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Karera, MGD, Omar, MA orcid.org/0000-0002-3459-2011, Nabirye, E et al. (2 more authors) (2022) Mobile Technologies for Palliative Cancer Care in Uganda: Qualitative Secondary Analysis of Health Professional Perspectives. *Health Policy and Technology*, 11 (1). 100608. ISSN 2211-8837

<https://doi.org/10.1016/j.hlpt.2022.100608>

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Title: Mobile Technologies for Palliative Cancer Care in Uganda: Qualitative Secondary Analysis of Health Professional Perspectives

Running title: Mobile Technology for Palliative Cancer Care

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Keywords: Digital health, Palliative care, Health professionals, Sub-Saharan Africa

Abstract

Introduction: In sub-Saharan Africa (SSA) cancer care is characterised by limited funding, restricted access to curative therapies and 80% of cancers advanced at the time of detection and diagnosis. Palliative care need in SSA is significant, however, most countries in the region have limited provision. mHealth (i.e. medical and public health practice supported by mobile devices) is an approach that may support increased access and communication with palliative care services. However, there is a limited understanding of health professionals' views and perceptions on its use in the delivery of cancer care.

Methods: To understand health professionals' views and perceptions of the use of mHealth as part of palliative care delivery. Transcripts from interviews of health professionals in Uganda (n=20) were analysed thematically.

Results: The majority of participants were female (75%, n=15). Average years of experience was 15.8 as healthcare providers and 8.2 years as palliative care providers. Four overarching themes were derived from the analysis: i) current use of mHealth in palliative cancer care provision; ii) advantages of using mHealth in palliative cancer care; iii) challenges to providing palliative cancer care using mHealth, and; iv) preferences for mHealth use in palliative cancer care.

Conclusions: mHealth is considered advantageous for the provision of palliative cancer care. There is a need to adapt training to improve competencies of palliative care professionals in delivery of care that leverages digital technologies. Development of mHealth initiatives needs to consider how best to maintain patient privacy and ensure inequities in access to care are not worsened.

Public Interest Summary

Palliative care provides a crucial role in supporting the multiple needs of patients with advanced cancer. In sub-Saharan Africa, there is very limited access to palliative care services. Digital technologies, such as the use of mobile phones, are increasingly being used to support communication between health professionals and patients with cancer and their caregivers. mHealth refers specifically to medical and public health practice supported by mobile devices including phones and tablet computers. The views and preferences of health professionals about the use of digital technologies to support patients with cancer in countries in the region is not clear. We interviewed 20 health professionals providing palliative care across clinical sites in Uganda. Key areas of importance highlighted by participants included their current use of mHealth in care, alongside the advantages and challenges to their use. Health professionals see digital technologies as promising for enhancing care, but key considerations include patient privacy, the need for mHealth training and ensuring inequities in access to care are not worsened.

Introduction

Worldwide, cancer incidence has increased for the last two decades with a marked rise of cases in low- and middle-income Countries^{1,2}. In 2020, over 330,000 cases of cancer in the Eastern region of Africa were estimated, with over 200,000 deaths³. These numbers are projected to double by 2040⁴. Viral infections, like human papilloma virus and hepatitis B, alongside lifestyle changes, including excessive alcohol consumption, unhealthy diet and physical inactivity are the major contributors of cancer burden in Sub-Saharan Africa (SSA)⁵. Moreover, the majority of cancer cases in SSA are detected at an advanced stage⁶. For example, a population-based study in SSA region found that about 65% of breast cancer cases were diagnosed at an advanced stage with almost 20% already metastatic⁷. Similarly, around two-thirds of cervical cancer cases are detected at a late stage⁸. This may result in limited treatment options which, in turn, makes palliative care the only realistic public health approach for the wellbeing of patients and that of their families.

