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Feasibility of a Palliative Care Intervention Utilizing Community Health Workers to Facilitate Delivery of Home-based Palliative Care in India

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Abstract

Objectives:

The purpose of this study was to evaluate the feasibility of a home-based palliative care program delivered by community health workers (CHW) in rural areas outside of Kolkata, India. The specific aims were to assess CHWs' ability to implement the intervention protocol and maintain records of care, to characterize patient problems and CHW activities to assist patients, and to assess change in patient pain scores over the course of the intervention.

Materials and Methods:

Four CHWs were hired to facilitate delivery of home-based palliative care services. CHWs were trained using the Worldwide Hospice and Palliative Care Alliance's Palliative Care Toolkit. CHWs provided care for patients for 3-months, making regular home visits to monitor health, making and implementing care plans, and referring patients back to the cancer center team for serious problems.

Results:

Eleven patients enrolled in the intervention, with ten of these patients participating in the intervention and one patient passing away before starting the intervention. All ten participants reported physical pain, for which CHWs commonly recommended additional or higher dose medication and/or instructed patients how to take medication properly. For two patients, pain levels decreased between baseline and end of study, while pain scores did not decrease for the remaining patients. Other symptoms for which CHWs provided care included gastro-intestinal, bleeding, and respiratory problems.

Conclusion:

The study findings suggest that utilization of CHWs to provide palliative care in low-resource settings may be a feasible approach for expanding access to palliative care. CHWs were able to carry out the study visit protocol and assess and document patient problems and their activities to assist. They were also able to alleviate many common problems patients experienced with simple suggestions or referrals. However, most patients did not see a decrease in pain levels and more emphasis was needed on the emotional aspects of palliative care, and so CHWs may require additional training on provision of pain management and emotional support services.

Keywords: Palliative care, Pain and symptom management, Feasibility trial, Intervention, Home-based palliative care, Community health worker

INTRODUCTION

In 2014, the WHO published the Atlas of Palliative Care, which documents the global distribution of need and availability of palliative care. While palliative care primarily exists in North America, Europe and Australia, approximately 80% of patients who need these services live in low to middle resource countries. ^[1] Rigorous palliative care research has primarily been conducted in high resource countries. ^[2] These studies have demonstrated that patients who receive palliative care experience reduced pain, nausea, and bed sores, improved quality of life and greater likelihood of dying in their own home. ^[3,4] At a health-system level, palliative care can reduce hospitalizations, emergency department visits and health-care costs. ^[3,4] In the Atlas of Palliative Care report, the WHO recommended that research is urgently needed to adapt and test palliative care models in low to middle resource countries. They emphasized that palliative care in low resource countries must be well-integrated within existing health-care systems and ideally utilize community-based navigators to expand the reach of scarce health-care providers if palliative care is to be feasible and sustainable. ^[1]

Among low resource countries, India presents with a unique need for palliative care. It is the second most populous country in the world with 1.3 billion people, of whom 22% of the population live below the poverty line and 66% live in rural areas.^[5] Due to a poor economy, lack of insurance and low health literacy, most patients present with late stage cancer, making palliative care an urgent priority.^[6] With little access to palliative care and pain relief, <3% of cancer patients receive the adequate pain relief that they need.^[7]

The Worldwide Hospice Palliative Care Alliance (WHPCA) published the “Palliative Care Toolkit: Improving Care from the Roots Up in Resource Limiting Settings.”^[2] This document provides a training and implementation toolkit for empowering community members to deliver palliative care in resource poor settings. The premise of the toolkit is that basic, effective palliative care can be delivered within existing community and health structures by people who do not have specialized training. The WHPCA and WHO have encouraged organizations to begin utilizing and evaluating palliative care outcomes following implementation of the toolkit. To address this need, the current study was conducted to evaluate feasibility of implementing a home-based palliative care intervention In Kolkata, India, which is built upon the Palliative Care Toolkit and utilizes community health workers (CHW) to facilitate delivery of home-based palliative care.

MATERIALS AND METHODS

The purpose of this feasibility trial was to assess the feasibility of utilizing CHWs to facilitate delivery of a home-based palliative care intervention for rural cancer patients. The specific aims were to assess CHWs’ ability to implement the intervention protocol and maintain records of care, to characterize patient problems and CHW activities to assist patients, and to assess change in patient pain scores over the course of the intervention. This report builds on our prior formative evaluation work to inform development of the intervention and our qualitative evaluation of the feasibility and acceptability of the intervention from the perspective of diverse stakeholders within the system.^[8,9]

Study setting

This research was a collaboration between the Medical University of South Carolina (MUSC) and the Saroj Gupta Cancer Centre and Research Institute (SGCCRI). MUSC is a tertiary care teaching hospital in Charleston, South Carolina. The study was conducted at the SGCCRI, located in the rural Thakurpukur region of Kolkata, India. In 2010, SGCCRI established the Palliative Care Department that provides an infrastructure to deliver palliative services such as inpatient, outpatient, and limited home-based care. Institutional Review Board (IRB) approval was obtained from the SGCCRI IRB, with the MUSC IRB approving MUSC investigators to access deidentified study results.

