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Research Article

Needs Assessment and the Identification of Palliative Care Dimensions of the Essential Service Package for the Elderly with Alzheimer's Disease: A Mixed Exploratory Study

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Abstract

AIM: This study was conducted with the aim of assessing the needs and determining the care dimensions of the essential palliative care service package for the elderly with Alzheimer's disease.

METHOD: The mixed exploratory study was conducted in three phases. The first phase of the study was conducted in the form of a qualitative study and a literature review. This qualitative research was done through in-depth and semi-structured interviews with 19 qualified caregivers (11 informal caregivers and 8 formal caregivers) The samples were selected using the purposive sampling method by referring to hospitals, nursing homes, and active branches of the Alzheimer's Association in some provinces. In the second phase, the dimensions of palliative care were codified, and in the third phase, the prioritization and the validation of the dimensions of palliative care were performed in the form of two Delphi rounds.

RESULTS: Based on the results of the first phase of the study, the care dimensions of the service package were placed in eight categories based on National Consensus Project. In the second phase, the needs of Alzheimer's patients were arranged in the form of a questionnaire consisting of 8 parts, with 180 indicators. Then, in the third phase, the dimensions of the palliative care essential package were designed with 74 items in the form of 4 dimensions.

CONCLUSION: The dimensions of the essential service package of palliative care included a series of interventions as well as physical, psychological, cognitive, and spiritual support.

Keywords: Alzheimer's disease, Iran, palliative care, primary health care, service package

Introduction

Alzheimer's disease is a cerebrovascular degenerative disease that worsens over time. It is predicted that the number of patients with Alzheimer's disease will reach 82 million by 2030 and 152 million by 2050, that is, it will be tripled (World Health Organization, 2019). The prevalence of this disease in the Middle East is reported as 3.6% (Adlimoghaddam et al., 2018). It is estimated that 700,000 elderly people in Iran are affected by Alzheimer's disease, and every 11.5 minutes, 1 person is diagnosed with it (Iranian Association Alzheimers, 2018; Salehi, 2011). Alzheimer's disease is reported to be the second leading cause of death in this age group after ischemic heart disease (Naghavi et al., 2017).

The most important consequences of Alzheimer's disease include cognitive disorder and abstract thinking, the inability to perform daily life activities, impaired judgment, the inability to walk, the inability to communicate, the incontinence of urine and feces, and seizures. Eventually, the patient will be in need of continuous and accurate monitoring, as well as high-quality care and support, due to the conditions of the disease (Li et al., 2022; Lyketsos et al., 2011; Oh & Rabins, 2019; Walsh & Crumbie, 2007).

Caring for Alzheimer's patients exposes caregivers to adverse psychological consequences, including the physical, emotional, and economic pressures resulting from the disease, anxiety, and depression (Ashrafizadeh et al., 2021a; Kucmanski et al., 2016). The diversity and multiplicity of problems, as well as the personal, family, and social consequences caused by Alzheimer's disease, make it complicated to provide care for these patients and their caregivers (Iranian Association Alzheimers, 2016).

Since the management of Alzheimer's disease is complicated due to the variety of symptoms, and as the long process of this disease can impose high out-of-pocket costs to the families (Harris, 2007), the patients with Alzheimer's will need palliative care. Palliative care is an approach that improves the quality of life in incurable patients and their families through prevention, relieving pain and suffering, and supporting physical, emotional, psychological, spiritual, and social needs through

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early diagnosis and correct assessment and treatment (World Health Organization, 2020). In addition, the World Health Organization introduces palliative care as a human right (World Health Organization, 2020). Based on the results of the studies, the standards of care for patients with advanced Alzheimer's disease are poor, and there is a lack of high-quality evidence for palliative care in Alzheimer's disease (Hughes et al., 2007).

Palliative care, as a comprehensive type of care, considers all the needs of patients and requires a coordinated multidisciplinary team (Rassouli & Sajjadi, 2016). In most countries, nurses form the greatest part of the health system's manpower, who have the most contact with patients (Murrells et al., 2008). Nurses play an important role not only in raising the level of society's awareness and supporting people but also in caring for the patient's pain and disease-related symptoms and emphasizing the different aspects of the patient. That is why in most of the hospitals with palliative care systems, counseling, as well as care and treatment services are provided by nurses (Silbermann et al., 2012).

One way of providing quality care is to offer cost-effective service packages. The essential health service package is a set of essential and high-priority services, in the development of which the economic, social, cultural, and political conditions of the target community are taken into consideration. Besides, a prioritization process has been used to select the relevant interventions. The purpose of designing these packages is to rationally redesign the health care system, reduce public health care costs, create universal access, and establish justice in the distribution of health services (Vice-Chancellor Health Affairs, 2015). The implementation of clinical guidelines, on the one hand, improves the quality of life in Alzheimer's patients and, on the other hand, helps nurses with making treatment decisions based on scientific evidence. Developing care service packages can be the basis for providing services at the clinic (Rassouli & Sajjadi, 2016). Through using these packages in hospitals and outpatient clinics, the dispersion of performance can be prevented in different areas to some extent. It can also lead to patients, care providers, and families' satisfaction.

Since the lack of these packages in Iran has caused many challenges, such as patients and caregivers' lack of access to daily, short-term, and long-term care, insufficient and incomplete insurance coverage for home services, and the lack of knowledge of the disease and care, designing organized care programs in accordance with the society in the form of service packages is an unmet need in the country's health system for these patients (Rassouli & Sajjadi, 2016). The first step in designing service packages is to identify the needs and the dimensions in which care should be provided. Several studies show that many of the palliative care needs of Alzheimer's patients are unmet (Black et al., 2019; Cohen-Mansfield et al., 2015; Mazurek et al., 2019). If the patient's need is answered in an inappropriate way, it will be referred to as an unmet need (Sandman & Hofmann, 2019). Therefore, perceiving and responding to the needs of these patients and determining the care dimensions can directly affect how communication and care provision take place. Various packages have been designed for the care of Alzheimer's patients (Sun et al., 2021), but since the needs and the ways of responding to them vary depending on individuals' perception, which is affected by individual, cultural, and social differences (Zamanzadeh et al., 2014), conducting a research in this field, in the social and cultural context, will be useful, taking into account all the dimensions, the human and social values, the culture, and the relationships related to the society in which the elderly lives (Rostami et al., 2019). In this study, in order to provide the minimum comprehensive and integrated services, efforts were made to include all the services needed by these patients in the form of a palliative care essential service package.