Palliative care aims to improve the quality of life for patients with advanced, incurable diseases by preventing and alleviating their physical, psycho-emotional, spiritual and social distress and associated problems⁹. Studies on symptom prevalence among patients with advanced cancer have shown pain as the most common symptom, alongside “lack of energy” and “feeling sad”^{10, 11}. Access to health services for pain medication, essential equipment, appropriate nutrition and care assistance remain a challenge due to the cost and time for long distance trips to health facilities to seek treatment. This, in turn, results in significant unmet health care needs and prolonged suffering¹²⁻¹⁴. Despite the significant need for it, palliative care provision in SSA remains underdeveloped¹⁵.

The World Health Organisation has endorsed the use of digital health approaches which can support health system strengthening and contribute to achievement of Universal Health Coverage¹⁶. Digital health is the use of information and communication technologies to improve healthcare delivery¹⁶⁻¹⁸. Considering the benefits of digital health interventions in providing consultation and treatment to patients and families in chronic disease management, it may have a role in supporting palliative care needs^{19, 20}. For example, mHealth is medical and public health practice supported by mobile devices and can be succinctly defined as “the use of mobile wireless technologies for health”^{16, 17}. mHealth can

assist in healthcare provision by overcoming barriers associated with the time and place for healthcare delivery²¹.

In SSA, 44% of the adult population have mobile phone subscriptions, with almost a quarter of the population being regular mobile internet users. Mobile phone ownership is projected to keep growing up to a half of the population by the year 2025²². Mobile phone interventions are being developed and can deliver benefits to palliative care service provision in the SSA region²³. However, there is limited evidence on the views and perceptions of healthcare professionals regarding their use in the delivery and adaptation of palliative care²⁴. This study aims to explore health professionals' perceived role of mHealth in palliative cancer care, the challenges associated with its use and how it might support the advancement of palliative cancer care.

Methods

Study Design

This is a qualitative study using a supra analysis approach which involves secondary qualitative data analysis to answer a new research question²⁵. Secondary qualitative data analysis is increasingly recognised as an effective means of adding value to original research by re-analysing data to bring new substantive and methodological insights, maximise learning from existing data, and inform health policy²⁶. The parent study, in which data were originally collected, was a multi-country (Nigeria, Uganda and Zimbabwe) exploratory qualitative study. The parent study sought to describe how patient-level data, obtained using digital technologies, could be used to improve the delivery of palliative cancer care²⁷. The published main analysis from the parent study provided an overview of key findings from four stakeholder groups (adult participants living with advanced cancer, their caregivers, their healthcare professionals, and policymakers) but did not allow for in-depth exploration and reporting of individual stakeholder perspectives. A secondary analysis of policymaker perspectives has been published by the research team²⁸. Our rationale for this analysis was to undertake an in-depth analysis of health professionals' accounts of the perceived role of mHealth for palliative cancer care in Uganda. This will produce novel and as yet unreported findings from the perspectives of those delivering frontline care. The findings derived from this approach are intended to inform mHealth intervention development

for palliative cancer care in Uganda and the wider SSA region. To provide assurance of fit and relevance of pre-existing qualitative data for the planned secondary qualitative analysis, we assessed the health professional transcripts and research question explored in this study against a rubric²⁹.

Setting and Participants

The parent study²⁷ recruited adult participants living with advanced cancer, their caregivers, their healthcare professionals and policymakers. Healthcare professionals participants were purposely selected using eligibility criteria of those who worked with palliative care patients at palliative care facilities for at least 6 months. The target sample size was 20 participants.

Data collection and analysis

All participants provided written informed consent. Semi-structured interviews with health professionals were conducted using a topic guide that explored current interaction with patients and the existing and potential role of digital health in facilitating communication and delivery of care. Interviews were conducted in English and were transcribed verbatim, and deidentified. For this secondary analysis, a thematic analysis approach was adopted using NVivo 12 software³⁰, with the process outlined in **Figure 1**. Two authors (MGDK and MJA) familiarised themselves with the data by reading and re-reading through the interview transcripts. A coding framework was developed from which themes were grouped and refined by three authors (MGDK, MAO and MJA). Derived themes were reviewed to identify those that are relevant to the aims of the study. Although nuances within sub-themes were still emerging towards the end of data analysis, the themes were being replicated, indicating a level of completeness across sample characteristics. The results were reported following criteria for reporting qualitative research (COREQ)³¹.

