional marriage mediators, may assess the sexual history and health of couples in their preparation for marriage; this assessment and their instructions on responsible sexual behavior may promote community cohesion through participation in traditions while reducing the risk of spreading HIV/AIDS in their community (Trinitapoli, 2015).

2.3. Movement, community, and Women's work

The Government of Malawi estimates that 84% of Malawi's residents live in rural areas (Manthalu, 2017). Sixteen percent of Malawi's population lives in urban areas, with an unnamed number of both these groups residing in towns or transitional peri-urban areas. While all women in our study were situated outside Malawi's largest population centers, many had moved between rural villages and towns or trading centers both over the course of their lives and during end of life. On the one hand, their movements are part of (trans/national) patterns of migration for labor, marriage and family, social services, and survival that have marked Malawi for centuries (Anglewicz et al., 2019). As Englund (2002) noted, migration to urban areas should not be thought of as a unidirectional process. Instead, it is often impermanent, intended to improve life back *ku mudzi* -- in “the village.” Money and people thus circulate back and forth among peri-urban, town, and village locations. On the other hand, women at end of life were often moving because historical assumptions about people having a home community—their “mudzi”—to which they could return and access resources and care were not functioning in practice. Changes in kinship support structures over the course of the HIV/AIDS pandemic have been well-documented (e.g. Young and Ansell, 2003); recent work examining the complex interplay of health and migration (e.g., Anglewicz et al., 2019) has noted how women's health at the time of migration significantly impacts children's health outcomes.

Participants in our study moved to gain access to various resources including regular caregiving, to draw support from relationships, and to attempt to provide basic security for themselves and other family members. For women who moved at end of life to access care networks, necessities were sometimes secured through exchanges of money, sometimes through bartering, and sometimes from community networks in displays of care and solidarity. These findings point to ongoing changes in the centrality of mudzi-based kinship networks in providing care for family members (Nagoli and Chiwona-Karltun, 2017), and speaks to the importance of developing new models for understanding care and community at end of life.

We observed, as others have described, that household social reproduction rested almost entirely on the unpaid contributions of women (Young, 2016) and on people's ability to access no- or low-cost natural resources (e.g., water, firewood, wild foods) on which this reproduction depends. In Malawi, women's work commonly includes agriculture, childcare, fetching water, cooking, washing clothes, and other household- and care-related duties (Mkandawire-Valhmu et al., 2020). Urban living might bring certain eases (such as a nearby water tap and school), but bring other constraints (such as less access to land, wild food harvest, or firewood).

Demands on women's labor are very high. Women at end of life and their caregivers are structurally some of the most vulnerable in Malawi. They often struggle to gain and maintain access to basic necessities for palliative care; gender inequities may render them less able to claim land or other natural resources than men in similar situations; and caregivers' gendered labor is physically, emotionally, and temporally intense. Women and their caregivers thus made complex calculations about where they and their dependents might best secure their wellbeing. Their narratives indicate that they often relied on complex webs of geographically-proximate familial, extended kin, neighbor, and religious community systems for physical, social, and emotional survival and thriving. These systems were generally themselves quite precarious, leading women and their caregivers to navigate changing relations of care as individuals and systems shifted, changed, or passed; in turn supporting the provision of care in different ways, at different times.

We turn now to describing our qualitative critical ethnographic study, which examined the changing dynamics of community cohesiveness and support, focusing on implications for women's health and wellbeing at the end of life.

3. Methods

3.1. Design

Through this qualitative study, we sought to better understand the experiences of women at end of life using critical ethnography. We conducted open-ended interviews in order to allow women to share information if and as they were comfortable doing so, and also allow the women to focus on situations they found important. The study received Institutional Review Board approval from the organizations in the US and Malawi. The senior author conducted the interviews over a period of two years. They also spent 8 months in the field, not only collecting data but also becoming more familiar with rural communities in Central Malawi, how community members access the healthcare system and are cared for at end of life. The co-authors assisted with data analysis and writing up findings.

