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Addressing the information needs of informal carers in Malawi: a healthcare intervention based on co-creation

Abstract

HIV/AIDS patients in Malawi are typically supported by their informal carers, who usually do not have formal training in healthcare. The compounding broad lack of accurate and timely information with regards to caring for their loved ones can cause emotional distress and sometimes additional harm to the person they care for. The aim of this study was to address the unmet information needs of Malawian informal carers. We report on a three-year, two-phase project (2019 – 2022) during which we conducted focus groups and workshops with informal carers, medical doctors and NGOs to co-create health advisory messages on HIV/AIDS-related aspects and wellbeing advice to be circulated among local support groups for carers. The impact of this intervention was assessed through observations and questionnaire-based surveys over this period for quality, clarity and usefulness. Our results show that, via word of mouth, the messages were disseminated beyond the local support groups and reached a much wider community, and informal carers reported both short- and medium-term benefits for their own and their loved ones' wellbeing. Information intermediaries also proved to be crucial actors for the dissemination of information and its uptake. Our study provides a method for addressing carers' information needs despite the lack of infrastructures and highlights the importance of understanding the contextual conditions of informal caring and that of co-producing interventions with the people these aim to benefit.

Keywords: uMunthu; informal carers; co-creation; Malawi; health advisory messages; information needs

1 Introduction

Informal (or unpaid) carers are those who, despite not having any formal training in healthcare, offer care and support to loved ones, including family members, partners and friends (Horrell et al., 2015). Informal carers are an irreplaceable support mechanism for the person in care, and across the Organisation for Economic Co-operation and Development (OECD) countries, it is estimated that about 13% of those who are over 50 years old provide unpaid care in some capacity on a weekly basis (OECD, 2019). Yet, similar estimations for informal carers within the Global South[1] context do not exist, as typically such assessments are not conducted.

In the Global South, and African countries in particular, where kinship is extremely valued, informal carers often provide day-to-day care for an extended family by default (Moore & Henry, 2005). Such caring responsibilities can pose significant challenges, for both the carer and the person they care for and can have significant emotional and financial implications (Ismail et al., 2020; Merrilees, 2016). At the same time, being required to adopt a new, unfamiliar role, can result in informal carers feeling helpless and uncertain as to how they can care for their person and what might be the most appropriate course of action. Such uncertainty is further compounded by the lack of adequate information resources (Hargreaves et al., 2022), which is common in the Global South context due to less robust health and social care systems (Kruk et al., 2018).

In this study, we present an intervention for the delivery of health advisory messages, targeting specifically informal carers in Malawi, one of the least developed countries in sub-Saharan Africa. We present the results of a three-year project (2019 – 2022) that was inspired by the uMunthu philosophy and cocreated with Malawian informal carers, medical doctors and

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[1] We use the term ‘Global South’ with caution and we recognise that countries commonly described as belonging to the Global South are very diverse and that the use of this term homogenises inaccurately regions and populations. In this article we use it as a shorthand to refer to countries that have been affected by colonial and neo-colonial policies and uneven distribution of their resources that has led to poverty and pandemics.

non-governmental organisations (NGOs) to promote better health and wellbeing outcomes among the local communities. The main objectives of this study were a) to explore and understand the information needs of Malawian informal carers; b) to identify and develop sustainable ways to meet such information needs; and c) to examine whether and to what extent the co-created intervention led to improved health and wellbeing outcomes. Our field study took place in the Namwera area within the Mangochi district of Malawi, which borders with Mozambique and has one of the highest prevalence rates of HIV/AIDS in the country (PHIA, 2022). Our study follows a mixed-methods approach, whereby our empirical material derives from focus groups with informal carers, workshops with medical doctors and NGOs, questionnaire-based surveys with local communities, as well as our own observations from the grounds.

Our findings suggest that adopting a co-creation approach for the identification and the delivery of a health intervention can lead to increased ownership over the result and therefore encourage adoption and further dissemination of the advisory message within the local community. In addition, identifying focus areas for developing said advisory messages together with the target community can lead to improved outcomes, specifically because the intervention then addresses real needs on the grounds. While equivalent findings are often reported by studies adopting a co-creation or participatory approach, even in more commercialised settings (e.g., Roberts et al., 2022), we argue that in the particular case the positive outcomes have been propagated across local communities beyond the scope of our study via word-of-mouth and information intermediaries, specifically because informal carers felt motivated to adopt and disseminate information on caring as a result of the uMunthu philosophy of being that has shaped their identities, everyday lives and communities. Our findings provide a rare glimpse into the information needs of informal carers in the Global South and contribute by offering a method for identifying and meeting information needs based on the principles of co-creation that can be applied to other largely underserved social groups and/or within the Global South.

In what follows, we present an overview of the literature on informal carers and their information needs, and we then present a discussion on the uMunthu philosophy. Next, we discuss the co-creation method we adopted for this study, and we present our findings. We conclude the article with a discussion, where we draw attention to theoretical and methodological contributions.

2 Background

Informal caregiving is often described as providing unpaid care and support to people with long term conditions and/or are unable to care for themselves, who may be family members, friends, spouses and partners, and neighbours (Wang et al., 2022). Depending on the condition of the cared for person, informal carers may need to devote a lot of their time to caring, with negative implications for their own wellbeing, employment and personal life (Clancy et al., 2020).

Informal carers do not have formal training nor education in healthcare (Horrell et al., 2015). Therefore, when taking up the role of the informal carer for the first time, they are rarely aware of what to expect (Biliunaite et al., 2022) with regards to, for example, the symptoms and progress of a given disease, whether it is curable and how it needs to be managed, which is essential knowledge to provide adequate care (Beaver & Witham, 2007). Being unaware of how to manage the disease, its symptoms and the patient, in some cases can cause additional, possibly irreversible and even fatal harm to the cared for person (Everhart et al., 2020), which can be debilitating for the informal carer, as well (Koo, 2012). The above, combined with the high and often competing demands of unpaid caring (e.g., caring while working full time)

(Carduff et al., 2014; Spann et al., 2020) very often leads to emotional distress, poor wellbeing (Koo, 2012), which are further compounded by financial precarity (Lightfoot et al., 2021).

2.1 Informal caregiving in the Global South

In many countries, informal care is preferred for a number of reasons (Wang et al., 2022), including enabling the cared for person to age in place (de Jong et al., 2022), providing greater socialisation and improved wellbeing, and for reducing budgetary expenditures for providing formal care via the health and social care infrastructure (Bremer et al., 2017). In Global South countries, informal care is very common; however for different reasons. Often, the healthcare and social care systems in the Global South are characterised by poor access to resources (Pallangyo & Mayers, 2009), meaning informal care is the only solution to provide support to a person in need. In African countries, in particular, extended families are typical and kinship is viewed as the safety net for many needing care (Moore & Henry, 2005). However, the experience of informal care and perceptions around it in such settings differ considerably from what is typically observed in Western societies. While this is an under-researched phenomenon, evidence from Rwanda suggests that providing informal care is ingrained to the cultural value system, whereby communitarianism emphasises the welfare and the interests of the community, which leads to a heightened sense of responsibility of caring (Tuyisenge et al., 2020).