Research Questions

1. What are the unmet palliative care needs of Alzheimer's patients?
2. What are the dimensions of palliative care, essential services package for the elderly with Alzheimer's disease?
3. What are the most priority palliative care needs of elderly with Alzheimer's disease?

Method

Study Design

The current study is a type of Health System Research (HSR). It has been designed in three phases from March 2019 to April 2022, using a mixed exploratory method. The study phases are presented in Figure 1.

Conceptual Frameworks

The conceptual framework of this research is based on the National Consensus Project (NCP). This project defines palliative care as an activity focusing on managing pain and other symptoms, assessing and supporting the caregiver's needs, and coordinating care, which leads to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. According to NCP, palliative care is a personal and family-centered approach to care, which helps the patients with serious illnesses and suffering from the symptoms and the stress of them to get rid of this suffering, and improves the patients and their families' quality of life. The NCP has considered eight care dimensions for the patients suffering from life-limiting and incurable diseases and has specified palliative care guidelines in these eight dimensions. These eight dimensions include care structure and process, the physical dimensions of care, the psychological dimensions of care, the social dimensions of care, the spiritual, religious, and existential dimension of care, the cultural dimensions of care, the dimension of patient care in the final stages of life, and the ethical and legal dimensions of care (Project, 2018).

The First Phase of the Study

The first phase of the study was conducted (March 2019-January 2020) in the form of two sub-studies. The first sub-study was a qualitative study with a directed content analysis approach, with the aim of *examining the perception of the stakeholders (family caregivers, official caregivers, and policy makers) of the palliative care needs of Alzheimer's patients* based on the framework of the National Consensus Project. This qualitative research was done through in-depth and semi-structured interviews with 19

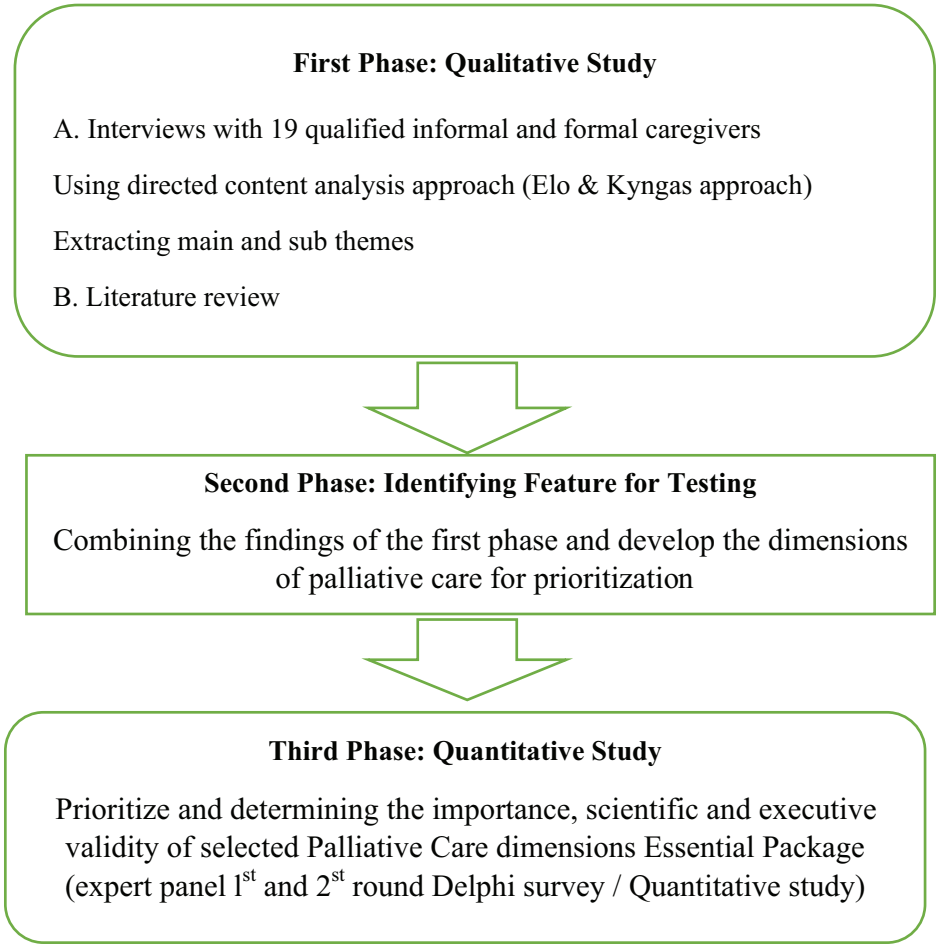

Figure 1.
Study Step Exploratory Mixed Methods Design Based on Creswell et al. 2018.

qualified caregivers (11 informal caregivers and 8 formal caregivers) with a mean age of 46.05 ± 10.98 years. The inclusion criteria for the family caregivers consisted of being able to speak Farsi, being at least 18 years old, being the patient's first-degree relative, having been responsible for taking care of the patient for at least 6 months, not suffering from psychiatric disorders, and being willing to express one's experiences regarding taking care of a patient with Alzheimer's disease. The healthcare providers with at least 1 year of experience providing healthcare services for the elderly with Alzheimer's disease were also invited to take part in the research.

Considering the research community, the participants were selected from among experts, care providers, and the family caregivers of Alzheimer's patients using purposeful sampling through referring to hospitals, nursing homes, and active branches of Alzheimer's Association in some provinces. Sampling continued until data saturation was reached. The criterion of the research team for reaching data saturation was the previous data's being repeated, that is, the researcher's confronting data which repeated regularly. For instance, when the researcher received similar and repetitive comments in the interviews, she could guess that she had reached data saturation. However, after realizing that data saturation was reached, some additional interviews were conducted to confirm theoretical saturation.