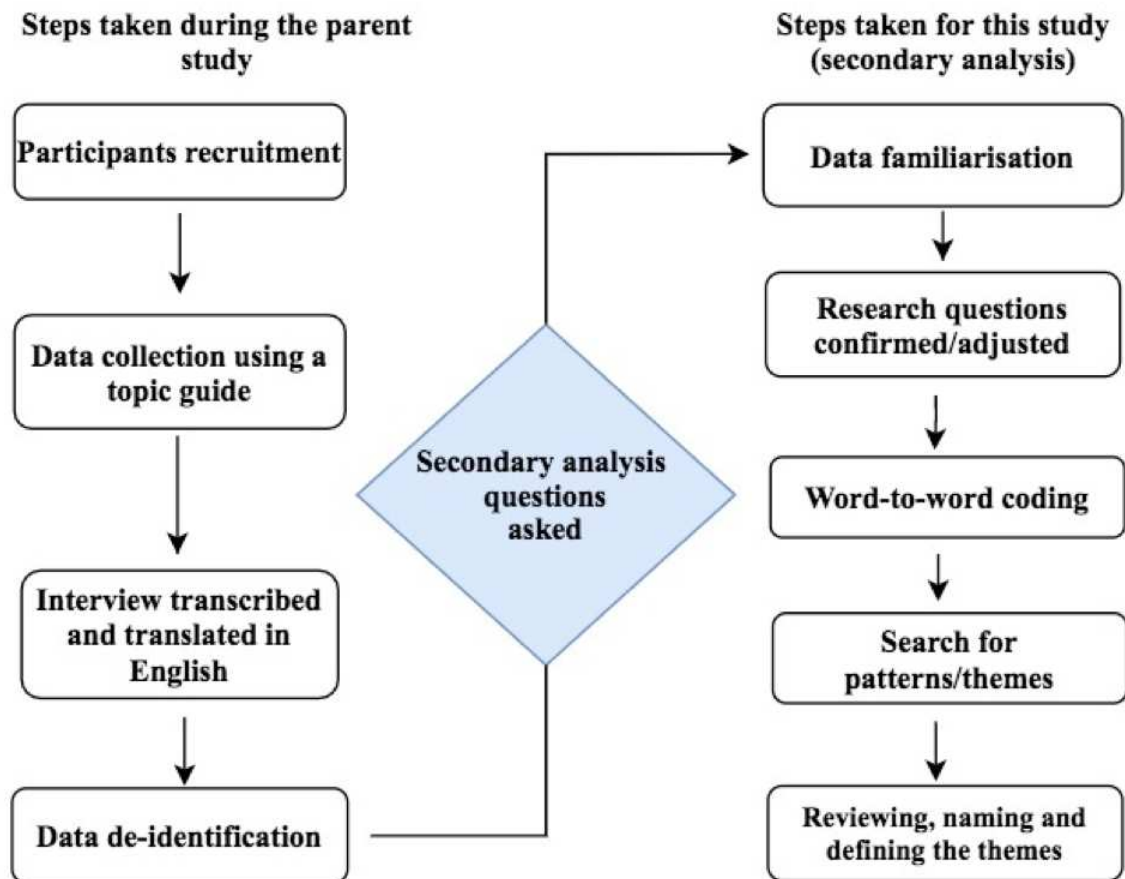


Figure 1: Overview of the thematic approach adopted for this study

Ethical approval

Before data collection, the study protocol²⁷ for the parent study was approved for use with human subjects receiving care for any form of cancer in the hospital, hospice or in a palliative centre across Uganda, Zimbabwe, and Nigeria. Written informed consent was obtained from each of the participant before the commencement of interview. Ethics approvals were obtained from the Institutional Review Boards of University of Leeds (Ref: MREC 18–032; 11th January 2019), College of Medicine University of Lagos (Ref: HREC/15/04/2015; 28th December 2018), Uganda Cancer Institute (Ref: 19–2018; 23rd January 2019), Medical Research Council of Zimbabwe (Ref: MRCZ/A/2421; 5th March 2019), Uganda National Council of Science and Technology (Ref: HS325ES; 14th March 2019), and Research Council of Zimbabwe (Ref: 03507; 2nd April 2019). The project was aligned with the Medical Research Council good research practice guidelines³² and H3Africa framework for conducting ethically responsible biomedical research³³. The study was registered with ISRCTN registry (reference number: 15727711).

