A Qualitative Evaluation of a Home-based Palliative Care Program Utilizing Community Health Workers in India

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Abstract

Aim: In India, the need for rural palliative care is increasing with the rising number of people diagnosed with late-stage cancers. Rural areas also have a shortage of trained medical personnel to deliver palliative care. To address these needs, a home-based palliative care program using community health workers (CHWs) to facilitate care delivery was developed to extend the reach of a cancer center's palliative care services outside of Kolkata, India. The research question guiding this qualitative study was, how feasible, useful, and acceptable was this program from the perspectives of the clinical team and CHWs who delivered the intervention? **Methods:** This qualitative descriptive study used a grounded theory approach and the iterative constant comparative method to collect and analyze data from the key stakeholder interviews. Ten qualitative interviews took place at the Saroj Gupta Cancer Center and Research Institute and were conducted with the CHWs who delivered the home-based palliative care intervention ($n = 3$) and the clinical team who provided them with training, support, and supervision ($n = 7$). **Results:** Three major themes emerged (a) CHWs' desire and need for more training, (b) the need for tailoring of existing intervention protocols and modifying expectations of stakeholders, and (c) the need for considerations for ensuring program sustainability. **Conclusions:** The study provided evidence that the utilization of CHWs to facilitate delivery of palliative care is a feasible model worthy of consideration and further research testing in low-resource settings.

Keywords: Community health workers, India, less-developed countries, palliative care

What is already known about the topic?

- Most states in India lack palliative care, especially in rural areas
- Physicians and other types of providers such as nurse practitioners and registered nurses are also scarce in rural India
- Local, rural, unlicensed, and untrained rural medical practitioners could be trained and may be a feasible and available community health worker (CHW) resource for rural India and other low-resource areas.

What this paper adds

- This paper adds to the evidence that trained CHWs are a potential, viable resource to facilitate the delivery of palliative care in low-resource rural areas from the perspective of the CHWs and cancer hospital palliative care clinical team members.

Implications for practice, theory or policy

- Implications for practice include the need to conduct studies examining the impact of trained CHWs on rural palliative care and identify means for sustainability of the work
- Implications for policy include the need for local, state, and national support of training programs for rural CHWs.

INTRODUCTION

Over one million new cancer cases occur annually in India, where over 80% of cancers are diagnosed as late stage.[1,2]

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Often, the only possible patient care plan is pain and symptom management, given the reality of late-stage diagnosis in most patients.[3] Outside of Kerala state, majority of the states in India lack evidence of providing palliative care.[2,4] Most palliative and hospice care services are offered in large cities and regional cancer centers.[1,5] Rural cancer patients are challenged in accessing palliative care due to poverty, lack of insurance, and transportation.[1,5-7] At the health system level, lack of health-care facilities and coordination of health-care services limit palliative care provision. Access is also limited at the societal level because of the underdeveloped health-care workforce, particularly in rural areas.[1,5-7]

Physicians and other types of providers such as nurse practitioners and registered nurses are scarce in rural India. For every 10,000 people living in rural areas, there is only one licensed, qualified physician.[8] In such low-resource areas, community health workers (CHWs) may provide a workforce that could potentially help to fill the critical gap in health services.[9-12] CHWs are defined as "health workers who receive standardized training outside the formal nursing or medical curricula to deliver a range of basic health, promotional, educational, and outreach services and who have a defined role within the community system and larger health system."[10] A common, untrained CHW workforce in India is unlicensed rural medical practitioners (RMPs) that deliver health-care services in rural communities. RMPs do not have formal medical training but offer rural patients' basic health-care services for health problems such as pneumonia, diarrhea, and gynecological issues.[13] Informal RMPs represent a well-established workforce that tends to be trusted in their communities.[14-17] Since this workforce is already providing basic care for colds, coughs, fevers, aches, and pains, it may be feasible to train and utilize this workforce to increase the reach of scarce palliative care services given the lack of trained providers in rural areas.

The research question guiding this qualitative study was, how feasible, useful, and acceptable was the piloted palliative care program from the perspective of the clinical team and CHWs who delivered the intervention?

