



Original Article

Training Improves Community Health Workers' Knowledge and Perception of Palliative Care: A Quasi-experimental Study

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ABSTRACT

Objectives: Community health workers (CHWs) are the frontline workers providing primary care. This study aimed to assess the impact of training on CHWs' knowledge and perceptions of palliative care (PC).

Materials and Methods: A mixed-method research design was adopted. The participants included CHWs posted in a block of North India. Using a pre-post quasi-experimental design, the PC knowledge questionnaire-basic (PCKQ-B) was used to assess the PC knowledge of CHWs before and after a 3-day PC training programme. Paired *t*-tests, one-way analysis of variance, and Tukey *post hoc* tests were used to determine the pre- and post-training differences in knowledge within and between groups. Responses to the open-ended questions and participants' narratives during the training were coded, thematically analysed and triangulated with quantitative results.

Results: Of 49 CHWs who attended the training, 45 completed both pre- and post-tests. The training was associated with a statistically significant increase in mean PCKQ-B score (18.4 ± 2.942 post-training vs. 12 ± 3.422 pre-training; $P < 0.001$). Six out of seven domains showed improvement in the perception of CHWs regarding PC, with the highest impact on bereavement care (1 ± 0.00 post-training vs. 0.54 ± 0.501 pre-training; $P < 0.001$). Baseline PC knowledge and improvement in knowledge post-training were significantly associated with participants' designation and gender. Training improved participants' perception of PC from being just basic nursing care (pre-training) to a holistic care which extends beyond death to include bereavement care (post-training) and the importance of communication skills in fostering trust and reducing anger and frustration. Fear and anxiety about cancer, poverty, lack of resources, poor trust in public facilities, myths, lack of health awareness, social stigma and non-supportive families were identified as challenges to providing PC in the community.

Conclusion: Short-term PC training contextualised to the local needs improved CHWs' knowledge and perceptions of PC. Future trainings should emphasise addressing the psycho-social and spiritual domains of care.

Keywords: Community health workers, Community-based palliative care, Palliative care, Quasi-experimental, Thematic analysis

INTRODUCTION

Palliative care (PC) aims to improve the quality of life of chronic terminally ill patients throughout the disease trajectory. PC has evolved over decades from its roots dating back to the 19th century. Since then, various models for delivering PC, from community-based to in-patient and hospice, have come into effect. Despite numerous efforts, <4% of the Indian population has access to a PC.^[1] Community-based PC (CBPC) is cost-effective and preferable to the patients due to the comforts of a familiar

environment.^[2] The concept of community health workers (CHWs) was introduced under the National Village Health Guide Scheme, with one CHW serving 5000–10,000 people.^[3] Accredited Social Health Activists (ASHAs) and auxiliary nurse midwives (ANMs) are the main frontline workers improving the accessibility of the healthcare system to rural communities in India.^[4] Health and wellness centres (HWCs) were introduced under the National Health Mission to ensure comprehensive primary healthcare delivery comprising preventive, promotive, curative, palliative and

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rehabilitative services. Community health officers (CHOs) are qualified nurses and are appointed as the first point of care and source of information at these HWCs.^[5] Poorly defined job responsibilities and poor financial remuneration of the CHWs negatively impact the delivery of equitable, high-quality healthcare to remote areas where nearly 60% of the population resides.^[6]

Many training programmes and models have been developed in the past two decades to improve CBPC in India.^[7-10] However, empirical data assessing baseline PC knowledge and the impact of PC training on the knowledge of CHWs, especially from rural North India, have been limited. To address this gap, the present quasi-experimental study aimed to assess the impact of short-term training on the PC knowledge and perceptions of CHWs and explore challenges in the provision of CBPC.

MATERIALS AND METHODS

Ethics

The study presents findings of a part of a multi-phase project aimed at developing and implementing a comprehensive coordinated CBPC model for cancer patients (C3PaC).^[11] The study was conducted after obtaining permission from the Institutional Ethics Committee (IEC/AIIMS/BTI/157) and registration with the clinical trial registry of India (CTRI/2023/04/051357). Written informed consent in the participants' vernacular language was obtained from all the participants.

