Original Article

Adaptation of Interdisciplinary Clinical Practice Guidelines to Palliative Care for Patients with Heart Failure in Iran: Application of Adapte Method

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Abstract

Background: Clinical Practice Guidelines (CPGs) have been recommended to manage palliative care and take the best treatment measures and decisions. This study aimed to adapt the interdisciplinary CPG to provide palliative care for patients with Heart Failure (HF) in Iran based on the ADAPTE method. **Materials and Methods:** Guideline databases and websites were systematically searched up to April 2021 to determine appropriate publications related to the study topic. Followed by assessing the quality of the selected guidelines via the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE II), those with appropriate standard scores were selected to be used in designing the initial draft of the adapted guideline. The developed draft contained 130 recommendations and was evaluated by a panel of interdisciplinary experts in terms of its relatedness, comprehensibility, usefulness, and feasibility in two phases of Delphi. **Results:** In the first phase of Delphi, the adapted guideline was derived from five guidelines and evaluated by 27 interdisciplinary pundits working in the universities of Tehran, Isfahan, and Yazd cities. After the assessment in Delphi Phase 2, four recommendation categories were removed because they did not receive the required scores. Finally, 126 recommendation items were included in the developed guideline, which were classified into three main categories of palliative care features, essentials, and organization. **Conclusions:** In the present study, an interprofessional guideline was designed to enhance palliative care information and practice in patients with HF. This guideline can be administered as a valid tool for interprofessional team members to provide palliative care to patients with HF.

Keywords: *Heart failure, palliative care, practice guideline*

Introduction

Heart failure (HF) is a chronic, progressive, costly, and debilitating common health problem worldwide,[1] leading to an inability in the heart muscles to pump the required blood to meet the body's oxygen needs.[2] In Iran, Najafi-Vosough, quoted by Ahmadi: "HF has a prevalence rate of higher than 8%, which is high compared to other countries in the region and the world".[3] Patients with HF suffer from progressive physical and psychological symptoms as well as problems that reduce the quality of life, such as shortness of breath, pain, anxiety, depression, sleep disturbance, fatigue,[4] significant weight loss, inability to perform daily activities, frequent hospitalizations,[5] high treatment costs,[6] loss of independence, and disruption of social roles.[7] Bagheri quoted by Koelling: Optimal management of these problems requires a comprehensive, interdisciplinary, and patient/family-centred care plan[8] to support patients in all care environments (hospital, hospice, or home). Such healthcare programs were found to play a relatively effective role in reducing the rates of readmission and mortality while improving the patients' quality of life.[9]

Based on the literature, the administration of palliative care is of great significance in taking care of patients with HF since it is a comprehensive and supportive care program with an interdisciplinary approach that focuses on the patients' quality of life but is less considered, unfortunately.[10] This program also improves the patients' symptoms and performance[11] by addressing their physical, mental, and psychological concerns and provides support for their family members during periods of grief and

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sadness after the patient's death.[12] In this vein, Clinical Practice Guidelines (CPGs) have been recommended to properly manage the patients' palliative needs and provide them with the best treatment strategies and decisions.[13] The CPGs are able to provide the most efficient solutions by collecting and combining highly relevant pieces of evidence and combining them with local problems and challenges.[14] The application of CPGs improves the quality of care, reduces discrepancies in care provision, enhances the health care standards, upgrades clinical outcomes,[13] saves costs,[15] establishes professional autonomy, and ameliorates personnel performance.[16]

Meanwhile, no comprehensive clinical guideline is available to provide palliative care for patients with HF in Iran. Moreover, the guidelines accessible in other countries are neither feasible nor adaptable to the local culture, context, and facilities of Iran. The policies set by the Ministry of Health, Treatment, and Medical Education, programs of the Deputy of Nursing in the field of palliative care, and research priority at Isfahan University of Medical Sciences have been aimed to develop interdisciplinary CPGs on palliative care for patients, especially those with HF. Thus, the present study aimed to adapt an interdisciplinary clinical guideline to provide palliative care for patients with HF.

