How a Digital Case Management Platform Affects Community-Based Palliative Care of Sub-Saharan African Cancer Patients: Clinician-Users' Perspectives

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Abstract

Background   Symptom control among cancer patients is a Tanzanian public health priority impacted by limited access to palliative care (PC) specialists and resources. Mobile Palliative Care Link (mPCL), a mobile/web application, aims to extend specialist access via shared care with local health workers (LHWs) with the African Palliative care Outcome Scale (POS) adapted for regular, automated symptom assessment as a core feature.

Objective   The aim of the study is to assess clinicians' attitudes, beliefs, and perceptions regarding mPCL usability and utility with their patients within a government-supported, urban Tanzanian cancer hospital setting.

Methods   We used a mixed methods approach including surveys, qualitative interviews, and system usage data to assess clinicians' experience with mPCL in a field study where discharged, untreatable cancer patients were randomized to mPCL or phone-contact POS collection.

Results   All six specialists and 10 LHWs expressed overall satisfaction with mPCL among 49 intervention arm patients. They perceived mPCL as a way to stay connected with patients and support remote symptom control. Timely access to POS responses and medical records were identified as key benefits. Some differences in perceptions of mPCL use and utility were seen between clinician groups; however, both expressed strong interest in continuing app use, recommending it to colleagues, and extending use throughout Tanzania. Primary use was for clinical status communication and care coordination. Pain and other symptom progression were the most frequently reported reasons for provider–patient interactions accounting for 34% ($n = 44$) and 12% ($n = 15$) of reasons, respectively. Usage barriers included time required to create a new clinical record, perceived need for response to non-urgent reminders or alerts, and training.

Keywords
► mobile devices
► user-centered mobile
► palliative care
► cancer
► sub-Saharan Africa

necessary for competent use. System-level implementation barriers included variable patient access to smartphones and SIM cards and unreliable Internet access.

Conclusion   This work demonstrates broad clinician desire for digital health tools to support remote community-based PC among cancer patients, particularly pain management.

Background and Significance

Cancer is a growing sub-Saharan Africa (SSA) public health priority.[1–3] While cancer mortality to incidence rates in the United States (US) are continuing to fall, approximating 33% in 2020; in SSA this was 67% in 2018, revealing stark disparities in cancer control globally.[4] Due to high care costs and insufficient treatment facilities, SSA cancer mortality rates are growing, anticipated to surpass the global average by 30% over the next 20 years.[5–7]

These data highlight the critical need to address barriers to palliative care (PC) among cancer patients. A two-country SSA study showed unnecessary suffering among late-stage cancer patients; most often uncontrolled pain (87.5%), followed by low energy (77.7%), sadness (75.9%), drowsiness (72.3%), and worry (69.6%).[8] PC leads to better patient and caregiver outcomes, including quality of life (QoL), patient satisfaction, and reduced caregiver burden.[9] Of relevance to under-resourced countries like Tanzania, U.S.-based work reveals that PC access improves late-stage cancer life expectancy.[10] While Tanzanian PC initiatives exist, rising cancer rates reveals the pressing need to extend the restricted pool of resources nationally.[11–13]

New opportunities to support PC have emerged from major shifts in the digital health ecosystems in SSA over the last several decades, including implementation and expansion of Digital Health Information Software 2 for[14] district- and national-level health data surveillance and reporting, availability of broadband connectivity, and increasing use of smartphones.[15] WHO called for 80% availability of affordable technologies addressing non-communicable diseases, including cancer.[16] With 65% of Tanzania's population residing in rural settings as of 2020,[17] sustainable, community-based user-centered digital solutions hold promise to scale PC to these harder-to-reach communities with limited resources and access to small numbers of PC specialists. However, barriers to digital health access such as the urban–rural and gender divide, low digital literacy, and unreliable electricity and connectivity still remain in many areas.[15] Further, successful large-scale adoption necessitates perceived value and utility from target end users themselves. The Technology Acceptance Model, which has been widely studied and expanded in health informatics,[18,19] including applications to PC,[20] posits that the behavioral intention to use motivated by underlying attitude (i.e., perceived ease-of-use and usefulness) is a key driver to actual use of technology. To directly address this critical factor to implementation, here we focus on the perspectives of clinicians, a key target end user group of the m-Palliative Care Link (mPCL) system, as there are known technical, indi-

vidual, and systems-level barriers to health care provider adoption of digital health tools.[21,22]