2.2 Information needs of informal carers

Information needs of informal carers can be examined and understood through various theoretical lenses. However, when considering information needs of carers from Africa, it is crucial to account for the cultural, social, and healthcare contexts of the region. While there may not be specific theories solely focusing on such caregivers, two broad theoretical approaches have been considered to frame the work we have done for this research. First, we considered the Information-Motivation-Behavioural (IMB) model (Fisher, W. A., Fisher, J. D., & Harman, J. (2003). The information-motivation-behavioural skills model: A general social psychological approach to understanding and promoting health behaviour. Social psychological foundations of health and illness, 22(4), 82-106), which focuses on health-related behaviours and information needs. This model suggests that individuals' behaviour change is influenced by three key factors: information, motivation, and behavioural skills. In the context of informal caregivers, the model suggests that their information needs can be addressed by providing relevant and practical information about caregiving tasks, healthcare management, and support services (e.g. Chen, Y., Zou, H., Zhang, Y., Fang, W., & Fan, X. (2017). Family caregiver contribution to self-care of heart failure: an application of the information-motivation-behavioral skills model. Journal of Cardiovascular Nursing, 32(6), 576-583). The IBM model has been widely used in African contexts, with a particular focus on the uptake of and adherence to antiretroviral therapy (e.g. Movahed, E., Morowatisharifabad, M. A., Farokhzadian, J., Nikooie, R., Hosseinzadeh, M., Askarishahi, M., & Bidaki, R. (2019). Antiretroviral therapy adherence among people living with HIV: directed content analysis based on information-motivation-behavioral skills model. International Quarterly of Community Health Education, 40(1), 47-56; Kiene, S. M., Fisher, W. A., Shuper, P. A., Cornman, D. H., Christie, S., MacDonald, S., ... & Fisher, J. D. (2013). Understanding HIV transmission risk behavior among HIV-infected South Africans receiving antiretroviral therapy: An Information—Motivation—Behavioral Skills Model analysis. Health Psychology, 32(8), 860) and for prediction and promotion of health behavioural change (e.g. Ameri, M., Movahed, E., & Farokhzadian, J. (2020). Effect of information, motivation, and behavioral skills model on adherence to medication, diet, and physical activity in HIV/ADIS patients: a health promotion strategy. Journal of Education and Health Promotion, 9). Second, we reflected on the Afrocentric paradigm, which emphasises the importance of African cultural values, beliefs, and experiences (Mazama, A. (2001). The Afrocentric paradigm: Contours and definitions. Journal of black studies, 31(4), 387-405) and highlights the significance of incorporating African cultural frameworks and knowledge systems in addressing caregivers' information needs. It recognises the distinct African worldview and the need to centre African perspectives in understanding information needs. Caregivers in Africa have specific information needs related to culturally appropriate care practices, traditional healing methods, and community-based support systems (Fairfax, C. N. (2017). Community practice and the Afrocentric paradigm. Journal of Human Behavior in the Social Environment, 27(1-2), 73-80). In this research, recognising and articulating their information needs within a safe space respectful of local ‘ways of life’ was the first step for carers to acquire knowledge, solving problems, and making informed decisions.

Research to date indicates that, despite the critical role informal carers play for healthcare, social care and the economy, their information needs are generally not well understood, and therefore remain largely unmet (Hargreaves et al., 2022). Indeed, earlier studies have shown that informal carers are not well supported at critical points in their caring journey and the information available with regards to the available support (practical and emotional) is either limited or completely lacking (Killen et al., 2016).

More specifically, the information needs of informal carers “have dual interrelated elements” (Hargreaves et al., 2022, p. 281), whereby the information required relates both to how to look after the cared for person as well as how to care for themselves and manage their role.

In terms of the information needs that relate to the cared for person, earlier studies have found that these can be quite diverse but will likely concern medication aspects, symptom identification and management, and management of behaviour and behavioural changes, among other (Hargreaves et al., 2022); as such, the exact needs will vary depending on the condition of the cared for person. With regards to informal carers of HIV/AIDS patients in particular, as in our case, first and foremost, information needs will relate to the diagnosis and the progression of the condition (Selman et al., 2009), i.e., information on how the disease might affect the cared for person over the longer term (Ogden et al., 2006). In addition, because of the nature of the particular condition, the information needs will cover aspects of access and dispensation of antiretroviral (ARV) therapy, nutrition, including managing stress (Mnubi-Mchombu et al., 2009), recognising and managing the symptoms of HIV/AIDS (Gysels et al., 2011) and of comorbidities that often affect HIV/AIDS patients, productive and reproductive activities (Asuquo et al., 2017), among others. However, as the condition and the circumstances of both the carer and the cared for person are likely to evolve over time, the information needs are also likely to evolve (Larkin et al., 2019). Furthermore, earlier studies have shown that informal carers not only value but often necessitate specific information that is tailored to their needs. This is because generic information often misses the nuances of somebody's circumstances and symptoms, and therefore, it can be irrelevant or inapplicable (Jarvis et al., 2019).

In terms of the information needs that relate to the informal carer themselves, these can be equally varied. For example, an informal carer will probably need to learn new skills that can help them in their caring role, they will need information in terms of managing their finances and their own health and wellbeing and, most crucially, they will require information in terms of support services, and who to contact when in need (Koya et al., 2022). What is important to note, however, is that becoming an informal carer might not be a straightforward process. The informal carer may take up this role very gradually depending on the condition of the cared for person, and therefore they may not recognise immediately that they are caring for another person in an unpaid capacity. Even if the transition is sudden, we often observe that informal carers may still not identify as such; instead, they see caring as part of their relationship with the person they care for (Carduff et al., 2014). What this means in terms of information needs is that if informal carers do not identify as carers, they are less likely to recognise their own information needs.

The above issues are further compounded by the nature of information needs more broadly. For example, some informal carers may be very aware of what information needs they have and they may be actively engaging in fulfilling them (recognised need). Others may not know what information they may need now or in the future, and therefore they will be unable to fulfil them (unrecognised need) (Alzougool et al., 2015). This awareness, however, will influence whether and to what extent the informal carer will attempt to meet their information needs. In other words, incognizance can be critical in terms of whether an informal carer will exhibit an information seeking behaviour at all (Li et al., 2022).

We can therefore summarise that informal carers' information needs relate to information specific to the condition/disease of the cared for person, whereby this needs to be accurate, credible and timely (Sbaffi & Hargreaves, 2021). These can be considered as formalised needs, as often the informal carer is able to define well the information they need (Koya et al., 2022). Yet, informal carers will also have less formalised information needs, on the one hand due to incognizance, and other hand because their circumstances and the condition of the cared for person will change over time.

2.3 Information Seeking Behaviours of unpaid carers

In contexts with uneven distribution of resources, or what Buchanan et al. (2019) refer to as disadvantaged circumstances, information intermediaries can play a critical role. When it comes to informal caregiving, such intermediation can be taken up by several actors. For example, the informal carers themselves might be an intermediary, whereby they access, gather and pass on essential information to the cared for person (e.g., in terms of managing their condition). Similarly, community actors, such as social care workers and others, might take up the role of intermediary, disseminating information to carers. However, when such professionals are not available due to resource issues, and when informal carers themselves lack access to accurate and timely information, gaps in information needs must be bridged through other means.

Earlier studies have found that, very often, informal carers join online social forums such as WhatsApp groups to get in touch with people in similar circumstances to theirs and use this as a means to seek information on caring for their patient (e.g., Bujnowska-Fedak et al., 2019), whereby online peers and the technology act as information intermediaries. However, as Duncombe and Heeks (2002) show, technology may not always perform this role satisfactorily. Further, unvetted online resources cannot replace information via formal providers, such the healthcare professionals. In addition, in the Global South, access to such online sources may not be an option at all due to poverty and lack in infrastructure. Instead, research suggests that in such settings, help, support and information are organised and provided via less traditional structures, such as regional and local support groups of carers (Wright & Jayawickrama, 2021), or trusted individuals with some prior experience, who can be the intermediaries. For example, Tuyisenge et al. (2020) discuss that in Rwanda information and advice on maternal health is provided via unpaid social care workers who have undergone through the experience of motherhood. They further note that this approach enables communities to bypass to some extent the obstacles posed by poor access to resources, but also that it is heavily influenced by the way of life observed in Rwanda, namely interconnectedness, compassion, and mutual caring because of the country's Ubuntu organising logic, which gives these unpaid social workers a sense of responsibility towards the community. In what follows, we discuss the uMunthu philosophy, a version of Ubuntu relevant to the Malawian context, where our study takes place.

