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Embracing uMunthu: How Informal Caregivers in Malawi use ICTs

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Abstract. This paper explores the way informal caregivers in Malawi use different types of ICTs for the purposes of caring for their loved ones, supporting each other and building a community under adverse circumstances. We collected empirical material in the Mangochi district during a field study through a focus group and a workshop with informal caregivers and NGOs. For the purposes of our analysis, we draw from the uMunthu philosophy of Malawi in order to explore and understand the contextual conditions and the local phenomena. Our findings show that, the communal character of ICTs and their shareability often allows informal caregivers to come together as a community and overcome the scarcity of ICT resources through sharing, which is in line with the uMunthu principles. Quite often, though, sharing can lead to unintended consequences. The paper contributes to the ICT4D literature by theorising around the concept of sharing and shareability of ICTs; in doing so, we join our voices to the growing discussion on the use of southern theories and paradigms.

Keywords: informal caregivers, Malawi, uMunthu, ICTs, thematic analysis, shareability

1 Introduction

Informal caregivers are people without formal training or education in healthcare, who have taken up caring responsibilities for one or more family members [1]. In African countries, where extended families are the norm and kinship is considered one's "safety net", informal caregivers face the challenge of day-to-day care by default [2]. Yet, African philosophy does not consider this as a challenge but rather as a way of being. Specific to the Malawian context where this study is situated, the uMunthu philosophy entails that the essence of being revolves around responsibility towards the community, whereby caring, empathy [3] and sharing are core to one's identity [4]. This does not mean that caring for a family member comes with no challenges. In such resource-

constraint settings, it rather means that there are additional caveats, such as being the sole provider for the household.

To address this challenge, existing literature has emphasised the role of ICTs. Some studies have focused on how ICTs can support health-related outcomes in developing countries [e.g., 5, 6], whereas others discussed how ICTs promote social connectedness, and empowerment [e.g., 7]. Others, however, have focused on detrimental effects of ICTs, such as economic inequalities [e.g., 8]. However, studies that look directly into ICTs and informal caregivers themselves within a developing country context are lacking.

The aim of this study is to fill this knowledge gap by looking into the way informal caregivers use ICTs. We explore how and what ICTs are used by informal caregivers in Malawi. Our empirical material derives from a field study in the town of Namwera, in the Mangochi district of Malawi. The analysis of the collated material uncovered two important, and to an extent interrelated, themes. ICTs are primarily shared rather than owned. Through sharing, informal caregivers manage to support each other in line with their uMunthu philosophy of being. However, sharing ICTs often leads to unintended consequences.

Therefore, the research question driving this study is: in what ways are ICTs affecting the daily life of informal caregivers in rural Malawi?

In what follows, we present a brief overview of the literature on ICTs and informal caregivers and then present a discussion on the uMunthu philosophy. We then present our methodology and our findings. We conclude the paper with a discussion on the implications of our study.

2 Informal Caregivers and ICTs in Developing Countries

A major area where we see multiple ICT-based interventions is that of healthcare, possibly because healthcare is burdened with multiple inequities, adversely impacting the poorest of society [9].

There is a wealth of studies focusing on how ICTs can facilitate health-related outcomes in developing countries. For example, Holeman and Barrett have examined the implementation and the redesign of technology for the support of healthcare workers in Kenya who work in the cold storage of vaccines [10]. Similarly, Mbelwa et al. have looked into the factors that drive healthcare workers to adopt mobile health applications, with the aim to increase the collection and transmission of remote data, thereby improving healthcare services [11].

Another stream of ICT4D research focuses on the use of ICTs by the patient, with the aim to either self-manage their condition and/or to become empowered, socially embedded and financially included. For example, mobile phones, even simple ones, can be gateways of information. In India, mobile phones are used to disseminate information on health programmes and healthy practices [9]. Other studies show that mobile phones can help not only reduce maternal morbidity and mortality rates, but also support pregnant women in identifying and using entrepreneurial opportunities [7, 12].

Yet, there is a lack of ICT4D studies that place the informal caregiver at their core. Generally, studies at the nexus of ICTs and informal caregivers design and develop ICT-based solutions within and for western paradigms [e.g., 13]; as such, findings and solutions are not typically transferable within the Global South, where the contextual conditions are strikingly different. On the other hand, assuming that the informal caregiver is treated as co-producer of sustainable healthcare ICT solutions [14] and that ICTs can indeed be beneficial, even in their simplest form [15], it is critical to first understand the local ways of knowing and being. This not only provides the researcher with sensitivity regarding the local context, but also with a way to appreciate what informal caregivers value for themselves and their communities.