METHODS

Parent study: Home-based palliative care program

A small feasibility study was conducted to evaluate a home-based palliative care program that used RMPs as CHWs to facilitate delivery of palliative care for rural cancer patients outside of Kolkata, India. The purpose of this feasibility study was also assess the potential for future, broader scale testing, and implementation of the palliative care program. The program was a collaboration between the Saroj Gupta Cancer Center and Research Institute (SGCCRI) and the Medical University of South Carolina (MUSC). The pilot trial was a small, single-arm feasibility study. Materials from the Worldwide Palliative Care Alliance (WPCA) Palliative Care Toolkit (2008) were used to train the CHWs and provide patient management tools [Table 1]. After training, CHWs

Table 1: Palliative care toolkit forms used in patient management

	Purpose	Completed by
Type of form		
Patient assessment and care plan	Described baseline patient needs at the first hospital visit for palliative care. Recorded patient information, diagnosis, brief history of illness, patient knowledge about their illness, special concerns about patient/family, and plan of care including any emotional, social, or spiritual issues	Admitting oncologist
CHW workflow		
Patient register	Recorded patients in their caseload: patient information, diagnosis, end-of-care date, and outcome	CHW
Travel log	Tracked travel for project, home visits, and trips to cancer center and elsewhere	CHW
Palliative care monthly report	Listed patients under care, end-of-care discharge outcome, patient and family contacts, types of trips to the cancer center; handed off to study coordinator monthly	CHW
Patient care		
Pain assessment tool	A reference tool for assessing patient pain at each visit with finger rating scale, Wong-Baker FACES scale, and visual analog scale; used with patient visit record	CHW
Patient visit record for care providers	At every home visit, recorded date, location, patient pain level, problem, action plan, notes, and resolution of problem. Multiple codes for location, type of problem, and assistance needed were to be used	CHW
Referral to palliative care team	Completed on behalf of patient; recorded referral information, diagnosis for each patient referred to palliative care team at hospital	CHW
Appointment reminder	Given to patients by CHW to remind them of upcoming appointments - reason for appointment, location, date and time, and with whom	CHW
Patient-held		
Drug chart	Maintained for individual patients and held at patient's home; intended to remind patients of medication and dose, timing, and frequency	CHW
Morphine dose record	CHW taught patient/family to record each morphine dose taken at each point during day, every day morphine used	CHW Patient/family
Record for home-based care	Recorded summary of patient problems and recommendations for care for each home visit	CHW

CHW: Community health worker

supported the clinical team in assessing and managing the diverse palliative care needs of rural cancer patients living in their communities, supervised by the SGCCRI clinical team. For 3 months, CHWs visited patients each week, using the palliative care toolkit to monitor patients' pain and other symptoms, provide basic palliative care such as medications and wound care, help teach family members to deliver care, and help patients contact their oncologist and other supportive resources when necessary, as well as document patient needs and services received.

Study overview and design

This qualitative descriptive study was conceptualized to characterize the perspectives of key stakeholders (clinical team and CHWs) regarding the successes and challenges of utilizing CHWs to help deliver home-based palliative care in a rural area surrounding Kolkata, India. A grounded theory approach that included inductive/deductive evidence was used to analyze the data.[18] We began with existing evidence about the important domains in home-based palliative care and CHWs, which enabled us to compose neutral questions for the interview guides. Individual semi-structured interviews were conducted to evaluate stakeholder experiences with the program, focusing on evaluating program feasibility, acceptability, and usefulness. We used the iterative constant comparative method to collect and analyze data from the key stakeholder interviews. Themes were developed across all the data gathered until thematic saturation was reached. The MUSC's Institutional Review Board approved this qualitative interview study in June 2017, with written informed consent obtained from stakeholders before study participation.

Setting

Interviews took place at the SGCCRI in Kolkata, India. The SGCCRI was established in 1973 as a nonprofit organization and is a Designated Center of Integrated Oncology and Palliative care recognized by the European Society for Medical Oncology. The home-based palliative care program that is the focus of the current study was piloted in 2017 with SGCCRI patients who resided within the South 24 Parganas Region of Kolkata, India.