Critical ethnography is praxis oriented with a focus on addressing oppression in the lives of people who exist on the margins of society (Anderson, 1989; Chang, 2020). Our use of feminist theory was consistent with critical ethnography because it enabled us to design the study such that we centered the voices and experiences of women with the goal of ensuring that women engaged in participatory governance in contributing to health policy and future health interventions. In so doing, women have a say in their own emancipation, even at end of life. Additionally, we deliberately included palliative care experts as well as some of the agency staff where women were recruited, as co-authors on our manuscripts. This enabled us to share our findings with key experts in the palliative care field who are engaged with women at end of life on a daily basis and to closely liaise with them in the recommendations we propose (Hagues, 2021). In so doing, the recommendations made were practicable, timely, and translatable into practice.

3.2. Setting

We conducted our research in the central region of Malawi, where we completed interviews with 26 women receiving palliative care and 14 of their primary caregivers. The 14 caregivers were over the age of 18. In total, the 26 women had 42 caregivers. We originally intended to interview all caregivers; however, we did not receive IRB approval to interview caregivers under the age of 18 and so only spoke with the 14 caregivers who were over the age of 18. The 26 women receiving palliative care were outpatient palliative-care patients at a non-governmental organization-affiliated community clinic in rural Central Malawi. All were at various stages of end of life. We did not seek to identify specific diagnoses: however, women's narratives overwhelmingly referred to cancer, HIV/AIDS, or both.

This study's interviews and observations revealed that palliative care was not uniformly implemented across the district's health sector. Patients and caregivers were not always informed as to what palliative care entailed, and it often appeared to entail access to important medical resources, but little support for understanding end of life. Based on what was shared by patients and their caregivers, it appeared that there was no standard communication about illness trajectory or what they could expect. Nor did most patients and caregivers express understanding that treatment was not curative. Many of the patients and their caregivers came to the health facility to seek assistance managing symptoms they were experiencing, such as vaginal bleeding or leaking of stool from a rectovaginal fistula caused by cancer. On the one hand, healthcare providers were managing symptoms. On the other, patients and caregivers lacked knowledge of what was happening and appeared to still be in anticipation of a cure.

Interviews lasted an average of 90 min and were conducted in either homes or at the community clinic where recruitment took place. We conducted the interviews in Chichewa, the most common language in the region and one of Malawi's official languages. The last author audio-transcribed the recordings and translated them into English.

3.3. Data analysis

We used thematic analysis to systematically identify patterns (Tolley et al., 2016). The data were verified through triangulation within and across caregivers and patients. Data analyses were carried out by four of the coauthors to ensure verifiability of the findings. The analyses were further reviewed by other coauthors who had experience in Malawi across various disciplines including medical anthropology, education policy, and nursing. The multidisciplinary approach to data analysis and triangulation across samples served to enhance credibility. Regarding the words that are provided in Chichewa, we have provided translations of words in order to give the reader a more nuanced understanding of the women's words.

3.4. Findings

Participants described their community-based care experiences in ways that can be broadly understood as supportive or unsupportive to their wellbeing. Supportive community practices were described by patients and caregivers in terms of two key characteristics: *I stay with them well,* which speaks to the many small forms of assistance and encouragement that patients and caregivers experienced; and *we eat together,* which spoke to participants not experiencing stigma in relationships or access to resources.

Unsupportive community practices were characterized by patients and caregivers as: *everyone is for themselves*, which indicated a lack of assistance to patients and caregivers from other members of the community; and *she will not get healed*, which spoke to community members' acts of stigma and exclusion towards women, including expressing that idea that the patient would die. Clients and caregivers characterized some communities as generally supportive, and others as unsupportive. Within any particular community setting, however, patients and their caregivers often described both uneven experiences of emotional and material care, and a near-constant search for spaces of mutual care that could sustain their lives and the lives of their children.

