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Empowering nurses to provide palliative care for COPD patients in a pulmonary department: participatory action research

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Abstract

Background Chronic obstructive pulmonary disease (COPD) affects the quality of life of patients and their caregivers. Although palliative care can improve quality of life, COPD patients and their caregivers have limited access to palliative care services. This study was conducted to empower nurses to provide palliative care to COPD patients in the pulmonary department.

Methods This participatory action research (PAR) was conducted in four steps: observation, reflection, planning, and action. Participants included all nurses ($n = 18$) who provided PC to COPD patients in the pulmonary department. The research team, physicians and managers, and a multiprofessional palliative care team formed the core PAR team. The data were collected via PCKT, FATCOD-B, and PCPS questionnaires about palliative care, interviews, focus groups, and observation. Qualitative content analysis and paired t-tests were used for data analysis.

Results Three major themes emerged: professional incompetence in palliative care, basic shortages in palliative care, and a lack of professional support. Three changes were made including enhancing palliative care knowledge, establishing a palliative care team, and increasing career motivation. There were significant increases in PCKT, FATCOD-B, and PCPS scores before and after PAR ($p = 0.000$).

Conclusion Given the importance of providing palliative care, necessary measures, including PC training, and promoting inter professional collaboration and as well as motivating staff, should be taken by health managers.

Keywords Participatory action research, COPD, Nurse, Palliative care

Introduction

Nurses play an important role in meeting the needs of patients and providing quality services [1]. Despite significant advances in medical technology and treatments, health systems worldwide face various challenges. One main concern is the prevalence of chronic and incurable diseases, particularly COPD [2]. The prevalence of COPD is increasing due to smoking, urbanization, tanning, and industrial pollution [3]. The World Health Organization (WHO) predicts that COPD will be the third leading cause of death worldwide by 2030 [4]. These patients experience many problems, such as shortness of breath,

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cough, pain, insomnia, fatigue, anxiety, and depression [5]. As COPD progresses, patients typically experience respiratory infections, severe weight loss, and a decline in overall functional ability [6]. Patients may be unable to care for themselves without assistance and support, and this dependence on others is distressing for patients and family caregivers [7]. Comprehensive care of COPD patients can improve the quality of life of patients and their caregivers [8].

According to the WHO, palliative care (PC) is an interdisciplinary approach aimed at managing symptoms and improving the quality of life of incurable patients [9]. In 2022, the American Thoracic Society (ATS) published a cross-society policy statement emphasizing the need for early integration of PC care into the treatment of severe respiratory disease and addressing the significant burden on patients and caregivers. The ATS provides a framework for clinicians to provide high-quality PC [10]. The European Respiratory Society (ERS) has developed clinical practice guidelines for the initiation and integration of PC into respiratory care for patients with COPD and interstitial lung disease (ILD) [11]. In addition, clinical practice guidelines focusing on symptom management for adults with serious respiratory illnesses have been published [12].

These studies demonstrate the importance and benefits of PC and symptom management as essential components in the treatment of patients with COPD. The main focus of PC is to improve the quality of life from diagnosis to the end of the patient's life through symptom management with physical, psychological, social, and spiritual support by multi-professional teams [13]. Providing a PC creates optimal conditions that contribute to the patient's peaceful and comfortable death [14]. For comprehensive supportive care of COPD patients and their caregivers, it is essential to integrate PC early and concurrently with COPD-directed therapies. The integration of PC should be long before end-stage COPD, and its intensity should increase over time as symptoms, needs, and exacerbations worsen and EOL approaches. When primary and specialist PC is integrated, it can better prepare them for the EOL [15].

Studies have shown that early provision of PC improves symptoms, increases patient and caregiver satisfaction, and reduces hospitalization and treatment costs [12–14]. Despite the importance and benefits of PC, this care is not provided properly to COPD patients and has been identified as a major challenge in the health system [15].

