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m-PALLIATIVE CARE LINK: DEVELOPING A MOBILE APPLICATION TO IMPROVE SYMPTOM CONTROL AND INFORMATION EXCHANGE AMONG SPECIALISTS AND LOCAL HEALTH WORKERS TREATING TANZANIAN CANCER PATIENTS

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Abstract

Background: Improving access to end-of-life symptom control interventions among cancer patients is a public health priority in Tanzania in need of innovative community-based solutions. Mobile health technology holds promise; however, existing resources are limited and access to palliative care specialists (hereafter, specialists) is poor. A mobile platform that extends specialist access via shared care with community-based local health workers (LHWs) and provides remote support for pain and symptom management can address this gap in care, particularly in low-resource settings.

Objective: The aim of this study was to design and develop mobile-Palliative Care Link (mPCL), a mobile/web application to support symptom assessment and care coordination and control, with a focus on pain.

Methods: A human-centered iterative design framework was used to develop the mPCL prototype for use by specialists (palliative care physicians and nurses), poor-prognosis cancer patients and their lay caregivers (patients/caregivers), and LHWs. Central to mPCL is the validated patient-focused African Palliative care Outcome Scale (POS), adapted for automated, twice-weekly collection of patient/caregiver responses, and timely review, reaction and tracking by specialists and LHWs. Prototype usability testing sessions were conducted in person in a controlled setting with 21 key informants representing target end users. Sessions consisted of direct observations and qualitative feedback on ease-of-use and recommendations for improvement.

Results: from usability and pilot testing demonstrated that all users were able to successfully navigate the application and feedback suggests that mPCL has clinical utility. User-informed recommendations included: further improvement in navigation of the application, simplification of patient/caregiver components and language, and delineation of user roles.

Conclusions: We designed, built, and tested a usable, functional prototype of a mobile application supporting palliative care for cancer patients in Tanzania. mPCL is expressly designed to support coordinated care via customized interfaces supporting core users—patients/caregivers, LHWs and members of the palliative care team—and their respective roles. Future work is needed to demonstrate the effectiveness and sustainability of mPCL to remotely support symptom control needs of Tanzanian cancer patients, particularly in harder-to-reach areas.

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ABSTRACT

Background. Improving access to end-of-life symptom control interventions among cancer patients is a public health priority in Tanzania in need of innovative community-based solutions. Mobile health technology holds promise; however, existing resources are limited and access to palliative care specialists (hereafter, specialists) is poor. A mobile platform that extends specialist access via shared care with community-based local health workers (LHWs) and provides remote support for pain and symptom management can address this gap in care, particularly in low resource settings.

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Methods. A human-centered iterative design framework was used to develop the mPCL prototype for use by specialists (physicians and nurses trained in palliative care), poor-prognosis cancer patients and their lay caregivers (patients/caregivers), and LHWs. Central to mPCL is the validated patient-focused African Palliative care Outcome Scale (POS), adapted for automated, twice-weekly collection of patient/caregiver responses, and timely review, reaction and tracking by specialists and LHWs. Prototype usability testing sessions were conducted in person in a controlled setting with 21 key informants representing target end users. Sessions consisted of direct observations and qualitative feedback on ease-of-use and recommendations for improvement. Results were used to build a usable, functional prototype for subsequent real-world testing. Early pilot testing was conducted by deploying the app among ten patients/caregivers, randomized to mPCL use versus phone-contact POS collection, and then gathering feedback from the specialists, LHWs and nurses who used mPCL to manage care. This feedback was employed to further optimize the app for a

broader randomized field study to examine the app's effectiveness in symptom control among cancer patients.

Results. mPCL functionalities include the ability to create and update a synoptic clinical record; regular real time symptom assessment; patient/caregiver and care team communication and care coordination; symptom-focused educational resources; and easy access to emergency contact information. Results from usability and pilot testing demonstrated that all users were able to successfully navigate the app and feedback suggests that mPCL has clinical utility. User-informed recommendations included: further improvement in navigation of the app, simplification of patient/caregiver components and language, and delineation of user roles.

Conclusions. We designed, built, and tested a usable, functional prototype of a mobile app supporting palliative care for cancer patients in Tanzania. mPCL is expressly designed to support coordinated care via customized interfaces supporting core users—patients/caregivers, LHWs and members of the palliative care team—and their respective roles. Future work is needed to demonstrate the effectiveness and sustainability of mPCL to remotely support symptom control needs of Tanzanian cancer patients, particularly in harder-to-reach areas.

1. INTRODUCTION

Cancer is a growing public health concern in sub-Saharan Africa with at least 500,000 annual deaths in recent years, and a projected doubling of cancer incidence and mortality by 2030 [1-4]. Although data for Africa as a whole are limited, a study in South Africa and Uganda showed unnecessary suffering among late-stage cancer patients who most often reported uncontrolled pain (87.5%), low energy (77.7%), sadness (75.9%), drowsiness (72.3%), and worry (69.6%), with pain as the most severe symptom [5].

Due to a limited pool of palliative care specialists and low public and private investment in cancer control, there is urgent need for novel, sustainable, and community-based solutions to address inadequate specialty palliative care services throughout Africa [6-8], with a focus on the World Health Organization's (WHO's) four pillars: i) appropriate policies, ii) education (professional and lay), iii) drug availability, and iv) implementation throughout society [1, 9]. These are only achievable with high quality research to ensure that public health solutions are evidence-based, culturally-sensitive, feasible, responsive, effective, and scalable [1]. While palliative care progress has been made in nearly 50% of African countries, access to skilled palliative care providers and pain treatments is still severely limited.

With increasing adoption of mobile technology, there is great potential to improve cancer symptom management through remote access to palliative care. In Tanzania, cell phone ownership grew from 10% in 2002 to 73% in 2015 with smartphone ownership increasing from 8% to 13% between 2013-2017 [10]. Coupled with increased smartphone ownership, mobile health (i.e., "the use of mobile and wireless devices to support the achievement of health objectives") [11] promises to grow access to palliative care specialists (hereafter, specialists), resulting in improved symptom management among cancer patients in Tanzania, our study setting, and other low resource settings [12]. Although active (i.e., mobile survey assessments, digital journaling) or passive (i.e., wearables) collection of patients' symptom reporting may be feasible and reliable ways of assessing cancer patient symptoms remotely, there is limited knowledge about the effect of mobile health (mHealth) on outcomes of these apps relative to care coordination focused on symptom control and quality of life, with few efforts in the low resource setting. [13, 14]

A systematic review of existing mobile/web apps focused on pain control in a range of medical conditions, including cancer, reported that although the number of such apps is growing of those apps described in scientific databases, none were available commercially. Further, among the 283 pain control-related applications identified in the five app stores

(including Google Play, Apple App Store) searched, scientific evidence of efficacy was nonexistent [15].