2.4 The Umunthu Philosophy

‘Umuntu ngumuntu ngabantu’ is said to capture the essence of the uMunthu[2] philosophy. There are different translations of this phrase. The most popular translation in English is “I am because we are”, but it can also be translated as “[a] person is a person through persons” (Bandawe, 2005, p. 290). The uMunthu concept can be found in many of the African proverbs (e.g., ‘kali kokha nkanyama, tili awiri ntiwanthu’ is a saying in Chichewa, the local language in Malawi, that means “when one is on their own, they are as good as a wild animal; however, when they are two, they form a community”, Kayira, 2015) and it represents the worldview of living as one family (Sharra, 2009) where the emphasis is placed on kinship and interpersonal relationships that define expected behaviours and norms within communities (van Dyk & Matoane, 2010). At the same time, it places significant attention on empathy, caring, and understanding, and values the contributions of all members of the community, whereby everybody, irrespective of their circumstances, is equally valued and appreciated.

To date, many studies that adopt uMunthu as their framing lens focus on education and the development of a Malawian educational system that cherishes and values local epistemologies and knowledge (e.g., Kayira, 2015; Minoi et al., 2019). For example, Musopole (2018) criticises Malawian’s educational system for being rooted in colonial thought, and proposes an educational ethos that draws from the African worldview and the characteristics of uMunthu, to create a philosophy of education that is empowering, relevant and meaningful for Malawi. Focusing more on social care, which is the focus of this study, Wright and Jayawickrama (2021), for example, explore mental health support in Malawi and discuss how uMunthu drives practical support by providing strong community-based interventions and by enabling therapeutic approaches rooted in the community and the local culture. As such, a way

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[2] The term also appears as Umuntu.

of life that aligns with the uMunthu philosophy of being, and its other sub-Saharan variants, is supportive of social work, and of caring in broader terms, whereby those in need of care are surrounded by a community that cares for them (Mayaka & Truell, 2021). This does not mean that caring for a family member comes with no challenges. It rather means that there are additional needs, such as being the sole provider for the household, and finding alternative ways to locate information on how to care.

We posit that information needs can be better met by better understanding and leveraging the ways in which a society functions (Moore, 1997). Within a society, such as the Malawian one, where people rely on each other for support, we expect that they will do so also for the purpose of seeking, locating and using information too. Against this background, we report on a project where we leverage the uMunthu philosophy and its underpinning principle to identify, develop and launch initiatives for addressing the information needs of informal carers in Malawi. This approach enabled us to appreciate how the Malawian society functions and design a research project specifically addressing the information needs of this society. A question that remains to be answered is therefore, "how does the uMunthu philosophy espoused by Malawians help create a context for information sharing among informal carers that is sustainable?"

3 Methods

3.1 The Context of Our Study

According to the Official Development Assistance (ODA) list, Malawi is among the least developed countries (OECD, 2022). Its population exceeded 19 million in 2021, a little over than 50% is women (The World Bank, 2021) and about 18.5% resides in urban areas (Worldometer, 2022). HIV/AIDS and its associated comorbidities (such as hypertension and diabetes) are a severe national health emergency, and in 2021 there were about 1 million people living with HIV/AIDS. It is primarily women and children that are impacted by the disease, whereby 570 thousands of those infected are women aged 15 years or older (UNAIDS, 2021). Children are less likely to receive antiretroviral treatment and, in the whole, new infections among women are twice more likely compared to men (UNAIDS, 2020). As such, informal carers in Malawi are more likely to care for HIV/AIDS patients, therefore our study focused on them.

We conducted our study in the Mangochi district, and specifically in the Namwera area, where most of the population is from the Yao ethnic group. HIV/AIDS is a chronic and communicable disease that necessitates self-management, closely monitoring one's symptoms and focusing on a healthy lifestyle to ensure extended and better quality of life. This entails a need for considerable care and support directed to patients, to enable them to make informed decisions and adapt to living with HIV/AIDS (Battersby et al., 2010).

With regards to the healthcare and social care provision, Malawi, according to 2016 estimates, has about 0.12 healthcare workers for every 1,000 people, or 600 nurses, midwives, physicians, etc. in total (Africa Check, 2016). Such estimates suggest that the bulk of caregiving is undertaken in real terms by family members and the community. Presently, the poor quality of the transportation system, the lack of medical staff and low literacy levels are some of the major reasons for which informal carers are unable to access accurate medical advice which they can action to provide better care to their family members affected by the disease.

Within the Mangochi district, informal carers of HIV/AIDS patients have formed support groups at the community level, which have been introduced some years ago with the support of Malawi's National AIDS Commission (NAC). The size of these groups varies as well as the frequency of their meetings (biweekly, monthly, bimonthly) and the level of engagement offered. Typically, there are about ten to thirty members in each group, mostly women and children, who regularly attend the meetings. The purpose of these groups across the district is largely the same, i.e., to share their stories and experiences and spend time with others in similar circumstances. As such, these groups offer a way to support each other and learn from one another how to care for their loved ones and are thus critical for informing their caring role. Broadly, the activities they engage with include cooking meals together, exchanging ideas and tips about farming, nutrition and cooking, bathing and providing first aid. The group members bring food and other resources, such as oil, depending on their personal capacity at the time. One could therefore argue that these groups have adopted a sharing approach in terms of tangible resources and advice, and while not all groups are equally active and effective, to an extent they have managed to overcome the lack of healthcare advice provision.

This community-centric structure, whereby the informal carers share among them all that they have, including best practices, advice and resources, reflects uMunthu and the significance for them to share. In addition, it makes these support groups an important emotional anchor. Yet, and despite the effectiveness of these groups in offering sporadic advice, the carers themselves do not have access to any structured informational support, not within these groups nor in the larger community.

3.2 Research Design

The research design of the project was based on the principles of co-production. We approach co-production in research in line with Bello and Pahl (2018): co-production entails defining research aims and objectives 'with' the involved community partners rather than 'for' them, actively and genuinely inviting them to challenge our assumptions and knowledge structures, and reimbursing them for committing their time, providing emotional labour and sharing their lived experiences. Most importantly, co-production entails producing knowledge together with the research beneficiaries and meaningful interventions that are needed, desirable and shaped together with them (Filipe et al., 2017). As such, we followed a largely inductive research approach that leverages co-producing knowledge with the beneficiaries, thereby valuing their lived experience, understanding their own needs and perspectives (Glasby & Beresford, 2006) and allowing the research to evolve and be shaped by the data rather than a priori assumptions.

To achieve the above, we liaised from the conceptualisation stage of the research with our partners on the ground to explore local needs and priorities. We began working with the Blantyre Institute for Community Outreach (BICO), an NGO focused on improving the health of rural Malawians via community interventions (www.bicomalawi.org). Based on BICO's research director's local expert knowledge, our work began focusing on informal carers of HIV/AIDS patients and considering the role of the community as an enabler of improved health outcomes. To address our research objectives, we split our study into two phases: phase 1 focused on inductively understanding the information needs of Malawian informal carers and identifying sustainable ways to address them; phase 2 then focused on implementing the previously identified methods and examining whether and to what extent these could lead to improved health and wellbeing outcomes, i.e., we followed an inductive reasoning whereby phase 2 was shaped by phase 1 results.

3.3 Our positionality as researchers

In this section, we reflect on our positionality as researchers who conduct research in the Global South. The purpose of this reflection is to illustrate the relationships and the differences that exist between us, as individual research project members, and between us and our community partners. It also serves for highlighting the complexities and the tensions that influenced our collaboration and the project itself.

We followed a culturally responsive co-production approach to mitigate against the inescapable power dynamics that can emerge between research participants and researchers, and to continuously reflect on our positionality as researchers working in the Global South. Power dynamics can emerge due to differences “such as Western–non-Western, older–younger, blackness–whiteness, academic–non-academic, high formal education–no formal education” (Hovde et al., 2021). These differences are often unavoidable and it is important that researchers acknowledge them and their own positionality for overcoming dichotomies, understanding alternative ways of being and knowing (Jimenez et al., 2022), and for producing knowledge together with research participants by valuing their local expert knowledge.

The first and second authors (EZ and LS) are white European women with expertise in Information Sciences and Information Systems, who are both immigrants in the UK and work in a UK university. The third author (KK) is a black local Malawian medical doctor, with expertise on ophthalmology and who has completed his doctoral studies in the UK. He has extensive experience working within the community for improving healthcare and social care provision.