Although PC is often provided by a multidisciplinary team, the role of nurses in communicating with the team involved is key and important. PC nurses have a wide range of roles and responsibilities in caring for patients and their families [16]. They spend most of their time with patients and their families, making their role in providing compassionate, holistic care and symptom management critical. Focusing on nurses can help to form a culture of PC integration in nursing practice. Trained nurses can influence colleagues and other health care professionals by sharing experiences and specialized knowledge [17]. Conducting nurse-focused studies and carefully examining experiences will identify and address challenges such as educational needs, staffing shortages, increased workload, and insufficient resources that hinder the provision of PC [18].

However, few studies have investigated the empowerment of nurses in PC. Taleghani et al. (2018) reported that empowering nurses to provide PC to cancer patients through new and standardized training courses increases nurses' knowledge and improves PC quality [15]. Iran lacks a comprehensive care model for incurable patients and does not have adequate facilities, trained staff, or organizational structures for these services [13, 17]. Since in Iran, sufficient measures have not been taken to empower nurses to provide PC, and the number of COPD patients who need PC is increasing, it is necessary to design and implement studies to empower nurses. This study was conducted to empower nurses in providing PC to COPD patients in the pulmonary department.

Methods

Design of the study

The present study was carried out through participatory action research (PAR). In PAR, groups of individuals experiencing problems collaborate to bring about changes in their environments by identifying issues, generating new knowledge, and implementing solutions together [19]. In this study, the cycle model proposed by O'Leary was used. Each cycle has four stages: (a) observation and data collection, (b) reflection, (c) planning, and (d) action. O'Leary's model emphasizes that "cycles converge toward better situation understanding and improved action implementation and are based on evaluative practice that alters between action and critical reflection" [20] (Fig. 1). The study was inspired by nursing performance and observation of the lack of PC provision for patients with COPD.

Study settings, participants, and PAR team

The setting of the PAR was a pulmonary department at Imam Reza Hospital, Mashhad, Iran. The pulmonary department has 22 active beds, and COPD patients have the highest number of hospitalizations in this department. The average length of stay of patients in this department is 7–14 days. In this hospital, there was a specialized PC center that exclusively served cancer patients, and COPD patients did not have access to this service despite their high symptom burden.

