

Home Care Nurses' Attitude Towards and Knowledge of Home Palliative Care in Iran: A Cross-Sectional Study

Abstract

Background: Chronic and cancer diseases are expected to rise with the growing population of the elderly in the world. Home palliative care might be a possible solution for improving these patients' quality of life; therefore, the present study sets out to investigate home care nurses' attitude towards and knowledge of home palliative care. **Materials and Methods:** This is a descriptive cross-sectional study (2018-19), in which 168 home care nurses and nursing assistants in East Azerbaijan Province (Iran) were included (2018). The questionnaire used was specifically designed by Shimizu *et al.* in 2016 for determining the nurses' attitude towards and knowledge of home care. Data analysis was carried out using descriptive and inferential statistics (T-test and ANOVA). **Results:** In this study, 95 (56.60%) and 113 (67.90%) of the participants were found to have negative attitudes and limited knowledge, respectively. The other participants seemed to have neutral attitudes towards and average knowledge of home palliative care. The Mean (SD) attitude score on terminal home care was estimated 2.33 (0.83), and the knowledge score on dying care was calculated 41.76%, which were the lowest in comparison with the scores of other dimensions. **Conclusions:** The home care nurses' attitude towards and knowledge of home palliative care were found to be negative and limited, respectively, which underscores the need to endeavor to improve the attitude towards home care and the knowledge of dying care.

Keywords: Attitude, home care services, knowledge, nurses, palliative care

Introduction

Recent estimates indicate that more than one-fourth of the world population will be over the age of 65 years by 2050.^[1] Population ageing has substantially contributed to the rising number of new cancer cases worldwide, and it is predicted that there will be 14 million new cancer cases by 2035, representing almost 60% of the global cancer incidence.^[2] Palliative care is a possible solution for improving the quality of life of the patients with chronic diseases and their families, focusing on the period between diagnosis and the post-mortem period.^[3] Only 5.6 million of the 40 million patients in need of palliative care actually receive the required care while the rest receive only the routine care.^[4] Moreover, 67% of countries have failed to include palliative care programs in their health system policies and structures.^[5] There are currently no systematic structures for providing palliative care in Iran and only about 5 to 6 centres are active in this

field in Tehran, Isfahan, and Zanjan. These sites also provide palliative care in hospitals and home care models.^[6]

The study by Arnold *et al.* (2015) in Scotland unveiled the willingness of more than 50% of patients suffering from chronic diseases to receive home care and experience bereavement.^[7] Home-based palliative care is one of the palliative care models^[8] delivered through teamwork.^[9] Given the availability and the role of nurses in the arrangements made with patients, their families, and other healthcare team members, nurses play a substantial role in the delivery of palliative care.^[10] Research results have also indicated that home-based palliative care reduces the health system costs, the hospitalization period,^[11] and the hospitalization side effects, thereby preventing re-hospitalization and meeting the physical, emotional, social, and spiritual needs of patients.^[12] Nurses' lack of palliative care knowledge is noticeable,^[13] particularly while palliative care is shifting

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to the patients' homes.^[14] The lack of adequate preparedness of professionals for palliative care is also one of the barriers to the provision of palliative care in the world.^[15] In the study by Wilson *et al.* (2016), nurses who did not take the European Certificate in Essential Palliative Care (ECEPC) course had more limited knowledge of palliative care than nurses who took this course.^[16] Empathy with the patient correlates with the caregivers' attitude.^[17] Attitudes toward palliative care are thus an important factor in the behavior of nurses who are responsible for caring for people at the end of their lives.^[18] A positive attitude may improve care quality while a negative attitude could prevent the essential palliative actions.^[19]

Based on the research findings, the elderly population in Iran is expected to increase by 25% to 30% by 2030.^[20] In the 2006 classification of palliative care, Iran was put in Group 2, but in the 2011 classification of palliative care, Iran was placed in Group 3A. In this group, the provision of palliative care is carried out limitedly and separately.^[21] There is also no home-based palliative care plan in the health system of Iran, and the caregivers in the home care centres provide only the routine care to patients in need of palliative care.^[22] However, few studies have been carried out on the attitude towards and knowledge of home palliative care among home care nurses and personnel, using special questionnaires, which is why there is little information on this area. Hence, this study strives to measure the knowledge of and attitude towards home palliative care among home care nurses and nursing assistants.

