

To Assess the Improvement of Palliative Home Medical Care in Resource-Limited Settings in Elderly Users Through Collaborative Design of End-Of-Life Care Mobile Applications

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Abstract

Implementing mobile health (mHealth) in low- and -middle-income countries, utilizing internet coverage, is a promising way of improving the accessibility and quality of palliative care. This study aims to develop a mobile application for smartphones that will enable better communication between family carers, community carers, and palliative care teams while also assessing its acceptability, functionality, and efficacy mechanisms. The process of code signing the app involves collaboration with various stakeholders from China, Eastland, and Southern Land. The study includes training for carers on using the app to transmit weekly patient-reported outcomes to their palliative care providers via a centralized data dashboard. In total, 150 carers have submitted 828 assessments which were transmitted to the palliative care team through an outcome dashboard utilized on 355 occasions. Qualitative data collected through interviews reveal that both users and healthcare professionals have positive views of the app's effectiveness in enhancing symptom comprehension among team members as well as conveying patients' concerns appropriately. Additionally, incorporating more feedback mechanisms for carers, along with individual needs-based prioritization strategies could make this app even more effective. The app has received satisfactory feedback from both groups overall.

Keywords: Mobile app acceptability, Family and community caregivers, Healthcare professionals, Low- and middle-income countries (LMICs), Access and reliability issues.

INTRODUCTION

Families often feel morally obligated to care for their terminally ill loved ones, but this responsibility can be overwhelming. Palliative care experts advocate for specialized teams trained in pain management catering to the needs of both patients and their families to oversee the caregiving process. However, while technology at home can help carers, it may increase social isolation and further distress.^[1]

The attitude of healthcare teams significantly effect on caregiving families in various aspects, including communication, listening skills, and expertise. Studies^[2-4] indicate that sincere behaviors such as family training and empowerment yield positive results. The phrase “hands-on care” pertains to providing direct or indirect assistance when someone is in the final stages of life.^[5] Recent research suggests that these interactions encourage carers' personal and spiritual growth, as the allow them to reflect

introspectively on their experiences. However, it can also evince unfavorable emotions or prompt existential queries.^[6] Research suggests that typically, women aged 50 and above, along with their spouses and offspring are the primary caregivers. However, providing care often leads to a decline in well-being as they witness their loved one's health deteriorating. Most studies on caregiving focus on those caring for individuals with cancer and lack information regarding other types of patients.

This discussion aims to explain the theoretical foundation of palliative care, which is a strategy that enhances the quality of life for patients and their loved ones during the final stages of

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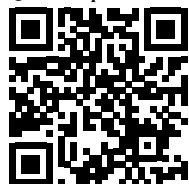
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a severe illness, as defined by the WHO. Palliative care aims to prevent and alleviate distress through timely recognition, precise evaluation, and management of pain and other issues across various health domains. Its primary objective is to consider patients holistically, rather than just focusing on their symptoms while providing emotional solace to both the patient and their significant others. Further research opportunities exist in managing service delivery alongside physical, psychological, and spiritual needs.^[7-9]

To fully evaluate and understand palliative care, it's important to distinguish it from other nursing practices and treatments. Specialized hospice teams rely on hospital liaison nurses and home-based programs to expand their services into mainstream healthcare. This literature review focuses on the care of patients nearing the end of their lives, examining factors such as irreversible physical deterioration, limited survival time, and the use of palliative treatments instead of curative ones. There is a growing need for evidence-based research to ensure appropriate resource allocation during economic downturns. By examining existing scholarly works related to palliative care, researchers can avoid duplicating previous efforts while also shedding light on new areas for exploration. [104 words]