Consider two examples in which care was limited to extended family. One patient participant explained: *"In the community it would just be the family. They really do help me. Like my mother-in-law, she really helps me. She fetches water for me. When my daughter is busy ... like when she goes to school, she (mother-in-law) cooks food and gives it to me."*

Another patient participant said, *"No, not people from the outside. Just my brothers when I am in need ... money for transportation to go to the hospital. When I don't have, they put money together ... little by little. 'Here you are.' Food, when I am in need, they give me a little, I eat."* The stories told to us by women at end of life and by those who cared for them often featured movement from one community to another to escape a negative community environment and to try to secure better support. We had expected that women would have deep social networks in their home communities, and would prefer to stay there, but in fact study participants actively sought locations in which community-level support made end of life easier. These efforts to move for care—despite pain and debility—are testament to the importance of community care. Where we can, we have pointed out whether a community was urban or rural for purposes of contextualization and to give the reader a better picture of participants' experiences. However, movement was relatively equally distributed between rural-to-urban and urban-to-rural migration, and both rural and urban communities were described in positive and negative terms.

3.4.1. Community care

Women at end of life were very geographically—and thus relationally—dispersed. Some participants lived in their natal home community, while others were living at their husbands' natal home. Others were living in a community to which they and their husbands had no natal tie, but where they had lived for a long time, felt at home, and had relatives nearby. For instance, a 58-year-old patient participant who was widowed, living with Kaposi's sarcoma and cancer of the palate, and primarily dependent on her 14-year-old granddaughter for care said, "My home is in (district in Southern region). That is my home. So here we just came. We came in '92. So when I just came here, we just stayed. We have gotten used to it like kumudzi [our home]."

In some cases, women moved from one community to another in order to be closer to family or to feel better-cared-for; in others, the women's caregivers had moved them to the caregivers' own community because they felt the patient was not being well cared for. Another patient participant, a widow living with HIV and Kaposi's sarcoma, described her decision to return to her natal home from her husband's home based on their lack of care for her there. While her husband's home community had not been supportive at all, in her own home community, not everyone was supportive either.

"[I am] here in [my natal] village because my husband died. So for me to stay here it's because shortly after he died, I started getting sick. Then because pachitengwa [virilocality; residence at a man's home] can be a challenging place to stay, I stay here [in my natal village] because of the illness. But some people do take care of me, some no." The narratives of these two patient participants featured ambivalence about community care; neither characterized her current situation as entirely supportive.

Other narratives drew clear pictures of communities with better-coordinated support for women at end of life. Coordinated care was manifested by members of the community taking turns to visit the patient participant. Church-group visits were a common form of support. One patient participant living with cervical cancer had recently moved from a rural community, where she had not been supported, to an urban community where her caregiver sister lived. She talked about the contrast in the care she received in her new urban community. She was Catholic, and Catholic members of the community immediately made arrangements to visit her and pray with her at home since she was unable to attend mass as a result of symptoms of advanced cervical cancer.

"I haven't started going because I came on Wednesday. But maybe this Sunday. If I can manage to walk I can get there … because what is giving me difficulty are my legs … they are heavy … Someone said that 'Maybe if you cannot make it, would you agree for the church people to come here?' And so yesterday I agreed that yes, they can come."

She also explained that other members of the community frequently visited and spent time chatting with her. These visits made her feel welcome in the community and enabled her to sometimes be distracted from her pain and the reality of her situation.

Patients who were able to continue attending church spoke about the value of this and how they and their children also received community support from members of the church. Another participant living with HIV, Kaposi's sarcoma, and cancer of the palate said, *"The church people, a lot of things I get from the church. A lot of times they bring me eggs, they bring me some sugar, they bring me porridge, indeed of rice."* Rice porridge is a valued staple in Malawi; relish is a source of protein, usually in the form of beans or vegetables, or if one can afford, meat or eggs. This patient continued, "*So no, they do bring for me. They bring for me relish. A lot."*

Yet another patient participant also living with HIV and Kaposi's sarcoma said,*"The church people helped me last month and last year when the pastor came to see my problems that I have here. They gave me a bag of maize. Then this year, they called for me at the church and they gave me a bag of ground meal when they saw that my problem was big."*