Sampling strategy

Two groups of stakeholders were recruited (1) the palliative care clinical team (physicians, nurses, behavioral counselor, and study coordinator) from SGCCRI that trained and supervised the CHWs and (2) the CHWs who facilitated delivery of palliative care to rural cancer patients. Of the six CHWs recruited, five completed training, and three of the five had patients in their village for whom they could help facilitate the delivery of palliative care. Of these three CHWs, two had degrees in homeopathic medicine and one had a certificate in paramedics. Ten persons participated in interviews, including all clinical team members who participated in the palliative care program ($n = 7$) and CHWs ($n = 3$) who helped to deliver palliative care during the program.

Data collection and management

The interviews were conducted during a 6-day period, and the total time for data collection and analysis was approximately 8 weeks. A demographic survey was administered to participants before their interviews to collect information about type of stakeholder, professional role, age, sex, language, religion, and education. The survey was translated into the local language, Bengali, by a professional translator.

Qualitative data were obtained through individual, semi-structured interviews to explore stakeholders' experiences with the program. A tailored interview guide that was translated by a professional translator was used for each stakeholder group. The guide included questions relevant across all stakeholder types and questions specific to each stakeholder group (i.e., clinical team members, CHWs). The multidimensional biopsychosocial model[19] and the social ecological model (SEM) guided the inquiry, capturing the holistic nature of palliative care, including biological and medical concerns, psychosocial and practical concerns, as well as the social, institutional, and cultural contexts of the SEM.[20]

Table 2 provides an overview of the interview guide questions. Using these two models, questions addressed program feasibility, acceptability, and usefulness to stakeholders. The interview guides were written in English and professionally translated into Bengali. Interviews were conducted in a private location at SGCCRI and digitally recorded. The interpreter was a native Bengali speaker. The principal investigator asked the interview questions in English, and stakeholders answered questions in English or Bengali, depending on their preference. When answers were given in Bengali, the interpreter translated the answers for the team members so that appropriate probes could be asked. Handwritten field notes were also taken. After the interviews, audio recordings were compared to the handwritten notes with Bengali data re-examined for translation accuracy, and missing information was added. Interview guide questions were modified as needed after each interview for clarity and to enable follow-up and on topics identified during prior interviews.

Data analysis

A thematic analysis integrated with a deductive/inductive approach was used.[21] An initial data codebook was created and then reviewed by a second investigator. As interviews were transcribed, they were analyzed using constant comparative methods to repeatedly compare existing data with new data and recode data as needed.[22] Transcripts were coded initially by a single investigator to identify emerging themes and subthemes, with review by a second investigator to identify additional themes as needed, and all three investigators validated final themes. Key quotations associated with the identified themes were then coded. The total time for data collection and analysis was approximately 8 weeks.

RESULTS

Demographics

Table 3 describes the characteristics of the ten interviewed stakeholders. Clinical team members included four palliative care physicians, two palliative care nurses, and the study coordinator. Forty percent of stakeholders were aged