CHW training

The SGCCRI team employed four CHWs from the South 24 Parganas Region where the intervention was piloted. The CHWs were recruited from a local association of rural medical practitioners in West Bengal. To recruit CHWs, the SGCCRI hosted a palliative care training that included assessment of pre/post testing of knowledge acquisition and interest in palliative care service. Following the training, the CHWs who scored highest in palliative care knowledge and expressed interest in palliative care service were inter-

viewed by the SGCCRI, and the best candidates were selected to serve as CHWs. These CHWs had varied allied health profession backgrounds, such as diplomas in homeopathic medicine and ultrasound technology.

Before the intervention, a study orientation was provided to the cancer center team, which included the CHWs and all palliative care clinical team members. The orientation included information about the intervention purpose, design and protocol, along with CHW's role and responsibilities. The team of CHWs received an intensive onsite 40-h training before the intervention. The didactic classroom training was a 20-h session delivered over five half days. It covered palliative care principles, navigation intervention protocol, local resources for patient support, strategies for team-based care, care for caregivers, communication skills, cultural and spiritual considerations at end of life, pain and symptom assessment and management, medications, and educational resources. Case studies were going to be used as part of the didactic training to provide CHWs an opportunity to apply their new palliative skills, but this did not occur due to cancer center preferences. CHWs also received 20 h of "hands-on" training by shadowing the clinical team on patient encounters at the cancer center and in patient homes.

Toolkit adaptations

The palliative care toolkit, the backbone of the palliative care intervention, includes seven chapters that provide essential information for delivering basic palliative care. These chapters include an overview of palliative care, different models of palliative care, teamwork and training guides, details on communication skills and spiritual support, pain and symptom control, helping children and families, and advocacy. The toolkit also includes forms for organizing and managing delivery of palliative care in the community. Our minor adaptations to these forms included addition of space to specify referral source, addition of an individualized care plan as part of the initial patient assessment, and modification of the patient visit record to include a pain score and action plan. We also added supplemental cancer specific educational materials and a form that CHWs could use to refer patients back to the cancer center for appointments. The original toolkit forms included codes for community providers to document patient health problems and activities carried out to assist patients, but the clinical team felt it was more feasible to record this information in text (as opposed to numeric codes), given concerns about CHW's level of health literacy.

Palliative care intervention

The palliative care intervention was implemented by the SGCCRI Palliative and Supportive Care Department in the South 24 Parganas region, with each patient scheduled to receive home-based palliative care support from a CHW for 3-months or until they passed away. Patients who required home-based palliative care were screened for the study by the SGCCRI study coordinator, and informed written consent was completed with patients who chose to participate. For each patient who enrolled in the study, the palliative oncologist assigned them to a CHW who resided closest to them to facilitate ease of making home visits. The CHW participated in the initial clinical team consultation with the patient/caregiver and was introduced as the team member who would provide home-based palliative care support. The CHW then visited the patient each week, or more frequently as needed. During these visits, the CHW used resources from the Palliative Care Toolkit to monitor the condition of the patient and their caregivers, manage pain and other symptoms, and assist patients to contact their provider, arrange appropriate referrals or obtain com-

munity resources as needed. CHWs were trained to maintain continual communication with the cancer center palliative oncologists and use their cellular phones (text messages, phone calls, or audio-video chats) to facilitate this process.

Data sources and collection

The primary source of study data was the patient care form in the Palliative Care Toolkit. These forms included: An initial patient assessment and care plan, a patient visit record, a patient-held record for home-based care, a patient-held morphine chart, and a patient-held drug record. The baseline patient assessment and care plan were used to document the patient's type of cancer and underlying health status, including physical and psychosocial health issues, barriers to care, support received from the community, life expectancy in months and status on the discussion about not resuscitating. This is also where information was recorded about what the patient and family knew about the terminal nature of the patient's condition, as it was a cultural practice that some patients were not told the terminal status of their condition to prevent despair. This information was recorded by the palliative oncologist based on discussion with patient and family and knowledge of the patient's medical history.

