Original Article

Design and Evaluation of a Novel Mobile Phone Application to Improve Palliative Home-Care in Resource-Limited Settings

Richard Harding, PhD, José Miguel Carrasco, PhD, Jordi Serrano-Pons, MD, Jeannine Lemaire, MSc, Eve Namisango, PhD, Emmanuel Luyirika, MFamMed MPA BPA (Hons) MB ChB, Terrymize Immanuel, MPH, Anil Kumar Paleri, MBBS, MSc PalMed, Lulu Mathews, MD Pediatrics, Dickson Chifamba, MBChB, DHSM, PG Diploma in Palliative Medicine MDPCZ, Lovemore Mupaza, Econ MA, Cristina Lasmarías Martínez, PhD, Ludoviko Zirimenya, MPH, Marie-Charlotte Bouësseau, MD, and Eric L. Krakauer, MD

Florence Nightingale Faculty of Nursing Midwifery and Palliative Care (R.H., E.N.), King's College Liondon, Cicely Saunders Institute, London, UK; Cooperativa APLICA (J.M.C.), Madrid; and UniversalDoctor Project (J.S.P.), Barcelona, Spain; UniversalDoctor Project (J.L.), Milan, Italy; African Palliative Care Association (E.N., E.L.), Kampala, Uganda; Institute of Palliative Medicine (T.I.), Kozhikode, Kerala; WHOCC for Long-term Care and Palliative Care (A.K.P.), Institute of Palliative Medicine, Kozhikode; Institute of Palliative Medicine (L.M.), Kozhikode, Kerala; and Island Hospice & Healthcare (D.C., L.M.), Harare, Zimbabwe; Catalan Institute of Oncology (C.L.M.), Barcelona, Spain; MRC/UVRI and LSHTM Uganda Research Unit (L.Z.), Entebbe, Uganda; World Health Organisation (M.C.B.), Geneva, Switzerland; Department of Palliative Care (E.L.K.), University of Medicine and Pharmacy at Ho Chi Minh City, Vietnam; Department of Global Health and Social Medicine (E.L.K.), Harvard Medical School; and Division of Palliative Care & Geriatrics (E.L.K.), Massachusetts General Hospital, Boston, USA; and ATLANTES Research Programme (J.M.C.), Instituto Cultura y Sociedad; University of Navarra, Navarra, Spain

Abstract

Context. Mobile health (mHealth) provides an opportunity to use internet coverage in low- and middle-income countries to improve palliative care access and quality.

Objectives. This study aimed to design a mobile phone application (app) to enable or improve communication between family caregivers, community caregivers, and palliative care teams; to evaluate its acceptability, processes, and mechanisms of action; and to propose refinements.

Methods. A codesign process entailed collaboration between a Project Advisory Group and collaborators in India, Uganda, and Zimbabwe. We then trained community and family caregivers to use an app to communicate patient-reported outcomes to their palliative care providers each week on a data dashboard. App activity was monitored, and qualitative in-depth interviews explored experience with the app and its mechanisms and impact.

Results. $N = 149$ caregivers participated and uploaded $n = 837$ assessments of patient-reported outcomes. These data were displayed to the palliative care team on an outcomes dashboard on $n = 355$ occasions. Qualitative data identified: 1) high acceptability and data usage; 2) improved understanding by team members of patient symptoms and concerns; 3) a need for better feedback to caregivers, for better prioritisation of patients according to need, for enhanced training and support to use the app, and for user-led recommendations for ongoing improvement.

Conclusion. An outcomes-focused app and data dashboard are acceptable to caregivers and health-care professionals. They are beneficial in identifying, monitoring, and communicating patient outcomes and in allocating staff resource to those most in need. J Pain Symptom Manage 2021;62:1–9. © *2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Address correspondence to: Richard Harding, PhD, King's College London, Cicely Saunders Institute, Bessemer Road, London, SE5 9PJ. E-mail: richard.harding@kcl.ac.uk

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Key Words
Mobile health, palliative care, global health, low income country, community health worker

Key message

In India, Uganda, and Zimbabwe, we developed and evaluated a mobile phone application to improve access to palliative care. Patient outcome measures reported on a data dashboard for professionals empowered community caregivers to better assess and communicate patient needs and enabled professionals to prioritize responses for those in greatest need.