Before accessing the interviews for this paper, data sharing agreements with the primary study data owner were signed following the “Data sharing code of practice” of the Information Commissioner’s Office³⁴. The study participants have agreed and consented for data sharing for secondary analysis and they have given right to withdraw their consent.

Results

Twenty interview transcripts were analysed. As shown in **Table 1**, most of the participants were female (n=15, 75%) and had, on average, 15.8 years (Range = 2-41years) of experience as healthcare professionals and 8.2 years (range: 8 months - 18years) as palliative care practitioners. As summarised in **Figure 2**, four overarching themes were derived from the analysis: 1) use of mHealth in palliative care provision; 2) advantages of mHealth for palliative cancer care provision; 3) challenges in implementation of mHealth in practice, and; 4) requirements for mHealth use.

Characteristics	Category	%(n or range)
Sex	Female	75%(n=15)
	Male	25%(n=5)
Profession	Nurses	50%(n=10)
	Doctors	30%(n=6)
	Social workers	10%(n=2)
	Counsellor	5%(n=1)
	Clinical officer	5%(n=1)
Experience (in years)	As healthcare professional	15.8(2-41)
	As palliative care practitioner	8.2(0.7-18)

Table 1: Summary of participant characteristics

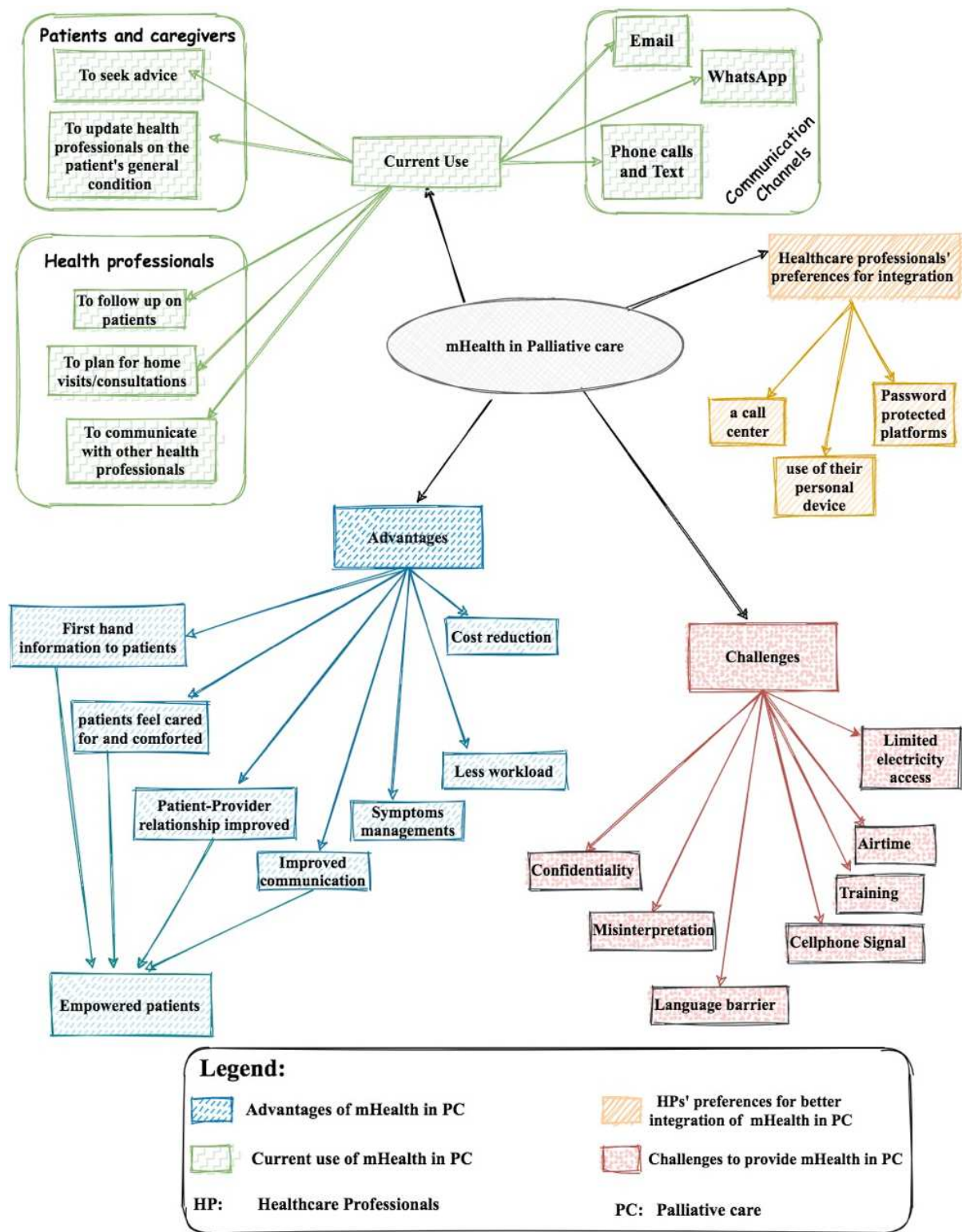


Figure 2: A thematic network diagram outlining the four overarching themes derived from the analysis.

Theme 1: Current use of mHealth in palliative cancer care provision

All participants stated that they use mobile phones to contact their clients between consultations through phone calls, text messages and a few participants used WhatsApp and emails, especially for documents sharing.

Participants also reported bidirectional communication using mobile phones usually with patient and caregiver dyads: from patients and their caregivers to healthcare professionals, and vice versa. While patients or their caregivers can initiate the contact, it is typically initiated by the healthcare professionals. When initiated by the patients or caregivers, they are either seeking advice on symptom management or how to administer prescribed treatment, or updating the healthcare professionals on the general condition of the patient, including when a caregiver needs to notify health professionals that a patient has died.