Data analysis has been done using Elo and Kyngas method, in three phases of preparation, organization, and reporting. In order to assess the accuracy and the validity of the study, the criteria provided by Lincoln and Guba were used: credibility (prolonged engagement with the data), spending enough time, combining several methods (interviewing, observation), review and investigation by the research team (Peer Check), dependability (auditing the phases of conducting the research by an external observer), confirmability (auditing the research in detail by the audience and the readers), and transformability (describing the characteristics and the experiences of the participants through providing details) (Guba & Lincoln, 1981).

The second sub-study was conducted with the aim of *reviewing clinical guidelines and the related protocols*. Searching was done using the keywords *evidence-based clinical guideline, guidelines, practice guidelines, palliative care, supportive care, end-of-life care, respite care, spiritually support, patient care, physical support, psychological support, social support, moral support, legal support, cognitive disorders, dementia, Alzheimer's diseases, nurses,* and *nursing care*.

The articles published from 1990 to 2021 were investigated in the databases *Scopus, PubMed, Web of Sciences, ProQuest, CINAHL, Medline Plus, EMBASE, Cochrane Library, Google Scholar*; important specialized journals in the field of palliative care and Alzheimer's; scientific and administrative documents; World Health Organization's reports and website; governmental websites and other valid websites; as well as major national and regional websites related to the organizations active in the fields of dementia, Alzheimer's disease, cognitive disorders, and palliative care. A prism diagram has been provided for further details. Identification and validation of the clinical guidelines and the related protocols were done in three phases: asking clinical questions and searching for the clinical guidelines, evaluating the extracted clinical guidelines using the tool *AGREE* (Appraisal of Guidelines for Research & Evaluation), and extracting the recommendations. This tool assesses the accuracy and the clarity of the content and the structure of the clinical guidelines. The purpose of using this tool is to evaluate, criticize, and provide a framework for examining the quality of clinical guidelines, which includes 23 main items in six domains: *vision and purpose, the stakeholders' participation, methodological accuracy and quality, expressiveness and presentation, applicability*, and *independence in editing* (Collaboration, 2009).

The Second Phase of the Study

At this phase (from January to September 2020), the findings of the first phase of the study (interviewing the stakeholders and reviewing the guidelines and the related texts) were consolidated. Based on the framework of the National Consensus Project (NCP), the participants' opinions, the official documents of the Iranian health system in the field of aging, Alzheimer's disease, and palliative care, as well as the guidelines of the World Health Organization, the proposed findings were arranged in the form of a questionnaire including 8 sections: *Care structure and process, The physical dimension of care, The psychological dimension of care, The social dimension of care, The religious/spiritual/existential dimension of care, The cultural dimension of care, The ethical-legal dimension of care,* and the dimension of *Patient care at the end-of-life stages*. Then, a list containing the palliative care needs of the elderly with Alzheimer's disease was prepared to be handed to the experts for prioritization using Delphi method.

The Third Phase of the Study

This phase was carried out (September 2020-April 2022) in two rounds in order to *prioritize the palliative care needs of the patients with Alzheimer's disease* in the form of a modified classic Delphi panel using the ten steps proposed by Fawle (Rauch, 1979). The questionnaire developed in the second phase was given to 48 health care providers, experts, and policy makers, who had enough experience and knowledge to comment on the topic under discussion and expressed their willingness to participate in the study, for the first round of Delphi. In this study, the members of the Delphi panel were selected through purposeful and snowball sampling methods. They were asked to prioritize the indicators mentioned in the questionnaire, considering their level of importance, as very high (4), high (3), medium (2), and low (1), based on their own views and experience. In this phase, the data was analyzed using Statistical Package for the Social Sciences software and descriptive statistics, and the mean and the standard deviation of the scores of each indicator were determined. Therefore, based on the approaches of similar studies (Ansari, 2018; Ansari et al., 2018), the indicators with high means (3 and above) were extracted. In the second round of Delphi, the priorities identified in the first round were examined in order to determine the care dimensions' level of importance, as well as their scientific and operational credibility. The dimensions which had priority were provided, in the form of a questionnaire, to 12 panelists of the first round of Delphi through e-mail. The participants were asked to express their opinions about each of the indicators and each criterion separately and in a range including low (1), medium (2), and high (3). Furthermore, in this phase, descriptive statistics and SPSS software were used for data analysis, too. Finally, after gathering the opinions of the expert group, agreeing or disagreeing with each of the items was determined by the mean and the standard deviation, and the items with an average lower than 2 were removed. At last, the options that were agreed upon by the panel group were identified as the needs and will be used in the form of palliative care dimensions of the essential package for Alzheimer's patients.

Statistical Analysis

Descriptive statistics (frequency, graphical representation, mean, standard deviation, median) were used to analyze the Delphi data.

Ethical Consideration

This study was approved by the Ethics Committee of Ahvaz Jundishapur University of Medical Sciences (IR.AJUMS.REC.1398.781). The ethical considerations in this study included the voluntary nature of participation in the research, provision of the participants with explanations about the study objectives, obtaining written informed consent forms, confidentiality of the participants' information, anonymity, the participants' right to withdraw from the study, and trustworthiness in using information and resources.

Results

The Results of the First Phase of the Study

In the first sub-study, 989 codes were extracted from the analysis of the data obtained from the interviews. After removing the duplicate codes and merging the similar codes, according to the framework of the National Consensus Project, they were classified into the 8 main categories: *Care structure and process, The psychological dimension of care, The physical dimension of care, Patient care at the end-of-life stages, The social dimension of care, The cultural dimension of care, The ethical-legal dimension of care, and The spiritual/religious/existential dimension of care, as well as* 21 subcategories, and 16 sub-subcategories (Table 1). The detailed information on the results of this sub-study has been published in two articles (Ashrafizadeh et al., 2021a, 2021b).