Materials and Methods

Totally, 168 nurses and nursing assistants working in eight home care centers (4 urban centers and 4 county centers) in East Azerbaijan Province (Iran) took part in this descriptive cross-sectional study from December 2018 to January 2019, the participants were sampled through convenience sampling. All nurses and nursing assistants employed in the home care numbered 180 (response rate: 93.31%). The sample size was calculated by $Z = 1.96$, $SD = 2.28$, $N = 200$, and $d = 0.34$.^[23]

In the present research we employed the questionnaire developed by Shimizu *et al.* (2016) for determining the nurses' attitude towards and knowledge of home palliative care, and developed valid and reliable scales to evaluate home care nurses' attitude and knowledge.^[24] The first part of this questionnaire covers the demographic properties and background information including 1) age, gender, marital status, and the number of children, 2) the major and level of education, 3) work experience and the experience of providing cancer care, 4) whether or not they have you taken the palliative care course, and if yes, how long the course has lasted 5) workplace and employment type. The second part of this questionnaire contains 12 questions about the attitude of the home care

nurses to palliative care, and this questionnaire consists of the following four subsets: (1) confidence in staff support (items 1-3), (2) confidence in communication with Physicians (items 4-6), (3) willingness to provide terminal home care (items 7-9), (4) confidence in terminal home care (items 10-12). Attitude was assessed using a 5-item Likert scale (ranging from strongly agree 5 to strongly disagree 1). Six of the items were worded positively and six were worded negatively. It had a 12-item rating scale with highest score of 5 for each option and total possible score was 60. The attitude scores were categorized positive ($\geq 76\%$), moderate (51-75%), and poor ($\leq 50\%$). In the third part of the questionnaire, there were 26 questions about the home care nurses' knowledge of palliative care. The scores ranged from 0 (minimum) to 26 (maximum), and the answers were either true or false. This section consisted of 6 subsets. Philosophy (2 items 1, 2), pain and opioids (6 items 3-8), dyspnea (4 items 9-12), psychiatric problems (4 items 13-16), gastrointestinal problems (4 items 17-20), and dying care (6 items 21-26). The knowledge scores were classified into poor knowledge ($>50\%$), fair knowledge (50-69%), and good knowledge ($\geq 70\%$).

In this study, first permission was sought from the original authors for the use and translation of the instrument, and once it was granted, the questionnaires were translated from English to Persian. The method proposed by Wild *et al.* (2005) was used to translate and carry out a cultural comparison of the questionnaires.^[25] First, in the forward translation phase, the questionnaires were separately translated from English into the target language by two translators. In a meeting attended by the researchers, the two translations were compared and corrections were made. In the back-translation phase, the translated version was translated into English by a native translator. The resulting English translation was, thereafter, compared to the original version of the questionnaire from the conceptual consistency point of view. The results were discussed in two meetings attended by the translators and researchers to confirm the consistency of the versions which were sent to the original designer to confirm that they convey the same content. And then, in the cognitive debriefing phase, the questionnaire was presented to 10 home care nurses to ensure their comprehension of the notions and that their opinions were applied. The required corrections were also made to finalize the questionnaires.