LITERATURE REVIEW

Acute pain is a vital aspect of human experience, according to Woolf^[10], and holds evolutionary significance from a Darwinian perspective. Pain serves as a cautionary mechanism that prevents further tissue damage and associated behaviors. While it is challenging to assess the unpleasant bodily sensation accurately, Jackson^[11] explains that it can only be recognized by public manifestations such as vocalizations or nonverbal cues since pain is inherently subjective, as suggested by Helman^[12]. According to Schaffner *et al.*'s^[13] claim, pain is universally acknowledged and serves as a driving force for seeking healthcare after diagnostic, surgical, or therapeutic interventions. Understanding the mechanics of pain supports the importance of social science in comprehending its implications beyond academics or philosophy, states Mitchell *et al.*^[14]. The perception of pain encompasses behavioral and emotional reactions that are culturally sanctioned and expected, as Melzack *et al.*^[15] posit similar findings on how culture influences one's feelings towards the concept of suffering. Mendell's^[16] research reinforces Melzack *et al.*'s^[15] sentiments by extrapolating that sensory discomfort stems from more than just physiological harm but also emotional and behavioral responses mediated by personal upbringing. Scholars like Helman^[12], Honeyman *et al.*^[17], and Ramer *et al.*^[18] have studied this biopsychosocial phenomenon in depth; they inferred that culture plays significant roles in determining various aspects of its experience and response based on Ho *et al.*'s^[19] observations.

Culture, Gender Ethnicity, and Pain

Culture is complex concept, and its interpretation in literature varies significantly. Ember *et al.*^[20] defined a cultural system as a set of values, concepts, beliefs, and

regulations that guide individuals' actions within a society. Berman and Snyder proposed dividing culture into two categories: Macro Culture, which includes nationality, race, and ethnicity; and Micro Culture which encompasses factors such as age, gender, religion, and spirituality. It's worth noting that Micro-Culture is nested within Macro Culture. Lasch^[21] acknowledged the influence of cultural factors on healthcare behavior, suggesting that culture significantly influences people's conduct when they are sick or seeking medical care. Davidhizar *et al.*^[22] assert that individuals conform to their society's expectations, resulting in personal or cultural interpretations of suffering. According to McCaffery *et al.*^[23], a person's expression of pain, as well as the reactions of others, are influenced by social, cultural, and psychological factors. Pain is subjective, meaning it is defined by the individual experiencing it at the time they deem it present. This viewpoint is widely accepted in Western medicine and incorporated into pain management curricula. However, studies^[24,25] have shown that health professionals' cultural perspectives significantly affect their responses to patients' experiences with pain.

Palliative care

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Objectives

A mobile phone application can be created to facilitate community caregivers, family caregivers, and palliative care practitioners to share real-time patient outcome information. This information will help in proper clinical monitoring and timely intervention. The goal is to gather feedback from community/family caregivers, palliative care professionals, and other stakeholders on how the app works and potential action modes.

METHODOLOGY

Study Design

The app was coded using codesign principles. To ensure its effectiveness, both quantitative data on usage and qualitative data on user experience were collected. The creation of the app followed the Medical Research Council's process for developing complex therapies.

Settings

The clinical sites were selected based on several factors that include the availability of oral immediate-release morphine, the capacity to enroll patients and family caregivers, potential support from regional health authorities, and the existence of a trained palliative care team. The chosen places include; Hospice Africa East land in East land which offers diverse multidisciplinary clinical services and home-based palliative care, along with family support. In addition, the Institute of Palliative Medicine in China was selected as it is a WHO Collaborating Center that provides various outpatient and home-based services for patients. Lastly, Island Hospice and Healthcare located in Southern Land, included as an option due to its offering hospital visits, roadside clinics, and walk-in clinics along with regular visits by its experienced multidisciplinary clinical team.

Procedure

The research methodology encompassed several objectives that were interrelated with the development and implementation of a mobile application for palliative care. The first aim of the study was to collaborate with carers and employees at field sites to co-design the patient data collection application. The goal was to identify and prioritize features that meet the specific needs of individuals receiving in-home care, which required gathering feedback from both formal community carers and informal family caregivers across all three research locations. The design methodology strived for universality while acknowledging differences between local care models and unpaid caregivers' tasks. On-site visits helped refine the mobile tool for palliative care by incorporating feedback obtained during training sessions and consultations with local collaborators. Objective 2 involves obtaining six weeks of weekly application usage data from carers. Additionally, baseline demographic data, including age, gender, education level, place of residence, proximity to the patient, primary diagnosis, family size, and socioeconomic status, were collected. The accuracy of this information was verified

through manual checks in an Excel spreadsheet. To maintain confidentiality for each participant's personal information, a unique ID was assigned to each carer. Once all data were collected from every site using the accessible web dashboard and then exported into Excel spreadsheets before eventually being consolidated into a single database. Finally, a thorough examination of the data took place to identify inconsistencies followed by quantitative analysis with SPSS software.