Table 2: Stakeholder interview guides

CHW interview guide

Q# and domain	Cancer center clinician
1. Job prior	Please tell me about your role at the cancer center
2. Involvement	How did you become involved with the navigator program?
3. Overall experience	Please tell me about your role in the navigator program Trainer/teacher? Other?
4. Patient physical problems	What are the most common physical problems patients face? From what you saw, how do you think the navigators worked with/helped patients with these problems?
5. Patient emotional problems	What are the most common emotional problems patients face? From what you saw, how do you think the navigators worked with/helped patients with these problems?
6. Patient practical problems	What are the most common practical problems patients face? From what you saw, how do you think the navigators worked with/helped patients with these problems?
7. N/A Medication process	One role of a CHW is to obtain pain medication refills for patients. (Not used - ethics committee SGCRI, legal issues)
8. Challenges in role	What challenges did you have while working with the navigators? (Prompts: Training, communication, motivation, confidence, paperwork, responsibilities, etc.)
9. Relationship with patients	From what you saw, what was the navigators' relationships like with patients and their families?
10. Relationship with team	What is your relationship like with the navigators?
11. Theoretical classroom training	Describe your experience with the theoretical training of the navigators a. What was your role in training? b. What parts were most helpful? Not as helpful? Why? c. How could the theoretical training be improved?
12. Clinical practical training	Describe your experience with the clinical training in the ward with the navigators a. What parts were most helpful? Not as helpful? b. How could the clinical training be improved?
13. Toolkit	How did you use the palliative care toolkit materials? (During training?) a. What parts of the toolkit were most useful? Not useful? Why? b. How can we improve the toolkit?
14. Satisfaction	How did you like working with the navigators? What tasks were the navigators able to do well? What tasks were they not able to do?
15. Improvement	What are your thoughts about the navigator program? a. Overall, what did you like best about the program? Least? b. How can the program be improved?
16. Sustainability	How do you think the program can continue?
17. Other	What else would you like to tell me?

CHW interview guide

Q# and Domain	CHW
1. Job prior	What was your job like before being a navigator?
2. Involvement	How did you become a navigator?
3. Overall experience	Please tell me about your experience working as a navigator a. What happens during a typical visit? b. How did you feel about your interactions with patients and families? c. What topics did you discuss with patients? d. How did patients and families follow your recommendations?
4. Patient physical problems	What were the most common physical problems patients had? How did you help patients with this problem? (Did you need to get help? What kind of help? How did you involve the family?)
5. Patient emotional problems	What were the most common emotional problems that patients had? a. How did you help patients with this problem? (Did you need to get help? What kind of help? How did you involve the family?)
6. Patient practical problems	What were the most common practical problems that patients faced? (e.g., finances, travel, housing, and bills) a. How did you help patients with this problem? (Did you need to get help? What kind of help? How did you involve the family?)
7. N/A medication process	One role of a navigator is to obtain pain medication refills for patients. Can you tell me how this process worked?
8. Challenges in role	What difficulties did you face as a navigator? a. Paperwork? Travel? b. Coordinating your work as a rural health doctor and as a navigator?

Contd...

Table 2: Contd...

CHW interview guide	
9. Relationship with patients	Tell me about your relationships with patients and their families a. What part of your job did you feel they valued the most?
10. Relationship with team	Tell me about your relationship with the doctors, nurses, and clinicians at the cancer center a. What part of your job did you think they valued the most?
11. Theoretical classroom training	What did you think about the theoretical training you received at the cancer center? a. What parts were most helpful? Not helpful? Why? b. How could the theoretical training be improved?
12. Clinical/practical training	Tell me about the clinical/practical training at the cancer center? a. What parts were most helpful? Not helpful? Why? b. How could the clinical training be improved?
13. Toolkit	How did you use the palliative care materials given to you during training? a. What parts of the toolkit were most useful? Not useful? Why? b. How can we improve the toolkit?
14. Satisfaction	What did you like best about being a navigator?
15. Improvement	What are your thoughts about this program? How can we improve it?
16. Sustainability	How do you think this program can continue?
17. Other	What else would you like to tell me?

CHW: Navigator refers to the community health workers, N/A: Not applicable

Table 3: Demographic characteristics of stakeholders

Characteristic	*n* (%)
Job type	
Clinicians	4 (40)
Nurses	2 (20)
Administrator	1 (10)
CHW	3 (30)
Age	
21-29 years old	4 (40)
30-49	3 (30)
50-60+	3 (30)
Sex	
Male	7 (70)
Female	3 (30)
Religion	
Hinduism	9 (90)
Islam	1 (10)
Education	
Graduate degree	4 (40)
Bachelor degree	4 (40)
Diploma or certificate	2 (20)
Marital status	
Married	9 (90)
Single	1 (10)
Employment	
Employed with an institution	7 (70)
Self-employed	3 (30)
Household members, not including self	
One person	2 (20)
Two to four persons	6 (60)
Five to eight persons	2 (20)

CHW: Community health worker

21–29 years, 30% were aged 30–49 years, and 30% aged 50 years or older. Most were male (70%) and Hindu (90%), with 40% holding graduate degrees, 40% bachelor degrees, and 20% diplomas or certificates.