“A patient caregiver would call you at night at 2 am and tell you my patient is feeling a lot of pain, what should I do? Then other time it’s to inquire may be about a prescription, that may be I was written this brand, but they have given me this, is it ok to take it?” (medical doctor)

“...even when the patient dies, they actually call there and tell you, you know this patient has passed away.” (nurse)

Healthcare professionals mainly contact patients using mobile phones to check on the patients or follow up on the use of medications. They call to find out whether the patient has gotten any better or if there are any complications alongside planning and coordinating home visits.

“Usually, before you see the patient, you have to plan, you know you don’t want to drive fuel to go to a patient’s home who might have gone to hospital, or who could have died or could have changed address...” (Clinical Officer)

Mobile phone calls are also used for communication between healthcare professionals. Participants use phone calls to direct, at community level health facilities, those staff who are often not familiar with the patients’ conditions, or to direct them on the management of some symptoms. This happens when patients or their caregiver call to report minor symptoms that can be managed at their local primary health facility. A junior medical doctor also reflected on how they present patients’ conditions to their seniors (often specialists) over the phone for better management. This approach is used when a patient has previously been seen by a specialist but is being supported by another doctor for follow-up consultations.

“...also we report to seniors about how, especially if the patient is assigned to them, how their patient is doing, so you can use the phone to discuss (with) them aah... they brought your patient so and so, this is how we are doing, this is what we have done... is there anything like a lab test, is there anything you would want to do, you would want us to add?” (Junior Medical Doctor)

Theme 2: Advantages of mHealth in palliative cancer care provision

Generally, healthcare professionals reported that mobile phones are beneficial in their daily routine, improving the frequency and ease communication with their patients. Instead of travelling long distances, healthcare professionals and their patients are communicating wherever they may be. Participants also reported being able to support symptom management remotely and this can support the patient to achieve comfort. Mobile phones are supporting speedier decision making.