In what follows, we discuss the data collection methods and the findings for each phase separately, to provide a more streamlined overview of our work, showcase the conceptual links between the two, and the ways in which our co-creation approach informed and shaped the second phase.

4 Phase 1: Immersion and Identification of Information Needs

In order to identify the information needs of informal carers, it was important to first be able to understand their everyday lives and the context within which they have been undertaking their caring responsibilities. To achieve this, we organised a focus group with informal carers in Namwera. The aim of the focus group was specifically to discuss with the carers themselves their lived experience of caring, the related responsibilities and their perceived quality of health. In addition, we explicitly asked them what information they feel they need in terms of looking after the person they care for, and in terms of their wellbeing and overall support. Recognising, however, that informal carers are often characterised by incognizance, i.e., being unaware of what information they might need, we conducted a further workshop with local stakeholders (see section 4.1) who provide support to informal carers, and consulted relevant literature to expand our understanding of the local context. These strategies helped us identify the information needs informal carers of HIV/AIDS patients have (both recognised and unrecognised) and the preferred mode for the delivery of such information.

Before actively engaging with informal carers, we secured ethics approval from the University of Sheffield, following the procedure that applies to research conducted outside the United Kingdom (overseas) in light of the absence of a similar procedure in Malawi and with the view to undertake a ‘belt-and-braces’ approach that would ensure ethical oversight. This approach entailed that, if and when sensitive topics are touched upon, our duty as researchers is to pause the activities, and provide support to participants in terms of information provision and resources that can help reduce the negative implications (e.g., emotional stress, feeling of being overwhelmed). However, none of our participants showed signs of distress or similar. Ethics clearance also entailed that none of the participants would be identified by name or another marker that could possibly risk their identification (we refer to each participant by a unique number). In addition, before engaging with them, we secured their informed consent which entailed explaining what the research is about, what is expected of them, including being able to withdraw at any time without providing a reason or suffering any consequences. We provided all participants with information on the project in writing (Chichewa and English) and for those of low literacy, this information was offered verbally.

4.1 Sampling and Data Collection

Informal carers were recruited directly by BICO in collaboration with the leader of one of the support groups based on their extensive prior relationships and because local support was crucial for engaging with carers. The focus group was hosted at a BICO facility in Namwera in June 2019 and comprised ten informal carers, of whom nine were women and one was a man, the leader of a support group. While there is a clear discrepancy in gender distribution, this skewness is reflective of the state of caring not only in Malawi but globally, whereby the dominant narrative of the informal carer is that of a woman stepping up to cover nurturing roles (Ama & Seloilwe, 2010; Shiu et al., 2016). Before starting the focus group, the informal carers were briefed about the research by a local research assistant in Chichewa, they asked questions regarding its scope and purpose and gave informed consent verbally. We collected information regarding their demographics through a short paper-based questionnaire, which was circulated just before the focus group, and in many cases, a local research assistant helped the carers to complete it in due to low literacy issues. Table 1 presents the demographics of the participants.

Table 1. Focus Group Participants

ID	Age	Gender	Household size	Marital Status	Education	Health	Years of caring
1	32	woman	4	single	primary education	very good	11
2	61	woman	8	widowed	primary education	very good	7
3	68	woman	6	married	primary education	fair	3
4	39	woman	N/A	widowed	primary education	fair	1
5	30	woman	5	widowed	no schooling	very good	12
6	48	woman	10	widowed	primary education	very good	7
7	30	woman	10	separated	no schooling	very good	8
8	49	woman	4	married	primary education	very good	9

9	30	woman	9	married	secondary education	very good	8
10	67	man	4	married	secondary education	fair	11

Following the focus group, we organised a workshop with local stakeholders and partners. There were eleven participants in total, all of whom were representatives of different local groups, including academia, NGOs and communities that work towards addressing health inequities and/or support HIV/AIDS patients and their carers (Table 2 offers a breakdown). The aim of the workshop was to understand the structures that currently exist to support informal carers, when and how informal carers interact at local and/or central level with the health and social care system, as well as the Information and Communication Technology (ICT) capacity or the region, which could be helpful to assess for the later deployment of our health intervention. Participants in the workshop were carefully chosen. While geographically they are quite distributed and most operate outside Namwera, they all share a common mission. The Chancellor College is committed to the sustainable social, economic and technological development of Malawi, with an emphasis on health informatics; MHEN works to achieve essential healthcare services; FOCUS works to support health and community development; Baobab Health is an NGO that specialises in the use of technology in healthcare settings; and lastly, our local partner BICO champions community health, especially for the prevention and control of avoidable diseases.

We purposefully chose to engage with the workshop participants separately from the focus group participants, to allow the latter to discuss their lived experience openly and in a safe space, without self-censoring due to the presence of others who can potentially influence their answers (e.g., their community chief).

Table 2. Workshop Participants

	Stakeholder	**Expertise/Contribution**
Academia	University of Malawi, Chancellor College	Health Informatics
NGOs	Blantyre Institute for Community Outreach (BICO)	Interventions to improve health quality in rural areas
	Malawi Health Equity Network (MHEN)	Promoting health equity for all
	Foundation for Community Support Services (FOCUS)	Participatory Learning Actions for empowerment of rural communities
	Baobab Health Trust	Healthcare information systems for developing countries
Community representatives	Two Community Chiefs	Insights into the functioning of the support groups and of the communities
	Namwera's Carers Support Group leader	

During both the focus group and the workshop, all questions were asked first in English and then a local research assistant translated them in Chichewa. All responses and ensuing discussions were then translated in English. These conversations were all recorded, and later transcribed by the local researcher, both in Chichewa and English. We enriched our understanding through archival research whereby we collected published project reports, statistics and other relevant information concerning informal carers, healthcare and social care interventions. Finally, we had the opportunity to have conversations with informal carers and their extended families during our visits to their villages, where we were invited to their houses and while the local research assistant translated back and forth between Chichewa and English. This opportunity was particularly helpful, as seeing first-hand the circumstances in which they live and care for others allowed us to later contextualise the information provided by focus group and workshop participants, validate our interpretations and get a better understanding of their everyday life.

A note on sampling. We identified participants both for the focus groups and the workshop based on considerations of who the stakeholders of our project might be, who might be interested in its outcomes, and who could possibly be affected by these, directly or indirectly.

In other words, we carefully considered and problematised our research work in a way that its results could be relevant, desirable and beneficial to our specific stakeholders (Davison, 2023).

4.2 Analysis and Findings

Our overall approach to data analysis followed the technique of thematic analysis (Braun & Clarke, 2006). We began by first reading the transcripts line by line and considering what has been shared with us while on the ground, inductively identifying relevant themes, from the bottom up. We triangulated the focus group empirical material with the material collected during the workshop and that gathered via our archival research and informal conversations with our local partners. To ensure validity, we consulted with our local partners. We analysed the data in a way that could contribute to identify information needs and how the community already shares information. This meant that we needed to explore how uMunthu manifests itself in their everyday life, as well as if, how and when informal carers use ICTs.

4.2.1 Identifying information needs

In the first instance, we identified at high level the type of information that would be of immediate interest. Carers' information needs were specifically regarding providing *first aid, healthy nutrition, medication regimes and dispensation, and the management of medication's adverse effects*. Specifically, carers indicated that the lack of information regarding caregiving, combined with the lack of infrastructure suggests that *"the carers would need to be trained in first aid and be given some basic information, basic drugs, painkillers and the like which they can use"*. Indeed, an HIV/AIDS patient can quickly deteriorate before their carer could be able to find help; therefore, having information on how to control or ease some of the symptoms, would significantly help the patient and the carer until such help would arrive.

Further, with regards to medication specifically, it was explained that ***"****when it comes to getting drugs at the centers for the ones on palliative care or the ones that are ill, they [informal* *carers] don't get any information except getting the drugs"*; this means that, while antiretroviral therapy might be available, those who typically administer it (i.e., the informal carers) do not receive any information on its dispensing, storage, and adverse effects. This is because it is assumed that "the person knows all the information" because they care for an HIV/AIDS patient. However, and especially during the early phases of caring, people without any medical training such as the informal carers, can easily misinterpret or ignore deterioration symptoms, administer medication in incorrect dosages and even harm the patient while administering said medication, or even providing first aid. Therefore, having information on how to engage in all the above is of paramount importance for the health and wellbeing of both the patient and their carer.