Reported previously, mPCL is a user-centered mobile/web application (app) that was designed and studied to improve symptom control and QoL among Tanzanian cancer patients through remote, real-time symptom assessment and interdisciplinary care coordination.[23,24] mPCL was built on Comm-Care, an open-source, secure cloud-based platform, accessible via native application on an Android device or web browser, with on- and offline data collection capabilities in low connectivity areas.[25] A community-engagement framework was used to build and field study mPCL, in partnership with representatives of three user groups including Tanzanian cancer patients and their lay caregivers (hereafter, caregivers); PC specialists (hereafter, specialists); and local health workers (LHWs). App functionalities include: (1) twice weekly, real-time patient/caregiver-reported symptom/QoL assessment via the APCA African Palliative Care Outcome Scale (POS)[18]; (2) a specialist-generated synoptic clinical record and PC plan, developed upon planned patient hospital discharge to home; (3) record of post-discharge user clinical interactions with patients/caregivers including phone calls and texts, home or clinic visits, and hospitalizations to document and share reactions to POS responses and clinical status changes, in support of interdisciplinary care coordination; (4) short message service (SMS) reminders to complete study-specific surveys; (5) an educational module providing basic, publicly-available, cancer symptom-focused information, adapted to local context and translated to Kiswahili[26,27]; and (6) direct patient/caregiver emergency clinician contact with clinician team members via hyperlinked phone numbers.

Objectives

The aim of the study is to assess field study clinician participants' attitudes, beliefs, and perceptions regarding mPCL ease-of-use and utility to improve symptom assessment and control through interdisciplinary PC communication and coordination in Tanzania.

Methods

Setting

This work occurred at Ocean Road Cancer Institute (ORCI), the largest national, government-supported cancer center, located in urban Dar es Salaam, and involved researchers at Muhimbili University of Health and Allied Sciences (MUHAS), located near ORCI.

Participants

The field study involved untreatable hospitalized cancer patients, randomized at discharge planning to mPCL or phone-contact POS collection (49 patients/arm). Details of the field study are reported elsewhere.[24] Six ORCI specialists (five oncologists and one PC nurse) and 10 community-based LHWs were involved in the care of mPCL intervention patients, discharged to home in greater Dar es Salaam, and followed for up to 4 months. All participants had access to and were trained in mPCL use, loaded onto their own Android device or a loaned study device, with added specialist access via secure computer or tablet.

Study Design

This mixed-methods study consisted of an mPCL usability survey administered 6 weeks after the start of the intervention period (►Supplementary Appendix A, available in the online version); in-depth, one-on-one interviews at end of study; and post-hoc analysis of clinician passive mPCL usage data.

Usability survey: The survey assessing perceived mPCL benefits and limitations, was adapted from existing assessments, translated in Kiswahili and validated for local context readability and use.[23] Disseminated to specialists and LHWs at 6-weeks post-discharge of all mPCL intervention patients, the survey consisted of 26 Likert-scaled items scored with three responses (Definitely agree, Agree somewhat, and Disagree) adapted from a survey used to assess providers' perceived benefits and barriers to standardized outcome measures.[28] Two open-ended questions assessed: (1) system benefits and (2) improvement recommendations, respectively. Responses were collected in Kiswahili and translated post-hoc for analyses.

Clinician interviews: Conducted by a usability specialist (co-author R.S.M.), remote end-of-study in-depth, semi-structured interviews followed a guide, focused on user experience, and were completed via Skype[26] between January and March 2020. These included a convenience sample of specialists and LHWs, and the physician field study coordinator (co-author RM, employed by MUHAS). When necessary, interviews were supported by a Kiswahili-language interpreter ($n = 6$).

Guide items probed how mPCL was used, as well as impressions and recommendations for improvement. App helpfulness or usefulness and recommendation to colleagues were captured with verbal responses to 2 Likert-scaled items from 1 (least useful/helpful or likely to recommend to colleague) to 10 (extremely helpful/useful or likely to recommend to colleague), respectively. Interviews were audio-recorded with de-identified transcriptions analyzed.