Study design

This was a pre-post quasi-experimental study where a mixed-methods approach was adopted.^[12] The quantitative data comprised demographic and baseline characteristics of the participants and PC knowledge assessed by the PC knowledge questionnaire-basic (PCKQ-B) before (pre) and after (post) the training using a one-group quasi-experimental design. The qualitative data in the form of responses to the open-ended questions and collection of participants' narratives during the training were analysed to provide in-depth insights into CHWs' views about PC, supporting their dichotomous responses to PCKQ-B and any other domain not covered by the PCKQ-B.

Study population

The study was conducted among CHWs posted in a block of Bathinda district in North India. The block consists of 6 sectors with 27 sub-centres and 1 community health centre and has a population of approximately 2,09,650.^[11] There are approximately 184 ASHA workers, 38 ANMs and 25 CHOs posted in the block. For this study, a total of 49 participants were sampled using purposive and convenience sampling, ensuring maximum participation without affecting routine clinical work at the respective HWCs. Twenty-seven ASHAs,

seventeen MPHWs and six CHOs nominated by the district health authorities were included. Participants who did not consent, did not complete the training for any reason, or did not complete both the pre- and post-test were excluded from the study. Individuals wanting to attend the training but not consenting to participate in the study were allowed to do so.

Intervention

The participants attended a 3-day PC training conducted by a multidisciplinary team of experts (doctors and nurses) specialising in PC, oncology and public health at a tertiary care hospital. The 3-day training included lectures, role-plays, practical training in the outpatient and inpatient wards and video case-based demonstrations on various aspects of PC. Interactive discussions among the participants and faculty were allowed throughout the course. A PC training manual was developed to guide the sessions and as a resource material for the CHWs. The training manual was adapted to the PC needs and barriers identified, as well as the learning needs of the CHWs. The content of the training manual was developed using an iterative process of literature review of existing PC training manuals for CHWs and consultation with experts in PC. The training manual was translated into the local language and validated by language experts. All the participants were assigned to one group and evaluated at pre- and post-training.

Study tools

A pre-tested questionnaire translated into the local language was used to collect participants' demographic details, including age, gender, highest educational qualification, job designation, clinical experience, and number of cancer patients cared for in a month. The case record form used for collecting demographic details included two open-ended questions assessing the participants' baseline understanding of PC and their views on the challenges in providing PC at home. In addition, interactive discussions during the training were audio-recorded. PCKQ-B was used to assess the PC knowledge.^[13] The assessment was done twice, once before (pre-training) and the other after the training (post-training). The questionnaire was translated into Punjabi using the European Organisation for Research and Treatment of Cancer (EORTC) forward-backwards procedure for a clear, easy-to-read and conceptually equivalent translation of the original questionnaire.^[14] The PCKQ-B for assessing PC knowledge comprises 25 questions with true/false/do not know answers. The questionnaire covers the philosophy of PC to non-oncological conditions (5 items, items no. 2–6), pain and its management (5 items, item no. 7–11), myths surrounding morphine and colostomy care (6 items, items no. 12–17), communication of prognosis (2 items, item no. 18 and 19), resuscitation in cancer patients (2 items, item no. 20 and 21), psycho-socio-spiritual issues (2 items, item no. 22 and 23), bereavement care (2 items, item no. 24

and 25) and the importance of taking care of the caregivers (item no. 1). The total score ranges from 0 to 25 (1 point for each correct response and 0 point for each incorrect or 'don't know' response), with a higher score indicating higher level of knowledge.^[13]

Data analysis

The participants' responses were exported to Google Sheets and anonymised for analysis. All the statistical calculations were done using Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, software version 29 for Windows). The discrete and continuous data were reported as proportions (%) and mean \pm standard deviation, respectively. Pre- and post-training comparisons were performed using a paired *t*-test. One-way analysis of variance was used to statistically analyse the association between demographic variables and PCKQ-B score differences. Tukey *post hoc* test was used for multiple comparisons between designations and the difference between pre- and post-test PCKQ-B scores. The qualitative data were transcribed verbatim, analysed thematically and triangulated with the quantitative data.^[15]

RESULTS

Participant demographics

Out of 49 CHWs who attended the training, 45 completed both pre- and post-tests, resulting in a response rate of 91.8%. The majority (82.22%) of them were female. The demographic details are shown in Table 1.