Community care also entailed community members working together to help meet the basic needs of the patient. For instance, one patient participant spoke of how people in her rural community were preparing to build a new home for her, as she could no longer work and could therefore no longer pay rent: *"Indeed they have done well. They dug the mud over there. I just saw it today ... when I complained that 'Look at me. The rent has suffered the children.' So they said, 'Let's construct a small one for you,' so that I should go and stay over there near the child (daughter). Yes."*

Chiefs also played an important role, both by helping to meet patients' needs directly and by rallying and coordinating support from other members of the community. One patient participant spoke of how she could rely on the support of the village chief, stating: *"That is not even something I can complain about. Even the chief ... he provides the money with which to buy medicine. He gives 500 (kwacha) sometimes ... sometimes he gives me 1000. If he doesn't have ... 200. Can I then say they are not taking care of me?"*

Relatives who lived in the community also offered support. One patient participant said the following about the role her husband's family played, *"I don't go to the borehole. I stopped a while ago. Some of my in-laws fetch (water) for me. Sometimes they fetch for me. But I don't really cook. The in-laws ... when a person is sick, there are some who fetch water for you. They help you in various ways ... water. If they have a little bit of maize, they will go to the mill for you. Then it means that they will share with me."*

Moreover, patients deeply valued the role community members played in helping to care for children, fetching water, praying together, and performing household activities that women could no longer perform because of the nature of their illness.

Most patient participants and their caregivers pointed out how people in their communities were also struggling with poverty, had limited access to resources, and were thus unable to share food or other basic necessities. One patient participant said, *"The people ... I stay with them well ... because they too have their own homes, their own families. They cannot help you all the time, no."* Participants recognized the limitations that community members faced in caring for them and valued the sense of belonging and non-financial forms of care they received.

3.4.2. We eat together

Communities that were supportive of patients and their caregivers were also characterized by a lack of stigma. One patient participant living with HIV and Kaposi's sarcoma explained, *"There, I really do live well. I really do live well. I do feel* supported*. The* support *is that they do not stigmatize us. If it's food, we eat together. Like some say, 'This one no, because she is like this [living with HIV].' But no, nsima, we eat together. We also sleep together."* To eat together in this case speaks to the African traditional value of eating from one bowl or one plate, a practice that provides a sense of closeness for people in the community, especially when they are unwell. Dipping one's hand in the same bowl as someone signifies connectedness or togetherness. Prohibiting someone from eating from the same bowl as others as a result of illness is the ultimate form of stigma; it would take an obvious toll on the mental and spiritual wellbeing of the individual experiencing it. Eating the daily meal of *nsima,* a stiff maize porridge that is a Malawian staple food, and sleeping on the same mat, are less about sharing resources and more about a shared feeling of belonging.

Another patient participant spoke of how members of her community did not hesitate to bathe her when she was bedridden or care for her as she needed, *"The help I am receiving is really good. They really help me a lot. When I get sick to the point where I lie down, they put water for me for bathing. Then they take me to the bathroom to take a bath. When I come from there, they cook food for me, I eat. They really take care of me."*

Yet another participant who was living with Kaposi's sarcoma and HIV said, *"In the community where I live, the help they give me ... it looks like they have become accustomed to my life ... that this is her sickness. They do not stigmatize me. So there is help. Whatever I am lacking, it means they will come and give it to me."*

3.4.3. Everyone is for themselves

While many of the patient and caregiver participants spoke of how members of their community supported them, there were many others in our sample who spoke of how their current or previous community settings lacked togetherness or were not cohesive and how this ultimately affected their well-being. One patient participant, for instance, said, *"Here in the community, aliyense amaona zake [everyone is for themselves]. There is no one who is taking care of me. It's just my husband. The person who helps me is my husband. There isn't anyone else."*