Themes

Overall, CHWs were able to facilitate delivery of meaningful palliative care to patients and extend the reach of a cancer center's home-based palliative care program, providing evidence of the feasibility of the program. They developed positive relationships with patients and found the experience personally rewarding. They learned about diseases and symptoms from the training and wanted the program to continue. Three major themes concerning the feasibility, usefulness, and acceptability of the home-based palliative care program emerged (1) desire and need for more CHW training, (2) tailoring of existing intervention protocols and modifying expectations of stakeholders, and (3) considerations for program sustainability. The information gained from this evaluation study and the evidence it provided suggested that this palliative care program will be feasible to implement and assess on a broader scale.

Community health worker training protocol

Details of the CHW training protocol and curriculum are described in Table 4. The palliative care training included (1) a few days of informal shadowing the palliative care team for 4 h a day before the formal training and (2) a week-long formal training that included 3 h of shadowing and 4 h of didactic classroom training a day delivered collaboratively by SGCCRI and MUSC at the cancer center. The training was based on the Palliative Care Toolkit, a resource that offers evidence-based strategies to deliver home-based palliative care in low-resource areas.[23]

Theme 1: Community health worker desire and need for more training

Theoretical and practical training

CHWs were eager to learn, attended all trainings, and wanted more training. One CHW stated: "Five days of didactic

Table 4: Community health worker training protocol

Days	Didactic training	Daily experiential training
1	History of SGCCRI and its palliative care program	Part A
	Overview of palliative care project and research protocols	Shadowing palliative care physicians in the palliative care ward
2	Concept of palliative care	
	Basics of oncology and chemotherapy	Introductions to patients in ward by nurses
	Geriatric care	Brief interviews with patients conducted by CHWs and supervised by physicians, nurses
3	Symptoms of cancer: pain, nausea, vomiting, breathlessness, constipation, diarrhea	
4	Nutrition in cancer	Part B
	Pain assessment, pain scales	Patient review by CHWs with oncologists - discussion of physical and emotional symptoms identified by CHWs
	Antidepressants	
	Palliative care emergencies	Training in common cancers: gastrointestinal, gynecological, lung, cancers of head and neck
	Spirituality, end-of-life care, bereavement	
5	Patient documentation	Detailed patient history by oncologists with discussion of modifying CHWs' treatment plan to match goals of palliative care
	Overview of patient forms	
	Pain assessment tool	
	Management materials from palliative care toolkit	
Continuing education		
a. Weekly individual meetings with oncologist to discuss patient caseload		
b. Monthly group CHW meeting with oncologist for debriefing, support, and program improvement		

SGCCRI: Saroj Gupta Cancer Center and Research Institute, CHWs: Community health workers

training is just not enough for this program. We also need more clinical shadowing experience." During CHW training, didactic presentations were given for 5–6 h per day, and CHWs shadowed the clinical team for one or two cases per day, all of which took place after the CHWs had already cared for patients in their own practices. The CHWs reported that it would help to spend more time shadowing the clinical team to observe their palliative care practices. A common suggestion was that the overall training needed to be held over a longer duration, with shorter 3–4 h training sessions to allow time for integration of the materials and to manage training alongside their private practices.

Physicians were pleased with CHW engagement with training materials and wanted more training for CHWs. One physician described "at the end of the day, the CHWs must know how to identify and manage symptoms." This physician also thought that the CHWs needed more experience with preterminal palliative care patients, as the reality was that the CHWs primarily saw patients who were very ill. Training over a month's time, he suggested, would provide CHWs the opportunity to see patients at different stages of illness. Continuing education is also important for CHWs "so that they are in the community doing the right thing" in their own practices and in the palliative care program. Based on input from CHWs and clinical team members, there was consensus on the need for more initial didactic and clinical shadowing-based training, for this content to be broken up into shorter periods per training to aid in knowledge retention and for continuing education and support.