3 The uMunthu Philosophy

‘Umuntu ngumuntu ngabantu’ captures the essence of uMunthu¹. Its English translation is “[a] person is a person through persons” [16], which emphasises the importance of kinship, whereby interrelationships among individuals define behaviours and regulate communities [17]. Ultimately, this means that the fate of an individual and that of the community are inescapably linked [16]. The uMunthu philosophy prioritises empathy, caring, and understanding, where the contributions of all individuals are equally valued and cherished, and where reciprocity and responsibility towards the community and others are of distinct importance [3]. In other words, duty outranks privileges, and sharing is seen as testament to their social interconnectedness [18]. As such, sharing and “neighbourly assistance” is part and parcel of the African identity [4].

¹ The term also appears as Umuntu and Umunthu

The core values of uMunthu are: respect for all human beings and their dignity and life; and “sharedness, obedience, humility, solidarity, caring, hospitality, interdependence and communalism” [17]. Several of these values seem counterintuitive to the Western ones, and we note that for African countries, collectivism and communal embeddedness are the mainstream [16]. Due to this focus on collectivism, uMunthu has been criticised for imposing compliance over individualism [3]. However, this is a misconstrued criticism, as uMunthu promotes personal development, personal interests and preferences as well as individuality, without promoting individualism, as long as individuals remain aware of their interdependence to others, and their community [3].

4 The Context of the Study

Malawi is among the least developed countries according to the ODA list. Its population is approximately 18.6 million and, in 2018, there were 1 million people living with HIV/AIDS, with 38,000 people newly infected with the disease [19]. Informal caregivers of HIV/AIDS patients in the Mangochi district have formed support groups at community level, and meet on a regular basis (biweekly, monthly, bi-monthly etc). The purpose of these groups is to support one another and learn from each other how to care for their loved ones along the lines of nutrition, cooking, bathing tips, first aid etc. The carers bring food and other resources (such as oil) and cook together, share stories and experiences. While not all support groups are equally effective, those that are have managed to substitute the formal healthcare provision that is severely lacking.

4.1 Data Collection

In order to gather in-depth knowledge on informal caregivers’ unmet needs and use of ICTs, this study adopted a qualitative research design involving a) a focus group with primary informal carers of people living with HIV/AIDS and b) a workshop with relevant stakeholders in the field of HIV/AIDS, both of which took place in June 2019.

For the focus group, we adopted convenience sampling. The participants were recruited through one of the community-based support groups for informal caregivers. The focus group consisted of 10 informal caregivers, nine females and one male. The gender discrepancy is a

reflection of the current caring situation in the country, which, traditionally, still requires women to cover nurturing roles. Upon their arrival, the participants were briefed about the scope of the study by a Chichewa-speaking (a local Malawian language) Research Assistant functioning as translator and we obtained verbal informal consent. We wanted to get insights into the experiences of the caregivers as lived and felt. As such, we wanted participants to feel free to contribute and express themselves or feeling pressured in anyway by the presence of individuals who could potentially influence and exert power over them (e.g. Community Chiefs).

The workshop was organised separately from the focus group. The participants to the workshop, 11 in total, were representatives of key stakeholder groups including academia, NGOs and local communities. The objective of the workshop aimed at understanding the structures and mechanisms that underpin the healthcare system in Malawi, and exploring the existing and foreseen government initiatives at local and central levels. In addition, we wanted to gauge a higher level understanding with regards to how ICTs are actively used today in Malawi and how they can support informal caregivers in the future in caring for their loved ones.

Both the focus group and the workshop were audio recorded; the questions were first asked in English and the Research Assistant translated them into Chichewa. Responses by individual participants were then translated back into English.

In addition, we collected empirical material through archival research into published reports with regards to ICT-driven initiatives and projects undertaken by the government in Malawi in recent years. We also collected material via informal discussions with informal caregivers and their extended families during visits to their villages and households. This helped us contextualise some of the information offered by our participants, cross-validate our interpretations with regards to findings, and gain an intimate understanding of their everyday life.

4.2 Data Analysis

We coded the empirical material using the NVivo package, and we started by using a broad coding scheme, as themes begun emerging from our preliminary reading of the transcripts. In our study, three main themes emerged: sharing and shareability, supporting each other and giving back to the community, and unintended consequences. For each

of these themes, we coded our material in a data-driven and theory-driven way, drawing both from our empirical data and from the relevant literature, as proposed for thematic analysis studies [20].