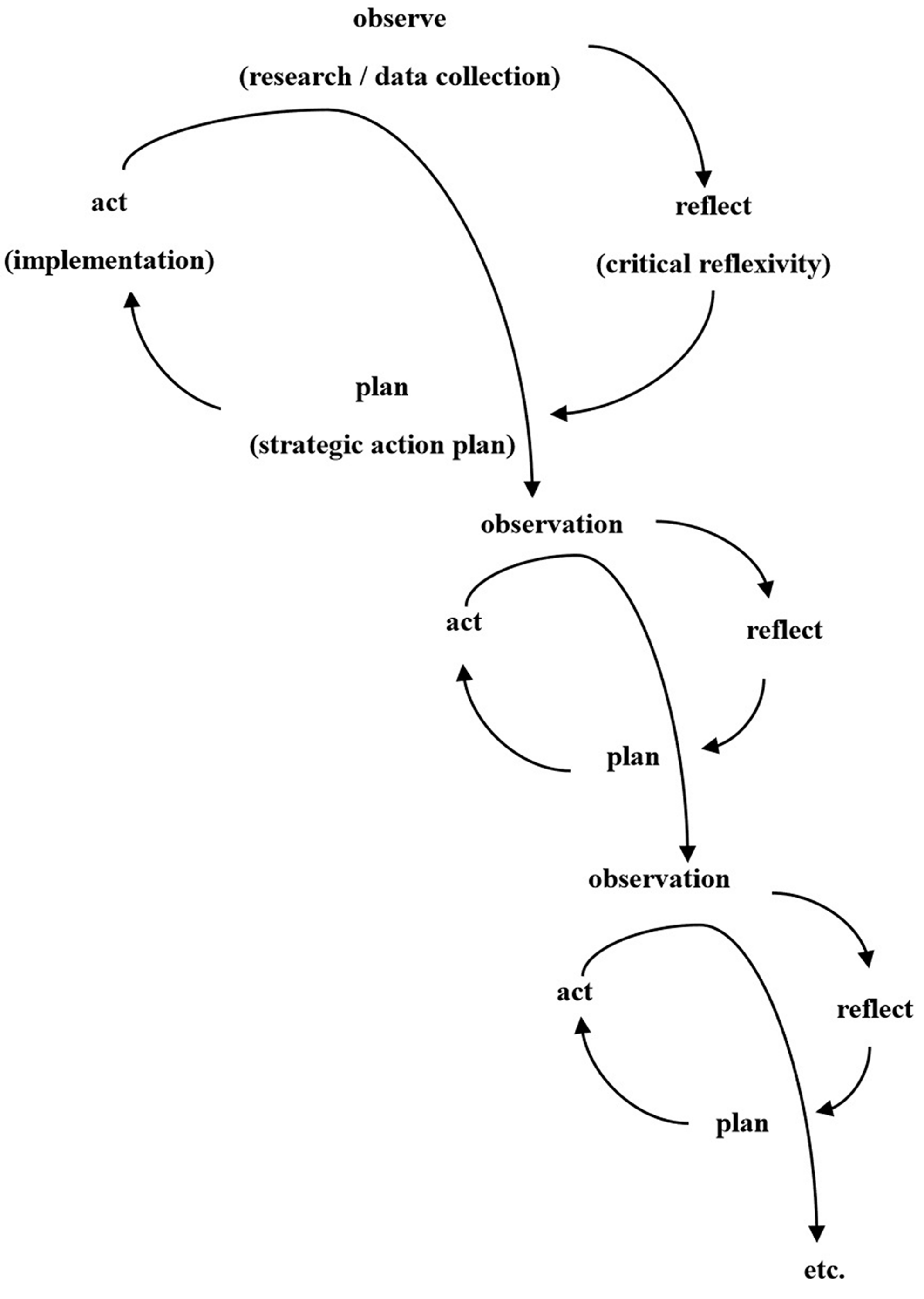

Fig. 1 O'Leary Cycles Action Research

The participants in this research were members of different levels involved in education and clinical, who were invited according to the requirements and stages of the research. A purpose-based sampling method was used. In the present study, considering that there was a need to make changes in the department, all nurses of the pulmonary department ($N = 18$) actively participated in PAR. Two nursing faculty members, one PHD student, nine physicians and managers (four pulmonologists, one head nurse, one matron, and three supervisors), and one palliative care team (PCT) (social worker, psychologist, nutritionist, and clinical chaplain) formed a core PAR team. The hospital director was invited to the first FGD and presented his suggestions. The study was conducted from December 2022 to November 2024.

Data analysis

Qualitative data analysis was performed via the conventional content analysis approach according to the steps of Graneheim & Lundman [21] and MAXQD software (v.20). The interviews were transcribed immediately after they were conducted. The interview transcripts were read and reviewed several times. Data analysis was performed concurrently with data collection by the first author of the article. Then, the interviews and initial coding and categories were re-examined by the research colleagues and three expert professors in the field of qualitative research. Quantitative data analysis was performed via descriptive statistics and paired sample t-tests with SPSS (v.18).

Rigor

Trustworthiness was ensured via Lincoln and Guba's evaluative criteria [20]. Constant engagement with data and data verification by participants, allocating enough time to the study and open and empathetic communication with participants were also among the factors that increased the validity of the study data. In the field of transferability, manuscripts, interviews and units of analysis were extracted along with primary codes and presented to the participants, and their additional comments were received and necessary corrections were made and suggested points were taken into account. Also, Re-examination of the interviews and initial coding and categories by the researcher's colleagues and three faculty members who were experts in qualitative research. The use of maximum diversity sampling increased the confirmation, verification and transferability of the data. Allocation of sufficient time to the study and open and empathetic communication with the participants, obtaining permission from the ethics committee, explaining the purpose of the research, the purpose of using the audio recorder, how to collect data for the participants and obtain their cooperation, obtaining written consent for informed participation, ensuring the anonymity of the participants, answering questions, the right to refuse to continue the research, and informing about the factors that increase the validity of the study data.

First cycle

Observation & data collection Both qualitative and quantitative methods were used for data collection.