To achieve our third objective, we conducted interviews with family carers, community caregivers, and healthcare professionals to gather their perspectives on the app's content, usability, support needs, and recommendations for improvement. After transcribing the interviews, we used NVIVO software to conduct a thematic analysis. Codes were then generated based on the study topics alongside different stakeholder groups' perspectives.

The fourth objective involves analyzing the data collected from previous objectives and providing recommendations for improvement. The app's codesign process prioritized non-urgent patient and family outcomes over urgent clinical needs. For this study, we used the African Palliative Outcome Scale, a valid and reliable measure for capturing concerns of patients needing palliative care in sub-Saharan Africa. Changes to the app included altering reporting options, expanding the dashboard, and enhancing outcome metrics based on feedback from platform users.

The research covered different areas, including app usage, subject recruitment, data collection, and management. The clinical lead at each trial location offered caregiving advice and continuous clinical support. However, there were disparities in the distribution and management of mobile devices across locations, which may have influenced the data collection process. The methodology incorporated a participatory approach by seeking perspectives from carers and healthcare professionals to develop and implement a mobile application for palliative care. Insights from stakeholder interviews and feedback from app users helped to enhance the application and improve patient care.

RESULT AND DISCUSSION

The distribution of mobile devices among a set of participants is shown in Table 1. Each participant's numerous qualities are included in the data. Along with numerous demographic and socioeconomic factors that may affect participants' mobile device use habits, the table provides a thorough summary of the distribution of mobile devices among participants.

Table 1: Distribution of Mobile Devices

Participant ID	Age	Gender	Education Level	Home Location	Relationship to Patient	Patient's Primary Diagnosis	Family Size	Socioeconomic Status
1	35	Female	Bachelor's	Urban	Spouse	Cancer	3	Middle class
2	45	Male	High School	Peri-urban	Child	Organ Failure	4	Lower class
3	28	Female	Master's	Urban	Sibling	HIV/AIDS	2	Upper class
4	50	Male	Doctorate	Peri-urban	Parent	Cancer	5	Upper middle class
5	60	Female	High School	Urban	Spouse	Cancer	2	Lower middle class
6	40	Male	Bachelor's	Peri-urban	Child	Organ Failure	3	Middle class
7	55	Female	Master's	Urban	Parent	HIV/AIDS	4	Upper class

The Android mobile application was developed by English experts, who utilized wireframe, mockups, and prototypes to evaluate the functionalities, features, navigation, and content architecture of the app. As a result, portable electronic devices were manufactured after various development stages of the app's code. An English language-based online dashboard of the web-based backend application was designed for family or community caregivers to submit reports that could be securely saved on cloud servers. The Laravel framework enabled setting up server configurations along with dashboard designs comprising clear columns and rows displaying data specific to each report submitted through the app. Clinical teams can

view patient symptom severity represented by color codes applied in response format alongside dashboard filters of date or carer ID.

Carers had concerns during the developmental and instructional phases of using the application for palliative care in China. Some issues raised included data protection, potential replacement of home visits with app usage, and timely submission of reports in East Land due to complications arising from mobile phone usage. Connectivity problems led to duplication or incomplete reports initially in the Southern region but were mitigated through carer mentoring as evidenced by Table 2 and Figure 2.

Table 2: Objective 3: Stakeholder Views

	Data Collection Method	Sample Size	Participants	Support Staff
Site 1	Exported from the data server to Excel spreadsheet via the dashboard	50	Family Caregivers: 25 Community Caregivers: 25	3
Site 2	Exported from the data server to Excel spreadsheet via the dashboard	50	Family Caregivers: 25 Community Caregivers: 25	3
Site 3	Exported from the data server to Excel spreadsheet via the dashboard	50	Family Caregivers: 25 Community Caregivers: 25	3
Total (Entire Study)	-	150	-	-