A more recent systematic review examined available full text publications on mobile apps with the following characteristics: focused on cancer pain; downloaded and registered on either a mobile phone or computer; using a numeric scale to assess pain; reporting patient follow-up for more than a week; and available in English language. Of the 13 studies reviewed, five were randomized controlled trials. Results of this review revealed that app-supported pain control is generally effective. Specifically, among the randomized controlled studies reviewed, patients who used the tested apps had less pain than patients without access to the apps. Other outcomes, such as quality of life, pain catastrophizing and pain self-efficacy were also improved in those patients offered the apps tested versus those from control groups [16]. Existing mobile apps used in cancer pain management often offer a range of functions and specifications, including shared records, training, and real time feedback. They educate patients about pain and allow for documentation of the type of pain experienced as well as feedback regarding symptoms [16]. Apps allow patients to control their pain in the outpatient setting—to include those individuals living in rural communities—and to relieve depression [17].

Few studies have examined mobile palliative care solutions in the low resource setting among those with noncommunicable diseases (NCDs) despite increasing awareness of the symptom control needs of chronic diseases patients, including cancer patients, and knowledge that by 2030 NCDs will be more prevalent than communicable diseases [12, 18-29]. Limitations to previous studies include small sample sizes and varied follow-up times, including some as short 14 days. There has been a call for larger samples and longer randomized controlled trials as well as further assessment of the apps' functions most critical to symptom control [16, 31]. Importantly, previous studies have included limited involvement of health care providers in the design and development of apps; a limitation likely influencing the utility of these apps [15, 32, 33]. In close partnership with Tanzanian target end users [physicians and nurses trained in palliative care; patients/caregivers; and local health workers (LHWs)], we employed a human-centered design (HCD) framework to design, develop, and validate the usability of a mobile-Palliative Care Link (mPCL) prototype, a web/mobile app focused on symptom assessment and control for Tanzanian poor-prognosis cancer patients that extends access to a limited pool of specialists through partnerships with community-based LHWs.

2. MATERIALS & METHODS

This study was approved by the Muhimbili University of Health and Allied Sciences (Dar es Salaam, Tanzania) Institutional Review Board. Signed informed consent was obtained from all participants prior to engagement in study activities.

2.1. *Overview.* Using WHO palliative care pillars (policy, education, drug availability, implementation) as a framework [9] and responses to the validated African Palliative care Outcomes Scale (a ten-item quality of life-focused survey instrument; hereafter termed POS) [34, 35] as an outcome measure (see Figure 1), we partnered with Dar es Salaam-based Tanzanian specialists (i.e., palliative care-trained, Ocean Road Cancer Institute-affiliated oncology physicians and nurse), cancer patients/caregivers and LHWs to develop, pilot test, and validate the usability of the mPCL prototype.

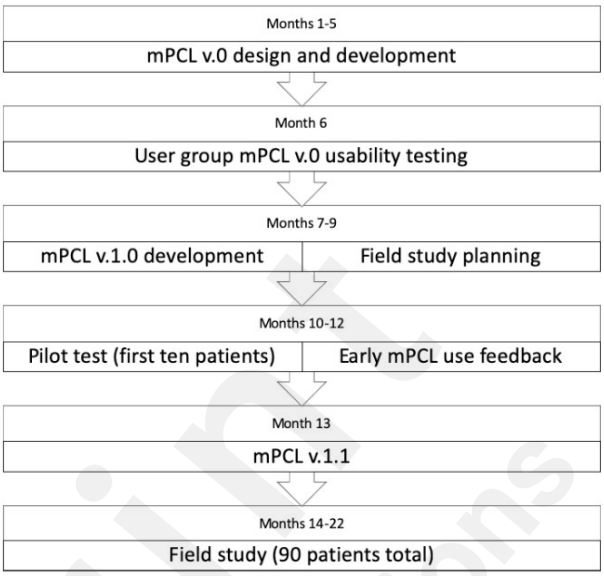
Figure 1. *mPCL POS for Patient and Caregiver (for display in Kiswahili). N/A indicates "caregiver not present." [Reference 27]*

REPORT HOW YOU ARE FEELING PATIENT QUESTIONS							
Q1. Please rate your pain during the last 3 days (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	no pain					worst/overwhelming pain	
	0	1	2	3	4	5	
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	not at all					overwhelmingly	
	0	1	2	3	4	5	
Q3. Have you been feeling worried about your illness in the past 3 days?	not at all					overwhelming worry	
	0	1	2	3	4	5	
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	not at all					yes, I've talked freely	
	0	1	2	3	4	5	
Q5. Over the past 3 days have you felt that life was worthwhile?	not, not at all					yes, all the time	
	0	1	2	3	4	5	
Q6. Over the past 3 days, have you felt at peace?	no, not at all					yes, all the time	
	0	1	2	3	4	5	
Q7. Have you had enough help and advice for your family to plan for the future?	not at all					as much as wanted	
	0	1	2	3	4	5	
FAMILY CAREGIVER QUESTIONS							
Q8. How much information have you and your family been given?	none		as much as wanted				
	0	1	2	3	4	5	N/A
Q9. How confident does the family feel caring for [patient]?	not at all			very confident			
	0	1	2	3	4	5	N/A
Q10. Has the family been feeling worried about [patient] over the last 3 days?	not at all			severe worry			
	0	1	2	3	4	5	N/A

2.2. *Stages of mPCL development.* The app design and development process consisted of six stages, as follows:

2.2.1. Stage 1 – Establishing the design team. The multidisciplinary team established included Tanzanian- and US-based partner institutions/organizations: Muhimbili University of Health and Allied Sciences (MUHAS), Ocean Road Cancer Institute (ORCI), Maine Medical Center (MMC), and a social software enterprise, Dimagi. Team members included Tanzanian and US palliative care specialists, health services researchers, software engineers and designers, and a user experience (UX) specialist (author, RM). The team met remotely via videoconference on a monthly basis and communicated via email throughout the design, development, and testing periods (see Figure 2).