Materials and Methods

The present study was conducted based on the ADAPTE approach provided by the International Guideline Network in three main phases during 2021 [Figure 1]. The ADAPTE approach provides a systematic approach to adapt the guidelines developed in one setting for application in a different cultural and organizational context.[17]

Phase 1: Set-up: The executive committee, including two nursing faculty members specialized in palliative care, one HF subspecialty, and a Ph.D. nursing student, was formed to investigate the feasibility of the adaptation process. These pundits examined the available CPGs related to the study topic by searching through valid websites and scientific databases. As a result, several CPGs were identified in the field of palliative care for patients with HF, entitled "adaptation of the interdisciplinary palliative care guideline in patients with HF."

Phase 2: Adaptation: At this stage, the five steps were taken: 1. The items were developed using five options with the abbreviation PIPOH [Table 1]; 2. The related guidelines and other pieces of evidence available in databases of Excerpta Medica Database, MEDLINE/PubMed, CINAHL, and Guideline websites, including the National Institute for Clinical Excellence and National Guideline Clearinghouse, were investigated and reviewed using a combination of keywords. Terms searched included (guideline or recommendation or protocol or pathway) and ("palliative care" or "terminal care" or "hospice care" or "end of life care"), and ("heart failure" or "cardiac failure" or "heart

Table 1: The PIPOH* components defined in the present study

Patient	**Adult patients with HF**
Intervention	Palliative care for patients with HF**
Professionals	Health team members involved in caring for adult patients with HF
Outcomes	Improving patients' quality of life
	Enhancing the quality of care
	Reducing the costs
	Reducing the rate of unnecessary hospitalizations
Healthcare setting and context	The guideline can be administered in hospital, hospice, and home settings according to the available measures and facilities.

*Patient, Intervention, Professionals, Outcomes, Health care setting and context (PIPOH). **Heart Failure (HF)