Passive usage data: A deidentified set of all post-discharge clinical interactions recorded by providers, stored within CommCare, was analyzed to explore symptom-focused communication and care coordination. Interactions were recorded in mPCL by clinician end users over the field test period of between October 2018 and December 2019. We analyzed types of users who interacted, interaction number per patient, reasons and modality used.

Data Analysis

Basic descriptive statistics—, i.e., mean, median, standard deviation (SD), frequency—were used for all quantitative data, including 6-week survey data and end-of-study interview Likert-scaled items. Interview transcripts and responses to open-ended survey items were analyzed using a priori content analysis and grounded thematic analysis to identify emergent issues and insights on clinician user experience.[27,29] We used member checking in real time during interviews, employing periodic confirmation and clarification.[30] Passive mPCL usage data were analyzed using basic descriptive statistics (i.e., mean, median, SD, frequency) by clinician user group as well as for user group comparisons.

Results

Usability Survey

Survey responses were collected for a total of 85 provider/patient dyads; seven LHWs and five specialists submitted responses for 45 unique patients (four missing, due to loss-to-follow-up). Thirteen mPCL intervention patients died during field study (median of 61 days). There was 100% agreement that mPCL helped direct the plan of care ($n = 85/85$ responses), increased care access (84/84) and efficiency (83/83), helped prioritize care needs (84/84), attain better outcomes (83/83), and patient QoL (84/84), and enhanced quality of services (85/85). While most responses suggested that mPCL was usable, 33% of responses agreed that the POS is difficult for independent patient use (28/85), and 20% agreed that the POS was difficult for clinicians to interpret, e.g., do not know what norms are, how score relates to severity, or what a clinically important change might be (17/85). Twenty-one responses addressed system benefits with 72 improvement recommendations. Examples of benefits include: "builds closer patient–doctor relationship" (SP9) and "increased our awareness of symptoms…to provide education to the community" (LHW12, translated from Kiswahili). Examples of improvement recommendations from specialists include incorporation of notification flags in the event of immediate patient needs, e.g., "use of SMS to notify (the clinician of) the high POS score" to ensure prompt response (SP10). See ►Supplementary Appendix A (available in the online version) for full survey results.

Post-Field Study Interviews

In-depth interviews were conducted with five specialists, one PC nurse, six LHWs, and the field study coordinator. Rating how useful or helpful mPCL was on a scale of 1 to 10, scores ranged from 7 to 10 with a mean score of 9.1 (SD = 1.12); participants were generally likely to recommend mPCL to a colleague (NPS = 92; mean score of 9.6 out of 10, SD = 0.87, range = 7,10) (►Table 1).

Four main themes emerged from interview data: (1) how mPCL affected communication between care team members and patients/caregivers; (2) how mPCL affected care efficiency; (3) barriers to mPCL use; and (4) implementation feasibility and recommendations for future app iterations.

Table 1 Interview participant profile. Clinical role (LHW, specialist, nurse, study coordinator), gender, frequency of mPCL use, device ownership, number of patients cared for, type of device used (phone/computer), helpfulness (aggregate), and Net Promoter Score (NPS)[33] or how likely the participant is to recommend the system to a colleague (aggregate) are shown by participant role

	LHW (n = 6)	Specialist (n = 5)	Nurse (n = 1)	Study coordinator (n = 1)
Gender				
Male	3	1	0	0
Female	3	4	1	1
Frequency of mPCL use	4x/wk	2x/wk	2x/wk	2x/wk
Device ownership	4 study/2 personal	5 personal	Mixed	Mixed
Self-reported avg. num. of patients cared for during the study period	5	10	52	n/a
Type of device used (phone/computer)	6 Phone	5 Phone	Phone/tablet	Phone/tablet/computer
Helpfulness rating	9.8	8.2	10	10
NPS (%)	100	80	100	100

How mPCL Affected Communication between Care Team Members and Patients/Caregivers

