



# The Lack of Systematic Training for Health Care Providers, A Challenge for Providing Pediatric Palliative Home Care: A Comparative Study

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#### Abstract

**Background:** The growing prevalence of chronic diseases in children has increased their need for palliative care. We aimed to compare pediatric palliative care and home care training in Iran and in the selected countries.

*Materials and Methods:* This comparative study was conducted based on the classifications of palliative care for children and using databases such as Scopus, Science Direct, Ovid, ProQuest and Medline, websites affiliated with communities and associated with palliative care and home care services and according to the framework of World Health Organization's Public Health Road Map. The selected countries consist of England, Canada, Australia and South Africa, where home care services are provided for children in addition to palliative care.

#### Results

There is a pediatric palliative care training program for doctors in the selected countries. Home care is part of these programs in these countries. Despite the lack of an independent nursing course in postgraduate education in England, Canada, and Australia, community health nurses are responsible for providing care responsible to provide care for children with life-threatening diseases in the community and at home. In South Africa, a home-based palliative care training and support package for children was designed for community care workers. In Iran, pediatric palliative care is in the early stages and home care is evolving as a need.

#### Conclusion

Education is the most important factor for integrating home care and pediatric palliative care into the health system. In countries with advanced pediatric palliative care, the knowledge and skills of care providers have been considered. In Iran, revising medical and nursing curriculums and the integration of palliative care and home care programs into the curriculum are essential.

Key Words: Education, Home care, Pediatric, Palliative care.

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#### **1- INTRODUCTION**

In recent years, an increase in the prevalence of chronic diseases with complex care needs in children has caused changes in children's health status (1-3). The prevalence of chronic diseases and life-threatening disease in children over 1 year of age is estimated to be 18.5 to 32 per 10,000 children (1). The incident rate in children under 1 year of age is higher and measured to be 127.3 per 10,000 (4). No accurate statistics of children with chronic and life-threatening disease are available in Iran. The incidence of childhood cancers in Iran is estimated to be 48-112 and 51-141 cases per million in girls and boys, respectively (5). Moreover, the study of Caspian III has reported the prevalence of Chronic Kidney Disease (CKD) stage 3-5 in school aged children to be 14.5 cases per million, which is higher than many countries around the world (6).

The increase in the number of children with chronic diseases is a global issue, and the improvement of the quality of life and healthcare in these children is one of the major challenges for health systems in any country (7). Palliative care is an attempt to improve the quality of life in patients with refractory and advanced diseases (8). Pediatric palliative care is a holistic approach for providing children with physical, mental and psychological care and for supporting the family, which goes on regardless of treatment, as soon as the disease is diagnosed (9). The purpose of this care is to relieve pain in children with life threatening diseases and their families which can be done in the hospital, in the community and at the child's home (9, 10).

Since no organized pediatric palliative care exists in Iran (11), family members will experience emergency referrals, child's hospitalization and his/her transfer to the Intensive Care Unit, which cause a large financial burden for the family and the health system (12). In countries with organized palliative care, however, the child is hospitalized only for complex and specialized care, and palliative care is offered mostly at the primary and community levels (13). World Health Organization (WHO) also emphasizes the provision of pediatric palliative care at home and at community level (9). To overcome such a challenge that is mostly common in developing countries, the study conducted by Khanali-Mojen et al. (2018) with the aim of presenting a conceptual model of pediatric palliative care provision in Iran showed that by integrating palliative care into the health system of the country, the first and second level services can be provided at home. Providing care for a child in a familiar environment, such as home, is a solution for providing appropriate care and accessing primary care services (14), and is an indicator of good end-of-life and even death care (10).

Despite the advantages of home care and its positive effects on the quality of life in children and their families (15), one of the challenges in this regard, especially in low-income and middle-income countries, is to provide efficient pediatric palliative care (16), among which education is the most important one (17, 18). The shortage or lack of basic knowledge of palliative care among health system staff is a common problem (19). Therefore, educational programs with the aim of developing competencies in this group seem to be necessary (20).

In Iran, evidence indicates a low level of knowledge for care providers, which can be attributed to the lack of attention to this concept in the curriculum of related disciplines (21). The studies on the feasibility of home care from nurses' viewpoint in Iran also showed that despite the social acceptance of home care, the lack of sufficient educational opportunities for nurses is a major issue regarding cancer patients (22). Therefore, in order to provide care for patients with refractory diseases and to empower care providers, providing an appropriate curriculum is a top priority (8). The Iranian Minister of Health highly emphasizes home care and its implementation (8) which, due to the special circumstances of the country is a necessity for the health system and will have economic and social benefits (23). Considering the poor educational status of care providers, as well as the importance of eliminating barriers to the establishment of home care, it is important to take necessary measures in this regard. To this end, investigating curriculums, healthcare standards. and using the successful experiences of other countries to identify strategies for appropriate healthcare establishment can be helpful. This study aims to describe the pediatric palliative home care educational systems in England, Canada, Australia, and South Africa and to compare them with that of Iran. Also, the basis for the selection of the countries the classification of pediatric were palliative care besides home care.

# **2- MATERIALS AND METHODS**

The present study is a comparative study aiming to compare the pediatric palliative home care educational system for children with chronic diseases in Iran and in the selected countries and to identify their similarities and their differences. Comparative analysis means describing and explaining the similarities and differences in situations or outcomes among large-scale social units at regional, national, social and cultural levels (24).

The research population consisted of countries around the world according to the classification of pediatric palliative care system, which was revised in 2015 (25). The classification of results is shown in **Table.1**. The selected countries also had home care programs for children.