4.2.2 Modes of delivering health advisory messages

Together with the participating informal carers and local partners, we devised the design and delivery of health advisory messages in relation to HIV/AIDS and caring for patients. Based on the uMunthu-related values of reciprocity and sharing, we developed a dissemination process that aimed at functioning as a nucleus from which information would travel and diffuse geographically across Namwera by word of mouth, and therefore contributing to improvements in communities outside the immediate scope of the project. In other words, addressing the previously identified information needs entailed leveraging the local cultural norms, whereby the Malawian way of life could be mobilised for delivering the health advisory messages.

Sharing with others one's experiences, resources and knowledge is part of the underlying mechanism that motivates the support groups and part of everyday life. For example, we observed that smartphone ownership was not common at all among the focus group participants, as only one had a smartphone, and about half of them had a simple mobile phone. Yet, at times of need, informal carers and community members more broadly, all have access to a mobile phone. Sharing a mobile phone within the household and with neighbours is the norm: when asked how people without a mobile phone communicate with others, we were told that *"[they] borrow from those that have the phones"* and that *"what they do is if there is some emergency, when they have some money, they buy airtime and put it in somebody's phone and they speak while the owner is there"*. Moreover, radio receivers were almost ubiquitous, whereby at the end of the day a family would sit around the radio and listen to it to catch up with the news and receive health advisory messages transmitted over it (*"Here in Malawi, we have radio listening clubs where people come together around one radio receiver. [...] people who were diabetic would sit down just to listen to health education materials and all that").*

Another aspect of the Malawian way of life revolves around reciprocity. For example, while the main objective of the support groups is to exchange information and knowledge regarding caring, informal carers find it important to exchange information that can help other carers on a personal level too, as for example their wellbeing: *"So for us we start with the guardian* [informal carer], *guiding her that it is not the end of the world. She then in turn will encourage the patient not to think this as the end."* In other words, the support groups have built caregiving capacity and are a vehicle to enable informal carers to enact their sense of responsibility towards their community, offering counselling and encouraging others to proceed with diagnosis (*"Actually now we are the ones who are doing counselling in our communities to those who used to discriminate us. We are the ones who encourage people in the community to go for HIV testing").*

However, we observed early on that delivering an intervention based on a health advisory system would pose some challenges. Namely, it was made clear that literacy levels were low among informal carers. Indicatively, out of the ten participating carers in the focus group, only two had attended secondary education, and we were told it was common for villagers not to have attended school at all or having attended primary school only partially. This means that a large part of the population across Mangochi and specifically the rural areas are unable to read and/or write. However, and while mobile phone ownership was low, because the villagers are keen to share their resources, they are still able to receive important information through sharing devices with others: "*some people in the village were asking me some questions and I was able to play some clips on my phone. So much as they did not have a phone, but they could take a message along"*. This suggests that, because of the affordances of a particular application, i.e., audio and image recordings, villagers with low literacy levels can access information in other formats besides written texts, by borrowing and/or sharing their device with others.

Based on these findings and having developed an understanding of the particularities of our research context, we moved to phase 2 with the view to identify sustainable ways for delivering the health advisory messaging service to informal carers.

5 Phase 2: addressing informal carers' information needs in a sustainable way

Based on phase 1 findings, we began considering using WhatsApp for delivering the messages, as this would help us deliver voice messages, which could be listened to rather than read out, thereby overcoming the challenge of low literacy levels. In addition, people in the communities were evidently familiar with forwarding voice recorded messages and listening these in groups, which was supportive of wider dissemination.

We used the focus group's insights to identify the broad content of the advisory messages on first aid, nutrition, medication regimes and management of medication adverse effects, and we held preliminary meetings in mid-2020 with Area Development Committees, Village Development Committees, and five support group leaders to further clarify the specific topics for the advisory messages and the language used. During these meetings, the local research assistant also provided training to said leaders on the use of the WhatsApp audio and playback functions, the use of solar batteries for charging mobile phones (due to lack of electricity and power infrastructure in most villages). Before proceeding further, we reapplied for ethics approval via the University of Sheffield following the same belt-and-braces procedure. After we received the approval, we engaged with two medical doctors (general practitioners), a social care worker and two support group leaders to develop the actual content for each message and consulted BICO, our local partner, regarding the relevance of the developed messages for the local communities.

Initially, we developed five health advisory messages aimed at supporting daily caring activities in relation to the management of HIV/AIDS, based on the focus group's insights. These messages were largely based on the explicit information needs that carers shared with us during Phase 1. However, our study was intercepted by the global pandemic (Spring 2020) and consultations with informal carers and community chiefs indicated that carers were unaware what the pandemic and the local response entailed for them in terms of their caring role (e.g., likelihood of immunocompromised to get infected, hygiene and measures to avoid infection). As such, we began our interventions by distributing the first message which was specifically on caring for HIV/AIDS during Covid-19. During the distribution of the first five messages to the informal carers, we collaborated with them and the support group leaders to identify an additional topic of potential interest. Based on their inputs, we developed a message related to safe pregnancy and motherhood in the context of HIV/AIDS.

5.1 Data Collection and Analysis

In Namwera there are 16 informal carers support groups, all having received support and training in the past by the Namwera AIDS Coordinating Committee (NACC) and the Community Home-Based Care Programme (CHBC) over the last 25 years. For phase 2, we worked with five of these support groups, which were chosen based on their proximity to BICO to facilitate travelling of the local research assistant between their headquarters (BICO) and the involved villages. Information on size and demographics is found in Table 3.

Table 3. Participating HIV/AIDS informal carers support groups.

Support Group	Year established	Women	Men	Total
Balakasi	2008	60	11	71
Chingwenya	2008	23	26	49
Lusangwisi	2003	70	12	83
Namawerenga	2014	44	13	57
Somba	2009	28	18	46

As shown in Table 3, most informal carers in the support groups are women. We discovered via conversations with our local partners that this difference in attendance between women and men is because attendance suggests disclosing indirectly one's or their family's HIV/AIDS status to the wider community; as such, men fear that this could result in them not having future sexual relationships. An exception to the composition of women/men is the Chingwenya support group. This group is attended by more men than women, and the number of men of this group is overall larger compared to all other groups. This is the result of a door-to-door initiative pursued by the support group leader who wanted to highlight the importance of men's role and the benefits of attendance for the community regarding managing the disease and controlling future infections. Most participants (71.3%) self-reported good/very good health, and of them many were affected by HIV/AIDS, but they also cared for others in their extended family, who were in worse health conditions. More than half (54.7%) cared for children with HIV/AIDS and the rest cared for their partner (18%) or their siblings, parents and grandparents (27.3%). The period of caring spans from a few months to twenty years or more, with about half of the informal carers having taken up this role over the last year (52.1%).

All six messages were being broadcasted via the support group leaders during the support group meetings using the leader's mobile phone and bluetooth speakers. In addition, we followed a similar approach and distributed these messages to five community chiefs, to specifically target those informal carers who may have been members of any particular support group. All messages were pre-recorded in audio format, both in Chichewa (official language) and Chyao (local dialect). The co-produced messages were 9-15 minutes long and used lay language, in an effort to avoid medical jargon and to consider the low literacy levels of the communities. The complete list of messages can be found in Table 4.

Table 4. Topic and Timing of health advisory messages.

ID	DISTRIBUTION	TOPIC
1	November 2020	Covid-19 and HIV/AIDS
2	December 2020	HIV/AIDS and nutrition
3	January 2021	HIV/AIDS and emotional/social support
4	February 2021	ARV* dosage, side effects and myths
5	March 2021	First aid and safety in caring for HIV/AIDS patients
6	June 2021	Safe motherhood and HIV/AIDS

Note: *Antiretroviral therapy

Overall, we distributed six health advisory messages across five support groups, meaning our intervention directly reached 306 informal carers over eight months. However, we note that the messages themselves diffused beyond the confines of each of the support groups via word-of-mouth, and thus more informal carers benefited from this intervention.