In the second sub-study, in order to extract the appropriate clinical guidelines, firstly, the clinical question was developed based on the PIPOH method; 85 clinical guidelines, clinical

Table 1.
The Main Categories and the Subcategories Extracted from the Directed Content Analysis of the Interviews

Main categories	Sub-categories
Structure and process of care	Need for development of diagnostic and screening services
	Need for specialized care services
	Need for home care services
	Need for hospice services
Psychological and psychiatric aspects of care	Need for Psycho-emotional needs management
	Need for Psycho-cognitive needs management
	Need for psychological needs management of informal caregivers
Physical aspects of care	Need for controlling progressive physical symptoms
	Need for controlling the secondary complications of treatment
	Need for controlling the physical symptoms of informal caregivers
Spiritual, religious, and existential dimensions of care	Stability and endurance
	Spiritual growth
	Satisfaction with care
Social aspects of care	Need for support on the part of the government and social systems
	Need for empowerment of informal caregivers
Cultural aspects of care	Need for destigmatization
	Need for cultural interventions
Ethical and legal aspects of care	Need for ethical care
	Attention to patients' undeniable rights
Care of the patient nearing the end of life	Need for comfort care
	Need for selecting a preferred place for death

practices, and evidence-based programs related to the purpose of the study were extracted using the relevant keywords (Figure 2). The initial assessment of the retrieved clinical guidelines was performed by the researchers, and the quality of 12 guidelines was evaluated using the Farsi version of the critical appraisal tool and AGREE research guide (Table 2). After selecting the evaluated clinical guidelines and reviewing the sources and the evidence, the recommendations regarding NCP dimensions were extracted with 65 indicators.

The Results of the Second Phase of the Study

After merging the findings of the first phase, a questionnaire was developed, consisting of eight sections: *Care structure and process, The psychological dimension of care, The physical dimension of care, Patient care at the end-of-life stages, The social dimension of care, The cultural dimension of care, The ethical-legal dimension of care, and The spiritual/religious/existential dimension of care,* with 180 indicators (115 indicators obtained from the qualitative study, and 65 indicators obtained from the clinical guidelines and guides).

The Results of the Third Phase of the Study

In this section, the indicators regarding the palliative care dimensions of the essential needs of the elderly with Alzheimer's disease in Iran were extracted, consisting of 4 items and 74 indicators; 35 questionnaires had been answered completely. Four items (*The cultural dimension of care, The ethical-legal dimension of care, The social dimension of care, and patient care at the end-of-life stages*) did not receive sufficient scores and priority according to experts' opinions; therefore, they were decided to be included in the augmented package in the next studies. Considering that none of the indicators had a mean lower than 3, the number of indicators remained 74 at the end. In Table 3, the mean score and the standard deviation of a sample of the items, along with the related domains and sub-domains of the criterion of *importance*, are presented. In the second round of Delphi validation, the level of importance, as well as the scientific and the operational acceptability of the palliative care dimensions of the essential package for the patients with Alzheimer's disease were examined. As none of the indicators had a mean score lower than 2, the number of the indicators finally remained 74. Table 4 shows the mean and the deviation of the domains and the relevant sub-domains of the criteria of importance, scientific acceptability, and feasibility.

The findings of Table 4 show that in the dimension of *care structure and process*, the domain of *need for hospice services*, and in *the physical dimension of care*, the domain of *the need to control progressive physical symptoms* have gained lower scores regarding the indicators of *importance*, *scientific acceptability*, and *feasibility* compared to other domains. In *the psychological dimension of care*, the domain of *the need to manage the psychological symptoms in informal caregivers* has gained a lower score regarding the indicator of *feasibility*, and in *the existential/religious/spiritual dimension of care*, the domain of *spiritual distress* has gained a lower score regarding the indicators of *importance*, and *scientific acceptability*, and the domain of *spiritual care* has gained a lower score regarding the indicator of *feasibility*.

Discussion

This study was conducted with the aim of identifying palliative care needs and determining the care dimensions in order to be applied in designing the palliative care essential service package for the elderly with Alzheimer's disease and their family caregivers in the primary health care system in Iran. These dimensions are discussed in the form of care structures and processes, the physical care needs, the psychological care needs, and spiritual, religious, and existential care needs.

Based on the findings of the present study, *care structure and process*, includes the domains of *the need for the development of diagnostic and screening services, the need for specialized care-treatment services, the need for home care services, and the need for hospice services*. The provision of palliative care services necessarily requires structures each undertaking the task of providing a part of these services (Ashrafizadeh et al., 2021a, 2021b). In this dimension, the indicator of *providing care in the hospice* has received the lowest mean score compared to other indicators. Establishing hospice centers and providing