“...for example (when) the pain is high, you can make a decision via phone, such that when you go there you can find at least when the client is relieved, a bit relieved. So

you can say for example if someone is on oral morphine you can say let me take and increase to such and such amount, such that by the time you reach there the client at least is not in overwhelming pain so it helps you to take the decision very fast” (Nurse)

Participants felt that mobile phone applications or a website for patients to provide updates on their health would be helpful resources to support their management of a patients' condition, including both those in hospital and in community settings. Participants also felt this could reduce costs for both patient and themselves, minimising the cost and burden of travel. For social workers, it could provide more efficient means of working, reducing face-to-face interaction where it may not be necessary or possible.

“I think it will be more efficient, it will help. supporting patients will become easier, because when like a patient has issues they don't need to have transport to come, sometimes they come and bounce, they don't find me because I don't know the appointment, so when they have that kind of communication gadget with them wherever I am, I am able to link up with the patient... especially in situations where a patient cannot afford transport to come to the organisation and yet patient may not be necessarily coming for, to see a clinician for physical pain, but on our part as social workers I think it will be more beneficial...” (Social Worker)

Participants also reflected on how mobile phones would lessen their workload and improve their relationship with patients while enhancing their responsiveness. Typically, if a patient consults a healthcare professional, they will be required to undergo a process of having their documents checked and undergoing baseline tests, which may be a lengthy process. Most of the participants thought mHealth approaches and online resources, would prevent unnecessary tests, especially when the patient has symptoms which may appear minor but require an urgent response.

“Some of them have their vitals change from home, somebody temperature rises, and you are not aware, but if you got to know that somebody in Kawempe, the temperature is 38 you there and then you take a decision and take this patient probably use this other drug. But now what is happening this patient will ignorant move from where, he is to come to you go through all that hospital process until he gets to you. By the time you see him and make a decision of managing his temperature probably he is dead.”

(Nurse)

Some participants suggested that having an application or software being used by patients may increase their sense of comfort for they would feel supported when receiving direct information from their healthcare professionals. It may empower patients to express themselves or to disclose issues in more details which, in turn, may provide more detailed information to inform participants' management of them.

“... they (patients) will know that they are getting the first (hand) information and they are confident that even if they are not in the hospital, they are getting someone who is concerned....” *(Nurse)*

Theme 3: Challenges in implementation of mHealth in practice

Participants talked about the challenges they currently face and those their patients may experience with some mobile phone applications. While the majority reported the lack of money for airtime, network connectivity issues and language barrier as their main concerns, some participants outlined that misunderstandings may arise when communicating using mHealth. This may happen, for example, when a patient, caregiver or health professional misinterprets information provided, without the ability to identify or clarify errors.

“the relatives may not tell what exactly, what is happening, and sometimes you could give a wrong advice, they told you something else, and you think of something else

and could give a wrong advice. Sometimes they don't have money, and you call, and as you are talking also your airtime wears off... the network can be bad, you don't hear very well what they are saying, and you keep saying pardon, pardon, pardon... so basically the poor network, the airtime running out, and misunderstanding of what they are saying" (Nurse)

"...we have patients coming here who speak different languages, you know and may not be similar to the usual dialect to what people here are speaking, you know like refugees and other people. So it's almost difficult to properly and clearly assess those people and manage them efficiently" (clinical officer)

Mobile phone ownership is requisite, but some patients do not own their own mobile phone. For patients, technical necessities, such as charging phones may not always be possible due to a lack of consistent or readily available access to electricity, particularly for patients residing in the most remote areas of the country, which may lead to unreliable connectivity.