Introduction

Palliative care is a human right[1] to be provided "throughout the illness course" as an essential component of primary health care and universal health coverage (1b, 5, 6). Increasing access to palliative care is particularly important in response to the rising prevalence of chronic noncommunicable diseases in low- and middle-income countries (LMICs)[2] and persistent morbidity and mortality due to infectious diseases such as HIV/AIDS and COVID-19. In 2018, for example, there were 69,000 AIDS-related deaths in India and 310,000 in sub-Saharan Africa.[3] By 2060, there will be 39 million annual deaths with moderate or severe illness—related suffering in LMICs, with the greatest global increase in low-income countries (159%) and due to malignant disease.[4]

As LMICs industrialize, they are predicted to bear 70% of global cancer cases by 2030,[5] and clinicians anticipate poorer cure rates than high-income countries because of late presentation, lack of locally adapted protocols, and fewer resources.[6] World Health Assembly (WHA) resolution 67.19 states that “palliative care is an ethical responsibility of health systems” and calls for palliative care to be "a component of integrated treatment throughout the life course."[7] The Declaration of Astana adopted in 2018 states that “promotive, preventive, curative, rehabilitative, and palliative care must be accessible to all.”[8] The recent Lancet Commission on Palliative Care and Pain Relief concluded that the current inequality in access to palliative care between higher and lower income countries is “abyssmal” and requires international action and research.[9] To achieve these policy goals and implement the WHO public health palliative care strategy, research must be undertaken on best ways to increase access to palliative care.[10]

The WHA resolution on palliative care urges Member States to “provide basic support, including through multisectoral partnerships to families, community volunteers, and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate.”[7] Family caregivers are crucial to community- and home-based care of patients with palliative care needs in LMIC. Access to palliative care in the community can improve patient outcomes, provide financial risk protection for patients’ families, and reduce costs for health-care systems.[11] Family caregivers of patients have identified information and communication as their primary support needs,[12] yet there is a paucity of evidence on effective ways to provide this support.[13]

The challenge of meeting current and projected need for palliative care and for supporting caregivers in particular to deliver home-based palliative care may be met in part through mobile health (mHealth) approaches. mHealth is viewed as one of the most promising investments to improve health care in LMICs because of the frequent use of cellphone and wide coverage and uptake.[14,15]

This study aimed to design a mobile phone application to enable or improve communication between family caregivers, community caregivers (community health workers), and palliative care teams; to explore its acceptability, processes, and mechanisms of action; and to propose future refinements.

Methods

Study Design

This pilot study used codesign principles to develop the mobile phone application (app), with single-group quantitative longitudinal data on application usage and qualitative cross-sectional stakeholder data on the user experience. The sequential design and initial piloting followed the Medical Research Council framework for the development and testing of complex interventions.[16]

Objectives

The study objectives were to 1) develop a mobile phone application to enable community caregivers (community health workers) and family caregivers to provide real time patient outcome data to the patient’s palliative care provider that facilitates appropriate clinical monitoring and intervention; 2) to explore application usage activity; 3) to determine stakeholder (community/family caregivers, palliative care providers) views on the app processes and potential mechanisms of action; 4) to propose refinements to the application.

Settings

Clinical sites were selected in line with the following criteria: existence of a trained palliative care team providing community-based and home-based care and willing to participate in the project, availability of oral immediate-release morphine, ability to recruit the required sample size of patients and family caregivers, and potential support for the project from local health authorities. The selected sites were as follows: The Institute of Palliative Medicine in Calicut, India, a WHO Collaborating Center that provides multidisciplinary home care and outpatient and inpatient services; Hospice Africa Uganda, Uganda, which offers multidisciplinary clinical services, outpatient and home-based palliative care, and family support; Island Hospice and Healthcare, Zimbabwe, which offers hospital visits, roadside clinics, walk-in clinics, and home visits by a multidisciplinary clinical team.