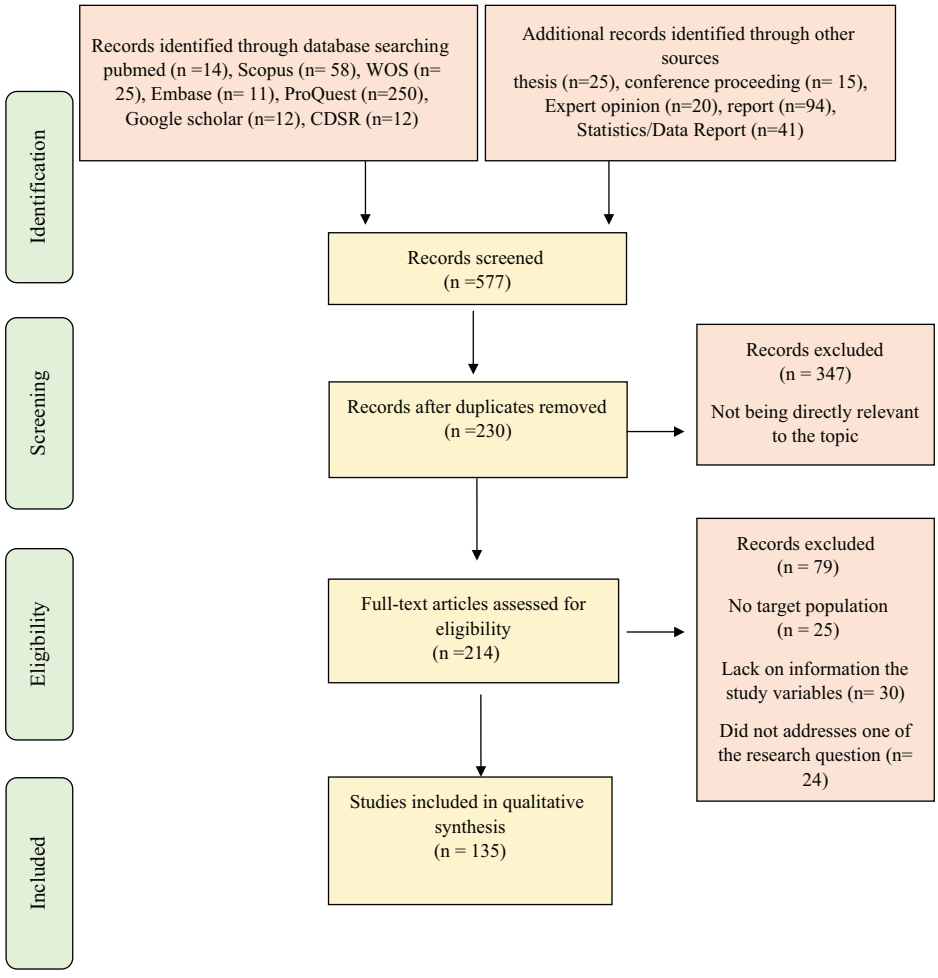

Figure 2.
Prisma Flowchart for Search Strategy and Its Results.

comprehensive care in these centers is a perceived need in Iran's health system (Beiranvand et al., 2022); the results of the studies have emphasized setting up and establishing the centers dedicated to providing care in the end-of-life stages and hospice services. However, according to experts, the feasibility of these centers is lower in comparison with other care delivery structures (Ansari et al., 2018, 2019; Borhani et al., 2014; Valiee et al., 2012). Caring for end-of-life patients in the special units of hospitals creates many challenges for nurses and other members of the treatment team, among which the exorbitant costs of hospitalization, providing useless care, psychological pressure, and moral distress (Ansari et al., 2018; Borhani et al., 2014; Valiee et al., 2012). Patients and their caregivers' cultural, social, and demographic features have a major impact on the acceptance and use of hospice services, because people's cultural, ethnic, and racial background influences their end-of-life decisions and preferences, as well as individuals' perceptions of the quality of life and palliative care (Aseyedali et al., 2019; Fallahi et al., 2017). The Iranian society has a wide ethnic diversity and various subcultures, and these cultural differences affect their beliefs and health behaviors; choosing the place of receiving care, how to go through end-of-life stages, and the place of death is rooted in their culture (Mogadasian et al., 2014; Saccomano & Abbatiello, 2014). The results of a study in Iran show that most of the study samples tend to receive end-of-life care preferably at home, and then in hospitals and inpatient centers (Heidari et al., 2018). Therefore, the establishment of these centers requires attention to individuals' cultural differences, conducting more research, and providing the necessary conditions and facilities for its implementation. On the other hand, *developing assistive technologies and remote care* was one of the indicators of *care structure and process*, which has received the highest mean score compared to other indicators. Assistive Technologies (AT), mechanical and electronic devices, and the robots used in dementia and Alzheimer's disease care can be generally classified as reminder or stimulation devices, monitors, the detectors for supporting safety, safer walking technologies, communication devices, and the devices for support patients' leisure activities (Fleming & Sum, 2014). Assistive technologies help to improve and maintain the quality of life, increase safety, improve patients' cognitive and social functioning, and reduce treatment costs (Daly Lynn et al., 2019; Meiland et al., 2017). Iran is facing two basic challenges in this regard: firstly, the care centers in Iran are at the beginning of the path of utilizing information and communication technologies and, secondly, either there is not sufficient awareness and knowledge

Table 2.
The Quality Evaluation Results of the Clinical Guidelines using AGREE in Terms of Percentage

Guidelines name	Scope and purpose	Stakeholder involvement	Rigor of development	Clarity of presentation	Applicability	Editorial independence	Final results
Dying Well Improving Palliative and End-of-Life Care for people with dementia	55	50	23	77	0	0	Recommended.
Palliative care and dementia	100	85	80	75	55	50	Recommended.
End-of-Life and Palliative Care for People with Dementia Framework (A framework for developing local palliative care service delivery guidelines for people with dementia)	66	50	38	75	55	0	Recommended.
New Zealand Framework for Dementia Care	100	50	47	100	100	100	Highly recommended.
California Workgroup on Guideline's for Alzheimer's Disease Management	67	94	72	83	60	0	Recommended.
British Columbia Ministry of Health	78	70	62	72	50	64	Recommended.
European Federation Neurological Sciences Dementia	80	52	60	91	16	94	Highly recommended.
Guidelines for Care: Person-centered care of people with dementia living in care homes	33	50	71	50	0	0	Recommended.
Palliative care for advances dementia and Alzheimer guidelines and standards for Evidence-Based care	88	50	76	100	88	50	Recommended.
Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and other Dementias	100	83	100	100	100	100	Highly recommended.
Dementia A NICE–SCIE Guideline on supporting people with dementia and their careers in health and social care	100	100	100	100	100	100	Highly recommended.
NICE clinical guideline Dementia: supporting people with dementia and their careers in health and social care	88	50	100	100	66	100	Highly recommended.

of using information and communication technologies for the managers and the investors of care centers, home care services, and nursing homes, or it is not desirably up-to-date. Regarding using information and communication technologies, the centers under the supervision of the welfare organization are at a lower level in comparison with other existing centers. There is a wide range of challenges on the way of using information and communication technology in the centers providing home care, which can be categorized from the aspects of technological issues, human factors, and management factors. Then the existing challenges can be prioritized according to the needs of the centers in order to prepare a guiding map for the managers and the investors (Ajami & Chelongar, 2019). It seems that using technology is inevitable in this age. Through providing round-the-clock services and following up patients, the consequences of out-of-hospital care can be investigated in order to improve it, and Iran's health system should try to overcome these challenges and obstacles.