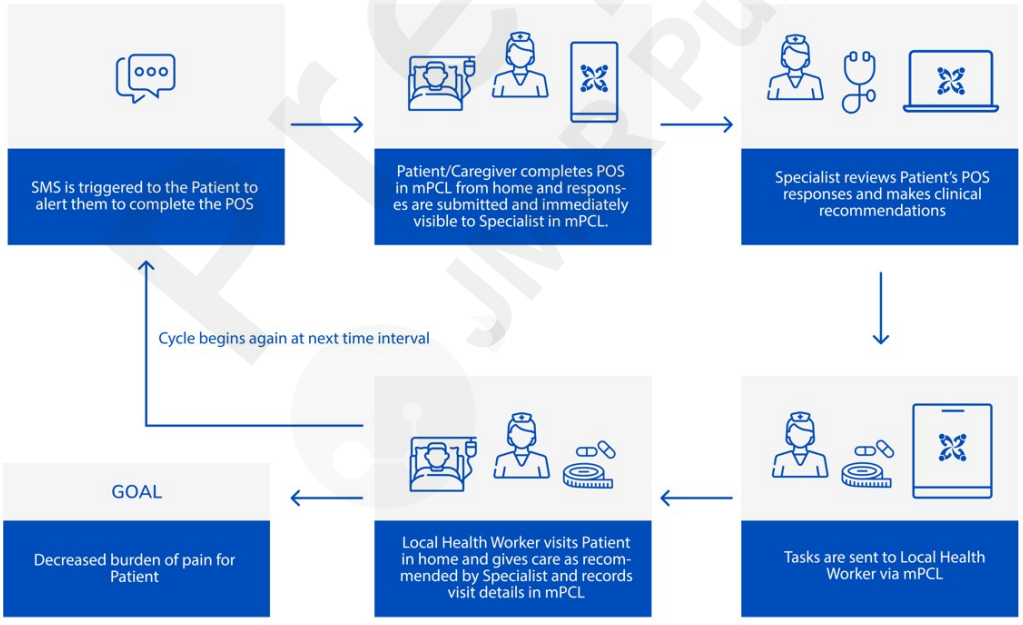
Figure 2. *mPCL design and development timeline. (Early mPCL use feedback involved only specialists and study personnel; Field study results reported elsewhere)*



app

2.2.2. Stage 2 – Defining a set of app design requirements. The team defined the three mPCL design requirements based on a proposed workflow that was endorsed by clinical study team members. Figure 3 shows the care communication and coordination app-facilitated workflow.

Figure 3. *mPCL design focused on patient/caregiver and care team communication and care coordination.*



Design requirements were as follows:

Requirement 1. Streamlined and timely collection of patient self-reported symptoms. Central to mPCL's utility is its ability to regularly and in real time assess the patient's quality of life (with a focus on pain control) through the scheduled, twice-weekly delivery and

collection of the POS that includes seven patient-focused items and three caregiver-completed items (see Figure 1). Permission was secured to adapt this survey instrument for mobile delivery and collection.

Requirement 2. Interdisciplinary care coordination. Following a patient-centric, interdisciplinary system of care coordination, mPCL was designed for access and use by the patient/caregiver and key members of the patient's clinical care team to deliver high quality, community-based palliative care services. We define these roles as follows:

1. Specialists include hospital-based **specialist physicians** (oncologists trained in palliative care) and palliative care nurses (hereafter referred to as **nurses**). The specialist physician's primary tasks are to generate a shared synoptic clinical record and palliative care plan, review POS results and oversee the patient's care. The nurse supports development of the synoptic clinical record, conducts visits with the patient/caregiver in coordination with the LHW, and serves as a liaison between all care team members as well as an emergency contact for patients/caregivers. As such, both the specialist physician and the nurse play a role in creating the synoptic clinical record in mPCL. The clinical record and care plan are viewable by other members of the care team and can be updated at any time by the specialist based on POS responses and input from the nurse, LHW, and patient/caregiver. Specialist physicians have the exclusive ability to prescribe, supply and make adjustments to morphine and other medications critical to pain and other symptom management.
2. The community-based **LHW**, located in close proximity to the patient's/caregiver's home, assists with regular remote assessment, monitoring and management of the patient's symptoms via in-person visits recorded in the form of mPCL follow-up interactions, and through mPCL communication/care coordination in partnership with other team members, thereby providing frontline care based on direct ongoing specialist guidance and the needs of the patient.
3. The cancer **patient** receiving outpatient, home-based palliative care, as well as their lay **caregiver** who is responsible for providing in-home patient support, can access and use the app to complete the ten-item POS and submit results to mPCL's cloud-based server for subsequent review by the LHW and review/action by a specialist. Additional patient-centric design specifications include a set of low-literacy educational resources, developed in Kiswahili (Tanzania's primary language) with a focus on the causes and management of common late-stage cancer symptoms.

Requirement 3. Symptom response-focused communication between care team and patient/caregiver. Shared access to POS results, an evolving synoptic clinical record and palliative care plan, and follow-up notes by care team members on interactions with the patient/caregiver allows for: i) timely communication to support patient-centered care plan decision-making in response to a LHW's in-person assessment of the patient experiencing escalating symptoms or other needs; ii) coordination of care to implement changes to the care plan; and iii) important updates regarding change in patient status (i.e., hospitalization or death). mPCL also provides patients with emergency phone contact information to reach a specialist or LHW in the event of rapidly escalating symptoms or acute change in clinical status.

2.2.3. Stage 3 – Defining User Requirements. In accordance with human centered design methodology, user characteristics and needs were gathered and analyzed to create a set of user requirements. The first step in doing this was to create a set of user personas. Each persona presented a summary of the key characteristics, background and needs of a representative user from each user group. The personas were developed in conjunction

with and reviewed by all team members, including those in Tanzania who had the closest understanding of the prospective users of the app. After the personas were complete, a set of user stories was created. Each user story described how one or more users (represented by the personas) would use the app, either on their own or together. The user stories functioned as a means to clearly and concisely define how the app would be used by each user group. As with the personas, the user stories were reviewed by all team members.

2.2.4. Stage 4 – Creating the app prototype, mPCL v.0. The app prototype, mPCL v.0, was designed and built to directly support core requirements defined in Stage 2, summarized above. The process of designing and creating the prototype involved: i) drafting the data architecture, ii) creating display pages and input forms to populate with content, and iii) defining custom user interfaces and permissions for types of users based on their specific roles and tasks on the clinical care team. Periodic technical reviews and audits were conducted internally by Dimagi to ensure optimization of the app design and verify technical requirements for data collection and analysis, e.g. configuring unique user names, updating a change in medication. The back and front ends of the functional prototype were built and prepared by the Dimagi staff with advisement from clinical team members and the team's UX specialist. mPCL was developed on CommCare; Dimagi's HIPAA-compliant open source cloud-based case management platform that allows end users to collect data and deliver interventions via custom-built mobile and/or web apps. This enabled the team to both rapidly iterate on the design and to prepare a functional prototype for testing and use. [36]

2.2.5. Stage 5 – Expert UX Review. Once the prototype was complete, an expert review was conducted by the UX specialist. The goal of this review was to identify and fix areas where the app was not in compliance with established UX best practices. The UX specialist identified areas of improvement and suggested changes. These changes were then reviewed by team members and implemented into an updated version of the app. Key improvements included reorganizing the workflow in the app to make it easier for specialists and LHWs to access patient data, changes to the set of data shown for each user group to ensure that all needed data was available, and updates to labels and terminology to improve clarity and ease-of-use.