There was a continuous comparison between our coding, the interpretations of our findings and the literature. Newly identified themes formed new codes, and secondary material from our archival research, and our observations helped us corroborate evidence from the focus group and the workshop, further enabling triangulation.

5 Findings and Discussion

In this section, we begin with what ICTs informal caregivers share and how they use them. We move on to highlight how informal caregivers have managed to support each other under adverse circumstances, and how they have arrived at a point to be able to give back to their community. Finally, we discuss the unintended consequences of their sharing practices, as documented during our field study.

5.1 Sharing and Shareability of ICTs

Sharing of resources, however scant, is considered the norm in the community. This includes ICTs as well, such as mobile phones and radio receivers, as well as other technologies, like solar panels, which are quite popular in the villages.

It is very common to have a radio receiver within the household, and once the chores of the day are done, the caregiver usually spends some time with their loved ones to discuss the events of the day. In addition, there are several radio listening clubs, whereby people from the communities come together, catching up with the news, or more specifically, in the case of informal caregivers, to receive radio-transmitted health advisory messages: *“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.”*

With regards to mobile phones, ownership is not very common. Among our participants, only half of them had a mobile phone, and only one had a smartphone. If a phone is owned, this is usually shared with the rest of the household. However, in many cases, there are households without any communication means. This poses a significant

challenge for informal caregivers, especially in times of a crisis, i.e., when the patient needs immediate help which the caregiver cannot provide. In such a case, “[they] borrow from those that have the phones” or “just send boys or someone to go to those houses that have got phones.” This allows them to call the closest health centre and get some immediate advice, or call the district hospital and possibly arrange to have their family member transported there.

Informal caregivers are able to enact sharing practices because the available ICTs exhibit a degree of shareability. In their striking majority, mobile phones are used with pay-as-you-go schemes. This suggests that caregivers can buy credit from one of the many operators, top up somebody else’s phone and use it for their own purposes: “*The others [those without a mobile phone], 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. They say what they want and then after that they are done, they give back the phone. They can just have some money and put in some units.*” Alternatively, they can reimburse the owner for the airtime they have spent.

Smartphones are uncommon. However, when they are available, their enhanced capabilities allow for different ways of sharing: “*This year our political campaigns used social media quite a lot. Messages went through WhatsApp (...) even some people in the village were asking me some questions and I was able to play some clips on my phone.*” In other words, while people cannot make direct use of the smartphone, they can still access informational resources through third parties, and, from there, diffuse the information within their community, hence resembling the principles of the radio listening clubs.

5.2 Supporting Each Other and Giving Back

The caregivers support each other on different levels. They encourage each other against the challenges of everyday life and of caring for their family members (“*We also go to that support group once a month where we also do counselling and encourage each other.*”). They further share their caring and life experiences, best practices and what they have learned by caring for their family members, through doctors’ and or healthcare workers’ visits. They do so during the support groups meetings. Similar support groups exist for children who have been found positive to HIV/AIDS, where they can play with each other, learn skills and tips for caring for themselves and easing the burden on

their mothers (*“And there we have two groups, we have adults therapy and we have got children therapy of which we normally discuss how to take the drugs at what time and advise what to eat and what not to eat.”*).

At the same time, the support groups serve a purpose in helping the caregivers to improve their own well-being, as well as initiate small scale entrepreneurial activities, such as preparing, cooking and selling samosas in the market: *“It’s like we teach each other cooking methods like how to prepare and bake samosa, doughnuts so that we don’t rely on begging for support from our relatives and friends. We can open up small scale businesses and make some income.”* Such advice is of critical importance for the caregivers, because in their vast majority they are the sole household provider, and often have needs that extend beyond the disease: *“I am taking care of a child and in the past we didn’t worry about school materials and needs but now the child has started school and I don’t have the money to buy school books, uniforms and other materials”*.

The support groups are crowdsourced, which poses several challenges. For one, it means that when the caregivers have no resources, i.e., no ingredients for cooking, baking, or no fertiliser for gardening and farming, the support group cannot function as well, which denotes in many cases a financial dependency. Each caregiver brings whatever they have available. However, when they do not have anything, they revert to less resource-intensive activities, like talking. Ultimately, by pooling their knowledge and experiences, they have managed to build a crucial capacity of best practices around caring and caregiving through meetings and interactions over the last few years.