In the physical dimension of care, palliative care assessment, care planning, and the treatment of physical symptoms have been described with an emphasis on comprehensive and key patient care (Project, 2018). The indicator *using pharmacological interventions to control non-cognitive and behavioral symptoms* has obtained the highest mean, and the indicator assistance in training/management of neurological and behavioral symptoms by informal caregivers has gained the lowest in comparison to other indicators. As the physical care of Alzheimer's patients, especially the ones at the end-of-life stages, is closely related to perceiving the patient's goals regarding psychological, emotional, and spiritual care, another care dimension of this essential service package was the psychological dimension of care.

Table 3.
The Main Domains and Items Extracted from the Findings of Phase 1 (Qualitative Study and Literature Review), and the Mean, Minimum, and Maximum Scores of the Items in Phase 2 (Minimum Mean Score = 1, Maximum Mean Score = 4)

Domains	Subdomains	Items	Mean ± SD
care structure and process	Need for specialized care services	Developing a comprehensive care plan agreed upon by the Ministry of Health to take into account the changing needs of the patients with Alzheimer's disease and their primary care providers	4.00 ± 00
		Clarifying the role and the duties of the specialists, employees, and different agencies involved in providing care to the patients with Alzheimer's disease in order to provide comprehensive services	4.00 ± 00
		The need to develop assistive technology and telecare	3.87 ± 0.35
		Separation and stratification of patients (disease stages one to four) in all care centers	3.68 ± 0.67
		Creating an integrated system for patient referral	3.65 ± 0.72
	Need for developing diagnostic and screening services	Developing physical rehabilitation services (occupational therapy, physiotherapy, exercise, etc.)	3.85 ± 0.55
		Developing mental and cognitive rehabilitation services in order to strengthen the memory	3.85 ± 0.35
		Developing screening services to prevent disease progression	3.85 ± 0.42
		Developing diagnostic services to differentiate Alzheimer's disease from other cognitive disorders in the early stages of the disease	3.62 ± 0.73
	Need for home care services	Providing home care services and expanding them	3.94 ± 0.23
		Household structural changes (such as removing the stairs, lighting adjustment, providing a ramp, taking measures to secure the entrance to prevent leaving home, etc.) according to the patient's condition	3.88 ± 0.40
		Easy access to essential medicines at home based on the patient's symptoms	3.71 ± 0.62
		Observing the process of caring for a patient with Alzheimer's disease at home by the treatment team	3.60 ± 0.69
		Evaluating and monitoring the medical equipment used at home	3.45 ± 0.74
	Need for hospice services	Providing hospice care at home in case there are existing family caregivers	3.71 ± 0.71
		The existence of centers for taking care of Alzheimer's patients in the final stages	3.62 ± 0.68
		Providing care in hospice centers	3.37 ± 0.84
Physical aspects of care	Need for controlling progressive physical symptoms	Using pharmacological and non-pharmacological interventions such as aromatherapy, multi-sensory stimulation, music therapy and/or dance therapy, therapy with the help of pets, and massaging in order to control the non-cognitive and the behavioral symptoms	4.00 ± 00
		Helping to teach/manage behavioral symptoms such as unusual behaviors, wearing inappropriate clothes, the inability to regulate water temperature, the inability to take a bath, and go to the toilet by informal caregivers	3.85 ± 0.35
		Helping to train/manage the neurological symptoms such as the loss of consciousness; impaired swallowing, speech, and body fitness by formal and informal caregivers	3.76 ± 0.41
		Helping to train/manage the patient's musculoskeletal symptoms such as the inability to stand and walk without assistance, long-term immobility, and osteoporosis by formal and informal caregivers	3.71 ± 0.61
		Helping to train/manage the gastrointestinal symptoms such as nausea, vomiting, constipation, appetite loss, etc. by formal and informal caregivers	3.68 ± 0.57
		Helping to train/manage the general symptoms such as infection, appetite loss, itching, fatigue, cachexia, etc. by formal and informal caregivers	3.63 ± 0.68
	Need for controlling the secondary complications of the treatment	Managing the secondary complications of the treatment such as the complications of polypharmacy, drug interactions, and surgeries by official caregivers	3.65 ± 0.68
	Need to control the physical symptoms in informal caregivers	Managing the general symptoms of informal caregivers such as fatigue, general weakness, and sleep disorders as a result of changing day and night hours by formal caregivers	3.71 ± 0.51
		Managing the musculoskeletal symptoms of informal caregivers such as the backache caused by moving the patient for a long time by formal caregivers	3.68 ± 0.63

(*Continued*)

Table 3.
The Main Domains and Items Extracted from the Findings of Phase 1 (Qualitative Study and Literature Review), and the Mean, Minimum, and Maximum Scores of the Items in Phase 2 (Minimum Mean Score = 1, Maximum Mean Score = 4) (Continued)