Procedure

Objective 1: Mobile Phone Application Codesign. The initial development phase was led by a Project Advisory Group, with assistance from field site staff who consulted with caregivers from community and families. Discussions (telephone, online, and in the three field sites) concluded that the application should focus on collection of patient- and family-reported information that would enable palliative care teams to recognize and respond to the needs of home-care patients. The codesign meetings aimed to design the minimal app content to achieve a common product for all three sites. Family caregivers were defined as "unpaid, informal providers of one or more physical, social, practical, and emotional tasks."[17] Community caregivers (community health workers) were defined as lay individuals (paid or unpaid) providing direct care and support within patients' homes according to the local model of care.

The mobile palliative care tool was initially designed and refined through consultation during field visits. These "Training-Feedback" visits at each site aimed to refine the tool and train local collaborators on implementation, and the visits yielded specific recommendations.

Objective 2: Application Usage. Caregivers were asked to use the app weekly for six weeks. Each caregiver completed a baseline demographic questionnaire including age, gender, highest level of education, home location (urban/peri-urban), relationship to patient, and the patient's primary diagnosis, family size, and socioeconomic status. These data were entered manually by local clinical staff into a specially designed Excel spreadsheet with logic and consistency checks to reduce errors. A participant ID was provided to each family and community caregiver to preserve their anonymity and confidentiality.

Data collected from each site were exported from the data server through a browser-based dashboard to an Excel spreadsheet on the local computer. Data were included in a single database, linked to sociodemographic data, and then checked for inconsistencies (which were resolved by reviewing original documents). Descriptives for the sample characteristics were reported alongside app usage (number of reports sent by country, number of weekly reports sent during the follow-up). SPSS V19 (IBM Corp., Armonk, NY) was used for quantitative analysis.

Objective 3: Stakeholder Views. Inclusion criteria for family and community caregivers to participate in piloting the app were 1) at least 18 years of age; 2) able to provide informed consent to participate; 3) access to internet connectivity via Wi-Fi or 2G, 3G, or 4G mobile networks; 4) at least primary level education and ability to read, write, and operate the phone; 5) actively caring for a patient with at least two-month life expectancy and a diagnosis of advanced cancer, major organ failure, or HIV/AIDS who is receiving hospice or palliative care at home at one of the three study sites.

The sample size to pilot the app at each site was $n = 25$ family caregivers and $n = 25$ community caregivers (total $n = 50$ per site, $N = 150$ for the entire study) with consecutive enrollment. Three clinical staff members (doctors, nurses, or allied health professionals) were recruited at each site to support implementation.

For qualitative interviews, purposive sampling at each site identified $n = 3$ lay community caregivers, $n = 9$ family caregivers (sampling criteria: age and gender reflective of a prior study of the caregiving experience in sub-Saharan Africa[18]), and $n = 3$ professionals (sampling criteria: doctor or nurse, based on a prior study of multiprofessional views of the outcome measure in sub-Saharan Africa[19]).

The qualitative data collection was conducted through semi-structured individual interviews. The topic guide for qualitative, in-depth interviews with caregivers addressed app content and format (information most/least helpful, ease of use), how it was used by each stakeholder (including mechanisms of action, i.e., how any perceived benefits were achieved[16]), expectations, support needs, usability, and recommendations for improvement. The topic guide for qualitative in-depth interviews with healthcare professionals addressed application content and format, how the application fitted into routine practice, utility of the dashboard, how data were accessed and used, perceived benefits and risks, and suggested refinements. Topic guides were developed in English by the cross-national study team, and interviews were conducted by bilingual researchers in the appropriate language for the research subject.