"not all people have electricity, sometimes the batteries may be down, I mean they may not be charged, that one also hinders the... hinders me from communicating to the patient." (Nurse)

"... you may find that they have to charge the phone, like they have to take it miles from where they stay..." (Nurse)

Participants also raised concerns about breaches in confidentiality that may arise. For example, a nurse noted how it may be possible to access patients' information without their knowledge or consent. For example, in instances where mobile phones are shared between households.

“I might be at home and the client sends me some information regarding his/her health and probably I gave my phone to someone who can access (patient’s) information without my consent...” (Nurse)

Participants also noted that there are gaps in their current training which do not cover competencies in using mHealth as part of patient care. Some participants felt it may be a challenge for some health professional to manage patients using information received via a mobile phone as they are trained to talk and consult with patients face-to-face.

“... So sometimes may be, for some people it may be tricky how far they would go in terms of managing the patient using the data received on the phone.” (Medical Doctor)

Theme 4: Healthcare professional preferences for mHealth use

When asked about their preference for mHealth use in the delivery of palliative care, the majority of participants said that they would prefer to receive updates and notification about their patients’ conditions on their personal mobile phones, whether information is displayed via a phone application or requiring the health professional to access a website via the browser on their phone. However, there were reservations associated with the need for internet connectivity and the process of accessing an online resource may delay the health professional response.

“it will be easier (to) direct on someone’s phone as opposed to the website, because a website, you have to have access to internet in a given, like a fixed place, ... I think the website will delay getting back to the patient...” (Nurse)

To maintain patient confidentiality, which may be compromised using personal mobile phones, most participants suggested that the mobile applications should be password protected. This would prevent

access to patients' information by other people who have access to health professionals' personal mobile phones.

“if we may get like a lock such that for me to access that data I have to feed in some, some figures to unlock the App, that would be very ok, because if I may say I give my phone to someone and that someone can access some information of mine accidentally so if this one is locked, that would be very proper.” (Nurse)

Furthermore, some participants also suggested the establishment of a centralized mechanism for managing contacts by patient that involve voice calls. Participants suggested that there should be a person or a team in charge of receiving patients' contact and concerns, directing them to relevant units or individual healthcare professionals depending on their area of specialisation.

“...may be having like a centralized call centre whereby patients can call, I think that's what we need for the start” (Medical Doctor).

Discussion

This qualitative study explored the views and perceptions of healthcare professionals on the use of mHealth in the provision of palliative cancer care in Uganda. Mobile phones are commonly being used regularly for communication between patients with advanced cancer and their health professionals (e.g. to seek and give advice on medications provided, and to organise home consultations). Mobile phones are also used for interaction between healthcare professionals to support the management of patients. Healthcare professionals noted that digital technology approaches improve communication with patients, facilitate symptom management, reduce costs, and burden of travel, and empower patients to participate in their own healthcare. The main challenges healthcare professionals cited were poor mobile phone signal, limited electricity access, language barriers and misinterpretation of information shared by patients and their caregivers via mobile phone. Participants outlined their views on factors that should be considered for future development of mHealth interventions for palliative cancer care provision. These included protection of data (e.g. protecting mobile applications with passwords) and establishing central call centres to receive patients' complaints and direct or triage them to specific centres or appropriate health professionals.

The scope for mHealth to enhance care illustrated in this study has been reflected by health workers beyond palliative cancer care. The advantages described by participants align with wider literature describing the improved communication with patients³⁵⁻³⁷, symptoms management³⁵, reduced cost of travelling^{19, 38} and empowered patients to participate in their own care³⁹⁻⁴¹. Demonstrating acceptability within provision of palliative care can provide confidence in the continued development of mHealth to address the unmet needs of patients with advanced cancer in the East Africa region¹⁰. Challenges to digital technology use, including poor phone signals, limited electricity access and misinterpretation, reiterate those reported mainly by studies in low resource settings⁴²⁻⁴⁹. Furthermore, as yet unreported challenges were described in the current study, including the need to adapt training to improve competencies of health professionals in the delivery of palliative care using mHealth approaches. The challenges and requirements outlined in this manuscript have relevance across all countries in the SSA region. There is growing recognition of the need to increase access to and capacity to deliver effective palliative cancer care integrated into existing health systems⁵⁰. mHealth approaches present a means

to methodologically and rigorously gather data to develop the evidence base across SSA countries to better understand current practice and inform future development and adaptation of palliative care services⁵¹. Our paper can guide the design of mHealth approaches, providing developers with requirements to ensure they align with the needs and preferences of health professionals where they are intended end users.