The validity of the questionnaires was assessed through content validity. To assess the validity of the translated questionnaires, we presented them to 7 nursing professors at Tabriz University of Medical Sciences, who confirmed the cultural and religious consistency of the questionnaires. The internal consistency reliability of the questionnaires was also calculated (Cronbach's alpha for attitude and knowledge were = 0.79 and 0.77, respectively). Managers of home care centers in East Azerbaijan Province received a letter, introducing the project and asking for participants

in the study. The total number of the nurses and nursing assistants employed in the home care was 180. The questionnaires distributed among all nurses and nursing assistants were returned within 3 months. The inclusion criteria were as follows: 1) home care nurses or nursing assistants 2) home care experience of more than three months. The participants were allowed to exit from the study whenever they were unwilling to cooperate. The normality of data was assessed, using Shapiro–Wilk test ($p = 0.09$). The collected data were analyzed by SPSS 21 (version 21.0., IBM Corp., Armonk, NY, USA). A complete data analysis was also carried out, using the descriptive statistics (mean, standard deviation,) and the inferential methods (t-test and ANOVA).

Ethical considerations

This study was approved by the regional research ethics committee at the Tabriz University of Medical Sciences (IR.TBZMED.REC.1397.675). All participants were informed of the study procedure and that their participation in the study was voluntary. The participants were assured of the confidentiality of data and that they had the right to refrain from participating at any point without negative consequences. Informed written consent was obtained from the participants. This study has been extracted from a dissertation entitled “development of home-based palliative care program for patients with cancer: An action research study” and all researchers involved in the study declared no conflict of interest.

Results

According to the results, out of the 180 distributed questionnaires, we collected 168 in which all questions had been answered (93.31%). More than half (55.40%) the personnel of home care centers were males. Most participants (79.20%) also worked in urban centers, while 49.70% of the personnel were nurses and the rest were nursing assistants. Besides, 97% of the personnel worked on a case-by- case basis, while a few worked in these centers on contract bases.

There was no state-run home care center and all centers were private. The mean (SD) work experience in these centres was 7.07 (3.36) years. Most of the employees (90.50%) had attended no specialized courses on palliative care, and a few (16.50%) had taken training courses lasting for a week. However, 46.60% of the respondents stated that they had previously delivered cancer care [Table 1].

The overall attitude mean (SD) score of the nurses and nursing assistants on home palliative care was 29.73 (4.10) out of 60. The minimum and maximum scores were 18 and 39, respectively. The investigation results also indicated that none of the participants had scored higher than 75 nor did any have a good attitude. Furthermore, 56.60% of the participants had negative attitudes and scores lower than 50, while 43.50% had scores between 50 and 75, which

was interpreted as the average attitude. Among the four attitude subsets, the participants gained the highest score on the “willingness to provide terminal home care” subset, whereas they gained the lowest score on the “confidence in terminal home care” subset. The average score of the correct answers in all subsets and the number of respondents answering each question are listed in Table 2.

The overall mean (SD) knowledge score of the nurses and nursing assistants on home palliative care was 12.49 (2.67) out of 26. The minimum and maximum scores were 6 and 18, respectively. The investigation results also indicated that 67.90% of the participants scored lower than 50, which was interpreted as they having limited knowledge. Furthermore, 32.10% of them were considered as having average knowledge, having scored between 50 and 69. However, none of the participants gained a score higher than 70. This scale consisted of six subsets. The highest score was obtained on the gastrointestinal problems subset, which 59.82% of the participants had answered correctly. The lowest score was obtained on the dying care subset, where only 41.76% of the participants answered the questions correctly. Therefore, it is concluded that the

Table 1: Demographic characteristics of the participants

Variables	n (%)	Mean (SD)
Age		
Male	93 (55.40)	32.60 (6.46)
Female	75 (44.60)	
Total	168 (100)	
Urban	133 (79.20)	
County	35 (20.80)	
degree of education		
PhD	2 (1)	
Master	2 (1)	
Bachelor	68 (35.60)	
assistants	98 (50.30)	
employment status		
Contractual	5 (3)	
Case	183 (97)	
official	0	
Job experience		7.07 (3.36)
1-5 years	102 (53.40)	
6-10 years	50 (26.20)	
11-15 years	16 (8.40)	
16-20 years	0	
Have course palliative care		
Yes	16 (9.50)	
Not	152 (90.50)	
Duration		
One week	16 (9.50)	
One month	0	
Tree month	0	
Ccare of cancer patient		
Yes	78 (46.40)	
No	90 (53.60)	