Interviews were transcribed verbatim and translated to English in each site. Transcripts were subjected to thematic in NVIVO V12 (QSR International Pty Ltd., Doncaster), using a deductive approach to answer the research questions stated in the methods. Transcripts were initially line-by-line coded by one researcher (R. H.). The emergent themes built the coding frame, which was a single coding frame to enable each research question to be understood from the perspective of each stakeholder group's data. The coding frame was built flexibly, with codes split and merged as each transcript was imported and analyzed. The resulting coding frame and all illustrative quotes coded into that frame were reviewed and agreed with the Project Advisory Group. For final reporting, quotations are provided from across the sample with anonymous ID codes to ensure that the breadth of the sample was used. For each reported quotation, we pseudonymized the data to maximize confidentiality.

Objective 4: Proposed Refinements. Findings from objectives 1 to 3 were reviewed by the Project Advisory Group, and recommendations for refinement were generated using the data from each objective.

Ethics Review and Approval

The protocol of the study was approved by the WHO Ethics Review Committee (reference ERC.0002957), as well as the research ethics committees of the Institute of Palliative Medicine, Kozhikode (18/07/2018), the Hospice Africa Uganda Research and Ethics Committee (reference HAUREC 045/18) with regulatory approval from the Uganda National Council of Science and Technology, and the Medical Research Council of Zimbabwe (reference MRCZ/A/2346). All participants gave written informed consent or a thumbprint, including the patients for whom family caregivers reported data.

Results

Objective 1: Mobile Phone Application Codesign

During the codesign phase, the Project Advisory Group decided that it was beyond the capacity of this study to implement an application for communicating and generating a response to urgent or emergent clinical needs because of uncertainty about availability of local staff at each site to respond at all times. The novel intervention consisted of an application for family or community caregivers to report nonurgent patient and family outcomes that appeared on a dashboard accessible by the clinical palliative care team. A core mechanism of action for the application was to improve clinical care through real-time detailed patient and family outcome data. This builds on evidence that collection, transfer, and usage of patient-reported outcome measures (PROMs) can improve care processes and quality in palliative care.[20] The PROM selected and agreed with all partners was the African Palliative Outcome Scale, which has been shown to have validity, reliability, responsiveness, and clinical utility within a broad range of diagnostic groups, reflecting the most common symptoms and concerns of patients in need of palliative care in sub-Saharan Africa.[19,21,22] It measures physical, psychological, social, and spiritual outcomes, in line with the WHO definition of palliative care, and is one of the most widely used palliative care outcome tools in research and clinical practice.[23,24]

Site feedback during the design and training meetings included the following proposals: 1) to change "editing" and "trash" options during reporting to prevent erroneous deletion of records; 2) to edit response bars for outcome measure items to more easily distinguish between levels of severity; 3) to use the shortened version of symptom burden (i.e., a global symptom score rather than individual symptom scores); 4) that all items should require a response to be recorded even if it is refusal or inability to answer; 5) that the dashboard of scores for the palliative care team should visually categorize patients according to score severity, for example, the use of a red flag icon for highest scores (i.e., most severe discomfort or distress). Data elements collected in the mobile app were transferred via https to a server database, and these datapoints were then visualized in a specific format in the dashboard.

Participating palliative care teams had various views on potential benefits of implementing the app within existing workflow. These were 1) improvement of symptom assessment, better prioritization of patients, and improvement in communication; 2) facilitation of patient review during clinical team meetings and recognition of trends in each patient's outcomes; 3) strengthening the voice of the patient and introduction of accountability in community care giving; 4) potential future cost saving through prioritization and improved timeliness of interventions.

Two training sessions were conducted at each site: Session 1 on use of the app, and session 2 on subject recruitment, data collection (quantitative and qualitative), and data management. Following this, the study's clinical lead at each site provided caregiving training and ongoing clinical support. The distribution and management of mobile devices differed depending on the specificities of each site as shown in Table 1.