There was good agreement that mPCL afforded a way for patients/caregivers and their PC team to remain connected and communicate remotely following hospital discharge, which was seen as a major improvement from few to no existing community-based symptom control resources. One LHW (LHW3) remarked that mPCL served as "a connector between the patient, doctor, and LHW." Another specialist (SP1) felt more connected to patients through mPCL, reporting that mPCL "actually decreased the gap between me and my patient" and "anytime the patient wishes to communicate with me she was able." Access to POS responses from the patient/caregiver enabled prompt follow-up communication. A specialist (SP5) noted that mPCL makes it "easier for [patients] to communicate" particularly when they may be experiencing pain control issues, [mPCL allows the patient to] "just write [what] he or she feels, and then the physician responds accordingly."

Despite near universal agreement that mPCL improved clinicians' ability to assess, real-time, patient symptoms, and remain directly connected following hospital discharge, there was potential concern regarding easier specialist access via app-based hyperlink to their personal phone, despite instructions that this be reserved for emergencies. A specialist (SP4) shared, "sometimes it was a burden to me because sometimes the patients they're gonna be calling several times despite of whatever you provide," however, "few patients by the way, were really calling every time."

How mPCL Affected Care Efficiency and Quality

Having a shared platform between patients and LHWs enabled triage of patients with less severe symptoms to be treated more efficiently, real-time. A LHW (LHW6) noted that mPCL has "really helped in getting a clear picture of the patient's condition before she decides either to go to visit the patient, or for the patient to come back to the clinic." One specialist (SP1) shared that mPCL changed their care of outpatients: "I could care for a patient who is outside of the hospital. On a regular basis (without mPCL), I would not be able to attend to a patient who is not at a hospital, who is not admitted."

Relative to other app features, one specialist (SP2) remarked that access to mPCL educational resources is helpful because "sometimes you, you can explain and explain, so [instead] you can just tell them "you can open this and read this"." Further, providers noted that remote assessment and management of symptoms reduced patient care-access burdens. One LHW (LHW3) remarked, "It is very useful because not all patients have the finances to come on time when it is their follow-up clinic and this mPCL will help them even if they are at home to get some sort of an assistance before they are able to come to the follow-up clinic." Thus, mPCL promises to improve both the timeliness and efficiency of care, while at the same time addressing transportation, financial, and other patient-specific barriers to traditional PC.

Barriers to Use

While providers found mPCL highly usable and beneficial, particularly in the triage of symptom control needs and the ability to assess and care for patients remotely, barriers to use were noted. One usability issue identified by specialists was difficulty in creating a clinical record for a newly enrolled patient. "Say the patient has been treated for too long, so to get the history from the beginning cancer can be cumbersome (SP1)." Another issue identified was the need to respond to real-time reminders or alerts in the event of routine, non-urgent updates to a patient's status such as a newly enrolled patient, a new POS response, or acknowledgment that a patient accepted a suggested medication change. Providers also reported difficulty with the level of training needed to use the system competently. System-level implementation barriers included inconsistent patient access to phones and SIM cards and unreliable Internet availability. One LHW (LHW4) remarked, "when the network is not so good, then it is challenging opening the mPCL" even though it was theoretically possible to access the app offline. Further, "when the patients themselves, they do not know what to do,

that can also be hard." On several occasions, technical support was needed to help patients and caregivers reload the app on their device. Feedback also revealed that study-specific activities, such as completing and submitting study instruments and time-intensive patient enrollment processes, to include generation of the clinical record and PC plan, added to perceived barriers. For example, the random assignment of a patient to a specialist who had no previous knowledge of that individual's history impacted mPCL ease-of-use and utility. However, although mPCL required specialist time in generating the medical record and PC at hospital discharge and in regularly reviewing/reacting to POS responses and other care needs, these efforts may be balanced out by fewer clinic- or hospital-based demands.

Implementation Feasibility and Recommendations for Future App Iterations

Despite reported barriers, most providers felt that mPCL was "easy to use" and all providers reported that they would continue to use mPCL if it was available to them. Future large-scale mPCL implementation, fully optimized based on field study feedback, was desired by participants. One such optimization recommendation was the ability to localize a patient's home via the app, i.e., via web mapping, because "if we just say a street name, it is big, so finding the exact house is challenging" (LHW5). Specialists expressed mPCL satisfaction as a native application on their mobile devices as oftentimes issues arose while they were remote and lacked hospital record access. Providers requested extended cover-age to include patients living outside of Dar es Salaam. One LHW (LHW2) remarked, "[I] would love mPCL to be readily available for all patients, for this study to expand more so that a lot of patients can benefit by the use of mPCL."