Domains	Subdomains	Items	Mean ± SD
Psychological and psychiatric aspects of care	Need for managing the patients' psycho-emotional needs	Using pharmacological and non-pharmacological interventions such as memory therapy, multi-sensory stimulation, therapy with the help of pets, and exercising in order to control the cognitive and the psychosocial symptoms such as overcrowding, the lack of privacy, inactivity, insufficient caregiver attention, poor communication, and conflicts between Alzheimer's patients and their caregivers	4.00 ± 00
		Using pharmacological interventions to control violence and aggression in patients	4.00 ± 00
		Using physical restraint in compliance with the relevant standards (hiring trained people who do not harm the patient, and who act calmly, but firmly and confidently) following medical prescription, in case other methods of restraining the patient in order to control violence have not been applicable or successful, as well as tension reduction techniques	3.93 ± 0.35
		using pharmacological interventions along with cognitive behavioral therapy to manage anxiety and depression	3.81 ± 0.52
		Helping to train/manage the psychological needs of patients such as depression, anxiety, restlessness, isolation, and mood disorders, etc. by formal and informal caregivers	3.79 ± 0.41
		Helping to train/manage the emotional needs of patients such as the lack of communication with others and family, the lack of the ability to express interest, etc. by formal and informal caregivers	3.76 ± 0.44
	Need for managing the patient's psycho-cognitive needs	Trying to create a familiar care environment through minimizing transferring, and using permanent and fixed caregivers in order to reduce the patient's cognitive impairment	4.00 ± 00
		Helping to train/manage the cognitive needs of patients such as the loss of cognitive skills, memory, forgetfulness, judgment, and insight by informal caregivers	3.91 ± 0.28
		Using pharmacological interventions for cognitive symptoms and the maintenance of function in Alzheimer's patients	3.87 ± 0.35
		Managing the cognitive needs of patients such as the loss of cognitive skills, memory, forgetfulness, judgment, and insight by formal caregivers	3.85 ± 0.35
	Need for managing the psychological needs of informal caregivers	Individual or group psychological training, support, and informational support using the phone and the Internet for caregivers in order to prevent neurological disorders	4.00 ± 00
		Pharmacological and non-pharmacological interventions to manage the psychological needs of informal caregivers	3.82 ± 0.45
		Managing the psychological needs of informal caregivers such as depression, anxiety, discomfort/sadness, and anger by official caregivers	3.77 ± 0.54
		Using screening tools to identify the psychological problems of informal caregivers	3.31 ± 0.83
Spiritual/religious/existential dimension of care	Spiritual distress	Evaluating frustration and spiritual distress in the family	3.71 ± 0.51
		Evaluating hopelessness and spiritual distress in patients in the early stages of the disease	3.54 ± 0.70
	Spiritual care	Identifying the spiritual needs of the patients and their families	4.00 ± 00
		Using the indicators related to spirituality in order to increase independence, self-esteem, and the social interactions between the patients and their caregivers, and reduce burnout caused by care	3.85 ± 0.75
		Using adaptive spiritual methods to increase resilience and stability in caregivers and patients	3.77 ± 0.49
		Evaluating the patients and their families' satisfaction with the provision of spiritual services	3.65 ± 0.59
		Providing counseling and spiritual care for patients and their families	3.62 ± 0.62

This dimension is one of the most important dimensions of care in the national consensus project; the palliative care IDT team should systematically examine the psychological and psychiatric aspects of care in this group of patients (Project, 2018). The indicator *non-pharmacological interventions such as memory therapy, multi-sensory stimulation, therapy with the help of pets, and exercising in order to control psychological symptoms (depression, anxiety, etc.) in Alzheimer's patients* has gained the lowest mean, and the indicator *using pharmacological interventions in order to control anxiety and depression symptoms* has obtained the highest compared to other indicators. In this study, using non-pharmacological interventions for managing physical and psychological symptoms has lower scientific capability and feasibility in Iran, compared to pharmacological interventions. Non-pharmacological interventions, most of which are classified as TCM-based interventions, are defined as any intervention aimed at improving health or well-being which does not require taking any medicine (Laurence, 2010). The results of the study conducted by Rassouli et al. show that the most important challenges and potential obstacles to the use of Traditional & Complementary Medicine (TCM) services from the perspective of Iranian experts, include the negative attitudes of doctors

Table 4.
The Mean and the Standard Division Scores of Importance. The Scientific Acceptability and the Feasibility of the Sub-Domains in Phase 3 (Minimum Mean Score = 1, Maximum Mean Score = 3)

Domains	Subdomains	Importance (Mean ± SD)	Scientific acceptability Mean ± SD	Feasibility (Mean ± SD)
Care structure and process	Need for specialized care services	2.99 ± 0.02	3.00 ± 00	2.67 ± 0.50
	Need for developing diagnostic and screening services	3.00 ± 00	3.00 ± 00	2.69 ± 0.46
	Need for home care services	2.98 ± 0.03	3.00 ± 00	2.61 ± 0.59
	Need for hospice services	2.96 ± 0.10	2.93 ± 0.20	2.42 ± 0.76
Physical aspects of care	Need for controlling progressive physical symptoms	2.99 ± 0.02	2.99 ± 0.02	2.83 ± 0.37
	Need for controlling the secondary complications of the treatment	3.00 ± 00	3.00 ± 00	2.90 ± 0.30
	Need to control the physical symptoms in informal caregivers	3.00 ± 00	3.00 ± 00	2.85 ± 0.35
Psychological and psychiatric aspects of care	Need for managing the patients' psycho-emotional needs	2.97 ± 0.06	2.98 ± 0.05	2.77 ± 0.43
	Need for managing the patients' psycho-cognitive needs	2.97 ± 0.07	2.97 ± 0.07	2.76 ± 0.43
	Need for managing the psychological needs of informal caregivers	2.97 ± 0.07	3.00 ± 00	2.74 ± 0.48
Spiritual/religious/existential dimension of care	Spiritual distress	2.90 ± 0.30	2.90 ± 0.30	2.72 ± 0.64
	Spiritual care	2.98 ± 0.06	2.97 ± 0.09	2.67 ± 0.66

and medical staff towards these services, the lack of knowledge and awareness of the concept of TCM, geographical factors (such as distance and access), the gap between the patients' expectations and the goals of the plan of integrating these services (Shirinabadi Farahani et al., 2022), the inconsistency of TCM methods with the codes, patients' cultural and religious beliefs (Ben-Arye et al., 2012), and the uncertainty of the quality of services and the effects of TCM, which are the common concerns among all the stakeholders, i.e. patients, TCM specialists, and traditional medicine practitioners (Chan et al., 2020). This is partially caused by the lack of regulation and standardization of CAM practitioners and their practice standards, as well as the safety and the efficacy of TCM products (World Health Organization, 2013). Although non-pharmacological treatments have been recommended as the primary treatment for the management of behavioral and psychological symptoms of dementia (BPSD) in the patients with dementia and Alzheimer's disease, pharmacological treatment is required in many conditions. Medications, including antipsychotics, antidepressants, sedatives and hypnotics, mood stabilizers, cholinesterase and amantadine inhibitors are widely used in clinical practice for these patients (Wang et al., 2016). Since pharmacological treatments are insufficient and ineffective in some stages and, lose their effect when the disease becomes resistant, in the long run, and as they are associated with disrupting the hormonal balance, side effects, and high costs (Ahadi et al., 2019), using non-pharmacological interventions and rehabilitation is very helpful, as all international guidelines have referred to their effectiveness in disease management.