For many others, their experiences were mixed, with some members of the community being supportive and others not. For such patient participants, it was evident that the lack of a caring community response took a toll on their physical and mental wellbeing. One patient participant living with HIV and Kaposi's sarcoma said, *"Here in the village ... some, I live with them well. Some look at me differently because of my illness ... sandilabadila [they don't care about me]. But some do really give me love."* Another patient participant said, *"Some of them? Some of them just look at me [and say] that, 'That's her problem. Let her be sick'."*

In the case of everyone being for themselves, this at times included extended family members. One patient participant with advanced cervical cancer, for instance, said the following *"[The ones] who take care of me are my children. But my other relatives, no."*

The lack of support from extended family members or from other community members was especially challenging for patients who had school-going children, as it meant that the children had little reprieve from their caregiving responsibilities. It also meant that children were sometimes required to skip school to care for their ailing mother or grandmother.

3.4.4. She will not get healed

Communities that stigmatized patients cut them off from the relationships and resources that could support their wellbeing. One patient participant, whose husband was a primary school teacher and who had lived in an unsupportive community said of people in that community, *"... Some were encouraging me but others were saying things like, 'That one, even if she took medication, she will not get healed because if someone has cancer of the cervix it means that her whole stomach is now destroyed.' So they were really saying a lot about me."*

The above quote indicates in part how lack of knowledge about cervical cancer, leading to uninformed interpretations of what the patient participant's illness trajectory would look like. This patient participant was eventually moved out of that rural community by her sister, who was her caregiver, to an urban community that both the patient and caregiver participants felt was more supportive. The patient participant said this of her new community: *"People are taking care of me well ... because she [her sister] lives right at the trading center. No, they are taking care of me and I also chat with them well. They just come to visit me, chat with me, encourage me."*

Another patient participant living with HIV and cancer of the palate had moved from her rural natal community to an urban trading center because of the stigma she experienced after her husband died. The patient participant spoke of a disagreement she had with her uncle, who proceeded to point out in public that she was infected with HIV. She was so distraught following this experience that she left. She cried during the interview, *"When we just have a* *small argument they would say, 'Go away you person with AIDS. You person with cancer.' So I thought, I should just be the one to leave. There was so much noise."* While she was concerned about the urban environment to which she had moved, particularly for her 13-year-old daughter who was her primary caregiver, she spoke of her new community as being supportive. When asked whether she experienced stigma in her new community, she responded, *"No. There is also a lot of love. Maybe I can get sick ... because I get along with a lot of the women, it's possible they bring food, maybe for the morning, for the afternoon, they bring it."*

Stigma also manifested in community members anticipating the patient's death and speaking openly about it in a manner that took a toll on the patient's mental health. The caregiver-sister of the patient participant in the earlier narrative recalled how she was treated there: *"She was lacking someone to help her take care of the child. The man's family did not go to help. When the husband's family come to visit, and the child is crying they would say, 'This child is really difficult. We are going to struggle with her when her mother dies.' So this was really making her sad."*

4. Discussion and recommendations

Our study findings add to a small body of literature about community care and social in/exclusion of patients at end of life, as well as the literature on the role of community care in individuals' health and wellbeing. Interviews with both patients and caregivers demonstrated that even with the many limitations and barriers faced by patients and caregivers, many women were able to find community spaces and groups in which they felt supported at end of life. However, the natal or marital communities that were historically expected to play this role in Malawi often did not do so, leading patients and their caregivers to relocate to a new community, where family, extended family, and community relations better supported patients and their caregivers.

Support for women receiving palliative care took a number of forms, including emotional and spiritual care (most often in the form of visits and encouragement), direct care (e.g., cooking for or bathing the patient), or through gifts of money and food. Immediate kin most often provided daily, regular care, while extended family members, church members, and other community members more often provided visits, one-off financial support, or multiple forms of care during an emergency period. Care networks were for the most part very localized, with a limited role played by people who were not physically present on a daily basis.