Table 1
Distribution of Mobile Devices

Country	Distribution of Mobile Devices
India	All participants (25 family caregivers and 25 community caregivers) required to have an adequate mobile device; hence, no mobile devices were distributed for this project, but the app was installed on the caregivers' own mobile device.
Uganda	25 family caregivers and 25 community caregivers received mobile devices, with the app already preinstalled and web access prepaid.
Zimbabwe	25 family caregivers and 25 community caregivers received the mobile devices with the app preinstalled; as per advice from the local research team, all the mobile devices were kept by the community caregivers to avoid mismanagement.

The native Android mobile application was developed in English and included a wireframe, a mock-up, and a prototype to confirm features, navigation, functionality, and content layout. This was followed by the design phase and production of the mobile devices. Throughout these phases, we developed the code for the application, starting with creation of the architecture of the app and resulting in the final Android Package Kit file uploaded to Google Play. A web-based back-end application including dashboard was developed in English, to monitor the reports submitted by family or community caregivers. The reports were stored in a secure cloud server. The dashboard and server were configured based on the Laravel framework. Key aspects of the dashboard included a "report table" with one row for each report submitted through the app and columns dedicated to each item of the Palliative Outcome Scale. Palliative care team members could view the answers submitted for each report in a color-coded fashion indicating the severity of the patient's symptom or concern. While viewing the dashboard, users (clinical teams) could filter the reports by date or by caregiver ID.

Objective 2: Application Usage

Some delay was caused because of floods in India, the political situation in Zimbabwe, and the process for registering the mobile devices and the SIM cards in Uganda. Owing to these delays, the follow-up period of app piloting among caregivers was reduced from six to four weeks in Uganda and Zimbabwe.

Some concerns were raised by caregivers during development and training visits and communicated to palliative care team staff during ongoing app use. In India, there was concern that home visits would be replaced by the app, and also concerns regarding data privacy. In Uganda, difficulties in using the mobile phones resulted in delayed reports. There were connectivity problems, and failure to acknowledge receipt of reports led to multiple submissions at single time points. In Zimbabwe, there were connectivity problems, and there were initially many incomplete or duplicate reports. Mentoring for caregivers greatly reduced this problem.

Activity was monitored during August-November 2018 and is summarized in Table 2.

Objective 3: Stakeholder Views and Objective 4: Proposed refinements

Qualitative Data

Sample Characteristics. The target sample size and purposive sampling frame were achieved at each site ($N = 27$; $n = 9$ community caregivers, $n = 9$ family caregivers and $n = 9$ health-care professionals per site). Community caregiver age ranged from 20 to 64 years, and their sex was 8/18 female. Family caregivers were aged 25-88 years, and 14/18 were female. The most common patient diagnoses were cancer ($n = 8$) and HIV ($n = 8$). Among the health-care professional sample, $n = 4$ were nurses and $n = 2$ doctors, and 7/9 were female.

Main Findings. Five principle codes were generated and populated from the qualitative data: 1) advantages to using the app; 2) disadvantages to using the app; 3) influence on daily clinical and organisational practice; 4) learning to use the app; 5) suggested improvements to the app.

1. Advantages to using the app.
   All participants described positive experiences of using the app, although some disadvantages and suggested improvements were given (see codes 2 and 5 discussed in the following sections). Participants felt that patient assessment and management and care delivery were improved in the following ways:

a. Better understanding of patients' symptoms, concerns, and outcomes of care in "real time" with regular ongoing assessment.

A core mechanism of action for the application was improved clinical care through realtime detailed patient and family outcome data.

> *The specific thing I liked is that you can get [the] real time situation of the patient. So the caregivers would give the information about the patient and you know the current status of the patient, what issue needs to be attended to and basically how the patient is faring in relation to the treatment and the entire family as we look at the patient holistically.* (Uganda professional 1)

This information enabled individualized care.