At the same time however, the capacity they have built through the support groups, and as a result of their sense of responsibility for their community, they use it to give back to the community. They provide counselling themselves to others, who go for their first diagnosis and who find themselves in the same position (*“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, whereas most of the counselling services and advice provided by the formal healthcare structures in the area are directed towards the patient, our participants indicated that they themselves follow a different direction. They specifically start with the person who will be acting as the caregiver of the patient, or as

they call them, the guardian: *“So for us we start with the guardian, 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.”*

5.3 Unintended Consequences of Sharing ICTs

Sharing mobile phones with others comes with a price as it highlights and exacerbates the economic inequalities within the community [8], as well as raise privacy issues [21]. When caregivers have to make a call using somebody else’s phone, it means they have to sacrifice their privacy, as the owner of the phone will be present during the call. These phone calls are, in many cases, directed to immediate or extended family, living abroad, or, to emergency healthcare services: *“[When we want to talk to relatives abroad or in an emergency] we just use the phone. And there is no privacy at all since the owner is there with you listening.”*

When it comes to calls to family members, it is often the case that informal caregivers receive support from their siblings who live in the city or abroad (*“Whenever she is facing some challenges she has got some brothers working in South Africa.”*, *“I have brothers who send money to help take care of mom”*). They may wish to inform their families regarding the condition of the patient or ask for financial support. When the call concerns the healthcare services, by definition the call will concern healthcare-related matters, which are generally seen as private. As such, placing a call under these circumstances can be quite detrimental or stressful for the caregiver.

As mentioned earlier, another way caregivers go about sharing others’ mobile phones is by buying top up credit or reimbursing the owner for how much time they have used the phone. In these cases, what was shared with us is that what this arrangement means for the caregivers is that most often there is leftover credit, which the caregiver cannot use as it remains in the account of the mobile owner; as such the owner benefits at the caregiver’s expenses: *“When they have some money, they buy airtime and put it in somebody’s phone and they speak while the owner is there. (...) They can just have some money and put in some units. Then the owner benefits from the left over units.”* For some people, these leftovers may be the difference between feeding their dependents or not.

5.4 Embracing uMunthu

We have witnessed a number of ways in which informal caregivers experience and enact the uMunthu values in their everyday life. As part of the uMunthu philosophy of living and being, we have observed that for our participants, caregiving is not seen as a burden, as opposed to the Global North [22]. Instead, for Malawians, it is a way of life (*“We just think it is part of our life.”*, *“The problem is in my house so what else can you do.”*). In addition, sharing their experiences, as part of the support group and sharing their scant resources, is their only way of living. This attitude and openness to sharing are in line with the Malawian epistemology of uMunthu, whereby, what gives human life meaning is living as part of a community, where sharing is the organising logic of such community; it is only then that a person actually achieves their personhood [23].

While sharing can lead to unintended consequences, as shown earlier, we posit that, because the uMunthu values are so ingrained into the very fabric of everyday life, responsibility and caring for their dependents take precedence for the caregivers, who are, therefore, willing to sacrifice other things, such as their privacy (*“We make sure the patient is well and comfortable and then we can go and do what we can so that when we come back home we have something to eat with the patient.”*). uMunthu can be observed also in the informal caregivers’ commitment to their community, their support group and others in a similar role to theirs, as they become their supporters through counselling. Most crucially, as a result of their community-centric view that stems out of the Malawian uMunthu way of life, the caregivers are willing to share best practices and resources, as members of these support groups. Also, sharing with each other and through the support groups is seen as a fundamental emotional anchor.

6 Conclusions

Sharing and collectivism are critical factors for the wellbeing of caregivers in Malawi, which is in contrast to what we have come to know in the Global North. The sharing practices are discussed through the lens of the uMunthu principles. Although it is clear that ICTs are facilitating information exchange and support, there is still little evidence that Malawian’s lives are significantly affected for the better. Future ICT4D

studies might want to explore how this sub-Saharan humanistic approach can be channelled to promote and support better quality of life through the use of accessible and shareable technologies grounded in the Sustainable Development Goals.

Our study comes with some limitations. The participants of our focus group come primarily from one of the support groups, which comparatively is the most efficient one across the district. As such, our findings do pertain to those who are most committed and engaged with the community. We only focused on mobile phones, as these were the most prevalent in the area; different forms of ICTs could have possibly provided us with different findings. Finally, the theoretical link we identified among the emerging themes was that of the *uMunthu* philosophy, and we did not consider alternative explanations. However, we consider this to be a compelling enough theory, which manages to provide a holistic lens while having been brewed within the local context, and therefore being sensitive of the local dynamics and characteristics.

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