While many women reported finding a community in which they received the support needed to survive, almost all spoke of the harm they and their families faced when they experienced social exclusion. As we found in our study, women who felt supported were shown love through small acts: others drew water for them at the borehole, shared maize meal when they had it, or aided with a crying child. Those who did not feel supported experienced themselves as discarded, deemed unworthy of the expenditure of scarce resources of care, time, money, and food. Bateset al. (2018), in a photovoice study examining the daily lives of patients living with advanced cancer in Southern Malawi, identified social exclusion as a form of discrimination that patients experienced because community members viewed them as being "prematurely dead" (Bateset al., 2018; see also Selman et al., 2013). In that study, research participants identified lack of knowledge about the signs and symptoms of cancer among community members, especially in rural areas. Similar discrimination was described by at least one patient living with HIV, and also by some patients living with advanced cancer.

In our study, it appeared that lack of knowledge about cancer may have contributed to responses that included fear and resultant discrimination. Bates et al. (2018) spoke to the value of palliative care in helping to mitigate this type of discrimination. Healthcare workers providing educational talks on topics such as cancer and HIV could change community perceptions of these diseases, potentially shifting patient-community interactions. As others have shown, regular discussion by chiefs, pastors, and imams could help as well (Grant et al., 2011). Our study suggested that an awareness-raising component by respected local leaders could help community members recognize the importance of support for patients at end of life. Further discussion and exploration among community members and leaders regarding end of life care should be considered.

Patients' and caregivers' narratives clarify the many constraints that they and other community members face as the country navigates multiple crises. Even as some crises stabilize into a “new normal” (e.g., AIDS-related deaths decline because of access to anti-retroviral therapies), others increase and bring new stressors on end of life care. For example, participants cited lack of access to food and other resources as a challenge to receiving adequate care, and they cited lack of support for women's care work as a deep concern for the health and wellbeing of caregivers and patients' own children. With the limitations of palliative care resources in Malawi, it behooves communities and community leaders to address how to sustain care for those who are at end of life. In some cases, this may mean new policies and resources aimed at the particular situations faced by caregivers.

A large Australian study showed that advanced care planning improved end of life care and increased family and patient satisfaction, while reducing anxiety, stress, and depression among surviving family members (Detering et al., 2010). Advanced care planning protocols cannot be easily transferred from one place to another, however. Of particular concern in any such efforts in Malawi are patients' worries about what will happen to their children after their death, and caregivers' concerns about the impact of caregiving on their own families' wellbeing. Issues of planning are complicated in Malawi by the common perception that talking about someone's death encourages their death, and the common absence of key family decisionmakers who, at least traditionally, are responsible for assuring children's care after parental deaths.

Yet, advanced care planning (ACP) warrants further discussion. ACP involves planning for medical emergencies and end of life decisions “ahead of time” (NIH National Institute on Aging, 2018). Stanford et al. found in their study exploring ACP in South Africa, that cultural and contextual factors needed to be considered and that family members should be involved in the ACP process (2013). An additional key finding from their study was that there was a need to “improve public knowledge” (Stanford et al., 2013). Translating ACP into the Malawian context ought to then involve not only improving knowledge on ACPs (including key community leaders trusted in the community such as pastors, chiefs, and imams) but also through family involvement in the ACP process. Moreover, if family are not available and community support is found elsewhere, as was the case with several women in our study, then it may be advantageous to involve community members who are actually involved in supporting the individual receiving palliative care. Our findings provide insight into the reality of women's experiences at end of life in Malawian communities, insight that can be used in the implementation of Malawi's existing Palliative Care policy by incorporating interventions such as ACP in practical and meaningful ways.

An additional form of potential support is financial planning for the community and extended family. One method for enhancing the safety nets of rural communities within developing countries, is cash transfers, typically from governments, that are, “direct, regular and predictable non-contributory cash payments” (*Cash Transfers, 2011*, p. 7). Positive community care that included both emotional and financial support was of great benefit to women in our study. Cash transfers could benefit not only women receiving palliative care, but also any young children for whom the women at end of life are still responsible, and the caregivers and other community members responsible for the care of women and their children. Cash transfers are shown to be effective and could indeed be beneficial in the case of women at end of life In Ghana, for example, the Livelihood Empowerment Against Poverty Programme (LEAP), through the Ministry of Gender, Children and Social Protection, offers financial support through, “cash grants” to families living in poverty (Objectives – Livelihood Empowerment Against Poverty, 2022) While there have been some inconsistencies in the implementation of LEAP (Handa and Darko, 2013), LEAP still resulted in improved household savings, participation in school, and “strengthening social networks” (Handa and Darko, 2013, p. ii). The potential strengthening of social networks could complement and enhance existing community care networks in Malawi in support of women at end of life, their children and the community members responsible for their care.