Participants highlighted concerns around misinterpretation of information shared by patients and their caregivers. There is scope to explore the feasibility of augmenting digital health approaches that seek to lessen confusion or misinterpretation between patients and health professionals. For example, this could include the use of image-based interventions or using predefined lists where common terms and their definitions are provided⁵²⁻⁵⁴. Maintaining privacy and confidentiality for patients was a further concern for participants. The government of Uganda, alongside governments and multinational bodies across SSA, are well placed to define and demand appropriate digital data governance checks and balances, and there are currently governance frameworks being developed to guide practice⁵⁵. Equity, too, needs to be considered as part of digital technology development for palliative cancer care. Participants noted that some participants may not be able to access mobile phones, may share mobile phones across households, or could be unable to access electricity supplies for charging devices. Any use of digital technologies across healthcare needs to ensure it does not exclude or further widen inequities in access. Despite widespread mobile networks across SSA, digital divides by gender and socioeconomic strata persist. Costs associated with mobile phones remain high, and people from lower incomes and levels of education are less able to access and use a mobile phone^{56, 57}. The development and use of digital technologies for palliative care in Uganda, and broadly across any country and setting in which it is being developed, will need to ensure approaches do not worsen access or extend existing inequities in access⁵⁸. Parity of care provision should be maintained independent of whether a patient chooses to use digital or non-digital approaches to access or interact with healthcare providers.

Limitations

The in-depth and rich data collected in the parent study allowed this secondary analysis focusing on solely health professional perspectives. In terms of limitations, the parent study had a different primary aim, which means further elaboration and seeking of specific responses to address the focus of this secondary analysis was not possible. However, researchers (ENab, ENam, MJA) who had been involved in the collection and analysis of all data from Uganda in the parent study were involved in the team overseeing this secondary analysis.

Conclusion

This study outlines healthcare professionals' perspectives regarding the use of mHealth in the delivery of palliative cancer care in Uganda. mHealth is seen as an acceptable approach to delivering care with multiple benefits to patients. Issues highlighted around practical considerations aligned with previous research in low resource settings. With this study, we outlined as yet unreported issues that included misinterpretation of information shared via mobile phones between patients, caregivers and health professionals, and the need to adapt training to increase competencies of healthcare professionals in delivery of palliative care using mHealth. There is scope to adapt care provision leveraging mHealth approaches, but initiatives need to consider how best to maintain patient privacy and that existing inequities in access to care are not worsened.

Funding: This work was supported by the Medical Research Council (grant no MR/S014535/1) and Research England Quality-Related Global Challenges Research Fund (QR GCRF) through the University of Leeds.

Competing interests: None declared

Ethical approval: Ethics approvals were obtained from the Institutional Review Boards of University of Leeds (Ref: MREC 18–032; 11th January 2019), College of Medicine University of Lagos (Ref: HREC/15/04/2015; 28th December 2018), Uganda Cancer Institute (Ref: 19–2018; 23rd January 2019), Medical Research Council of Zimbabwe (Ref: MRCZ/A/2421; 5th March 2019), Uganda National Council of Science and Technology (Ref: HS325ES; 14th March 2019), and Research Council of Zimbabwe (Ref: 03507; 2nd April 2019). All participants provided written informed consent prior to enrolment in the study.

Data statement

The authors have full control over the primary data for this study. The data analyzed in this study are stored online in a OneDrive folder hosted by the University of Leeds. As per the ethics committee approval from all the countries involved, this dataset is subject to ethical restrictions and informed written consent of study participants does not include the publication of raw data in terms of interview manuscripts. Requests for metadata or queries relating to the dataset can be made to the corresponding author.

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