2.2.6. Stage 6– Testing the prototype. Usability and pilot testing were conducted with target end users whereby the mPCL prototype was iterated and further developed after each phase of testing.

Usability test. mPCL v.0 usability was assessed in individualized in-person usability testing sessions conducted by the UX specialist with participants representing target end users. Two site visits in Tanzania were led by US team members in partnership with MUHAS/ORCI team members to conduct in-person prototype usability testing and then train end users on the system just prior to the pilot test, respectively. The goals of usability testing were to: i) validate the design of mPCL and identify any remaining design issues, ii) uncover opportunities for system improvement, and iii) learn about the target user's behaviors and prototype app interactions [37]. mPCL v.0 usability testing was conducted with a diverse sample of patients, LHWs, and specialists (physicians and a nurse). Potential participants were identified and recruited by ORCI-based study team members. Eligibility criteria for patients included adult ORCI inpatients with known untreatable cancer. Specialists included ORCI-based oncologists and a palliative care nurse. LHWs were eligible to participate if they were within 50 km of ORCI and were actively serving cancer patients seen at ORCI. Written informed consent was obtained from all eligible study candidates prior to the usability testing session.

All usability testing sessions occurred in person, in a private space at ORCI. Testing for

patients and LHWs was conducted in Kiswahili with a translator. Testing for specialists was conducted in English. Patients were first briefly trained by a study team member on basic use of mPCL. They were then asked to use an mPCL-equipped study smartphone to perform the following tasks to assess usability: i) access educational resources; ii) complete and submit POS responses; and iii) contact a care team member. Specialist physicians were asked to use an mPCL-equipped tablet to: i) set up a mock patient synoptic clinical record, including a discharge palliative care plan; ii) review POS results; iii) enter follow-up patient notes, including changes in care plan; and iv) exchange notes with a LHW. These notes were intended to document requests for in-person assessment, collection of additional information, as well as treatment recommendations and changes to the patient's care plan. The nurse was asked to: i) register a mock patient into mPCL and enter relevant demographic and clinical information into the synoptic clinical record; ii) complete the POS for a mock patient; iii) record a note documenting an interaction with a mock patient; iv) review POS results and medications for a mock patient; and v) update contact information for a mock patient. LHWs were asked to use a study mPCL-equipped smartphone to: i) review a mock patient record including POS results; and ii) exchange notes with a mock specialist and patient regarding the patient's assessment and symptom control. All usability testing participants were observed performing the pre-defined tasks and all usability issues observed by the UX specialist (e.g., missteps in navigating through the app to perform a task, errors entering data into the app) as well as all participants' recommendations for changes to the prototype design were documented and reviewed with the study team. At the end of usability testing, all participants also completed a verbally administered survey that assessed users' perceived mPCL ease-/difficulty-of-use. A set of app-building recommendations was derived from usability testing feedback after discussion with study team members with UX and clinical expertise to inform the iteration of a more robust and user-validated mPCL prototype. App modifications ultimately accepted and employed were based on feasible design decisions with the goal of maximizing usability. The final mPCL v.1.0 prototype was then used in the subsequent pilot test.

Pilot test. As part of a larger 4-month prospective intervention study and field study of the system, cancer patients were enrolled and consented upon planned discharge to home from ORCI and randomized to either the mPCL intervention or twice-weekly phone collection of POS responses by an ORCI-based clinician team member. Here, we describe the pilot testing used to inform the final build of mPCL (v.1.1) deployed for field study completion. A full description of field study outcomes will be reported elsewhere (manuscript in preparation). In brief, patient eligibility for both the pilot test and field study included: i) an adult ORCI inpatient with known untreatable cancer due to be discharged to home; ii) a 4-month life expectancy or greater per specialist physician assessment; iii) residence within 50 km of ORCI for medication access; iv) caregiver available to support outpatient care for the illness duration; v) a LHW consented to support patient's outpatient care for the test's duration (at least 6 weeks and up to 4 months post-discharge); and vi) completed primary school education. Intervention patients lacking personal smartphones were loaned an Android device with the mPCL app pre-installed and available for use during the 4-month study period; and those with reliable access to their own personal smartphone were provided the option to install and use the mPCL app on their own personal device. An ORCI information technology (IT) specialist working directly with the study team assisted patients with the preparation and maintenance of devices for the purposes of the study (i.e., acquisition of SIM cards, installation of mPCL) and served as the first point of contact to respond to any emergent technical issues over the course of the study. For specialists, mPCL was accessible from their office-based computers as a web app as well as their smartphones as a web app or native mobile app. LHWs had the option to either use their

own mPCL-enabled smartphones or an Android device provided for use during the study with the mPCL mobile app pre-installed.

Real time feedback and input regarding mPCL use as well as study process or procedure problems were requested via email and during regular team meetings from specialist physicians, nurses and ORCI-based study personnel during the two-month pilot test period. In this time, a total of ten patients were enrolled and randomized to mPCL versus phone-contact. At the end of the 2-month pilot testing period, patient recruitment was held for close to a month during which time mPCL use feedback and pilot test process recommendations were compiled and analyzed and used to iterate on and finalize the app prototype, mPCL v 1.1 for further field study.

3. RESULTS

3.1. mPCL v.0 usability testing. A total of 21 potential target end users participated in mPCL v.0 usability testing: seven patients and caregivers, eight specialists, and six LHWs. Out of the seven patients who participated, six were women (one man) and none reported any secondary school education or spoke English. Patients' ages ranged from age 34-64 years, and two patients or their caregivers owned an Android smartphone, four owned a mobile phone, and one did not own a phone. Among specialists, seven specialist physicians and one nurse participated, six were women (two men). Specialists had 4-14 years of clinical experience, were English-speaking, and owned Android smartphones. LHW participants included four women and two men with 4-14 years of clinical experience and all owned Android smartphones. All LHWs were fluent in Kiswahili with a few also conversant in tribal languages and reported limited English language proficiency.