Knowledge improvement post-training

The mean PCKQ-B score post-training, 18.4 ± 2.9 (95% CI: 17.5–19.3), was significantly higher than the mean pre-training score of 12 ± 3.4 (95% CI: 10.9–13.0; $P < 0.001$). Nineteen out of 25 questions showed a significant increase in the post-training as compared to the pre-training, with the highest improvement observed in the awareness of the concept of bereavement care and care of the patients with colostomy bags [Table 2]. Significant improvement was seen in the participants' knowledge of placebo in pain, the role of oxygen supplementation and resuscitation at end-of-life. Non-significant improvement ($P \geq 0.05$) was observed in the need for PC in the total care of chronically ill patients, the need for non-steroidal anti-inflammatory drugs/paracetamol in patients on morphine, morphine always causes nausea/vomiting, prognosis should always be clearly communicated, and the role of nurses in psycho-socio-spiritual issues [Table 2].

Domain-specific improvement

Six out of seven domains showed an improvement in the perception of CHWs regarding PC, with the highest impact on the bereavement care domain [Table 3], as also supported by the participants' verbatims described below. A substantial

Table 1: Demographic details of the participants ($n=45$).

Variable	n (%)
Age (years)	
25–34	7 (15.56)
35–44	23 (51.11)
>44	15 (33.33)
Gender	
Female	37 (82.22)
Male	8 (17.78)
Education	
10 th standard	11 (24.44)
12 th standard	21 (46.67)
BSc. Nursing	3 (6.67)
Others	10 (22.22)
Designation	
ASHAs	22 (51.11)
ANMs/MPHWs	17 (35.55)
CHOs	6 (13.33)
Years of experience	
≤ 5 years	10 (22.22)
>5 years	35 (77.78)
Number of cancer patients cared for in a month	
≤ 5	43 (95.55)
>5	2 (4.44)
ASHA: Accredited social health activists, ANMs: Auxiliary nurse midwives, MPHWS: Multipurpose health workers, CHOs: Community health officers, $P < 0.05$: Statistically significant	

increase in the mean score for 'when do you think PC is needed?' depicted a better understanding of indications for PC, with almost all the participants aware of its applicability to non-cancerous conditions by the end of the training. However, a non-significant change was observed in the psycho-socio-spiritual issues domain.

Factors associated with improvement in knowledge

Female CHWs had significantly higher baseline PC knowledge (12.94 ± 2.79 vs. 7.37 ± 1.22 ; $P < 0.001$) compared to male CHWs. However, male CHWs had significantly higher improvement in knowledge post-training compared to the female CHWs (11 ± 1.80 vs. 5.46 ± 4.12 ; $P < 0.001$) [Supplementary File 1]. The CHWs' baseline PC knowledge was significantly associated with their qualification. CHOs performed significantly better in the pre-training compared to the MPHWS-Females ($P = 0.007$) and MPHWS-Males ($P = <0.001$). CHOs, MPHWS-Females and ASHAs performed significantly better than MPHWS-Males in the pre-training [Supplementary File 2]. Training was associated with a significant improvement in PC knowledge among all, with maximum improvement observed among MPHWS-Males [Table 4].

Table 2: PCKQ-B questions (n=45).