Concept of palliative care

The CHWs found the concept of delivering palliative care somewhat challenging, as they were accustomed to delivering curative care in their communities. Several CHWs said they felt like they had taken good care of their palliative care patients by extending their lives a little longer. Although CHW training covered the difference between curative and palliative intent, some clinical team members felt the CHWs needed to learn to customize the care they provided to focus more on emotional and end-of-life needs. These findings suggest that to make the paradigm shift toward palliative care delivery, more initial training and continuing education for the CHWs may be needed.

Psychosocial care

CHWs felt positively about their ability to comfort patients and offer support. One CHW stated that since his patients were in the terminal stages of their illness, "physical problems were out of the way, and emotional support was what I was providing them." Another CHW noted that the emotional issue his patients suffered from the most was fear of death: "when those questions were asked, I used to comfort the patient and family." However, several of the clinical team members believed the CHWs needed to focus more on psychosocial care. When the palliative care training was developed, there were plans to include case studies to allow CHWs to practice delivery of emotional support, but the case studies were removed to reduce training length. This finding suggests that the CHWs would benefit from additional training and the use of case studies on emotional aspects of delivering palliative care.

Keeping patient records

As shown in Table 1, 11 forms were used to maintain patient records, a number deemed by stakeholders to be too laborious. During the didactic training, two modules covered use of the forms and the importance of record keeping. Most forms were successfully filled out by CHWs, but data collection could be enhanced by ensuring that CHWs consistently recorded pain scores and completely documented services provided at every visit. CHWs suggested a maximum of two or three forms for record keeping to reduce administrative burden.

Training to teach family members

CHWs felt that they were intimately involved with families and wanted to teach family members how to care for the patient and keep the patient and his environment clean. Some clinical team members also said that CHWs needed to train families about the concept of palliative care, comfort versus curative intent. One doctor stated: "We need to educate the family to know that the CHW's injection is not going to save their family member; it is not palliative care." This finding suggests that patients and family members needed more information about managing their medical condition, about the process of dying, and the concept of palliative care.

Theme 2: Need for clear protocols and expectations for stakeholders

Patient and community health worker expectations about the program

During the program, CHWs knew that the patients needed them and this was rewarding for the CHWs. One CHW said, "Because the patient was in so much pain, she needed me, and the family saw that if the doctor (the CHW) comes, her pain will be less. They valued my help." Patients expected CHWs to respond when called, and CHWs, in turn, felt that they should be available 24 h a day based on how they ran their own practice. However, the home-based palliative care was not meant to be a 24-h service which caused patients' some frustration when they expected the CHWs to be there in the middle of the night. The findings illustrate the dedication of the CHWs for their patients and that these stakeholders need more training about the scope of the palliative care program.

Patient and community health workers expectations about emergencies

Patient and family expectations of CHWs were high, and CHWs were eager to help their patients. However, patients and families had trouble discerning what was an emergency and what was part of the patient's natural dying process. CHWs were called by patients at all hours, and only on visiting the patient could the CHW see that the situation was not an emergency. If an emergency occurred the CHW could not handle, he referred the patient to the cancer center. CHWs felt inadequately trained to manage some emergencies: "When we go to these patients' houses at the time of an emergency, (sometimes) we do not have training for that" and the family became frustrated. This was challenging for the CHWs. The findings suggest that the CHWs were eager for more training on handling emergency care for patients and that both CHWs and patients needed more education on what constituted an emergency and what to expect during the dying process.

Theme 3: Sustainability of the home-based palliative care program

Acceptability of community health workers

The CHWs were acceptable to the clinicians in their ability to provide basic care to patients, and the CHWs believed that they did so. The experience of CHWs in their own practice was seen as beneficial to the palliative care program. Despite the CHWs being unlicensed, they "already knew the basics of medical treatment," according to a physician. The qualifications of two CHWs as homeopathic doctors and one with a diploma in paramedics meant that they had some training.