Open-ended user feedback and usability issues identified during usability tests were itemized and reviewed by the mPCL design team for the optimization of mPCL v.0 to mPCL v.1.0. Direct feedback was probed and collected from users on role-specific tasks performed and navigation of custom interfaces designed for specialist physicians, nurses, LHWs and patients/caregivers, respectively. Design components were reviewed and validated. Examples of user task performance improvement recommendations included: i) reformatting the POS assessment for patients and caregivers to display assessment items one at a time instead of all on one page making it easier for those not accustomed to navigating a touchscreen; ii) adding more comprehensive clinical data for collection by specialists, specifically providing more detail on the patients' current and historical medications; iii) adding more information on the patient's social history to the clinical record (i.e., family support resources, such as their living situation and nutritional support); iv) translating all information displayed to LHWs into Kiswahili to make the app easier to use for those with limited English language proficiency; and v) including patient's cancer type and stage in the patient list display for easier identification of a patient. Other emergent themes in user feedback included the need for clearer delineation of user roles and tasks and related user permissions (e.g., creation of follow-up notes by a specialist physician and patient enrollment and registration by a nurse) and clarification of POS data collection and monitoring (i.e., reminder schedule and modality to prompt patients to submit POS assessments and notification mechanisms to alert care team of a new POS assessment submitted by a patient). As summarized in Table 1, the perception of mPCL's usability for tasks performed ranged from low degree of ease and acceptability (3/4) to very high degree of ease and acceptability (1/4). In general, respondents found mPCL easy to use with an average usability score of 2 and below for any given task. Of particular note, all LHWs (7/7) reported high degree of ease and acceptability for time spent reviewing the clinical record and time spent reviewing the POS assessments. Several respondents remarked that they anticipated that ease-of-use and acceptability would improve with increased experience using the app.

Table 1. *Prototype usability test survey results among patients, specialists, and LHWs (N=21).*

Survey item	Response*		Total Num. of Responses
	Mean	[Range]	
Patients			**7**
Ease or difficulty of POS completion	1.9	[1,3]	7
Acceptability of time to complete POS	1.3	[1,3]	7
Ease or difficulty of using educational materials	1.6	[1,3]	7
Ease or difficulty of making emergency phone calls	1.2	[1,2]	6
Specialists			**8**
Ease or difficulty of creating clinical record	1.5	[1,2]	8
Acceptability of time spent creating clinical record	1.5	[1,2]	8
Ease or difficulty of reviewing clinical record	1.1	[1,2]	8
Acceptability of time spend reviewing clinical record	1.3	[1,2]	7
Ease or difficulty of reviewing POS	1.6	[1,2]	5
LHWs			**6**
Ease or difficulty of reviewing clinical record	1.3	[1,3]	7
Acceptability of time spent reviewing clinical record	1	[1,1]	7
Ease or difficulty of reviewing POS	2	[1,3]	7
Acceptability of time spent reviewing POS	1	[1,1]	7
Ease or difficulty of recording patient interaction	1.8	[1,2]	4

* All survey item responses were scored from 1 to 4 with 1 = very high degree of ease or acceptability and 4 = very low degree of ease or acceptability. Abbreviations: POS = Palliative care Outcome Survey. LHW = Local health worker

3.2. mPCL v.1.0 pilot testing. During the 2-month mPCL pilot test period, four specialist physicians, one nurse, five LHWs, and ten patients who were randomized to mPCL use versus phone-contact POS collection were enrolled. A subset of mPCL users who were also ORCI-based study team members (coauthors TN, BM, HM, and MN) were asked to provide real time feedback on issues or questions related to either mPCL v.1.0 use or study processes and procedures, in preparation for the subsequent field study. As noted in Table 2, some of this feedback required immediate resolution while other feedback was addressed at the end of the pilot test period.

Table 2. *Examples of mPCL pilot test feedback and corresponding action taken.*

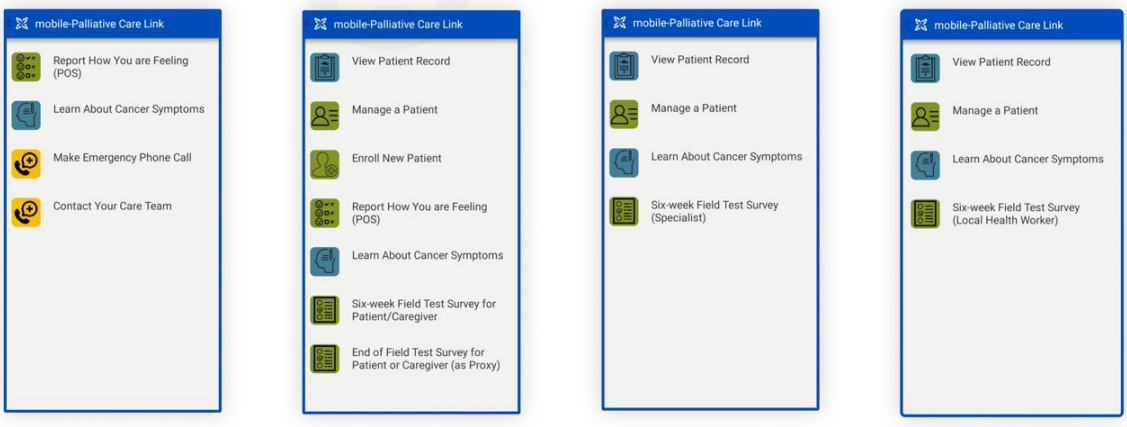
Issues requiring immediate resolution	Action taken
CommCare failed to recognize installation codes necessary to install the mPCL app on a study phone	ORCI-based team instructed on resolution
CommCare failed to install updates	ORCI-based team instructed on resolution
LHWs and patients unknowingly uninstalled mPCL or reset cellular internet settings	ORCI-based IT support team member added to address issues on demand
Study nurse could not complete the mPCL clinical record if the cancer stage was not known	“Unknown” was added as a response selection

Patients requested to use their own personal SIM cards rather than using SIM card provided by study	Personal SIM cards were allowed and custom fit for use with study phones with participant permission
Issues <u>not</u> requiring immediate resolution	**Action taken**
ORCI study team noted variability in the ease of training patients on the use of mPCL	Procedure established to capture data on patient's mPCL training ease or difficulty (e.g., number of times patient training repeated, specific challenges encountered during training)
Difficulty for the patient to select which care team member they wished to contact (i.e., nurse, LHW, or specialist)	mPCL adjusted to allow the patient to more easily select the desired care team member
Patients completed more than one POS in a given day	Feedback provided to patient that they were submitting duplicate surveys, including a reminder that they could contact their care team by phone in the event of escalating symptoms.