Table 2: The home care nurses and nursing assistant Attitude of home palliative Care

Statement Mean (SD)	Strongly disagree n(%)	Disagree n(%)	Uncertain n(%)	Agree n(%)	Strongly agree n(%)
Confidence in staff support Mean (SD) 2.51(0.83)					
I am confident in supporting staff to minimize a patient's pain and suffering as much as possible until the end of the patient's life.	61 (36.30)	40 (23.80)	26 (15.50)	32 (19.00)	9 (5.40)
I am confident in supporting staff concerning terminal home care.	52 (31.00)	44 (26.20)	30 (17.90)	18 (10.70)	24 (14.30)
I am not confident in supporting staff concerning care for home death.	29 (17.30)	27 (16.10)	20 (11.90)	50 (29.80)	42 (25.00)
Confidence in communication with Physicians Mean (SD) 2.39(0.95)					
I am confident in creating relationship of trust with family Hospital physicians.	52 (31.00)	38 (22.60)	19 (11.30)	37 (22.00)	22 (13.10)
I am not confident that I communicate well with family hospital Physicians.	12 (7.10)	17 (10.10)	25 (14.90)	41 (24.40)	73 (43.50)
I am not confident in cooperating with family hospital Physicians for care for dying patients.	19 (11.30)	28 (16.70)	22 (13.10)	36 (21.40)	63 (37.50)
Willingness to provide terminal home care Mean (SD) 2.65(0.81)					
I provide dying care at home activity.	57 (33.90)	60 (35.70)	6 (3.60)	20 (11.90)	25 (14.90)
I don't provide terminal home care activity.	25 (14.90)	44 (26.20)	19 (11.30)	24 (14.30)	56 (33.30)
I try to minimize a patient's suffering as much as possible when providing terminal home care	43 (25.60)	41 (24.40)	21 (12.50)	26 (15.50)	37 (22.00)
Confidence in terminal home care Mean (SD) 2.33(0.83)					
When if a patient or their family desires I am not confident in providing dying care at home.	18 (10.70)	24 (14.30)	4 (2.40)	64 (38.10)	58 (34.50)
When if a patient or their family desires I am confident supporting terminal home care.	59 (35.10)	61 (36.30)	3 (1.80)	24 (14.30)	21 (12.50)
When if a patient or their family desires I am not confident in minimizing the patient suffering until the end of the patient's life.	23 (13.70)	26 (15.50)	11 (6.50)	43 (25.60)	65 (37.80)

employees in the home care centers had more limited knowledge of dying care as compared to the other items. The mean score of the correct answers in all subsets and the percentage of respondents answering each question are listed in [Table 3].

The analysis of the nurses' and nursing assistants' attitudes toward and knowledge of home palliative care did not reveal a significant difference with age, workplace, employment type, and work experience, but there was a significant difference between the attitudes of the personnel with cancer care experience and the personnel with no experience of cancer care ($p = 0.03$). In the t-test, a significant difference was found between the Mean (SD) scores of the nurses 13.40 (2.20) and nursing assistants 11.81 (2.70) on the knowledge of home palliative care ($p < 0.001$). Moreover, there was a significant difference between the scores of the personnel who had taken the palliative care courses and the personnel who had not ($p = 0.04$) [Table 4].

Discussion

Our findings indicated that the knowledge of and attitude toward palliative care among the home care nurses and nursing assistants were average and negative, respectively. There was also no considerable difference between the

attitudes of the nurses and nursing assistants toward palliative care. However, the nurses' palliative care knowledge was vaster than the nursing assistants', while both had average to limited knowledge of palliative care. Therefore, there seems to be a need for providing training in all palliative care items (both knowledge and attitude) to improve the personnel's attitudes and knowledge. Smets *et al.* (2018) conducted a study in Belgium to investigate the palliative care knowledge of the personnel of 322 nursing homes in 6 European countries. They reported that the palliative care knowledge of the nurses and nursing assistants did not meet the standards.^[26] In addition, an integrated review of the analysis of 26 studies revealed the unsatisfactory palliative care knowledge of nurses and emphasized the need for paying more attention to meet this need.^[27] Therefore, since the results of the present study comply with these studies, and this lack of knowledge could be the result of the flaws in the curricula or on-the-job training programs in the health system, it is necessary to develop new strategies for increasing the knowledge of palliative care in Iran.