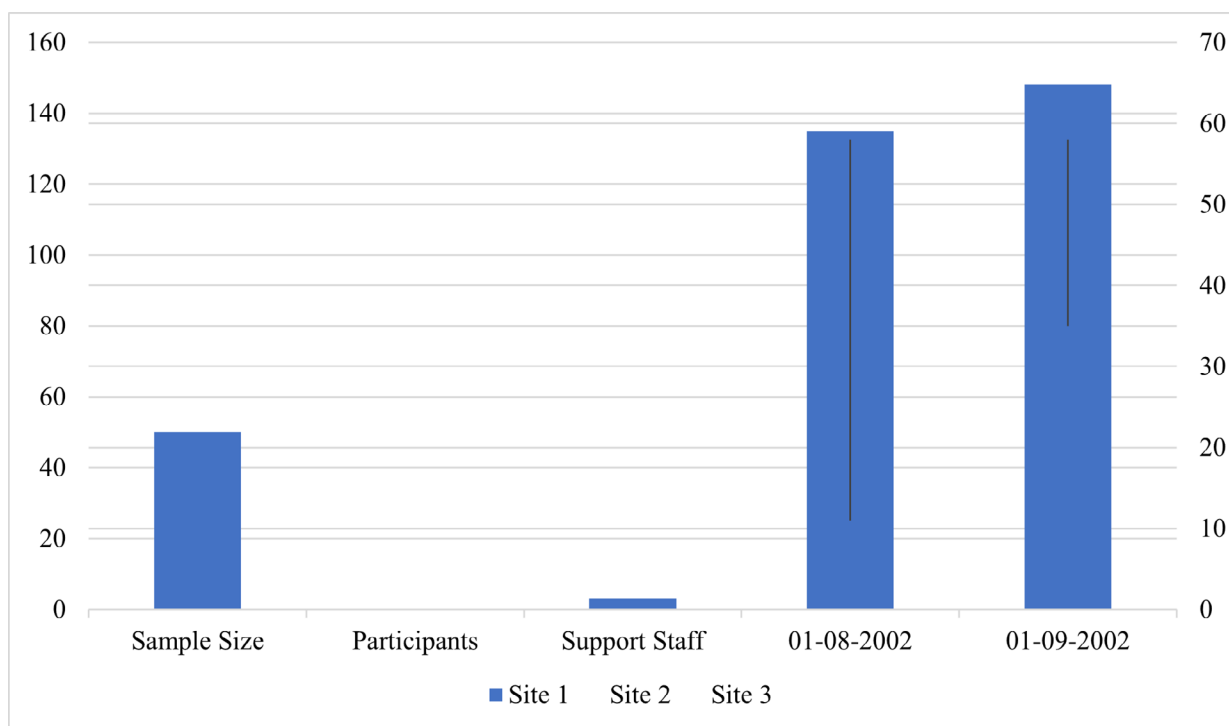


Fig 1: Stakeholder Views

The research study's Objectives 3 and 4 entail collecting stakeholder information across several sites. Table 2 summarizes the data collection process, including information on research participants, sample sizes, participant categories, support staff,

and outcomes for each location. It offers an in-depth overview of the entire process at each site while presenting comprehensive data in a way that is easy to understand.

Proposed Refinements

Table 3: Participant Characteristics and App Activity

Characteristics	China	Eastland	Southern land
Caregiver female gender	58	72	98
Caregiver mean age (years)	27.54	44.6	48.2
Caregiver's highest educational attendance	24	52	0
Secondary	9	3	11
Primary	6	2	6
No formal education	0	0	0
Patient diagnosis	66	65	80
Cancer	0	32	88
HIV	34	-	-
Other	-	-	-
Community	45	32	77
Family	52	55	23