Basic educational resources were incorporated into mPCL; feedback suggested that while useful, access to additional educational materials and telementoring could be optimized to promote more interaction between LHWs and specialists as well as in building LHW PC capacity and confidence. The perceived benefits of remote, real time, symptom-focused care and the potential to reduce the need for in-person visits were largely seen to outweigh the human capacity and financial costs of implementing the system. However, it was also suggested that to further scale the system it would be beneficial "to think about helping the local workers to do their work. A little fare to get to their patient" (LHW3).

Passive Usage Data

Shown in ►Table 2, passive usage data recorded in the form of clinical interactions revealed that POS-reported pain progression and other symptom control needs were the most common reasons for provider–patient interactions accounting for 34% ($n=44$) and 12% ($n=15$) of reasons reported in mPCL, respectively. While 32% ($n=41$) of all interactions occurred in-person as home or clinic visits, clinicians most often interacted with patients via phone or text (68%; $n=88$). Compared with LHWs, only about one-third the number of clinical interactions with patients recorded in mPCL were between specialists and patients/caregivers.

Table 2 Summary of mPCL interactions. Descriptive statistics of clinician end user interactions comprising seven of the 10 LHWs and five of the six specialists who recorded interactions for 39 unique patients with more than zero interactions recorded in mPCL

Total number of interactions	129
Clinician end user type	n (% of total interactions)
LHW	100 (78%)
Specialist	29 (22%)
Number of interactions per patient[a]	Mean = 4.0; SD = 2.75; Median = 3.5; Range = [1,9]
Reason for interactions[b]	n (% of total interactions)
Pain progression	44 (34%)
Other symptom progression	15 (12%)
Patient/Caregiver anxiety or depression	10 (8%)
Patients deceased	4 (3%)
Patient or family educational needs	3 (2%)
Patient/Caregiver social support needs progression	2 (2%)
Other reasons	2 (2%)
Type/modality of interaction	n (% of total interactions)
Phone call	87 (67%)
Home visit	31 (24%)
Hospital admission or discharge, clinic visit	10 (8%)
Text message (SMS, Whatsapp)	1 (<1%)

[a]For all 45 patients, including 13 patients with 0 interactions: mean = 2.9; SD = 2.96; median = 2.
[b]38% responses were missing reasons ($n=49$).

Discussion

Significant barriers to PC access among cancer patients in under-resourced countries include grossly inadequate numbers of PC specialists, as well as fragmented to non-existent community-based resources for cancer patients. Here, we explored the experiences of clinicians involved in the field study of mPCL to assess the app's acceptability and potential for generalizability and scalability.

While comparative data are not available, it appears that remote reporting of symptoms and care needs enabled issues otherwise requiring in-persons visit to be resolved remotely; a feature essential to care access and timeliness, two factors critical to patient QoL. The app appeared to promote interdisciplinary care coordination through ready access to shared medical records and real-time POS responses, as well as record of post-discharge clinical interactions with patients and longitudinal treatment decisions. Most clinical interactions with patients recorded in mPCL were between LHWs and patients/caregivers. These data hold promise relative to the app's ability to extend the reach of a limited pool of specialists through interdisciplinary care coordination with community-based LHWs. Automatic documentation of patients' reported social and emotional health in a system with shared care team access has the potential to improve interdisciplinary communication.[31]

Study participants expressed overall satisfaction with mPCL use. Critically, both clinician groups noted that mPCL allowed them to feel connected with their patients and enabled real-time, symptom control-focused communication. Timely access to both POS responses and medical records were viewed by both groups as key app features. Most expressed strong interest in continuing to use mPCL, sharing the app with colleagues and noted that extending use to patients throughout Tanzania could increase access to areas, particularly rural regions, that currently have limited to non-existent PC services.