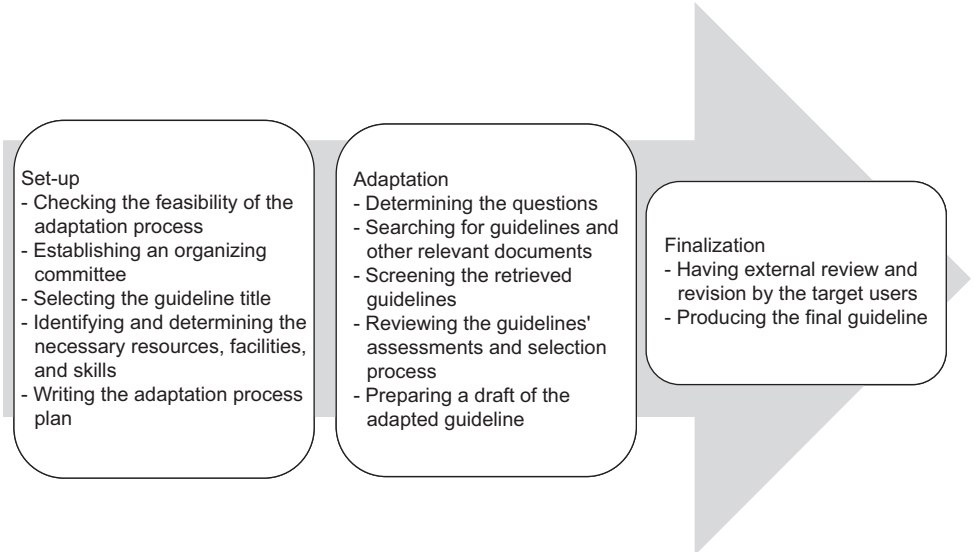

Figure 1: Phases of adaptation guideline

decompensation or "myocardial failure"); 3. The guidelines were checked by removing duplicates and reviewing titles and abstracts of the identified guidelines based on the inclusion criteria. To this end, clinical guidelines that had a clear introduction (e.g., a detailed explanation of palliative measures in patients with HF), were administered among adults ≥18 years of age, had an interdisciplinary design preferably, were focused on care, not on treatment, and received a consent letter from a national or international professional organization were included. However, the guidelines to which free full access was denied by the publisher were excluded from the study. Consequently, the full contents of the selected guidelines were reviewed by the research team, and seven guidelines were selected for the quality assessment using the Appraisal of Guidelines for Research and Evaluation Instrument (AGREE II); 4. The base guideline(s) were selected by obtaining scores from the quality assessment using AGREE II and considering the evidence-based and up-to-date guideline contents.[17] Finally, the recommendations presented by five guidelines were employed in developing the present adapted guideline. 5. The adapted clinical guideline was drafted, followed by holding an online meeting with the research team members where the necessary measures were decided upon in developing the initial draft of the base guidelines. After composing the initial version based on the selected guidelines, the draft was revised by the research team pundits in terms of its scientific content, compliance with the standard guidelines' framework, and appropriate composition rules.

Phase 3: Finalization: The external revision was performed by a panel of experts[17] using the RAND/UCLA appropriateness method. In this regard, a combination of the best clinical evidence and the specialists' judgments was used to determine the appropriateness of a caring or treatment method.[18] After the finally selected guidelines (n = 5) were reviewed comprehensively, a list of clinical guideline recommendations (n = 130) was developed in the form of a questionnaire and sent to 27 interdisciplinary specialists (cardiologists, nurses, psychologists, social workers, and spiritual caregivers) affiliated with medical universities of Tehran, Isfahan, and Yazd. These specialists had at least three years of experience in the field of heart disease and met patients during the study period (based on the participants' satisfaction/willingness). Each expert was required to evaluate the recommendations mentioned in the guideline based on the four criteria of "relatedness, comprehensibility, usefulness, and feasibility" on a scale dealing with the feasibility of recommendations ranging from 1 (the lowest) to 9 (the highest score).

In the next stage, the research group reviewed the questionnaire and calculated the mean score for each recommendation. The new questionnaire containing the calculated mean scores for each recommendation was presented in an online meeting with a panel of pundits to reach a consensus on the feasibility of items. Consequently, the recommendation scores within the ranges of 1–3.99, 4–6.99, and 9–7 were considered inappropriate, uncertain, and appropriate, respectively.[18] The final clinical guideline, including 126 recommendations, was accepted by the panel of experts after the systematicity, validity, transparency, viability, and reliability of the items were corroborated in the clinical setting of Iran after making the necessary revisions.

Ethical considerations

This study was approved by the ethics committee of Isfahan University of Medical Sciences. All attempts were made to prevent any types of biases in retrieving, reviewing, and reporting articles. (IR.MUI.NUREMA.REC.1400.123).

Results

In the first phase, the adaptation plan was drafted in the form of a proposal and registered. This research was funded by the Isfahan University of Medical Sciences.

In the second phase, 1501 pieces of data were retrieved from the initial search. Followed by removing the duplicates and guidelines that did not meet the inclusion criteria, 19 guidelines were studied thoroughly by the research team. In the revision process, guidelines focusing on a palliative dimension were omitted, and seven guidelines were evaluated in terms of their quality by five evaluators using the AGREE II. Later, the guidelines were evaluated and classified into highly recommended (standardized score ≥50% in all six domains), recommended by modifications (standardized score ≥50% in the overall quality assessment), and not recommended (standardized score ≥50% neither in the domains nor in the overall quality assessment) categories [Table 2]. The two guidelines that did not obtain the required feasibility scores were removed,[19,20] and the remaining five guidelines that obtained acceptable scores based on the AGREE II instrument were selected and adopted for further investigation.[5,21-24]

In the third phase, all recommendations were evaluated in terms of their acceptability based on the above-mentioned criteria. The results showed that only 17 items did not obtain the required feasibility scores. At the second phase of Delphi, 10 experts investigated these items in an online meeting and decided to remove or keep these recommendations after some revisions. Finally, four items were omitted, and 13 recommendations were maintained, followed by making the required modifications. As a result, a total of 126 recommendations were accepted and classified into three main categories of palliative care features, palliative care essentials, and organization of palliative care [Table 3].