3.3. mPCL v1.1 prototype finalization

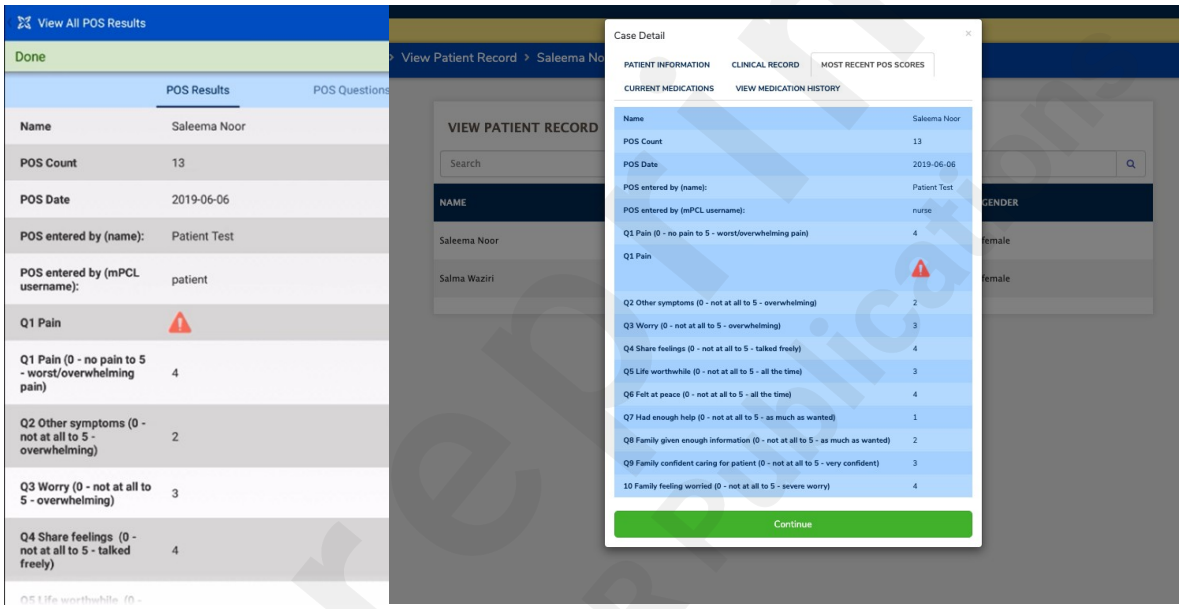
mPCL v1.1 prototype functionalities summarized below were focused on real time symptom assessment and care coordination, with the primary aim of effective symptom management and maintenance of quality of life. For the purpose of the mPCL field study, we defined and validated four individual mPCL user groups with interfaces, access and permissions to functionalities specific to each group's roles and tasks in managing study patients: specialist physician, nurse, LHW, and patient/caregiver. Specifically, a nurse was determined to be the only user group with the ability to register a new study patient in mPCL via the Enroll New Patient module. Additional tasks assigned to the nurse to support field study-specific activities (e.g., ability to drop a patient from the study) were built and validated in pilot testing in preparation for the subsequent field study. Study-specific surveys for each respective user group were directly included and disseminated to users through the app as well. (See Figure 4 for screenshots of user interfaces.)

Figure 4. *Four separate interfaces for four different user roles (from left to right): Patient/Caregiver, Nurse, Specialist Physician, LHW.*



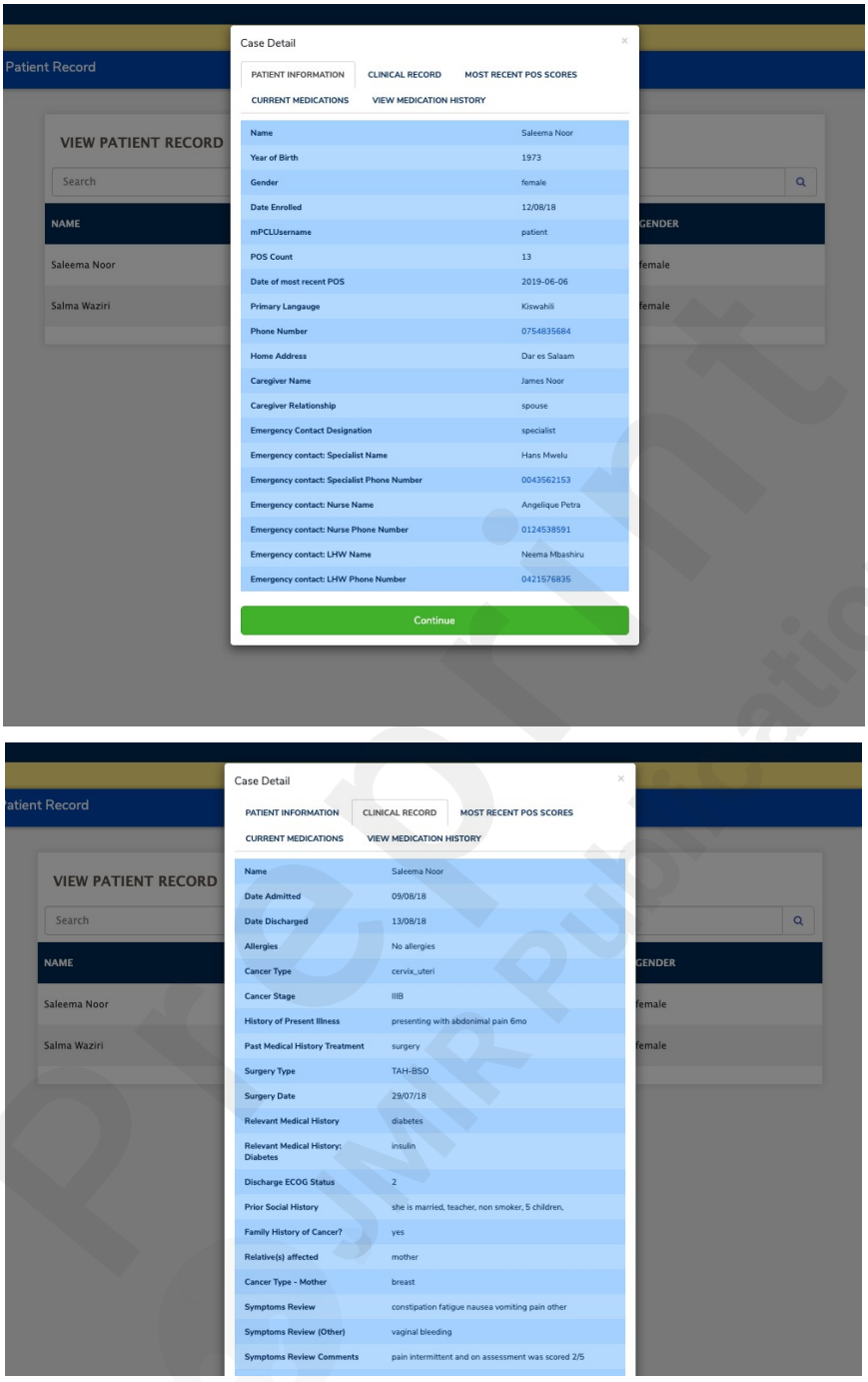
POS. The core priority of mPCL is adequate pain control based on patients' self-reported POS scores. The ten Likert-scaled POS items are included in mPCL as a survey form with single-choice response options ranked from 0 to 5 (low to high) corresponding to symptom severity. The assessment is displayed in Kiswahili and designed for collection of responses directly from patients and their caregivers. Scores are collected and automatically available for review by the clinical care team upon synchronization of data on mPCL-enabled devices connected to the CommCare cloud server back-end. Through mPCL, patients are reminded via SMS to complete the POS on a twice-weekly basis with results immediately accessible to the specialist, nurse and LHW for timely tracking, and action if needed. Flags signifying escalating symptom scores were built into the app for more immediate attention from the care team (Figure 5).