The patient visit record, completed at every home visit, was used to document information about the patient's condition and needs, pain score, actions taken by the CHW to assist the patient, and progress on addressing the patient's needs. Pain scores and their averages were calculated from these forms based on the weekly pain score that was reported by patients on a scale from 1 to 10. While the original Palliative Care Toolkit patient visit record included a comprehensive list of codes to record patient problems and clinical activities to assist, the oncology team felt like this information would better be recorded in a qualitative manner using short descriptions, as the CHWs might have difficulty using detailed codes to record this clinical information.

Data analysis

Since the purpose of the study was not to conduct a confirmatory trial, but to test our intervention and research methods, our small study sample size of ten participants was consistent with recommended best practices for pilot study sampling.^[10] Because this was a small feasibility trial, data analyses were descriptive. Data was extracted from the toolkit forms and managed and analysed in Excel. Data were checked for missing values and data inconsistencies. Continuous variables such as means, standard deviation, medians, and ranges were calculated as appropriate, with pain scores being non-Gaussian in distribution. Outcomes included characterization of patients served by the CHW, clinical concerns and needs reported by patients and their caregivers, pain scores, CHWs roles and tasks performed to assist patients, and accuracy and completeness of forms completed by CHWs.

RESULTS

Patient demographics

Eleven patients completed informed consent to participate in the study, with one of these patients passing away before they were able to start their study participation. [Table 1] provides an overview of the baseline characteristics of the ten patients who participated in the study. The mean age of patients was 58.5 years with a standard deviation of 11.7. Fifty percent of the patients were male. The most common types of cancer were head and neck cancer accounting for 30% of patients, and gastrointestinal cancer accounting for an additional 30%. Eighty-nine percent of patients reported physical problems at their initial patient assessment. The majority (67%) reported having adequate social support, but encountering emotional problems, which ranged fairly evenly between depression, anxiety, and existential worries about their own death and how family would cope without them. Sixty-seven percent of patients had not had any discussion with their oncologist regarding preferences about resuscitation. In addition, 45% of patients lacked understanding of their disease and prognosis and 11% reported transportation challenges.

CHW patient caseloads

Patients were assigned to CHWs who lived in their own communities to facilitate ease of regular home visits. Only four of the ten patients completed the intervention, with the remainder passing away before the end of the 3-month intervention. CHW 1 only had one patient who completed the intervention. CHW 2 had six patients, of whom four died before the end of the intervention period. CHW 3 had three patients, of whom two died before the end of the intervention period. CHW 4 did not have any patients assigned to him because he did not live in a community where any palliative care patients in the study resided.

Patient health issues and navigator actions

[Table 2] summarizes patient health issues and actions the CHWs took to address them. All patients reported having pain in some form ($n = 10$), and over half reported having bleeding issues ($n = 6$).

Gastrointestinal issues ($n = 5$), diet ($n = 4$), and respiratory problems ($n = 4$) were also commonly reported. Health issues that were less commonly reported included weakness, swelling, anxiety, urination problems, fever, fungal infection, and mouth/throat problems. Many of the actions that the CHWs took to assist patients included contacting the palliative care oncologist to work with the patient and family to adjust medications, initiate new medicine, or refer the patient to the hospital. All medication adjustments were performed by the SGCCRI palliative care oncologist, with the CHW facilitating dialog between the patient, family, and palliative oncologist through audio and video calls, and in person visits to the cancer center as needed. The median number of health issues per patient was 3 and ranged from 2 to 7.

CHW pain assessments

[Table 3] summarizes the pain assessments recorded at the patient visits, along with each CHWs caseload assignment. The table documents the baseline pain level, final pain level, and mean pain level. Baseline pain levels ranged from 0 to 8, with a median score of 7. The final pain level for all the patients ranged from 0 to 10, with 8–9 being the most commonly reported scores. The average pain level was also calculated. Of note, CHW 1 did not understand that he was supposed to record pain scores using a numeric scale, leading him to report pain scores verbally. To measure the completeness of the collected pain data, the ta-

ble displays the number of home visits made by the CHWs, alongside the number of these visits in which a pain score is recorded. CHW 1 only recorded verbal pain level for 58% of the visits. CHW 2 recorded pain levels for most of all the visits and CHW 3 recorded pain levels for all of their visits.

DISCUSSION

The primary finding of this study was that delivery of home-based palliative care by CHWs, with support from a cancer center oncology team, was feasible to implement. CHWs received training, coordinated their work with the cancer center oncology team, visited patients each week or more frequently as needed to assess and document patient problems and needs, develop action steps to assist, and assist patients and their families with identified problems. For the most part, pain levels were regularly recorded, with a few exceptions.