Another dimension of care to consider in the palliative care essential service package was the *religious/ spiritual/existential dimension of care*. Spirituality is recognized as a fundamental aspect of compassionate, patient- and family-centered palliative care that appears to be a favorable resource for coping with illness and the challenges of patient care (Ferrell et al., 2018). The results of this study show that counseling and spiritual care for Alzheimer's patients has gained the lowest mean score compared to other indicators from the experts' perspective. Spiritual care in Alzheimer's disease may be neglected (Bonelli & Koenig, 2013; Ennis & Kazer, 2013; Van der Steen et al., 2014). For example, in a hospital in Britain, it was recorded that the religious beliefs of patients with dementia were lower than those of other patients (Sampson et al., 2006). Similarly, in a nursing home in the USA, the patients with cognitive impairment received less support or care regarding their spiritual needs from the center's staff (Daaleman et al., 2008), and despite the efforts that have so far been made in the field of spiritual health training, the nurses who provide spiritual care are in the minority (Adib-Hajbaghery, 2014). The previous studies in different countries have identified some barriers to providing spiritual care for patients (Pesut, 2002). In certain religious environments like Iran, where spirituality and religion are intertwined, there are also barriers to providing care, as a result of which the spiritual needs of patients may be neglected for various reasons (Farahani et al., 2019; Memaryan et al., 2015). The most important obstacle to providing spiritual care in Iran is the lack of time and the fear of patient discomfort, which leads to their spiritual needs' remaining unknown (Farahani et al., 2019). Given that one of the goals of palliative care is paying attention to spiritual approaches, the challenges in this field should be identified. With the organizational and managerial support of health service providers, the provision of sufficient workforce, the revision of the strategies governing care environments regarding the allocation of the services of health service providers, the designing and the implementation of theoretical and practical training courses in the form of in-service training programs, it will be possible to solve the existing problems and promote the provision of spiritual care.

Using the indicators related to spirituality in order to increase self-efficacy, independence, and self-esteem in caregivers and

patients has received the highest mean score in this dimension compared to other indicators. Spirituality and religiosity are identified as important resources in the patients with cognitive disorders and the individuals who live with stressful life events, problems, and deprivations, which give individuals more ability to manage their problems through creating a strong inner sense (Salamizadeh et al., 2017). When an elderly person is diagnosed with Alzheimer's disease or other cognitive disorders, it can give a serious shock to the person, which questions not only their identity, but also the spiritual process itself. This new situation can lead to the deepening of this process, lead patients to continue their spiritual growth to transcend their personal boundaries (Agli et al., 2015). Snyder reports that a woman with Alzheimer's disease stated that her faith had strengthened after her diagnosis and that her faith had helped her to accept the disease. This researcher states that there is evidence of searching for meaning in Alzheimer's patients, who are relieved from worrying about an uncertain future by leaving their lives to a third party, i.e. God (Snyder, 2003). Other studies (MacQuarrie, 2005; Phinney et al., 2002) have shown that in the early phases of Alzheimer's disease, patients actively tried to adapt and cope with their memory loss, maintain self-worth, and keep the feeling of being normal. They compensated by relying on others, finding ways to be helpful, and focusing on the good things in life (MacQuarrie, 2005; Phinney et al., 2002). It seems that creating an interactive environment for this group of patients is very helpful. In such an environment, family caregivers and the individual should focus mainly on empowering the individual so that he/she can maintain his/her integrity as an individual (Dalby et al., 2011). Moreover, family relationships, as an important source for searching for meaning (Trevitt & MacKinlay, 2004), and emphasizing helping others, as a means of maintaining the continuity of the patient, will play a significant role in patients' self-efficacy (Dalby et al., 2011). Although most studies show the positive effects of spirituality and religion on the health outcomes of the patients with dementia and Alzheimer's disease, it should be noted that these concepts alone do not allow improving the health outcomes, and by facilitating better outcomes, promoting coping strategies after diagnosing the disease and during its daily management, helping to adapt to cognitive and behavioral disorders, and improving the quality of life will help to treat the patient (Agli et al., 2015). Therefore, paying attention to this dimension of care along with other care and support methods can facilitate treatment, which should not be neglected.

Study Limitations

One of the limitations of the current study was the conditions during the COVID-19 pandemic, which caused challenges due to the limitation of communication and individual interactions, the closure of gatherings, and the use of the Internet for conducting interviews and meetings with professors, experts, and the research population.

Conclusion and Recommendations

The dimensions of the palliative care essential service package for the elderly with Alzheimer's disease (EPPCAD) include a set of interventions, as well as physical, mental, and spiritual support. Undoubtedly, paying attention to the diverse and unmet needs of Alzheimer's patients, and determining the care dimensions will bring about positive effects for the patient and informal caregivers. This issue is of greater importance in Iran, which will be facing the phenomenon of population aging in the next few years. The findings of the current research can be used in various fields of education, research, clinic, and to empower caregivers in order to provide a comprehensive care. In addition, it is applicable in policy making, launching relevant services in the country, and developing the palliative care network, through identifying the needs of palliative care and determining the dimensions of care to be used in designing the palliative care essential service package for the elderly with Alzheimer's and their family caregivers. It can also be tested practically, and if proven to improve the quality of life in Alzheimer's patients and their families, to be cost-effective, and to have other benefits, it can be developed. On the other hand, through using up-to-date clinical guidelines in education, it will be possible to help improve students' performance and update their knowledge. Finally, in order to provide quality services, interdisciplinary and team collaboration is necessary, which requires developing the culture of team care provision among care providers, and it is necessary to explain these care dimensions along with human resources and care settings in another study.

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