To assess the success and scalability of this intervention, identify possible future actions and evaluate whether there are improvements in health outcomes and wellbeing, the local researcher interviewed informal carers every four months during their support groups (demographics details are found in Table 5). This helped us gauge impressions and evaluate the uptake of the messages, as well as adjust the wording and content of the messages.

Table 5. Phase 2 interview participants (N = 94).

		N	%
Gender	Women	81	86.2
	Men	13	13.8
Marital status	Married/With partner	62	66.0
	Widowed	10	10.6
	Divorced	13	13.8
	Single	9	9.6
Education	Not educated	46	48.9
	Primary school	42	44.7
	Secondary school	6	6.4
Occupation	Farming	76	80.8
	Casual worker	9	9.6
	Small business	6	6.4
	No occupation	3	3.2
Perceived health	Very good	25	26.6
	Good	42	44.7
	Poor	20	21.3
	Prefer not to say	7	7.4
Age	18-24	4	5.1
	25-34	11	14.1
	35-44	30	38.5
	45-54	22	28.2
	55-64	6	7.7
	>65	5	6.4

The local researcher conducted semi-structured interviews using a bank of open-ended questions related to the health advisory messages, which allowed them to direct the interview on what each participant was focusing more on. Each interview lasted between 20 minutes and one hour, with the average duration being 35 minutes. The interviews were not audio recorded, but the local researcher produced notes in Chichewa and later translated them to English. The collated material was then analysed following an interpretive approach, with the view to explore perceptions regarding the relevance of the messages for the informal carers' every day, perceived long term benefits and the quality of the messages (clarity and content).

5.1.1 Quality and distribution of the health advisory messages

As explained earlier, each advisory message was 9-15 minutes long and most participants considered this duration to be ideal. However, some participants noted that they were either too long or too short, and some indicated that the messages could be longer to allow additional information to be recorded. Generally, participants were satisfied with the audio format and the overall arrangement (i.e., during support group meetings, over bluetooth speakers) for delivering these to them. Two participants suggested that an option could be to distribute the health advisory messages directly to those informal carers who have a mobile phone, as this would facilitate reaching out to more people. In relation to this, others suggested that the pre-recorded audio messages could be complemented by printed posters and leaflets, which could be distributed among the communities and help reinforce the content of the messages, acting as reminders within the home environment.

While initially participants hesitated to share ideas for improvements, further probing resulted in several useful suggestions. First, several participants mentioned that the messages could be delivered in Chyao rather than Chichewa because most speak the local dialect. Most participants found the language clear and effective in communicating the main message. Two participants, however, noted that they had to seek additional explanations and have other carers explain the message in more simplified terms as they found the language used confusing; they thus said that the messages could have used simpler terms to be more effective.

In addition, they indicated that it would be useful to develop messages that target specifically younger people affected by HIV/AIDS, as infections are quite prevalent among children, many of whom attend support groups. Finally, most participants indicated their desire and need to receive more messages like those distributed as part of their regular support group meetings, and support groups leaders suggested that a similar intervention should be undertaken by the government and the Ministry of Health to provide support at national level.

5.1.2 Relevance of the health advisory messages

Participants generally found the messages relevant and, in their majority, confirmed that they were using the information provided as part of their everyday activities, exactly because the developed messages were responding to their information needs in terms of their caring role. This was not an unexpected outcome, however, because the advisory messages had been developed in consultation with them and based on their explicit needs (cf. Section 4.2.1). For example, knowing what foods are the most nutritional for HIV/AIDS patients is essential information for carers because nutrition can significantly help the HIV/AIDS patient to have a good prognosis. In addition, this information, i.e., that a good nutrition helps, is among the first things shared with said patients following their diagnosis. As such, participants were aware that this is information they needed as part of their caring role and explicitly shared this with us during Phase 1. To respond to this need, the relevant advisory message focused on nutrition and foods that can support the health of the cared for person. Also, as this and the other messages were being disseminated in the first instance via the support groups, group members were able to discuss and exchange ideas at the backdrop of this message regarding cooking methods and recipes that they themselves found useful and relevant in the context of their circumstances.

With regards to their health and that of the people they cared for, the messages helped them remember to "*take [their] medications [ART] daily*" or "*start taking dosage as recommended*". In many cases, they found the messages helpful for "*practicing safe sex by using condoms*" to reduce the spread of HIV/AIDS in their community. While medication and practicing safe sex are commonly known strategies against the spreading of a communicable disease such as HIV/AIDS, in our case we noted that several informal carers were unaware of this. Often the reason behind this was that the diagnosis of the condition, and therefore the accompanying advice were shared explicitly and solely with the patient rather than their carer as well; hence, informal carers, due to a combination of reasons, do not always have access to this information.

There were however a few exceptions, where the advice was not followed as much. Specifically, the message circulated in January 2021 on HIV/AIDS and emotional and social support was the least successful. The message included advice on having open conversations about HIV/AIDS with family members and the community, and described that, although HIV/AIDS is a life-changing condition, infected individuals should not be treated any differently from others. In addition, it mentioned that informal carers should consider turning to others for questions, sharing concerns and anxieties, and that by doing so they would be able to improve their own wellbeing and offer better support to the person they care for. Discussing the low success of this message, participants suggested that one's wellbeing is not a priority, and such intimate conversations are still perceived as socially unacceptable, even if they are held with close family members. Comparing this message with the others, they said that more practical advice was more useful and easier to follow. Indeed, messages on Covid-19, nutrition, safety in caring and medications (ARV dosages, side effects and myths) were deemed as the most successful and useful. We attribute this success primarily to the timing of the messages and the clear guidance these were offering. The dissemination of the Covid-19-focused message coincided with when the pandemic started having an immediate impact on their communities, with an increasing number of cases and measures being put in place. Therefore, participants were able to easily adopt the advice as part of their everyday routine as there was also a constant reminder of the Covid-19 impact. The first aid and medication messages, due to their content, implied a more ad-hoc approach, where the first entailed an 'incident' and the second involved a lapse in medication. In these cases, participants suggested that the messages were still very valuable and relevant, as for example: "*I will tell others to take medication and protect themselves for a healthy good life*" and *"Tell others on safety for healthy and good life"*. Indeed, we noted that the participants reported positive changes in their daily community life, evaluating it as good or very good.

5.1.3 Perceived long term benefits

Overall, participants expressed that the messages had the potential to improve their quality of life over the longer term, as they were already seeing positive differences over the period of the study *("I would compare my health from the time I wasn't following and instructions to now, there is a big difference. There is a positive change").* In Table 6 we summarise the most frequently reported experienced improvements as mentioned by the participants. We consider that, as our study was conducted during the first wave of Covid-19 in Malawi, it was expected that the message on hygiene, hand washing, and the use of face coverings would be quite relevant. As the pandemic was a new event impacting the lives of the informal carers, most of the participants were not yet entirely aware of the potential consequences this new disease could have on their lives and their communities. This message helped them develop positive habits ("*We are cleaner now as we wash hands frequently*", "*I have learned good habits from such message*") and adopt strategies that helped them reduce the spread of the virus ("*Washing hands and wearing masks can prevent Covid 19*"). This practice continued well beyond the end of the project and have been widely applied throughout the rest of the pandemic (personal communication with the medical doctor, May 2022).

Table 6. Reported improvements as a result of the intervention

Improved aspect	**Frequency**
Understanding the impact of Covid-19 and the importance of following the rules (e.g., washing hands, face covering)	20
Better understanding of HIV/AIDS, transmission means and safety	19
Better understanding of the impact of nutrition and food preparation	16
Better understanding of the antiretroviral therapy (ART)	8
Better understanding of how to practice healthy living	6

All messages related to HIV/AIDS and the management of this disease. As a result, participants were able to clarify questions they had regarding the condition and understand better how they could protect themselves and others: *"More people will know about the disease and not get infected"*. While, as discussed earlier, having open conversations was not seen as socially desirable, they suggested that, because of this intervention, they expected that *"more people will open up about the disease"* and *"more people can talk more openly and start the [ARV] treatment"*. In the longer term, such outcomes could support HIV/AIDS patients and their carers and help reduce the social stigma that is still associated to the disease. In addition, as participants said, talking about one's status could encourage *"More people to come in the open"* and *"open up about having the virus",* which could help with more infected people beginning their ARV treatment.