Qualitative data: Observation, field notes, semi-structured interviews, and focus groups were used to collect data. Interviews were conducted with the head nurse and nurses. Each interview lasted between 45 and 60 min. The interviews were held in a room in the pulmonary department. After conducting 10 interviews, data saturation was achieved. Two additional interviews were conducted to confirm that no new themes had emerged, and a total of 12 interviews were conducted. The study coordinator (first author) observed the nurses' behavior while caring for patients during three shifts in the pulmonary department. The field notes focused on clinical performance and the use of PC services in daily practice. The interview was initiated with general questions like: "Can you please tell me about your experience from a day of working with COPD patients?" As the interview, progressed, several follow-up questions were asked, such as "Can you clarify please" or "What do you mean." At the end of the interview, the participants were asked, "Is there anything you would like to clarify or add?" To ensure the face and content validity of the research, the interview questions were revised with the opinions of the supervisors and three nursing professors specializing in qualitative studies, and a final interview guide was prepared for this study (Supplementary file).

Quantitative data: Data were gathered using three questionnaires: knowledge, attitude, and practice towards palliative care.

1. The Palliative Care Knowledge Test (PCKT) was developed by Nakazawa et al. (2010). It consists of 20 true/false questions. The possible total score of the scale ranges between 0 and 20, with higher scores indicating higher knowledge of PC. The test covers various domains of philosophy (2 questions), pain [6], dyspnea [4], psychiatric issues [4], and gastrointestinal problems [4, 22].The scale was reported to be valid and reliable by Nikazawa et al. (2010), as Cronbach's alpha was reported to be 0.88 for the overall scale. The Cronbach's α coefficient of this questionnaire in the current study was 0.85.
2. Fromm el's Attitude toward Care of the Dying-form B scale (FATCOD-B) [23] is a 30-item tool answered on a five-point Likert scale. Scores range from 30 to 150. Higher scores indicate a positive attitude toward death and care for dying patients. The scale has been translated into multiple languages and has shown reliability. For the English [24], Spanish [25], and Turkish [26]FATCOD-B samples, Cronbach's α values ranged from 0.76 to 0.93 for the total scale. In our study, the Cronbach's α was 0.89.
3. The Palliative Care Self-Reported Practices Scale (PCPS) developed by Nakazawa and colleagues (2010) [22]. consists of 18 items on a 5-point Likert scale, with total scores ranging from 18 to 90. Higher scores indicate better performance. The scale consists of six subscales: care provided during the dying phase, patient- and family-centered care, pain, delirium, respiratory distress, and communication. Nakazawa and colleagues (2010) tested the scale, which turned to be valid and reliable with a reported Cronbach's alpha of 0.80 to 0.91 for the whole scale

and its subsections. For this study, the Cronbach's alpha for PCPS was 0.87.

Data collection was conducted between September 2022 and May 2023.

Reflection

The results of the quantitative and qualitative data analysis were shared with the participants in the focus group. The participants confirmed the findings and discussed the importance and priority of solving each problem. The reflection stage of the O'Leary model is crucial because it allows individuals and groups to critically evaluate their experiences. This process helps to identify strengths and weaknesses before the planning stage [20].

Planning and action

During four focus groups, participants were asked to suggest strategies based on the identified problems and the literature review. These suggestions were evaluated via five criteria: feasibility, cost, time, human resources, and management support. Eventually, the participants agreed on three plans and developed an action plan. Consensus was defined as 80% agreement or higher. The participants in the focus groups included were a combination of the matron, head nurse, supervisors, pulmonologists, and clinical nurses. At each session, 6–8 nurses participated. The focus groups lasted between 90 and 120 min and were managed by the PhD student and two research team members. The number of sessions in focus groups was determined based on the data saturation. The action plans were implemented over 8 months from September 2023 to April 2024.

Second cycle

The second cycle began in May 2024 and ended in September 2024. Qualitative and quantitative data were collected and analyzed during this time. Sessions were held with participants to review the action plan and discuss any related challenges. Based on these reflections, necessary changes and corrections were made to the program (Fig. 2).

Results

Observation & data collection

Qualitative data Three problems were identified through the analysis of observations, interviews, and Field notes (Table 1).