Figure 5. *POS responses (mock patient) as viewed in the mobile app on (left) and on web app (right) as viewed by the specialist. A red triangle icon is displayed to alert the care team to reported pain scores that are above set threshold.*



Synoptic clinical record and palliative care plan. A series of templated forms allow the specialists to create and share access to a synoptic clinical record and discharge palliative care plan that includes: the patient's basic demographic information, social history, disease type and stage, non-cancer comorbidities, a summary of previous cancer treatments, essential imaging and laboratory results, and a care plan, including medications and allergies. The synoptic clinical record facilitates clinical and social history data collection by the specialist physician or nurse immediately following inpatient hospital discharge of the cancer patient to home for ongoing palliative care coordination. This record is available to both the specialist physician and nurse with read/write access and LHW with read access (see Figure 6 for examples of parts of the clinical record that are viewable to care team users).

Figure 6. *Clinician web app view of patient information (top) and clinical record (bottom) of the mock patient record.*



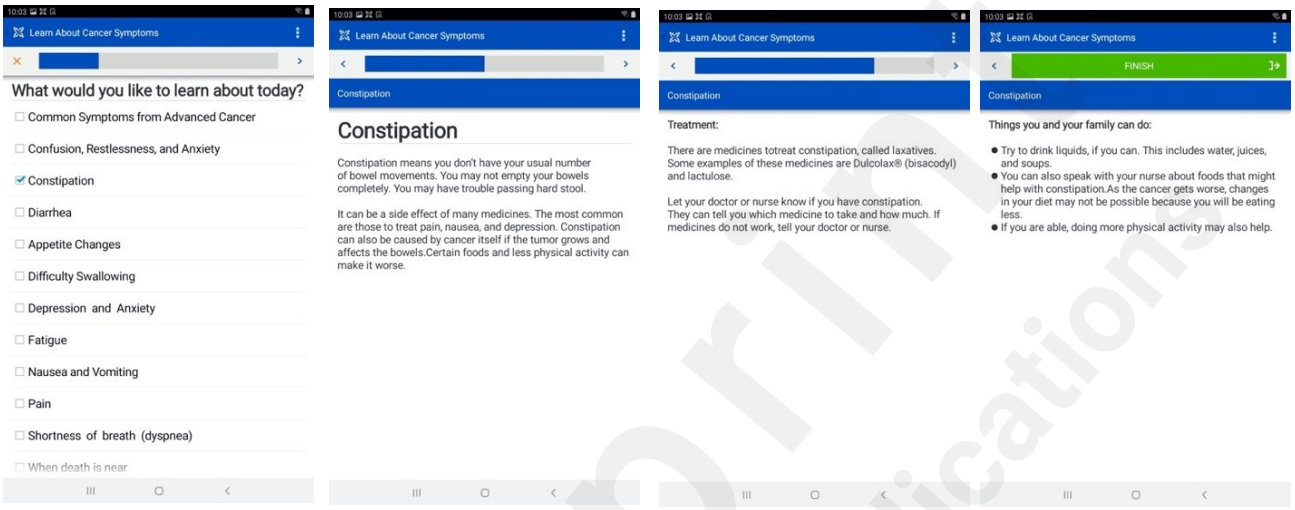
Follow-up patient interaction. Post-discharge change in clinical status, including any communication with or in-home assessment of the patient, readmissions, clinic visits, medication adjustments, or death are recorded in mPCL by a member of the care team using clinical follow-up form templates. This clinical documentation is intended for communication and care coordination among care team members and to update the patient case and alert other care team members of important changes in clinical status.

SMS messaging and reminders. One-way SMS messaging is enabled and programmable through the app to support, for example, scheduled reminders to complete the POS or other study survey instruments, and to address real time patient/caregiver needs (i.e., medication adjustments) or acute change in clinical status.

Educational module. Basic educational information, adapted from publicly available, web-

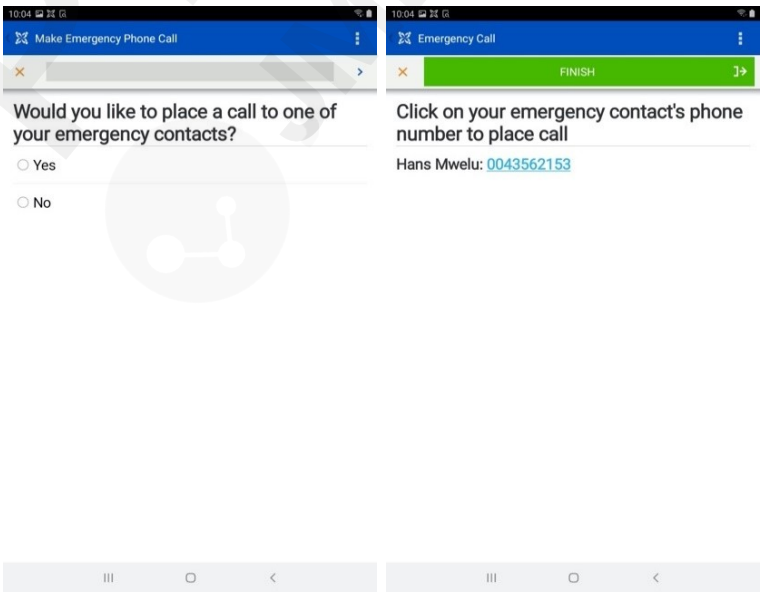
based resources [38, 39], was developed to improve the patients' and caregivers' awareness of the causes and management of a wide range of late-stage cancer symptoms (i.e., pain, nausea, constipation, shortness of breath). Through the support of a US-based literacy expert, the educational module was developed at a primary school reading level and then translated into Kiswahili with the assistance of and direct feedback from MUHAS/ ORCI clinical team members and input from patient/caregiver usability test participants (see Figure 7 for example).

Figure 7. *Example screenshots of the patient symptom-focused educational resource (displayed in Kiswahili for patients). Patients are able to first select specific content areas they would like to learn more about.*



Emergency contact. An emergency contact module was built to enable patients/caregivers to directly connect with a member of the care team via phone (see Figure 8).