Table 2: Clinical practice guideline domain scores using the AGREE-II *instrument

Guideline number	Clinical practice guideline title	Scope and purpose	Stakeholder involvement	Rigor of development	Clarity of presentation	Applicability	Editorial independence	Overall assessment	Classification level
1	Palliative care in heart failure NYHA class III and IV	100	100	52.90	92.20	76.60	100	93.30	Highly recommended
2	Living and dying with advanced heart failure: palliative care approach	64.40	63.30	8.75	82.20	40	6.66	60	Recommended with modifications
3	Clinical practice guidelines for quality palliative care	100	65.50	57.50	88.88	83.30	50	76.60	Highly recommended
4	Consensus document and recommendations on palliative care in heart failure of the Heart Failure and Geriatric Cardiology Working Groups of the Spanish Society of Cardiology	80	41.11	14.50	48.80	26.60	50	33.30	Not recommended
5	The 2011 Canadian Cardiovascular Society Heart Failure Management Guidelines Update: Focus on sleep apnea, renal dysfunction, mechanical circulatory support, and palliative care	81.10	42.20	20	60	21.60	46.60	30	Not recommended
6	Care for dying adults in the last days of life	95.50	92.20	93.70	93.30	73.30	73.30	93.30	Highly recommended
7	End-of-life care for adults: service delivery	95.50	92.20	93.70	93.30	73.30	73.30	80	Highly recommended

*The Appraisal of Guidelines for Research and Evaluation Instrument (AGREE II)

Discussion

The present study aimed to adapt the available CPGs for patients with HF in Iran using the ADAPTE method. In the first phase of Delphi, 17 recommendations did not receive the needed feasibility scores: participatory and interdisciplinary care, holistic care, patient-family participation in decision-making, providing care in every care environment, emotional support of the caregivers, training needed to increase cultural competence, and continuation of palliative care.

The category of participatory and interdisciplinary care indicates the significance of cooperation among different professional fields in the management of patients with HF in Iran. Similarly, findings of a study by Jasemi in Iran indicated that physicians had a limited view of interdisciplinary cooperation.[25] To fill this gap, the health team can be trained in the field of interdisciplinary cooperation, interdisciplinary and interprofessional decision-making sessions can be held, daily record forms can be designed and administered for patients using a team-based approach, the health personnel is suggested to be trained in this regard, and consultation, decision-making, and planning sessions are recommended among the team members.[26]

Based on the holistic care category, palliative care should be performed based on a holistic approach to taking care of patients with HF. It should not only ensure optimal management of physical symptoms but also identify and address the clinical, social, psychological, emotional, and emotional needs of the patients. According to Ghorbani, despite all educational efforts in developing holistic care, the provided care is focused on the patients' physical dimensions, so their mental and psychological dimensions are ignored. Although various factors are effective in developing the holistic view, including knowledge and awareness, personality traits of the team members, and interpersonal relationships, efforts should be targeted at institutionalizing the holistic view through education and removing its barriers by calling for serious attention of the authorities in the education and management fields.[27]

Participation of patients and their family members in the decision-making process requires the health care providers to consider the patients' mental capacity to participate in the decision-making process actively. In the case that the patient does not have the required capacity to make proper decisions, a process should be developed to receive the opinions of caregivers and individuals important to the patient.[23] However, families and patients in Iran's medical system play a diminished role in the treatment and care process, leaving this right to physicians and nurses.[28] To meet this problem, the necessary interventions should be carried out to educate individuals.