Another message that was deemed particularly helpful was that pertaining to nutrition and its impact on the management and progress of the disease. The message contained information on using local foods, such as cassava, green bananas and sweet potatoes, for a nutritious diet and diverse dishes. Our participants said that this advice was very welcome and helped them to *"differentiate from the past and make good changes from now on"*. However, maintaining a healthy diet is still challenge due to poverty: *"We are told to be eating food containing all 6 categories but we do not have the capacity to eat all of them"*.

Overall, it was reported that the advisory messaging service helped them develop more positive attitudes towards challenging everyday tasks, as the information allowed them to "*bring good health to all*" and "*improve life for all*". They further noted that regular use of the advice given would "*result in good decision making*" and help them "*learn good habits*".

6 Discussion

In this study, we focused on identifying the information needs of informal carers of patients with HIV/AIDS in Malawi and sustainable ways to address them. Our study bridges the gap in the literature around Global South experiences of informal caregiving, by offering a nuance perspective of what informal caregiving means in a Global South context, and what the information needs are regarding caring for an HIV/AIDS patient. In what follows, we discuss the theoretical and methodological contributions of our study.

6.1 Theoretical Contributions

HIV/AIDS is a transmittable disease that primarily affects Global South countries. Appropriate medication regimes and care can control the prevention of the infection and manage the course of the disease. For this to be achieved, both the patient and their informal carer need to have access to accurate and timely information. However, not much is known regarding the information needs of informal carers of HIV/AIDS patient and even less with regards to these needs within the Global South. Currently, research on the information needs of informal carers tends to be Western-based and centred around e.g., age-related frailties (e.g., Robben et al., 2012), cancer (e.g., Beaver & Witham, 2007), dementia (e.g., Hargreaves et al., 2022) and other acquired but non-transmittable conditions (e.g., Everhart et al., 2020; Girardi et al., 2021).

Our study provides a rare glimpse into the specific information needs of informal carers who care for patients with a transmittable condition in a resource-constraint context, further providing a method for addressing them despite the infrastructural challenges on the grounds. As our findings show, informal carers in Malawi require information on the monitoring and management of the disease, developing healthy habits, learning about nutrition, as well as remaining safe. Some of these information needs have been highlighted by earlier studies already, particularly those in relation to medication administration and management (e.g., Hargreaves et al., 2022; Horne et al., 2018), and there have also been attempts to develop protocols to support informal carers' informed decision making in terms of the implications of medications (Malloy-Weir & Kirk, 2017). However, our findings further highlight that informal carers require information in terms of their own personal wellbeing and health, as the condition being a communicable disease. In other words, their information needs can be considered in terms of physiological versus psychological, whereby the physiological ones take precedence (Buchanan et al., 2019). This is an important finding: on the one hand, it highlights the struggle of caring for somebody who suffers from a communicable disease, but on the other hand, it further underlines the importance of the informal carer being and feeling healthy, as it is only under this condition that they can provide sufficient care to others.

Further, we show that information intermediaries are crucial actors for the dissemination of information and its uptake. We initially chose to engage with informal carers, local support groups, their leaders and community chiefs so that they would champion the project among their communities and for the purposes of co-production. However, our findings further indicate that in many instances they have also functioned as information intermediaries, too. Information intermediaries are described as an important source of information, who they can support information needs recognition as well as tailor information to the particular needs of the other, especially in disadvantaged contexts (Buchanan et al., 2019). Earlier studies have identified that this role is primarily undertaken by information professionals, volunteers, nurses, social care workers, and family members (Buchanan et al., 2019; Ruokolainen, 2022), while a common assumption is that information intermediaries tend to have relatively strong language literacy skills and educational background and that they are well regarded by their communities (Seale et al., 2022). In our study we extend this understanding and show that information intermediaries can also be one’s peers who can enable them to begin understanding what information they need (e.g., information on how to protect against transmission following diagnosis) by further contextualising this drawing from their own experiences (e.g., preparing nutritional meals for the cared for person when resources are scarce).

We posit that the local support groups further complement the role of the information intermediaries. On the one hand, support group leaders were integral in how we created and later disseminated the advisory messages, as earlier explained. As a result, during the support groups, their leaders were critical in helping the carers comprehend the messages disseminated, by explicitly contextualising the content for the carers' everyday life. On the other hand, during these support groups, informal carers exchange information, ideas and insights regarding supporting their patient and themselves. In many cases, this involved the carers themselves explaining to their peers how they have been taking the advisory messages on board, what challenges they had faced in implementing the advice, but crucially the benefits they were seeing as a result of doing so. In other words, one's peers cannot only help others understand their needs and the information itself, but also encourage and champion the uptake of information and advice. Having said that, we also note that what seems as the common denominator is that information intermediaries need to be trusted or prominent others within one's community, and that the peers between them need to have an established and continuous relationship (support groups meeting every 2 weeks to every 2 months and having been active for several years) because this allows the information disseminated to be considered as more credible and thus beneficial (Hirvonen et al., 2018).

The above points draw further attention to the concept of information literacy. Enhanced information literacy is beneficial for one's health and wellbeing because it entails seeking to address information needs, being able to critically evaluate available information and thoughtfully using said information in everyday life (Martzoukou & Sayyad Abdi, 2017). In addition, scholars have indicated that the majority of the information literacy literature approaches this concept as an individualised activity, whereby the individual "constructs knowledge for themselves" and based on their own experiences (Walton & Cleland, 2017). While this might hold true in some contexts, we argue that, in our case, information literacy seems to be a collective practice, whereby informal carers within their support groups and communities, and on the basis of the health advisory messages, construct their collective information literacy for the purpose of critically evaluating each message in terms of its accuracy, usefulness and feasibility. In this sense, we argue that the information literacy of informal carers developed on the basis of a collaborative and sociocultural practice (Oliphant, 2021), which, however, would not have been possible without the uMunthu principles, and namely sharing, responsibility and reciprocity, due to the stigma associated with HIV/AIDS, which often alienates people from their communities.

Our research further sheds a light on the informal caregiving experience in the Global South. While there are multiple studies regarding the lived experience of informal carers in Western societies (e.g., Alba et al., 2020; Greenwood et al., 2019; Sbaffi & Hargreaves, 2021; Shiu et al., 2016), there are not many studies that explore the nature of informal caregiving in the Global South. Western-based studies often tend to centre the experience of caring around the caregiving burden (e.g., Berglund et al., 2015), or the implications of caring for the informal carer's identity (e.g., Moore & Gillespie, 2014). In our study, informal caregiving is an overall commitment to the welfare of the community and sharing information with others is governed by the same commitment: as indicated by our participants, knowing how to care for a HIV/AIDS patient and knowing how to protect oneself leads to better outcomes at community level. This is based on the same premise that the practice of sharing scant resources, experience and knowledge with others is so widespread in Malawi. The above arguments, however, do not suggest that caregiving is experienced without tensions. For example, when needing to use somebody else's mobile phone during stressful times (e.g., when requiring urgent advice or assistance), several participants indicated that they felt they had no privacy, as the mobile phone owner could see later who they called or would listen in on their conversations by standing next to them. Others showed some degree of frustration, as they felt obliged due to local norms to care for a spouse with HIV/AIDS because they were unfaithful. In other words, while the uMunthu values alleviate some of the pressures of informal caregiving by encouraging sharing resources and information, the ways in which this happens can be taxing.

In some ways, our findings are similar to Tuyisenge et al.'s on the experience and motivations of the volunteers acting as community health workers in Rwanda; however, the authors find that the burden of care may pose challenges for the sustainability of this initiative over the longer term (Tuyisenge et al., 2020). In our study, we find no evidence of experienced burden, and instead we highlight that it is the sense of responsibility and reciprocity as influenced by uMunthu that strengthens the sustainability of the described intervention.