As mentioned in the results, many patients (60%) died during the study period, not completing the three month intervention. Without complete data endpoints for all patients, it is difficult to measure intervention effectiveness. If the intervention is tested on a larger scale, it will be important for a majority of patients to complete the intervention to enable complete outcome assessment. While the patients who died were at very late stages of terminal cancer on referral to the program and deaths are unavoidable, recruitment for this type of intervention will need to minimize the effect of loss to intervention follow-up. To recruit patients earlier, it will be important to contact oncologists and other curative care providers to identify patients in an earlier stage of palliative care. Educating patients to seek cancer care earlier and providers to refer patients earlier to palliative care would benefit patients tremendously and support earlier recruitment of patients into palliative care research studies. Many patients (45%) lacked an understanding of the terminal nature of their condition. When patients are not aware that their disease is terminal, they are unable to understand the purpose of palliative care and the intervention. None of the patients in the study were receiving curative care, but patients were not always aware of this fact. This is a common phenomenon in India and Middle Eastern countries where health-care providers sometimes protect patients from being told that their illness is terminal, with the cancer patient having a more inactive role in treatment.^[11] This situation is complex but one explanation is that families and patients often associate cancer with death, and physicians' reason that the patients may lose hope. In addition, in Indian cultures families play a large role in decision-making processes including medical care, which can lead to families restricting their dying family members from knowing their terminal prognosis.^[11] This emphasis on family caregivers, family patriarch, and the involvement of the family may lead to lack of communication with patients about their illness, but it is most often not done with malice. Decisions to withhold information from patients about the terminal nature of illness are commonly driven by love, care, and the desire to protect their family.^[12] However, patients may still need to understand their medical conditions and the nature of the intervention in which they are enrolled. Ideally, education about palliative care and each patient's prognosis should be emphasized at the initial assessment. Because the practice of concealing a patient's terminal disease status to protect them is a deeply rooted cultural practice, it may take time for this practice to change.

The majority of patients (67%) struggled with emotional problems, based on the oncologist's initial baseline assessment. It is common for patients receiving end of life care to experience psychological distress.^[13] Considering the initial emotional problems reported by patients, we expected more documentation of emotional health issues on CHW's weekly home visit forms. However, anxiety was only recorded as an issue for two patients, and no other mental, emotional, or spiritual issues were documented. The CHWs doc-

umented on the forms that they addressed patient anxiety by telling them not to worry or be anxious, a response that seems to lack understanding of mental health. Interestingly though, in our prior qualitative interviews with the CHWs, the CHWs consistently described that a lot of their time was spent talking with patients and their families to address emotional issues and they were very passionate about this aspect of care,^[9] and so it is possible that CHWs were simply less likely to document these more informal interactions. While systematic screening for psychological distress was not incorporated into the intervention, the CHWs had received training on addressing these issues. An important next step for optimizing the intervention will be to train the CHWs to screen each patient at each visit for psychological distress and to document the steps they have taken to address these issues.

In a recent scoping review of CHW-based palliative care interventions in middle- and low-income countries, the authors reported that several other interventions have experienced challenges in fully addressing issues related to emotional support and recommended that CHWs receive more training in this area.^[14] In our own CHW training, practical case studies and role playing were planned, but this content was removed due to time restraints. Thus, the CHWs were unable to practice and receive feedback on how they interacted with patients to address emotional issues. In addition, while the CHWs came to the cancer center to meet with the oncology team and/or called the oncologist as needed, weekly debriefing sessions had also been planned to provide the CHWs and oncology team an opportunity to debrief regularly as a team, but this did not happen due to challenges scheduling the full team to meet at 1 time each week. Weekly team debriefing could have facilitated continuing education for the CHWs, including how to address emotional needs of patients and their families.

Several areas were identified for improving use of the Palliative Care Toolkit forms. While CHWs were trained to document pain scores at every visit, CHWs did not consistently record a pain score at every visit, and one did not use numerical values. In the future, the importance of consistency when collecting quantitative data needs to be reinforced, with regular audits to ensure complete documentation. In addition, medication details were recorded at every visit. The Palliative Care Toolkit recommends only filling out the medication chart when the medications change, not at every visit. Both examples suggest the possibility of a communication barrier between the CHWs and oncology team. Finally, the patient-held record in the Palliative Care Toolkit was adapted to be simpler and easier to use by removing numeric codes for recording patient problems and CHW activities to assist. In the future, it may be helpful to train the CHWs to use the numeric codes, which can provide more quantitative data for evaluation.