Professional incompetence in palliative care lack of knowledge, low self-confidence, and inadequate skills, were the problems identified in this category.

"How can I do PC when I do not know anything about it? PC is a new program that I do not think my colleagues know about either..." (p8). "I have been working in this hospital for several years. There has never been a PC workshop or class, and naturally, I do not know PC..." (p5).

Basic shortages for providing palliative care lack of nurses, inadequate facilities and equipment, a lack of clinical practice guidelines, and an inappropriate organizational culture, were some of the basic shortages. *"All patients require special attention and want to talk about their pain and suffering, but we often do not have the time to listen to them..." (p1). "Whenever I try to offer compassionate care to my patients, I hesitate due to the fear of being ridiculed by my colleagues..." (p18).*

Lack of professional support Ignoring nurses, inadequate organizational support, poor interdisciplinary communication, and nonpatient-oriented tasks were some of the problems mentioned by the nurses. *"Patient care is often fragmented, everyone works independently and may not be aware of other treatments or recommendations; from the moment a patient enters the hospital, they are faced with various referrals, specialists, and protocols, which can be costly and exhausting for the patient..." (p2).*

The quantitative data Before the participatory action research, the knowledge score was (10.6 ± 1.4), the attitudes score was (99.6 ± 7.9), and the palliative care practice score was (68.5 ± 3.4).

Reflection

In the reflection, all the participants agreed on the importance of PC education. *"In my opinion, PC education should be a priority. If the content is taught correctly and implemented in practice, many problems will be solved…" (p 21).*

The lack of nurses was a problem that most participants emphasized. *"A nurse performs many tasks during each shift. If we want to provide quality care for the patient, there should be basic planning for addressing the shortage of nurses..." (p 27).*

Nurses emphasized that feelings of discouragement and disappointment affect their performance. *"I am not encouraged when I do my duty properly, but if I make a small mistake, I am reprimanded and punished. Therefore, I have concluded that I should not do more than my duty..." (p6).*

Planning and action

Three action plans were developed and implemented (Table 2).