In an Australian study, nurses' knowledge levels were compared with those of nursing. A significant difference was reported between the knowledge of the nurses and the knowledge of nursing assistants.^[28] This finding is also

Table 3: The home care nurses and nursing assistant knowledge of home palliative Care

Statement	Correct n(%)	Incorrect n(%)	Don't know n(%)
Philosophy			
Palliative care should only be provided for patients who have no curative treatments available. False (F)	82 (48.80)	64 (38.10)	22 (13.10)
Palliative care should not be provided along with anti-cancer treatments. (F)	72 (42.86)	69(41.07)	27 (16.07)
Pain and Opioids			
One of the goals of pain management is to get a good night's sleep. True(T)	135 (80.40)	26 (15.50)	7 (4.20)
When cancer pain is mild, pentazocine should be used more often than an opioid. (F)	41 (24.40)	119 (70.80)	8 (4.80)
When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used. (F)	74 (44.00)	79 (47.00)	15 (8.90)
The effect of opioids should decrease when pentazocine or buprenorphine hydrochloride is used together after opioids are used. (T)	81 (48.20)	75 (44.60)	12 (7.10)
Long-term use of opioids can often induce addiction. (F)	44 (26.20)	120 (71.40)	4 (2.40)
Use of opioids does not influence survival time. (T)	93 (55.40)	44 (26.20)	31 (18.50)
Dyspnea			
Morphine should be used to relieve dyspnea in cancer patients. (T)	85 (50.60)	74 (44.00)	9 (5.40)
When opioids are taken on a regular basis, the use of opioids to relieve dyspnea will cause respiratory depression. (F)	43 (25.60)	119 (70.80)	6 (3.60)
Oxygen saturation levels are correlated with dyspnea. (F)	48 (28.60)	107 (63.70)	13 (7.70)
Anticholinergic drugs or scopolamine hydro bromide are effective for alleviating bronchial secretions of dying patients. (T)	107 (63.70)	54 (32.10)	7 (4.20)
Psychiatric problems			
During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort. (T)	96 (57.10)	65 (38.70)	7 (4.20)
Benzodiazepines should be effective for controlling delirium. (T)	103 (63.10)	62 (36.90)	3 (1.80)
Some dying patients will require continuous sedation to alleviate suffering. (T)	65 (38.70)	95 (56.50)	8 (4.80)
Morphine is often a course of treatment for delirium in terminally ill cancer patients' Gastrointestinal problems. (F)	95 (56.50)	60 (35.70)	13 (7.70)
Gastrointestinal problems			
At terminal stages of cancer, higher calorie intake compared to early stages is needed. (F)	132 (78.60)	27 (16.10)	9 (5.40)
There is no route except central venous for patients unable to maintain a peripheral intravenous route. (F)	86 (51.20)	75 (44.60)	7 (4.20)
Steroids should improve appetite among patients with advanced cancer. (T)	116 (69.00)	31 (18.50)	21 (12.50)
Intravenous infusion will not be effective for alleviating dry mouth in dying patients. (T)	68 (40.50)	89 (53.00)	11 (6.50)
Dying care			
Agonal respiration is a natural progress that occurs in 40% of terminal patients. (T)	75 (44.60)	83 (49.40)	10 (6.00)
Agonal respiration improves with suction. (F)	71 (42.30)	78 (46.40)	19 (11.30)
When dehydrated, most patients feel pain. (F)	58 (34.50)	92 (54.80)	18 (10.70)
Cyanosis in the terminal period improves with oxygen inhalation. (F)	60 (35.70)	100 (59.50)	8 (4.80)
Disturbance of consciousness is not the same as delirium and the level of consciousness often deteriorates when the patient is near death. (T)	92 (54.80)	63 (37.50)	13 (7.70)
When a patient dies within 24 h of the last consultation with a physician, the physician can publish the death certificate without re-examination. (T)	65 (38.70)	58 (34.50)	45 (26.80)