> *The information was very helpful because each aspect on the dashboard had some information on … the scores so you [would] know what was being scored and what it meant,*

Table 2
Participant Characteristics and App Activity

Characteristics	India	Uganda	Zimbabwe
Caregiver female gender	57%	73%	94%
Caregiver mean age (years)	29.9	40.7	45.3
Caregiver highest educational attendance	25%	53%	0%
University	67%	45%	86%
Secondary	8%	2%	12%
Primary	0%	0%	2%
No formal education	0%	0%	0%
Patient diagnosis[a]	67%	67%	90%
Cancer	0	33%	86%
HIV	33%	—	—
Other	—	4%	84%
Caregivers reporting data	$n = 51$	$n = 48$	$n = 50$
Number of reports following deduplication	$n = 263$	$n = 323$	$n = 228$
Number of dashboard actions	$n = 1528$	$n = 908$	$n = 934$
Number of follow-up actions by palliative care team (phone call, home visit)	$n = 274$	$n = 115$	$n = 27$
Number of downloads to the dashboard	$n = 154$	$n = 170$	$n = 31$
Caregiver role			
Community	47%	46%	78%
Family	53%	54%	22%

[a] Diagnosis does not add to 100% because of comorbidity.

> *whether the situation was mild, moderate, severe or overwhelming; or whether the situation was good or bad and this will help the intervention that would be accorded to the patient and the caregiver.* (Uganda professional 2)

b. Easy to use and understand.

> *"oh yes liked it … First of all when it comes to the app, it was very easy to understand, the questions are very clear, the responses are very easy to … you know … for somebody to comprehend …. it was short so it did not require a long time to fill. In a very short time, somebody would be through."* (Uganda caregiver 3)

c. Enables integrated patient-reported outcome assessment.

> *"Generally it's good because it covers all the aspects of the patient —socially, physically and psychologically so it's a good app …. It captured everything that was important about a patients' assessment-the pain, the symptoms and then the [family] caregiver since in palliative care we deal with the patient and the family so it captured everything."* (Uganda professional 2)

d. People-centred outcome measurement empowered family and community caregivers to ask the most relevant questions and thereby improve the morale of patients and caregivers.

> *"For the patient it was useful because it's like asking her boosts her [mood]; it's like someone is caring for you, asking you questions no one can ask most of the time. When you are sick, most people do not ask you anything they just say "are you ok?" … but … if you just get into the topics so about this and this and this, this person will [be] a little bit happy someone is caring for me and asking me deeper than expected so they are good questions … … they changed the way I'm able to speak to my mum and they also put a greater communication between us … with these questions you are getting deeper into her thinking and knowing some other parts of her thinking,"* (Zimbabwe family caregiver 29)

> *"I feel more people should have this app … if we use this app for more patients … the carer's caring attitude could be boosted. Patients' confidence also will be improved … [the] patient may feel a team is behind me to care [for] me, that is motivating."* (India community caregiver 48)

2. Disadvantages to using the app.

   Several disadvantages became evident. These were
   - reliance on internet connectivity, which is unreliable in some places;
   - disappointment by patients who expected to receive treatment immediately;
   - requirement that the caregivers be literate;
   - lack of confirmation for caregivers that their upload was received.

> *… if I send the messages and [it] says message sent … after … one week they could say … we never received anything.* (Uganda Community caregiver 3).

3. Influence on daily clinical and organisational practice.

The availability of outcome data enabled staff to prioritize patients.

> *For those who scored high scores for those symptoms, I would always call and ask the carer, how is the patient? I see the patient scored 5/5 how is the patient doing. Actually there was one who was scoring 5 always so I had to send in a clinician who covers that route to go and check on the patient. Actually I liked this App because it's easy to use, it saves time and it gives quick feedback about the patient-if a patient scored 5 in vomiting 5 for pain, you know which drugs to take with you and give them immediately.* (Uganda professional 2)

4. Learning to use the app.

A key challenge was the ability to learn everything needed within the time limitations of training, although over time users provided peer support to use the app efficiently

> *"In the training I was there but I was just listening since I did not have a smart phone. I attended and I had to learn everything from the other volunteer. The good thing is that we are neighbours … [at] first it was not easy at all but with time I started picking [it up]."* (Uganda community caregiver 24)

5. Suggested improvements to the app.

These included suggestions for content and layout, more time for training, and an improved data feedback loop.