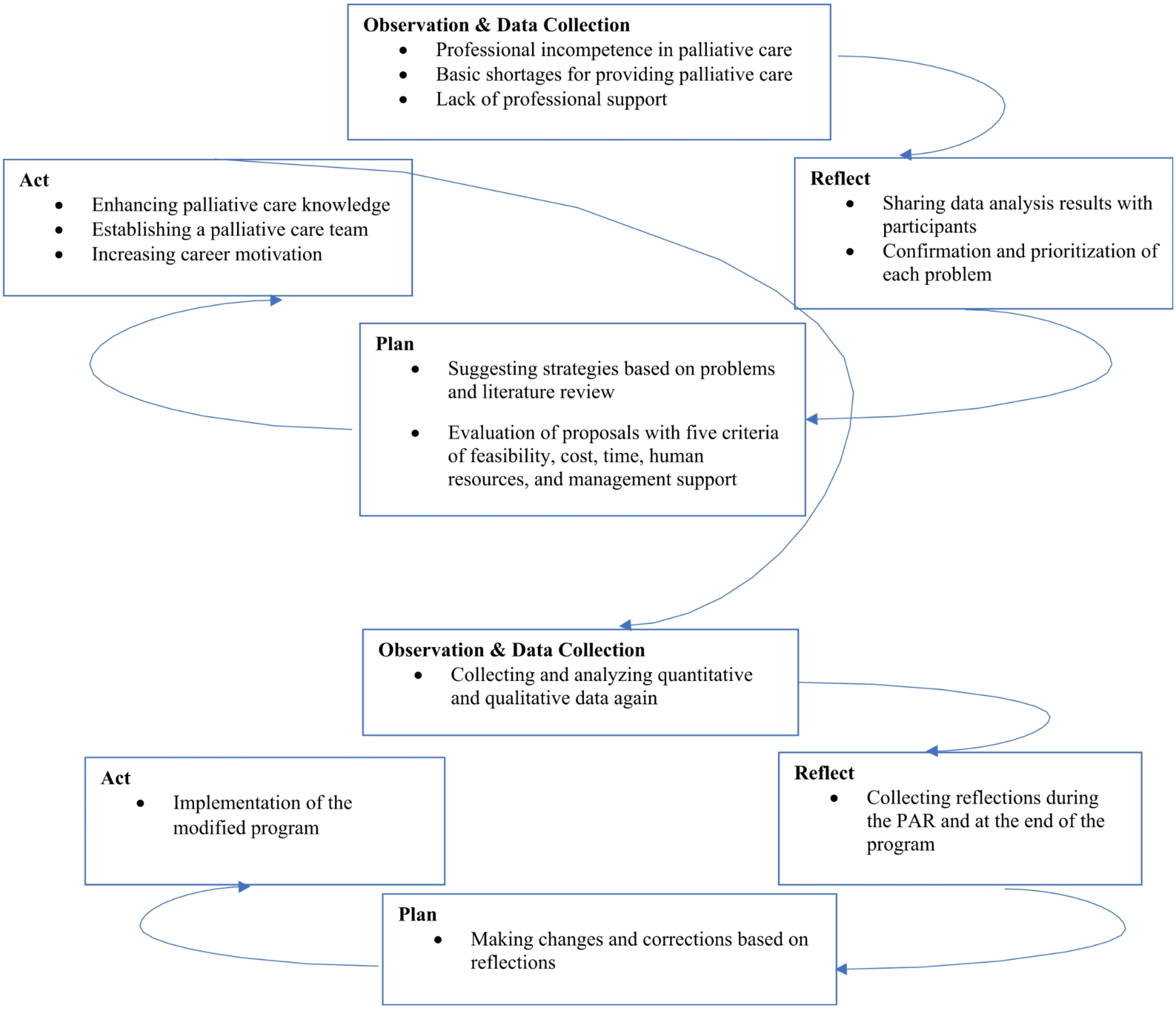

Fig. 2 Overview of the action research process

Table 1 Categories and subcategories derived from qualitative data analysis

Categories	Subcategories
Professional incompetence in palliative care	Lack of knowledge
	Low self-confidence
	Insufficient skill
Basic shortages for providing palliative care	Lack of nurses
	Inadequate facilities and equipment
	Lack of clinical practice guidelines
	Inappropriate organizational culture
Lack of professional support	Ignoring nurses
	Inadequate organizational support
	Poor interdisciplinary communication
	non-patient-oriented tasks

Table 2 Action plan for empowering nurses in providing palliative care

plan	Act
Enhancing palliative care knowledge	Palliative care educational workshop
	Intradepartmental educational conferences
	Journal Club Presentation
	Using e-learning platforms
	Learning through self-study
	Access to palliative care resources in the department
	education in all shifts
Establishing a palliative care team	Coordination with department head
	Identifying team members
	Preparing the team to provide palliative care
Increasing career motivation	Considering palliative care performance in the evaluation form
	Changing the evaluation period
	Selecting the best nurse based on the evaluation score
	Encouraging the nurse with the highest score

Palliative care nursing professional development Considering that the nurses working in the pulmonary department had no previous training in PC, implementing the PC training program was necessary to empower the nurses. Based on previous studies and literature review, the proposed content was presented by the research team, and the opinions of various experts, including nursing professors, nurses, and PC specialists, were used to ensure that the educational content meets the needs of the nursing staff.

All nurses participated in three 6-hour PC training workshops. The first and second sessions of the workshop were held by a professor with years of experience in nursing education and PC. In these workshops, topics such as the importance of caring for incurable patients, physical symptoms management, goals and principles of PC, the status of PC in Iran, nursing ethics, and the principles of patient education were discussed. In the third session of the workshop, topics such as effective communication, cognitive symptom management, spiritual care and end-of-life care were presented by two PCT members (a psychologist and a clinical chaplain) who also had experience working in the cancer PC center. In addition, some nurses volunteered to present conferences and journal clubs about PC in the department. The timetable of the educational programs was displayed at the nursing station, and a virtual channel was created to share educational files. Books in the PC field were also prepared for the ward.