in line with the findings of the present study. In addition, the between-group analysis in the present study unveiled a significant difference between the levels of palliative care knowledge in the participants who received palliative care training and the ones who did not. This finding complies with the finding reported by Pan *et al.* (2018) in Taiwan, who reported that training increased palliative

care knowledge and caused a significant difference after training as compared to the levels of knowledge prior to training.^[29] In this study, the participants who had the experience of providing cancer care had a more positive attitude than the other participants. Hence, it seems there are fewer challenges to the delivery of palliative care by experienced caregivers. This study had limitations

Table 4: Correlation between home Palliative Care knowledge and Attitude with background information

Main variable	Knowledge		Attitude	
	Mean (SD)	Significance level of test index	Mean (SD)	Significance level of test index
Gender				
Female	12.61 (2.50)	$(t_{167}=0.81, p=0.41)$	2.55 (0.33)	$(t_{167}=0.83, p=0.40)$
Male	12.32 (2.80)		2.51 (0.32)	
Resident				
Urban county	12.65 (2.60)	$(t_{167}=-0.41, p=0.68)$	2.54 (0.33)	$(t_{167}=0.82, p=0.41)$
	12.45 (2.60)		2.49 (0.31)	
Degree of education				
Nurse assistants	13.40 (2.20)	$(t_{167}=3.90, p<0.001)$	2.56 (0.31)	$(t_{167}=-1.20, p=0.20)$
	11.81 (2.70)		2.49 (0.34)	
Employment status				
Contractual case	14.00 (2.40)	$(t_{167}=-1.28, p=0.20)$	2.51 (0.40)	$(t_{167}=0.11, p=0.90)$
	12.44 (2.60)		2.53 (0.53)	
Job experience				
1-5 years	12.56 (2.90)	$(f_{167}=0.77, p=0.70)$	2.52 (0.37)	$(f_{167}=0.63, p=0.84)$
6-10 years	13.08 (2.80)		2.56 (0.25)	
11-15 years	11.66 (2.20)		2.61 (0.18)	
16-20 years	12.38 (2.10)		2.66 (0.40)	
Training palliative care				
Yes	13.42 (2.00)	$(t_{167}=2.10, p=0.04)^*$	2.44 (0.33)	$(t_{167}=-1.20, p=0.20)$
No	12.36 (2.70)		2.54 (0.32)	
Care of cancer patient				
Care experience not care experience	12.55 (2.60)	$(t_{167}=-0.18, p=0.85)$	2.61 (0.32)	$(t_{167}=0.90, p=0.03)^*$
	12.47 (2.70)		2.43 (0.32)	

**t*-test and ANOVA test significance was at the level of $p \leq 0.05$

regarding the shortage of similar studies carried out on palliative home care in Iran, which made the comparison and discussion rather difficult. The study suggests that curriculum designers should include specific courses about home palliative care in undergraduate nursing curricula.

Conclusion

There is a lack of positive attitude toward and knowledge of palliative care among the home care nurses and nursing assistants and improving the attitude to terminal home care, and the knowledge of dying care are strongly recommended. The findings of this study revealed that those who had taken part in the palliative care training courses had better knowledge and it is suggested that specific instructional programs be designed and provided through which one might get the knowledge of home palliative care nurses and nursing assistants enhanced. In addition, those who had clinical experiences had a positive attitude towards home palliative care, which suggests employing people with clinical experience could be helpful in educating other people.

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Conflicts of interest

Nothing to declare.

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