> *"It does not give feedback when carers send their reports; it does not show whether it has gone or not. I had five [caregivers] complaining that [they were told that] they have sent only one report, But when you check in their phones, they have sent religiously every week. But we do not know if these reports went or not so I wish it would have that feedback [stating] "message sent", "message received" so that we could be sure if the reports [were sent] or not."* (Uganda professional 2 nurse).

Discussion

This pilot study demonstrates that a mobile palliative care app developed in collaboration with potential users in LMICs can be used by stakeholders and may positively impact practice and outcomes. The app enabled patient-reported outcome measurement in routine practice in three LMICs that can facilitate patient assessment, staff awareness of patient concerns, communication, and possibly also improved patient outcomes.[25–27] Careful codesign and appraisal of the app and intervention from multiple stakeholder viewpoints are crucial to maximize acceptance and clinical benefit.

Our work was guided by the Medical Research Council Framework for the Development and Testing of Complex Interventions.[16] This pilot study reflects the initial development stage of the framework. Based on the positive results, the app is now ready for further study of its utilization processes, clinical effectiveness, and cost-effectiveness. Specifically, the app should be further refined with fuller modeling of its intended mechanisms. Specific questions are how and when the data should be received and interpreted by health-care professionals (e.g., according to a schedule, immediately); which health-care professionals should receive and interpret the data and decide on the appropriate response; which health-care professionals should communicate a response to which type of caregiver (community caregiver, family caregiver); which outcomes are targeted for improvement; and which people-centered outcomes should drive further refinement of the app.

We suggest that locally relevant Decision Support Tools should be developed at each site to enable an appropriate and effective response to threshold patient scores using available resources.[28]

Second, training in use of the app should be expanded with longer-term support and mentorship for end users. Implementation should be based on careful assessment of context to identify potential barriers, for example, internet connectivity and device cost.

Third, engagement and codesign with IT professionals, caregivers, and palliative care teams should continue to drive the refinement and delivery of this app. The potential for bidirectional communication, incorporation of video/audio, and emergency use should be explored.

Fourth, we recommend that outcomes data generated by the app be used to inform health service policy, planning, and management. In addition, health-care policy that endorses mHealth for palliative care may improve the quality and reach of the app and the benefits for individual patients and the community.[29]

The app thereby would contribute to implementation of the 2014 WHA Resolution on Palliative Care[30] and to universal health coverage.

There are a number of limitations to our study. First, a pilot study cannot determine the effectiveness of the novel intervention. Second, although we were able to pilot in three countries, other settings may require different designs. Third, selection bias in our pilot sites (i.e., those willing to pilot the app) may mean that other palliative care teams may find this app less useful. This bias may also have prevented us from identifying different challenges to use between stakeholder groups. Fourth, although we were able to purposively recruit $N = 27$ caregivers for qualitative interviews, the sample size does not allow us to separately analyze family and community caregivers.

In conclusion, our data suggest that this app is acceptable to family and community caregivers and health-care professionals in settings with similar characteristics to the sites where this study was implemented. However, we note that despite increasing access to mobile phones and the growth in heathcare delivery via mobile technology in LMIC, we found persisting access and reliability issues in our study.

It is useful to identify, monitor, and communicate patient outcomes and to allocate staff resource to those most in need. The codesign approach with stakeholders should be used in future mHealth palliative care studies to ensure that tools are appropriate to local contexts and care organizations. Studies of tools to obtaining clinical outcome data in real time have been carried out mostly in high-income countries, but our study has generated initial understanding of the potential impact of such a tool in LMICs. This initial evaluation facilitated stakeholder engagement at the outset of implementation which is key to successful use of PROM in palliative care.[31] Such research initiatives are essential to ensure that palliative care policy, and practice is underpinned by local evidence.

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The authors have no known conflicts of interest to declare.

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