Despite the near universal perception that mPCL improved both real-time symptom assessment and communication, we identified some differences in perceptions of mPCL use and utility, comparing groups. Although mPCL was developed to improve interdisciplinary communication and care coordination, both specialists and LHWs reported that greatest benefit was derived from the ability for the providers to interface with patients/patients' caregivers themselves, in support of real time symptom control. Improving networking capacity in advance of mPCL deployment and offering mentorship and train-the-trainer opportunities, e.g., via remote telementoring models such as Project ECHO,[32] may potentially help improve interdisciplinary care coordination by building confidence and establishing relationships.

Although specialists valued mPCL in improving their connection with patients following hospital discharge, one prototype feature was direct phone access via app hyperlink to clinician team members, to include the specialist. Although this feature was built to address emergency situations (e.g., severe, uncontrolled pain, or other clinical status changes) and patients/caregivers were instructed on when to use this feature, a specialist noted that this feature was perhaps over-used for non-emergencies. This use case was exhibited by only one patient; however, it suggests the added demands may be placed on a limited pool of specialists. It is thus important to optimize app features like this such that contact is triaged based on urgency, limiting specialist involvement to cases in need of their immediate input and expertise.

Digital health solutions must be focused on improving both the reach as well as the efficiency of specialist clinicians. Here we probed perceptions of mPCL efficiency and found important differences in comparing clinician user groups. LHWs felt that mPCL improved their efficiency by allowing them to remotely assess and manage the patient on a regular basis, often sparing them the need to visit the patient in-person. Among those patients requiring home visits, travel to and the ability to locate the patient's place of residence were often problematic, prompting recommendations to include ways to more easily locate the patient via the app. Ongoing development efforts, to include recent introduction of a zip code system in Tanzania, should also support mPCL scalability and utility.

Specialists voiced some concern that mPCL may reduce their overall efficiency due to perceived increase in involvement in non-urgent communications. Further, although the clinical record was seen as a critical app component for remote longitudinal symptom tracking and control resulting in improved access to community-based care, the time involved in the generation of a new clinical record added burden. It is possible that this perceived burden may have been due in part to field study design i.e., specialists being asked to attend to and manage patients that they had not cared for prior to study enrollment. Respondents felt that the development of the mPCL record could be much more efficient if available long-term and with use restricted their own patients. Additionally, there may be capacity for a portion of the clinical record to be developed by nonphysician staff, including oncology nurses, limiting the demands place on the physician.

Importantly, due to study design where the PC nurse was a member of the research team, we were unable to address the true impact of the PC nurse in facilitating user group communication and care coordination, a significant limitation of this study. Other limitations included small patient and clinician numbers from a single urban setting.

Conclusion

As the digital health infrastructure continues to evolve in SSA, there is promise of improvement and greater remote support for cancer patients and their caregivers through increased connectivity and integrations with other emerging systems. Results from this study clearly demonstrate broad clinician desire for digital tools to support remote cancer patient PC—particularly pain and other symptom management—and the potential for broader uptake of apps like mPCL to enable record-sharing and streamline communication between care team members and patients.

Clinical Relevance Statement

This study shares learnings from a novel, pilot deployment of a mobile/web application in Tanzania aimed at extending the reach of PC specialists and provides recommendations for improving future iterations of digital tools to support PC in under-resourced settings.

Multiple Choice Questions

1. What was the most frequently reported reason for provider–patient interactions?
a. Patient deceased.
b. Patient/caregiver social support needs progression.
c. Pain progression.
d. Other symptom progression.

Correct Answer: The correct answer is option c. Out of all the other reasons reported for provider–patient interactions in the usage data, pain progression was found to be the most frequently reported reason comprising 34% of the interactions.

2. What did Specialists, but not LHWs, perceive as a concern in the use of mPCL?
a. Time and workload burden of creating a new clinical record for a patient.
b. Lack of ability to locate a patient's place of residence.
c. Increased involvement in non-urgent communications.
d. Both a and c

Correct Answer: The correct answer is option d. Specialists noted time and workload burden of creating a new clinical record and increased non-urgent communications as concerns; the lack of ability to locate a patient's home was a concern raised by LHWs likely because their role required home visits.

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