Moreover, while community care and *not* climate change is the overarching focus of this article, it merits attention as it impacts the relationship on health. Climate change, for example, will continue to worsen resource availability in Malawi (Kerr et al., 2018), where many rely on subsistence agriculture, further increasing the precarity of food security, particularly for those most vulnerable – women at end of life. Climate change leads to more frequent floods and droughts (Hope, 2009; Kundzewicz et al., 2014), higher food prices, lower crop yields, greater scarcity, and increased poverty (Hertel et al., 2010). Even moderate droughts and floods have cumulative effects on agricultural productivity, making life more precarious for the 80% of families in rural Malawi who are dependent on subsistence farming for their livelihoods (Pensulo, 2020). A growing body of evidence documents the negative health impacts of climate change on human populations (Zhang et al., 2011). This is an area that warrants both further research and immediate action. Moreover, implementing policies that help to mitigate the adverse effects of climate change, which disproportionately affect communities throughout Malawi and sub-Saharan Africa, may help to ensure a more reliable food supply and access to fresh water (Blicharska et al., 2017). Reliable access to resources may help to promote community care and mutual support, which would also benefit women in end of life care and their caregivers.

In a similar sense, the role of policies, programs, and laws that support women's empowerment and that work to actively address the consequences of systems of oppression and the long legs of colonialism can also be essential components of transforming end of life care in Malawi. Women are providing the vast majority of caregiving in the country, and are themselves often patients. In these roles and in these transitional moments in life, the constraints that women face—from access to resources and decision-making power, to lack of research or funding for the medical issues they face, to support or remuneration for unpaid domestic labor—are glaringly clear, yet may not be considered an essential component of improving end of life or palliative care.

4.1. Limitations

Regarding the limitations of the study, the role of community leaders and religious institutions was not fully explored. As both were identified by at least some participants as essential to their communities of care, a more systematic examination of these institutions and their roles in structuring community care could have enhanced our understandings of and recommendations for how to better support community members.

Similarly, because the study was focused on end of life patients' and their caregivers' experiences, we did not systematically examine the roles, available resources, and opportunities within each community in which they were based. This could provide context to help clarify what components of community context, organization, and practices enhance community care and support those who are at end of life.

Lastly, our focus in the research was on patients' experiences of care at end of life, and the aspects of their situations that most affected their care trajectories. We did not collect a full audit from patients and their caregivers of the financial resources available to them before, during, and after end of life. This limits our ability to understand the full shape and scope of the financial situation that women and their caregivers are navigating, though did not limit our ability to analyze the relationships on which these resources depended.

5. Conclusion

Amy Moran-Thomas (2019:284) has recently written about a community in Belize struggling with extraordinary rates of end-stage diabetes and ecological devastation—often characterized as a process of "slow violence". She writes, "If slow violence is characterized as difficult to discern," she writes, "slow care might be even harder to see: meal by meal, gesture by gesture. Its culmination is not the moment when something dramatic happens. Its culmination is every day that it doesn't." Our study shows how important slow care at the community level can be. There is reason to expect that food, water and housing security will worsen in the decades ahead. Women at the end of life will be particularly vulnerable to these changes. Measures to enhance community cohesion and care, supporting Malawi's national policy, will be essential to successful palliative-care policies in Malawi and the many other nations facing these challenges.

Acknowledgments

This project was funded through the University of Wisconsin-Milwaukee Center for Global Health Equity and Sustainable Peacebuilding Program.

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