Figure 8. *Screenshots of the emergency contact module. When patient clicks "Yes" on the first screen of the module (left), the patient is advanced to the next screen (right) where the patient can click on a hyperlink to directly call the designated emergency contact.*



DISCUSSION

Here, we describe the process of designing and developing a secure web/mobile app

focused on extending the reach of a limited pool of specialist clinicians via specialist-LHW care coordination in order to improve symptom control and quality of life among poor-prognosis Tanzanian cancer patients. mPCL is a patient-centered system that facilitates real time symptom collection and reporting for direct communication between patients/caregivers and their clinical care team members and care coordination to support prompt and effective community-based symptom control.

In general, mPCL was found to be usable and useful for executing and fulfilling tasks specific to and expected of each user role. Users perceived clinical information to be up-to-date and the generation and tracking of the synoptic clinical record was not found to be cumbersome among the specialists who participated in both initial usability testing as well as early pilot testing.

Although this is not the first mobile app dedicated to cancer-related pain control, to our knowledge it is the first such system developed expressly to support palliative care in low resource settings using a community-based framework of care. Critical to the mPCL design process was input collected directly from potential target end users to inform iterations of the prototype before finalization of a version deployed in real-world clinical settings. While smartphone ownership and connectivity has greatly increased across Tanzania, more of this growth is among younger, more educated, and affluent populations [10], and the use of a smartphone app for delivering a symptom control intervention at a population level in Tanzania has only more recently emerged as an area of exploration for researchers and developers. As such, a full awareness and understanding of the target population's context is first needed to build a usable app in terms of access to technologies and resources, ability to adopt and effectively use the intervention, and preferences regarding design to include a careful assessment of the cultural competency of the app in different populations and settings, including those with varied education levels and language proficiencies.
There has been a call for standardized protocols and tools for pain (and other symptom) assessment as this would strengthen future studies and allow investigators to synthesize and compare results of individual studies in a range of settings and populations [31]. As with mPCL, individual applications can offer a wide range of functions and specifications such as educational resources, diaries, reminders, treatment recommendations, and real time communication with health care providers. There is need for comprehensive reporting and testing of these individual functions and features to examine which components are most helpful in symptom control and overall quality of life. Furthermore, a standardized quantification of patient-reported pain and other symptoms can be lacking or limited in apps.
Here, we designed and demonstrated the usability of an app directly addressing pain and other symptom (physical and emotional) assessment using a validated patient and caregiver-focused tool for symptom management (i.e., the African POS).

Cancer-related pain is a global issue with the greatest concern among those in the low resource setting where access to specialists and other resources, including medications, is limited or nonexistent. mPCL may represent the first app focused on pain and other acute and chronic late-stage symptoms-- directly linked to quality of life-- among cancer patients from a low resource sub-Saharan African country. The design of an interface and functionalities specific to the role of and usability tested among each member of the palliative care team promises to address some of the limitations cited in previous work in this area. Critical to the utility and usability of mPCL was attention to the unique cultural, sociodemographic and educational experiences (including language proficiencies) and

backgrounds of patients and their caregivers. We adopted a rigorous HCD approach with active engagement and participation of patients and caregivers throughout the app design process—a technique that is viewed as essential to the adoption and ultimate effectiveness (herein, reflected in improved quality of life among cancer patients) of new technologies in low resource settings [40-42].

Core to mPCL functionality is the scheduled delivery and collection of patient symptom and quality of life indicators made available real time to the all care team members. This functionality promises to deliver prompt response to escalating symptoms. The clinician end users viewed immediate access to the synoptic clinical record and follow-up notes, as well as functions focused on user group communication and care coordination as critical. In line with previous literature revealing that real time communication improves outcome relative to adequate pain control, access to emergency phone contact was seen as an essential component of mPCL [16].

Of note, both patients and LHWs reported the importance of the educational module in improving awareness of anticipated late-life symptoms as well as an understanding of the basic means to control these symptoms. Although these resources were directed at the patient and caregiver, LHWs reported that this information was informative for them personally and believe that it supported them in their care of cancer patients.

CONCLUSION

Here we describe the design and development of a mobile app aimed at extending the reach of a limited pool of specialists dedicated to symptom control and improved quality of life among late-stage cancer patients in the low resource setting. We followed an HCD framework with direct engagement of all target end user groups—specialists (physicians and nurses), LHWs, and patients/caregivers—to design the prototype. The central focus of the app was on real time symptom monitoring (using a validated scale) and communication. Usability testing revealed general acceptance of the app, and early pilot testing shows the app to be acceptable and feasible in the setting of a single urban cancer institute. The broader, randomized field study will provide further evidence regarding the clinical utility and effectiveness of mPCL. Additional questions related to this work include the generalization of mPCL in other geographic settings and in settings with less access to symptom control medications and other support resources. As mobile technologies continue to grow and evolve in low resource settings like Tanzania, the field of cancer medicine can greatly benefit from an understanding of how to build patient-centric tools optimized for remote symptom monitoring and tracking as well as effective and efficient care coordination. Further, rigorous studies of the use of tools like mPCL in practice will be critical to understanding how they can be widely adopted and scaled.

AUTHORS' CONTRIBUTIONS

The co-authors of this paper include the following individuals who were active contributors to the study and app design and development team:

Habiba Mahuna, RN, served as a Study Nurse on the project and reviewed and provided inputs to the manuscript on the role of Nurse.

Mamsau Ngoma, MD, served as a Co-Investigator on the project and reviewed and provided inputs to the manuscript on the role of Specialist Physician.

Joshua Mmari, BS, served as the primary technical focal point on this project and reviewed and provided inputs to the manuscript on the deployment of mPCL in the pilot study.

Twalib Ngoma, MD, served as a PI, contributed to the conception of the project and oversaw all study activities at ORCI. He reviewed and provided inputs to the manuscript.

Beatrice Mushi, MD, served as Study Coordinator and reviewed and provided inputs to the manuscript on methods.

Susan Miesfeldt, MD, served as lead PI and conceived of mPCL and oversaw the overall project. She contributed significantly to the initial draft and development of the manuscript.

Robert Morse, BS, led UX design and usability and pilot data collection and analyses. He contributed significantly to the initial draft and development of the manuscript.

Erin Quinn, MA, actively contributed to the design and development of the app and assisted with the generation of figures.

Kaley Lambden, MSPH, led the design and development of the app and assisted with editing portions of the manuscript and generation of figures.

Yun Xian Ho, PhD, served as a PI and oversaw the app design and development and contributed significantly to the initial draft and development of the manuscript.

Sarah Sagan, BA, managed the project timeline and design of the app and assisted with editing portions of the manuscript and generation of figures.

CONFLICT OF INTEREST STATEMENT

The authors wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

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