Questions	No. of participants who responded correctly pre-training (n)	No. of participants who responded correctly post-training (n)	Pre-training score (Mean±SD)	Post-training score (Mean±SD)	P-value
1. Taking care of the caregiver is equally important as patient care	34	43	0.76±0.43	0.98±0.15	0.005*
2. PC is needed in care of patients with advanced cancer	37	44	0.84±0.37	1±0.00	0.013*
3. PC is needed in total care of chronically ill patients	43	45	0.96±0.2	1±0.00	0.323
4. PC is needed in HIV/AIDS patients	35	44	0.78±0.42	1±0.00	<0.001**
5. PC is needed for chronic non-malignant diseases such as end-stage heart failure	35	43	0.78±0.42	0.98±0.15	0.01*
6. PC should start at the time of diagnosis of a life-threatening illness	34	44	0.78±0.42	1±0.00	<0.001**
7. Is pain a vital sign?	32	42	0.73±0.45	0.96±0.21	0.003*
8. Severity of pain determines the method of pain management	34	44	0.78±0.42	1±0.00	<0.001**
9. Most effective drug for cancer pain is Fortwin+Phenergan	9	30	0.2±0.41	0.69±0.47	<.001**
10. Use of placebo is appropriate in some type of pain	2	11	0.08±0.28	0.27±0.45	0.003*
11. A patient on morphine does not need NSAIDs (e.g. diclofenac)/paracetamol	8	15	0.22±0.42	0.36±0.48	0.058
12. Morphine causes addiction in terminally ill patients	16	27	0.35±0.48	0.6±0.49	0.006*
13. Morphine causes death in all dying patients	23	42	0.53±0.50	0.96±0.21	<0.001**
14. Morphine always causes nausea/vomiting	23	29	0.51±0.50	0.64±0.48	0.225
15. Patients with lung metastasis having breathlessness must be intubated (in palliative care)	3	22	0.08±0.28	0.51±0.51	<0.001*
16. Are you aware of problems and practical care of patients with colostomy?	13	38	0.27±0.47	0.87±0.34	<0.001**
17. Oxygen supplementation may help in the last difficult breaths	1	8	0.02±0.14	0.18±0.39	0.007*
18. Prognosis should always be clearly communicated	29	33	0.65±0.48	0.76±0.43	0.256
19. Prognosis should only be informed to family members	2	22	0.06±0.24	0.51±0.51	<0.001**
20. Resuscitation must always be performed if a patient is crashing, irrespective of advanced metastatic cancer	3	14	0.06±0.24	0.31±0.47	0.003*
21. Patients (if possible) and relatives both should always be involved in 'Do Not Attempt Resuscitation (DNAR/DNR)' decision-making	31	43	0.65±0.48	0.98±0.15	<0.001**
22. The role of nurses is to take care of the physical aspects of the disease only, psychological issues must be dealt by a psychiatrist or other professionals	19	20	0.43±0.50	0.44±0.50	0.811
23. The role of nurses is to take care of physical aspects of the disease only, social issues must be dealt by social worker or other professionals	16	19	0.37±0.49	0.42±0.49	0.372
24. Do you know what bereavement is?	31	44	0.69±0.47	1±0.00	<0.001**
25. Are you aware of the concept of bereavement care?	18	44	0.43±0.50	1±0.00	<0.001**

*Significant, **Highly significant. PC: Palliative care, PCKQ-B: Palliative care knowledge questionnaire-basic, NSAIDs: Non-steroidal anti-inflammatory drugs, HIV: Human immunodeficiency virus, AIDS: Acquired immunodeficiency syndrome, SD: Standard deviation. Pre- and post-intervention comparisons were performed using paired t-test. $P < 0.05$ was considered statistically significant.

Table 3: PCKQ-B domains ($n=45$).

Domain (total score)	Pre-training score (Mean±SD)	Post-training score (Mean±SD)	P-value
D1. When do you think palliative care is needed? (5)	4.20±1.11	4.98±0.15	<0.001**
D2. Pain in palliative care (5)	1.93±0.80	3.27±1.04	<0.001**
D3. Morphine in Palliative care (6)	1.75±1.35	3.75±1.21	<0.001**
D4. Communication of prognosis (2)	0.69±0.46	1.27±0.64	<0.001**
D5. Resuscitation in cancer patients (2)	0.75±0.56	1.29±0.45	<0.001**
D6. Psycho-socio-spiritual issues (2)	0.78±0.92	0.87±0.95	0.453
D7. Bereavement care (2)	1.09±0.84	2.00±0.00	<0.001**

*Significant, **Highly significant. PCKQ-B: Palliative care knowledge questionnaire-basic. Pre- and post-intervention comparisons were performed using paired t-test. $P < 0.05$ was considered statistically significant, SD: Standard deviation.