Establishing a palliative care team The PCT was formed to provide comprehensive care to patients and their families with the support of hospital management and in coordination with the department head. The PCT was obliged to collaborate with ward staff from admission to discharge and to play an active role in providing PC to the patient's caregivers during death and bereavement. Meetings were held with the PCT, and necessary training was provided.

Increasing nurses' career motivation Based on the participants' suggestions, a score for PC performance was considered in the specific index section of the evaluation form, and the evaluation period was conducted at 3-month intervals instead of annually. Additionally, with the participants' cooperation, a needs assessment and referral form to the PCT were prepared, and nurses were scored based on symptom management and collaboration with the PCT. Every three months, the nurse with the highest score was given an acknowledgment and a small gift from the head nurse.

Second cycle

The results of the reflections were mostly positive, and nurses reported that the changes had increased their ability to provide PC. *"I used to be hesitant to discuss end-of-life issues, but now I feel like I can talk to patients about it. I recently cared for an 80-year-old woman with advanced COPD. She expressed her desire to spend her last moments with her children and grandchildren… this conversation was satisfying for both of us…" (p18). "Teamwork has improved communication and increased respect among colleagues, but these programs should not be short-term… I think this is the beginning of PC and these actions should continue…" (p16).*

After PAR, significant changes in PCKT, FATCOD-B, and PCPS scores were noted. The total score changed significantly from pre-intervention to post-intervention ($p = 0.000$) (Table 3).

Discussion

Nurses play an important role in managing symptoms and improving the quality of life of incurable patients [27]. Nurses must continually improve their professional

Table 3 The mean score of knowledge, attitude, and practice of nurses

Scale (Number of items)	Pretest Mean ± SD	Posttest Mean ± SD	*p*
Total PCKT Scale	10.6 ± 1.4	17.8 ± 1.8	0.000*
FATCOD-B Scale	99.6 ± 7.9	101.9 ± 8.9	0.000*
Total PCPS Scale	68.5 ± 3.4	82.1 ± 6.7	0.000*

* Significant at the 0.05 level

competence to provide safe and high-quality care [28]. The current study showed that simple measures can improve PC. Using PAR as an approach with the dual purpose of practical problem-solving and empowering participants enables them to actively participate in the research process and benefit from its results [25].

Nurses encounter many challenges in clinical settings, and AR offers a way to address these challenges. In this PAR, we tried to reach a common understanding and consensus about empowering nurses in PC through collaboration and partnership. Constructive collaboration and interaction between participants and faculty and the integration of evidence-based research into patient care can help solve complex clinical problems. The results of the qualitative and quantitative study revealed that nurses lack sufficient knowledge and practice regarding PC. Price et al. (2019) emphasized that one of the major challenges in providing PC is the insufficient knowledge and skills of health professionals, which has significantly limited access to PC services [29].

The solution proposed by the participants was a combination of educational interventions on PC. Training through workshops, presenting journal clubs in the form of intradepartmental conferences, and sending educational files helped increase the participants' knowledge of PC. In Weiner et al.'s study (2015), implementing a multifaceted approach, such as experiential learning, educational interventions, creating learning opportunities, and constant training, increased the effectiveness of PC [30]. Nurses should use best practices to update their knowledge, and online learning is a good option for training [31].

Nurses have stated that they lack the motivation to provide high-quality care, causing them to focus on administering medication and writing nursing reports. By integrating the principles of PC into the daily practice of nursing in the care of patients with COPD, healthcare organizations can foster a culture in which all nurses are encouraged to provide comprehensive care and to consider the comfort and quality of life of patients and families alongside curative treatments. Ultimately, it ensures that all patients, regardless of their stage of illness, receive compassionate, person-centered care that addresses their unique needs. However, this requires specialized training of nurses in PC. This research shows that small actions, such as consideration of score for patient symptom management, collaboration with the PCT, and an acknowledgment and a small gift for compassionate care can help nurses feel more appreciated and valued in their work [32]. In a study by Baljoon et al. (2018), organizational factors such as nurses' empowerment, salary and financial benefits, contingent rewards, promotions, supportive relationships (coworkers), supervision, work engagement, communication, and the nature of work were identified to impact nurses' motivation [33].