6.2 Methodological Contributions

This study was designed on the principles of co-creation, whereby we engaged with our participants, i.e., informal carers, NGOs and other local partners, from the very early stages: it was their shared experiences that informed our overall approach, and their contributions shaped the design of a health advisory messaging service.

Adopting co-creation might be challenging and we consider that our study can be used to guide other researchers wishing to follow this approach. Co-creation has been heralded as one of the better ways to support sustainable projects and innovation in the Global South (Tesfaye & Fougère, 2021). However, to achieve this, the researcher needs to spend considerable time in the context they investigate to observe first-hand the phenomenon and engage in several iterations with the research participants while developing research outputs to understand the local ways of knowing and being. Such exposure will provide the researcher with greater sensitivity, both towards research participants as well as the nuanced interpretations of what takes place and why. This was achieved by the third author of this paper and who was instrumental in design this project.

We consider that co-creation approach is the critical success factor that allowed the health advisory messaging service to be well received, adopted and sustainable. When designing interventions and projects that take place in the Global South, sustainability beyond the funding period is often a concern. Very often, such interventions tend to be short lived, leading to what is known as “pilotitis”, i.e., projects start off as pilots but never manage to scale up (Toyama, 2015). We therefore had to carefully consider how we would avoid this. As such, we explicitly involved community chiefs to enhance the sustainability prospects of the intervention beyond the project life itself. In addition, as the type of intervention and the focal areas of the messaging were shaped by informal carers, it ensured that the overall approach was addressing real needs on the grounds, in a way desired by the carers themselves, while being aligned with their way of life and principles of being (uMunthu). These two points motivated informal carers to be involved, to embrace the intervention during and beyond the project, and to disseminate the content of the messages beyond their support groups and across their communities.

At the same time, however, the researcher needs to remain aware of their positionality (Jimenez et al., 2022). When we began collaborating with our local partners to scope areas of mutual interest and potential collaboration, being white and coming from a resource-rich context suggested that there would be power dynamics that could influence our collaboration and the direction of the project. In such cases, we believe the researcher needs to ensure that the knowledge and experience of local researchers are heard and valued, as they are better aware of the local needs. For the purposes of our project, this meant that, on the advice of local researchers and partners, and in collaboration with the research participants, we developed advisory messages that were specific to the local needs, rather than being influenced of the Western experience of caring. In the longer term, such an approach can support a partnership based on mutual respect, that is long term and bound to maximise the positive impacts for the final beneficiaries, who in our case were the informal carers and the people they care for. In addition, such attentive collaboration with local researchers can avoid developing interpretations that are based on misrepresentations, misunderstandings and differences in cultural beliefs and practices.

Further to the above, the positionality and role of the researcher needs to be checked also when interacting with research participants themselves. During our first visit to Malawi, our research participants invited us to their households, to share with us their living conditions and lived experience, meet their family members and often the person they cared for. While this made us welcome, in many cases it entailed meeting people, often underage, who had not provided informed consent prior to our interaction. Further considering that our research entailed discussing sensitive matters, and engaging with HIV/AIDS patients and their carers, who often had a similar positive status, our interaction could involve difficult conversations. Typically, research ethics procedures entail halting the conversation, and where possible signpost participants to relevant resources. These instances can be minimised when accompanied by local researchers and even social care and community workers, as in our case. These individuals are better equipped to identify early signs of distress due to familiarity with the context and able to advise regarding expected behaviour in relation to local ethics and customs.

6.3 Implications for Practice

Beyond theoretical and methodological contributions, our study has some important implications for practice as well. Practitioners (including researchers working in the domain of informal care) who consider initiatives for meeting the information needs of informal carers, will need to be aware of the diversity of carers, the diversity of their needs and of the contextual conditions within which informal carers provide care to others. In the first instance, we would suggest that our methodological approach provides important implications for practitioners; our bottom-up approach on the basis of co-production entailed that the above issues were identified early on, and that the resulting intervention was tailored to the specificities of the context. In our case, this approach allowed us to appreciate the barriers that informal carers were faced with and obstacles towards enhancing their information literacy and therefore addressing their information needs. Early engagement allowed us to appreciate that the unavailability of resources (such as broadband connection, mobile phones and other artefacts that can be leveraged for information dissemination) and the low language literacy levels would be hindering the success of the intervention, but also enabled us to identify solutions and overcome these barriers.

Further, such bottom-up approaches and early engagement with carers, or research beneficiaries more broadly, can ensure that the initiative or intervention will address, over the longer term, real needs through desirable solutions and mechanisms. Our findings suggest that informal carers value information that is not only clear and accurate, but also feasible to adopt. This means that initiatives that investigate addressing information needs in resource constraint settings will need to take into account what tangible and intangible resources informal carers have access to, and tailor advice and information provision on the basis of these. This relates both to the content of the advice itself as well as the means of disseminating the information beyond the specified number of people directly benefitting from the initiative.

6.4 Limitations

Due to the co-creation nature of this project, our work has been largely shaped by our research participants and guided by our local partners, which helped us develop a better understanding of informal care in Malawi and develop a desirable and needed intervention.

While we consider co-creation to be the most relevant research approach for studies that focus on underserved social groups, often co-creation may be leveraged as a way to exploit local partners and participants in parting with their knowledge and experiences for the benefit of a hegemonic project or even a corporation, and for providing a “social license” or acquiring legitimacy to operate in the particular context (Tesfaye & Fougère, 2021). A way forward to avoid this is by ensuring the researcher is aware of their positionality, and that the wellbeing and safety of research participants are always prioritised over project outcomes.

In addition, as explained earlier, there are numerous support groups across Mangochi and Malawi generally. In our study we engaged with those groups that were in good proximity to the local researcher’s headquarters in Namwera to minimise travel due to poor transport infrastructure. Also, all our participants are, indeed, members of a support group. As such, our findings and the overall design of the study was informed and shaped by the experiences of those informal carers who already receive some form of support through their group and are more committed and engaged with their community. Therefore, one should be careful whether and to what extent these insights are generalisable across Malawi and other African countries, or whether similar interventions would benefit those who do not engage with support groups.

7 Conclusions

Informal carers are a critical part of the society, offering unpaid care to those who need it. This labour, although unpaid, is of great significance for the wellbeing of people in care, and for the economy of all countries, as a result of poor healthcare and social care infrastructure and an ageing society (Wang et al., 2022). In resource-constraint settings, informal carers may be the only safety net for a person needing care. While in Western societies there has been progress regarding supporting informal carers, in the Global South this is not always the case. Developing and sharing accurate, practical and timely information resources which are specific to the disease/condition of the person they care for, can significantly improve the quality of care they provide, improve their own wellbeing and lead to improved health outcomes for the community as a whole.

In the two-phase study reported in this article, we co-produced a health advisory messaging intervention to address the information needs of informal carers in Malawi, by first identifying what information informal carers need and how they would prefer to receive it and then engaging with medical doctors and social care workers on the grounds to shape the content of the messaging service. Considering the particularities of the context, the organising logic of the Malawian life and other influential factors, e.g., the role of community chiefs, we delivered this intervention by using local support groups as hubs to broadcast audio recorded messages via an online application, enabling the spreading of the messaging via word-of-mouth across the entire communities.

Our study makes an important research contribution in identifying the information needs of a rather underprivileged and particular group, that of informal carers of HIV/AIDS patients from a Global South setting, further expanding the concept of information intermediaries; significant practical contributions in terms of improving perceived health outcomes for the people involved in our project and those beyond it; and methodological contributions, by contributing to a recent and ongoing discussion around participatory methods and research co-production. Regarding this latter point, our co-production approach further supported the uptake of the health advice. On the one hand, we identified information gaps by directly engaging with informal carers and then devising together with them how it should be formulated and delivered in a participatory way. As we did the above from the early stages of the project (ideation stage), there was enough time for them to build their trust towards and have open conversation, and it further empowered them to shape the project and its outcomes (Maclean et al., 2022). In other words, part of the practical contributions has been achieved because of our methodological choices.

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Declarations of Interest:

None