A positive correlation was observed between the designation and its impact on pre- and post-test scores difference ($P = 0.000$). There was a statistically significant difference in the scores of ASHA workers when compared with MPHW-Males ($P = 0.000$) and MPHW-Females ($P = 0.038$), with MPHWs having greater improvement in their scores as compared to ASHA workers [Supplementary File 3]. However, the difference was non-significant between CHOs and MPHW-Females ($P = 0.66$), MPHW-Males ($P = 0.07$) and ASHAs ($P = 0.704$) [Supplementary File 3].

Qualitative findings

Thematic analysis of the qualitative data generated following three themes. Only 31 (71.5%) of the participants answered the open-text questions.

Theme 1: Change in perception of palliative care

CHWs perceived PC as basic nursing care before training: PC is:

“Giving patients medicine on time” (Participant No. 1, ASHA)

“Putting on loose clothes and changing them every day” (Participant No. 3, ASHA).

“Taking care of what they eat and providing them with timely and proper meals” (Participant No. 9, ASHA)

However, training was associated with a significant improvement in their perception of PC. Participants considered PC as a holistic approach that encompasses not only the physical needs of patients but also their emotional and psychological well-being. Moreover, they realised that PC extends beyond death to encompass bereavement care:

“PC should be implemented throughout the disease course and is not over after the death of the patient, as the families need bereavement care. PC helps a patient die with dignity” (Participant No. 11, CHO)

Theme 2: Communication fosters trust and ameliorates inter-personal resentment

Effective communication emerged as a key element of PC and a critical skill that all healthcare professionals should

Table 4: Effect of designation on PC knowledge.

Designation (No. of participants)	Pre-training score (Mean±SD)	Post-training score (Mean±SD)	P-value
CHO (6)	15.33±2.06	21.33±1.63	0.001
MPHW-Female (9)	11.00±1.93	19.22±2.95	<0.001
MPHW-Male (8)	7.38±1.30	18.37±0.74	<0.001
ASHA (22)	13.09±2.83	17.27±3.15	<0.001

PC: Palliative care, CHO: Community health officers, MPHW: Multipurpose health workers, ASHA: Accredited social health activists, SD: Standard deviation, P-value: One-way ANOVA was used to statistically analyse the association between demographic variables and PCKQ-B score differences. P-value significance threshold: $P < 0.05$

master. Before the training, the participants had only a limited understanding of how communication skills could enhance PC delivery. However, after the training, some of the participants reiterated that compassionate interactions are essential in building trust and reducing anger and frustration among patients, their family members, and at an interprofessional level:

“In PC, first of all we should listen to the patient carefully, understand and give courage to the patient. No problems of the patients should be left unheard.” (Participant No. 30, ASHA)

“When a professional like her, who listens carefully, understands and explains every situation politely, anger is off the table. I haven't ever met a doctor who holds hands and tries to understand the difficulties the people face.” (Participant No. 6, ASHA)

Theme 3: Challenges in providing PC at home

Participants expressed fear and anxiety about cancer and its prognosis, and the financial burdens associated with the treatment, as challenges to providing home-based PC:

“Cancer patients fear a lot, tumours can be any, with a good or bad prognosis. But they cannot stand the fact that they have cancer. This fear increases with knowing about the cost of treatment and injection treatments. When they get over that fear enough to get started with the treatment,

they have already lost a lot of valuable time.” (Participant No. 15, MPHW)

CHWs enumerated poverty, lack of resources, poor trust in public facilities, myths, lack of health awareness, social stigma and non-supportive families as some of the other challenges in delivering PC:

“Family members often do not give full and correct information about the patient’s condition. On other occasions, they might hide the patient entirely from society. Families take the patient as a burden on themselves. Some do not get the treatment because of a lack of awareness. Patients below the poverty line are forced to stay at home with their conditions.” (Participant No. 10, ASHA)

In addition, misinformation and a lack of awareness among family members further complicated the situation. While some families concealed the patient’s condition from society, others viewed the patient as a burden, resulting in inadequate care.