Provision of care in every environment received a low

Table 3: Classification of the adapted guideline recommendations

Main categories	Subcategories	Number of recommendations
Palliative care features	Participatory and interdisciplinary care	7
	Holistic care and symptom management	42
	Providing 24-hour care	3
	Providing unique care	4
	Participation of the patients and their families in decision-making	5
	Providing care in any care environment	4
Palliative care requirements	Training required by the team members	7
	Emotional support of the team members and caregivers	5
	Effective interaction	7
	Members' awareness of their duties	5
Organization of the palliative care	Comprehensive assessment	18
	Advanced care planning	7
	Management of care transfer to care environments	4
	Continuation of the palliative care	8

score because palliative care is provided to patients based on different patterns, such as hospital-based, hospice-based, and home-based palliative care. Despite the numerous benefits of home-based palliative care and the willingness of most patients to receive care services in their place of residence near their family members, this method of care is not commonly available in Iran. In other words, home-based palliative care has no place in the Iranian health system and is not supported by insurance services. Therefore, home-based palliative care should be considered as one of the health system priorities in Iran to provide patients with the opportunity to experience a peaceful life with their families during the disease process and the last days of their life.[29]

Emotional support of caregivers was another dimension that did not obtain the required score. Family caregivers often experience a range of challenges, such as loneliness, sadness, depression, nervousness, and denial of the death (of a dear one) during mourning periods. While the presence of friends and acquaintances often can calm them relatively, some individuals need more specialized support and services from health team members and specialists. Family caregivers are not supported during the mourning periods in Iran. Based on the literature, caregivers of patients with HF believed that they received little family and organizational support in emotional-financial dimensions and often felt lonely and disillusioned due to the lack of support.[30] The findings of another study in Iran stated that caregivers of patients with chronic diseases have rarely been studied,[31] which necessitates interdisciplinary experts to support the patients' family members and caregivers from disease diagnosis until after the patient's death.

Considering the low scores obtained regarding the **palliative care follow-up**, it should be noted that palliative care is at a nascent stage in Iran. Even the results of studies in countries that excel in palliative care reveal that patients usually do not receive palliative care after discharge and are readmitted within 28 days of discharge. Furthermore, the follow-up interaction is often incomplete, especially in general practitioners.[32] To continue palliative care, some efficient strategies were reported, such as palliative counselling, discharge planning, advanced care planning, and patient follow-ups. Moreover, some innovative solutions have been highlighted to meet the need for outpatient palliative care, such as the administration and feasibility of telemedicine and mobile health technologies in rural areas.[33] In this vein, establishing reliable relationships with a small number of key healthcare professionals has been recommended to receive proper care and provide easy access to help.[32,34]

The training needed to increase cultural competence also did not obtain the necessary score. In the field of providing sensitive cultural care, the wide variety of ethnic, linguistic, and cultural diversity among the Iranian population has challenged healthcare organizations.[35] Nonetheless, cultural education is not in good condition in Iran[36,37] since it has been neglected or seldom considered by policymakers and key decision-makers.[36] So, this competence should be initially evaluated among the palliative specialists, and then the needed curriculum can be designed to facilitate learning the basic knowledge about different cultures, communication skills, self-reflection strategies, and adding courses on cultural competence, sensitivity, and humanity. Cultural awareness can facilitate working with linguistically and culturally diverse patients by developing and improving this competence among interlocutors.[38] In this study, using an interdisciplinary panel of pundits from different fields of the health care area has provided us with the opportunity to collect a wide range of viewpoints and opinions on the guidelines. In turn, this can help to enhance the feasibility and acceptability of the guideline by stakeholders.

Among the limitations of this study, the adaptation process cannot be generalized to other settings since it was carried

out for Iran's health care system. In addition, collecting the viewpoints of patients and their families on the guideline's adaptability was not possible in the present study.

Conclusion

The final product of this study was an interprofessional guideline for palliative care in patients with HF that can be used as a model for the adaption of clinical guidelines in other health conditions with various settings. This guideline is a valid tool for interprofessional team members to provide palliative care to patients with HF.

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Conflicts of interest

Nothing to declare.

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