Since the CHWs were part of their community, they were familiar with patients' needs and were connected to local MDs, which was beneficial to the program. The clinicians agreed that CHWs could handle many of the patients' problems: through mobile phones, the CHW could discuss the state of the patient and work to meet the patient's needs with the guidance of the physicians. The CHWs also believed that they met the needs of their patients: "As long as I was in the house, I could see they used to feel relaxed and less stressed." These findings confirm that the CHWs, while unlicensed RMPs, were perceived as being able to provide their patients with common supportive care.

Financial support

Stakeholders in the program, including nurses, physicians, and the CHWs, proposed ideas on how to continue the program. Suggestions for financial backing included having the cancer center charge fees to patients to support the program, incorporating CHWs into the cancer center as associate employees, and asking local corporations or nongovernmental organizations to help subsidize the program costs. These suggestions illustrate the desire of the stakeholders for the program to be sustainable and potential models of sustainability that might work.

DISCUSSION

Main findings

The overall perception of CHWs by clinicians was that given enough training and support, utilizing RMPs as CHWs would be an acceptable and ubiquitous workforce for facilitating delivery of palliative care to extend the reach of cancer centers and other health-care organizations in low-resource rural settings. The results of this small feasibility study suggest that this program is feasible to implement and evaluate on a larger scale.

When provided with proper training, it has been demonstrated that RMPs can serve in rural areas and thus decrease the gap in health-care providers.[24-26] Successful programs using CHWs require ongoing training and education for the CHWs.[27,28] Several models of training exist from rapid training to training that lasts over the years and concludes in a CHW certificate.[27] The palliative care program we evaluated used a rapid training approach to bring CHWs into the program without a time lag between recruitment and deployment.[27] We learned that a 5-day rapid didactic training for palliative care may not have been adequate for CHWs. In addition, case studies focusing on psychosocial care had been built into the training, but to accomplish classroom training within 5 days, the case studies were removed from the curriculum. We believe case studies that explore the emotional care of patients, and the holistic concept of palliative care is critical in training CHWs.

What this study adds

More intensive training, including didactic classes, shadowing of clinicians, case studies, and continuing education, would help to improve CHW skills in some key areas. These include (1) understanding the concept of palliative care and need for greater focus on emotional issues at the end of life and (2) distinguishing between what constitutes an emergency versus the natural dying process and conveying this information to patients and families.

Evidence supports the positive impact of CHWs as a care model in low-resource countries,[28] but little is known about effective strategies for the growth and maintenance of CHW programs.[29] The most frequently cited factors that enable scale-up and sustainability of CHW programs included consistent management and supervision of the CHWs and of the program, using CHWs from the community, and integrating CHWs and the program with the health-care system or health-care providers.[28,29] In our palliative care program, CHWs were recruited from local communities and thus were familiar with their patients. In addition, by linking these CHWs to the cancer center and training them by physicians, we found that most stakeholders wanted the program to continue and were eager to contribute ideas for its sustainability.

The most frequently cited barriers to scale-up and sustainability of CHW programs in the literature include lack of sufficient pay or incentive for CHWs, lack of community support or perceived value of CHWs, and the lack of respect for CHWs or a failure to integrate into the structure of the health system.[28,29] In our study, there was tremendous community support for the CHWs, and the CHWs were integrated into the health system. However, we did observe the potential for insufficient incentive for CHWs to continue working in the program once research funding had ended, as well as some lack of respect of the CHWs by the clinical team. Finding sustainable financial support for the CHWs and the overall program will be important to move the program forward. The evidence generated by this evaluation study indicates that this home-based palliative care program will be feasible to implement and further evaluate on a larger scale.

Study strengths and limitations

The main strength and limitation of this study was the limited sample size; although we had a small sample size, it did represent all clinical team members and CHWs who participated in the program. Another limitation was the absence of interviews with palliative care patients who participated in the program. Learning about patients' experiences in the program would offer additional insights into the development and sustainability of the program. However, interviews with patients were not possible due to practical considerations about getting the study approved in a timely manner.

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Conflicts of interest

There are no conflicts of interest.

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