Challenges we face in providing PC are:

“Limited resources” (Participant No. 2, CHO)

“Myths regarding the disease conditions” (Participant No. 8, CHO)

“Fear of confidentiality among patients” (Participant No. 14, CHO)

“Attitude of the family members regarding health services” (Participant No. 26, CHO)

DISCUSSION

This study showed a significant improvement in CHWs’ knowledge and understanding of PC after a short-term PC training. Multiple studies have shown similar benefits of continuing medical education of healthcare providers in improving the delivery of healthcare services.^[16-19]

Similar to our findings, others have also reported poverty, lack of resources, misconceptions and unawareness to be the major reasons for disproportionate healthcare allocation.^[20-22]

To mitigate these challenges and provide uniform accessibility to healthcare, education, sensitisation and training of both the general population and the healthcare workers are important.^[23] Our findings demonstrated a significant improvement in participants’ knowledge regarding the importance of communication skills. Besides benefits to the patients, effective communication has been shown to foster interprofessional relationships.^[24,25] However, non-significant improvement in the knowledge of psycho-socio-spiritual issues suggests that CHWs require further education and support in understanding and addressing psycho-socio-spiritual aspects of PC, indicating the need for further emphasis and possibly different educational strategies for these topics.

Misinformation and stigmas about morphine and its abuse potential make it necessary for the CHWs to be well-versed in the usage of opioid medications in patients requiring

home-based PC. Training is critical to improve competence in pain assessment.^[26] We found PC training to be effective in improving CHWs’ knowledge of pain management and dispelling myths related to opioid medications. Noteworthy, there were certain concepts that participants had difficulty understanding even after training, such as the role of placebo in pain, oxygen supplementation and resuscitation in patients with advanced metastatic cancer. These findings concord with the findings of Pruthi *et al.*,^[13] identifying areas for increased emphasis during future training.

Our findings suggest that short-term PC training tailored to educational needs can significantly improve the PC knowledge of CHWs. Overall, short but frequent training with multimodal learning sessions can help enhance the applicability of PC knowledge to clinical practice without adversely affecting routine practice.^[19] With disproportionately few training programmes for CHWs,^[27] a curriculum focusing on CHWs to close the knowledge gap is necessary for implementing comprehensive, coordinated CBPC.

Strengths and limitations

This study focused on healthcare professionals working closest to the patients. We used the PCKQ-B questionnaire to assess PC knowledge, as it has been developed and validated for Indian settings and recommended by others as well.^[13,28] Another strength of this study lies in its mixed-methods approach, allowing triangulation of data. The main limitation of the study lies in its purposive and convenience sampling, which might impact the generalisability of the findings. However, it was adopted to avoid hindering the routine clinical work at the respective community healthcare centres. Furthermore, the challenges faced might differ from one community to another, and it is important to identify the challenges unique to a region for better outcomes.

CONCLUSION

Short-term PC training contextualised to the local needs improves PC knowledge of CHWs. PC training improves the perception of PC from basic nursing care to the holistic care, which extends beyond death to include bereavement care, the importance of communication skills in fostering trust and reducing anger and frustration among patients, their family members and at an interprofessional level. Fear and anxiety about cancer and prognosis, poverty, lack of resources, poor trust in public facilities, myths, lack of health awareness, social stigma and non-supportive families were identified as challenges to providing PC in the community. Future training should emphasise addressing psycho-spiritual-social domains of care and dispelling myths related to opioids. Furthermore, follow-up studies are required to assess the long-term retention of PC knowledge and translation of knowledge to clinical practice.

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Ethical approval: The research/study was approved by the Institutional Review Board at All India Institute of Medical Sciences, Bathinda, approval number (IEC/AIIMS/BTI/157) and registered with the clinical trial registry of India, with number (CTRI/2023/04/051357), dated 06th April 2023.

Declaration of participant consent: The authors certify that they have obtained all appropriate participant consent forms. In the form, the participants have given their consent for their images and other clinical information to be reported in the journal. The participants understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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