The participants reported barriers that prevented them from providing PC. Some of these barriers are complex issues and are beyond the scope of this research. One of the identified barriers is the shortage of nurses, which contributes to increased workloads for nurses, job dissatisfaction, professional errors, staff turnover, and potentially, patient harm [34, 35]. In this study, PCT was effective in managing patient needs and addressing challenges related to nursing shortages. Another barrier was fear of ridicule, which can prevent health care professionals from providing compassionate care, especially in the context of PC. By integrating PC into daily practice, it not only enhances end-of-life care but also fosters a culture of empathy, collaboration and respect [36]. A focus on PC can profoundly affect the overall culture in a ward in several ways. By educating nurses, encouraging open conversations about difficult topics, such as death and dying, promoting team collaboration, emphasizing holistic approaches, and encouraging nurses to provide holistic care for terminally ill patients and support the patient's family [9, 37]. It is possible to create an environment where nurses can confidently provide compassionate care without fear of ridicule.

An interprofessional team is crucial for providing comprehensive and ethical care to palliative patients [38]. The success of a healthcare team depends on a supportive work environment fostered by effective communication, strong leadership, and mutual respect [39]. Sarta et al. (2022) identified a conflict between physicians and nurses and inadequate teamwork as the main issues. Strengthening relationships and teamwork can improve PC services [40]. Bennardiet et al.'s (2021) research demonstrated that effective interprofessional relationships are critical to the PC process and are considered key facilitators [41]. Therefore, considering the complex conditions and high symptom burden in COPD patients, PCT is necessary in the management of disease symptoms.

Limitations

As with most qualitative research, the study was conducted in one pulmonary department in Iran, and therefore, the findings may not be directly generalizable to other departments. Therefore, it is suggested that future studies explore the empowerment of nurses to provide palliative care in other departments with larger sample sizes.

Conclusion

After PAR, there was a significant increase in PCKT, FATCOD-B, and PCPS scores compared to baseline measurements. This study demonstrated that accurate planning, PC training can improve the competencies and skills of nurses involved in PC for patients with COPD. Moreover, recognizing and attending to nurses' intrinsic and extrinsic motivations is crucial for fostering a culture of care that integrates PC as a fundamental aspect of COPD patient care. Although this study focused primarily on nurse performance and empowerment, it is important to acknowledge that providing effective PC requires multidisciplinary collaboration. Therefore, managers and policymakers should allocate sufficient time and financing to empower nurses staff and promote collaborative practices within healthcare teams. By empowering nurses in PC and strengthening interdisciplinary teamwork, the support provided to patients and their families can be enriched.

Abbreviations

COPD	Chronic obstructive pulmonary disease
WHO	World Health Organization
ATS	American Thoracic Society
ERS	European Respiratory Society
ILD	Interstitial lung disease
PC	Palliative care
PAR	Participatory Action Research
PCT	Palliative Care Team

Supplementary Information

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Supplementary Material 1

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Author contributions

Z.M. conducted the study, contributed to data analysis and interpretation, and revised the draft. H.Z. contributed to data collection and writing the first draft. M.A. contributed to the translation and revising of the draft. N.H. contributed to data collection, drafting of the work, and critical revision of important intellectual content. All authors approved the final version of the manuscript and agreed on all aspects of the work.

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Data availability

The dataset generated and analyzed in this study is not publicly available to protect the privacy of the participants. However, it can be obtained from the corresponding author upon a reasonable access request.The authors of this study would like to express their appreciation and gratitude to all of the individuals who took part in this study.

Declarations

Ethics approval and consent to participate

The study has been approved by the Research Ethics Committee of Mashhad University (IR.MUMS.REC.1402.007). All the necessary permissions were obtained from Mashhad University of Medical Sciences and Imam Reza Hospital. Data confidentiality was strictly maintained and all data was anonymized. The authors confirm that written informed consent was obtained from all participants. Helsinki declaration in ethical codes was respected in all the stages of the study.

Consent for publication

All authors have provided their consent for publication.

Competing interests

The authors declare no competing interests.

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