CONCLUSION

In summary, the intervention was feasible to implement, and the CHWs were able to successfully carry out their role in facilitating home-based palliative care for the patients assigned to them. The CHWs regularly visited their patients per protocol, were able to complete the Palliative Care toolkit forms, made referrals back to the cancer center as needed, and established a strong rapport with patients. Several areas for intervention refinement were identified. Some patients' pain levels were not optimally controlled and CHWs did not report as much activity addressing emotional issues as we would have expected. Thus, the CHW training program will need to be more intensive and incorporate opportunity for the CHWs to practice their new knowledge and skills and receive booster training sessions, especially in regard to pain management and

emotional support. It will also be important to carry out regular debriefing sessions for the CHWs and palliative care team at the cancer center to regularly debrief and provide continuing education and support for the CHWs.

Footnotes

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

There are no conflicts of interest.

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Figures and Tables

Table 1:

Patient demographics*.

Age	
Mean (SD)	58.5 (11.7)
Gender (%)	
Male	5 (50)
Female	5 (50)
Type of cancer (%)	
Head and neck	3 (30)
Thoracic	2 (20)
Gastrointestinal	3 (30)
Prostate	1 (10)
Unknown	1 (10)
Physical problems (%)	
Yes	8 (89)
No	1 (11)
Emotional problems (%)	
Yes	6 (67)
No	3 (33)
Lack of social support (%)	
Yes	3 (33)
No	6 (67)
Transportation challenges (%)	
Yes	1 (11)
No	8 (89)
Awareness of terminal condition (%)	
Yes	5 (55)
No	4 (45)
Do not resuscitate order (%)	
Yes	3 (33)
No	6 (67)

*Baseline clinical information was only available for nine of ten patients

Table 2:

Summary of patient health issues and navigator actions to assist.

Problem type	Specific problem	Navigator actions to assist*
Physical		
Pain (n=10)	General pain (e.g. non site-specific pain that may cause aching, tingling, sensitivity or other discomfort) (n=6)	<ul style="list-style-type: none"> • Instructed to take morphine dose correctly • Pain medicines like Ibuprofen, Tramadol, Drotin • Take medications timely as prescribed • Admitted to hospital
	Back pain (n=6)	<ul style="list-style-type: none"> • Physiotherapy • Pain management • Take medication timely as prescribed • Morphine dose increased • Apply analgesic gel
	Pain in neck and throat (n=2)	<ul style="list-style-type: none"> • Added medication
	Pain in hepatic region (n=1)	<ul style="list-style-type: none"> • Pain management
	Pain in stomach (n=1)	<ul style="list-style-type: none"> • Take medications timely as prescribed
Gastro-intestinal issues (n=5)	General GI issues (n=1)	<ul style="list-style-type: none"> • Take medications timely as prescribed
	Constipation (n=5)	<ul style="list-style-type: none"> • Laxative (Duphalac) initiated
	Flatulence (n=1)	<ul style="list-style-type: none"> • Lighter diet/Dietary modifications
	Problems with oily food (n=1)	<ul style="list-style-type: none"> • Advised to not eat oily food
	Vomiting (n=2)	<ul style="list-style-type: none"> • Ondem
Bleeding issues (n=6)	General bleeding issues (n=3)	<ul style="list-style-type: none"> • Admitted immediately to hospital
	Bleeding in rectum (n=1)	<ul style="list-style-type: none"> • Referred to SGCCRI
	Blood in neck and throat (n=2)	<ul style="list-style-type: none"> • Added medications • Antibiotic medication
	Hemoptysis (n=1)	<ul style="list-style-type: none"> • Pause 500 initiated
Respiratory issues (n=4)	Cough (n=2)	<ul style="list-style-type: none"> • Cough syrups (Amtriptyline and Collintu) • Corticosteroids (dexamethasone) advised • Nebulization done

*All medication adjustments listed were advised under the supervision of the oncologist, SGCCRI: Saroj Gupta Cancer Centre and Research Institute

Table 3:

Pain assessment.

CHW	Patient	Base line pain level	Final pain level	Average pain level	Visits	Visits with pain recorded
1	1	Moderate Pain	Moderate Pain	Moderate-Worst Possible	12	7
2	2	0	7-8	1.0	12	7
2	3	4	9	6.30	13	13
2	4	8	9	8.25	5	2
2	5	7	9-10	7.32	14	14
3	6	4	0	1.07	14	14
3	7	6	6	7.33	3	3
2	8	6-7	8-9	6.71	7	7
2	9	6-7	4-5	6.62	16	13
3	10	8	4	6.82	17	17

CHW: Community health worker