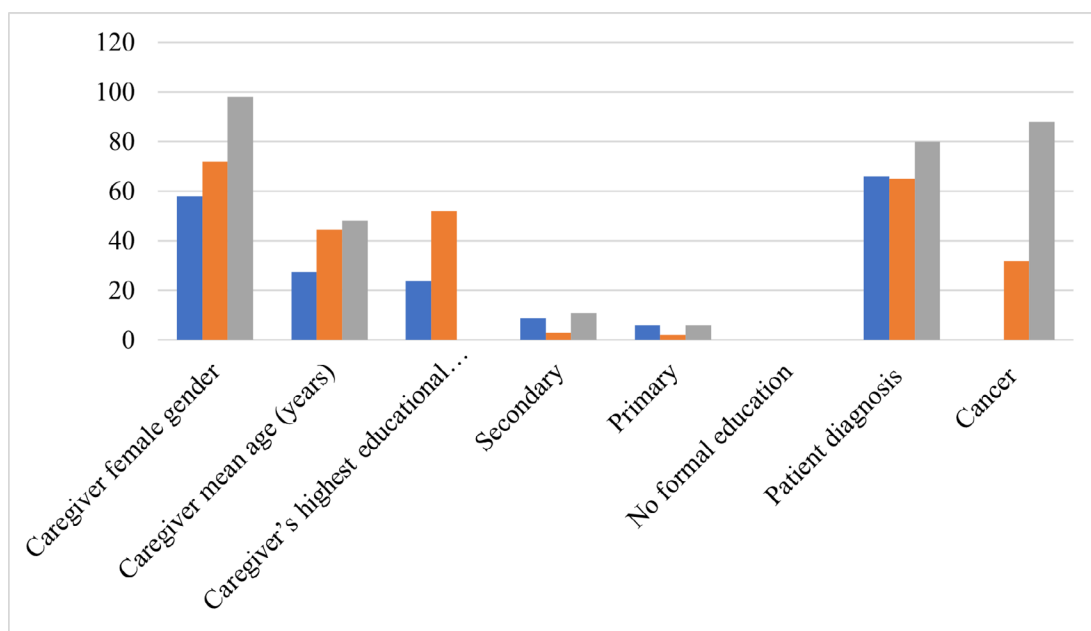


Fig.2. App. Activity of Participant

Table 3 provides a breakdown of carer characteristics across China's Eastland and Southern Land regions. In terms of gender, the data shows that the majority of carers in China are female, accounting for 58% of all caregivers. Female caregivers make up an even larger proportion in Eastland at 72%, while almost all (98%) carers in Southern Land are women. This suggests that caregiving is predominantly perceived as female role in these regions.

When it comes to age, the average age of carers is highest in Southern Land at 48.2%, followed by Eastland with an average age of 44.6%. In contrast, China had a much younger cohort of carers with an average age value of only 27.54 years old. The education levels among caregivers also varied significantly between regions, with over half (52%) of those surveyed who provide care in East Land having attained a secondary school education twice as many as those from China where only one quarter received this level of formal education.

These results indicate that East land may have a higher

incidence rate and quality standardization regarding secondary level education programs than its counterparts such as Southern land and China Eastland region because no caretaker possesses any secondary degree there.

According to data on cancer diagnoses for patients within our research sample size across China, among the tracked individuals, approximately 665 people diagnosed with cancer so far which needs attention from healthcare providers and researchers. Specifically 65% of the patients with cancer live in the Eastern region while 80% reside in the Southern region. This data suggests that cancer diagnosis is more prevalent in these regions compared to China. Regarding caregivers, 52% are family carers, and 45% fall under community carers. In East Land, indigenous people make up 32% of the population with a majority (55%) engaged in familial caregiving duties. Within the Southern region, most caregivers (77%) are found within communities as opposed to familial settings (23%). The table highlights differences across three countries, providing a comprehensive summary of patient

diagnoses, age, education attainment, gender composition, and carer allocation. These findings offer valuable insights for customized support and interventions based on the unique attributes of each country's caregivers.

CONCLUSION

The finding of our indicate that both healthcare professionals and family/community caregivers provided positive feedback about the mobile app we used. This suggests that the app has the potential to improve health delivery and patient outcomes. However, our analysis also revealed ongoing challenges related to access and dependability of the mobile technology, despite its growing availability in low- and middle-income countries (LMICs). According to our research, identifying, monitoring, and communicating patient outcomes while investing resources in vulnerable patients are key to improving Health palliative care. Using a codesign approach involves integrating local care groups into future studies to produce culturally suitable tools that meet their requirements. Our study expands the knowledge of real-time clinical outcome data collection systems beyond high-income nations and highlights its potential effects in low- and middle-income countries. Our stakeholder inclusive approach underpins the effectiveness of using patient-reported outcome measures (PROMs) in palliative care.

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