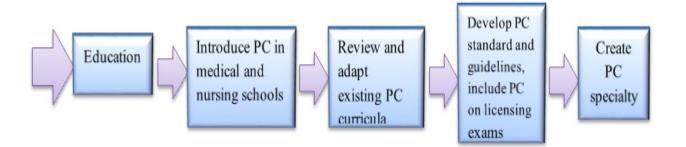
Searching was done in websites and online references in the field of pediatric palliative care, such as Palliative Care Australia, Palliative Care Australia Pediatric, Together for Short Lives, Palliative Hospice and Palliative Care Association. African Palliative Care Association , Canadian Association of Pediatric Health Centers, Canadian Network of Palliative Care for Children, International Children's Palliative Care Network (ICPCN), and in the databases Medline (via PubMed), Science Direct, ProQuest, Ovid and Scopus in the period between 2000 and 2018. In this study, the searching process was conducted using the following keywords used both separately and in combination: home-based care, home care services, home-based palliative care, children's palliative care, homebased pediatric care, home-based care education, community home based care, community health workers, health care providers, community healthcare staff and professional, child healthcare worker education, pediatric palliative care curriculum, palliative care curricula, palliative pediatric care course. professional competency examination. pediatric palliative care guidelines and standards, the United Kingdom, England, Canada, Australia, Iran, South Africa. To combine keywords "AND" and "OR" were used. The keywords were selected on the basis of the MeSH (Medical Subject Headings) terms in PubMed.

Data analysis was performed based on the World Health Organization Public Health Road Map (26). According to this framework, for the development of home care, it is required to consider the six dimensions of health policy, education, financial issues, legal issues, drug policies, and service provision, which is considered one of its six principles. In this framework, education has a hierarchy (Figure.1), which includes the introduction of palliative care in medical and nursing schools, reviewing and adaptation of existing curriculums, designing standards and guidelines for palliative care, and including palliative care topics on licensing exams and ultimately creating palliative care specialty (26). The items listed in the frameworks are different parts

of structures in which the existence of each part is necessary for provision of services.

| Level | Evidence                                     | Country  |  |  |  |
|-------|--|--|--|--|--|
| 1     | Evidence of broad palliative care provision  | Australia, Belarus, Canada, Germany,<br>United Kingdom, Netherlands, |  |  |  |
|       | for children. Approaching full integration   |  |  |  |  |
|       | within health care services as well as a     | United States of America.  |  |  |  |
|       | national policy to support children's        |  |  |  |  |
|       | palliative care.                             |  |  |  |  |
| 2     | Evidence of broad palliative care provision  | Argentina, Belgium, Costa Rica, France, India, Italy,                |  |  |  |
|       | for children with training available and     | Latvia, Malawi, Malaysia, New Zealand, Poland,                       |  |  |  |
|       | focused plans for development of services    | Singapore, South Africa, Uganda.                                     |  |  |  |
|       | and integration into health care services.   |  |  |  |  |
| 3     | Evidence of localized palliative care        | Austria, Brazil, Chile, Greece, Hungary, Ireland,                    |  |  |  |
|       | provision for children and availability of   | Georgia, Japan, Kenya, Kuwait, Philippines, Portugal,                |  |  |  |
|       | training.                                    | Romania, Russia, Saudi Arabia, Singapore, Swaziland,                 |  |  |  |
|       |  | Sweden, Switzerland, Tanzania, Ukraine, Zambia,                      |  |  |  |
|       |  | Zimbabwe.  |  |  |  |
| 4     | Evidence of capacity building activities for | Bangladesh, Botswana, China, Ecuador, Egypt,                         |  |  |  |
|       | the provision of children's palliative care. | Ethiopia, Finland, Iran, Iraq, Kyrgyzstan, Lesotho,                  |  |  |  |
|       | Some localized provision may be available.   | Mexico, Namibia, Norway, Nigeria                                     |  |  |  |
|       |  | Pakistan, Sudan, Turkey, Uruguay, Venezuela.                         |  |  |  |
| 5     | No known provision or capacity building      | All countries not listed above fall into this category               |  |  |  |
|       | activities for children's palliative care    | (25).  |  |  |  |
|       | _  |  |  |  |  |

Table-1: The ranking of countries in pediatric palliative care services.



**Fig.1**: A part of the World Health Organization framework for the development of palliative home care (26).

#### **3- RESULTS**

Based on the above framework, the axes mentioned in the field of education are evaluated in each of the selected countries, in the form of introducing palliative care in medical and nursing schools, designing curriculums or adapting the existing ones, and designing palliative care standards and guidelines and the inclusion of palliative care in the licensing exams. A summary of the status of the selected countries in the pediatric palliative care education at home is shown in **Table.2**.

| Country         | Medical and nursing schools | Pediatric<br>curriculums | Standards and guidelines   | Professional<br>licensing<br>exams |
|-----------------|-----------------------------|--------------------------|--|------------------------------------|
| England         | *                           | *                        | Independent palliative care guideline for<br>children and infants (35) | *                                  |
| Canada          | *                           | *                        | A part of hospice guideline (45)                                       | *                                  |
| Australia       | *                           | *                        | A part of palliative care guideline (51)                               | *                                  |
| South<br>Africa | *                           | *                        | Hospital-level standards (60)  | -                                  |
| Iran            | *                           | -                        | -  | -                                  |

Table-2: The status of pediatric palliative home care.

#### 3-1. England

England is the leading provider of palliative care in the world (27), and has 46 pediatric palliative home care teams (28). Connor et al. (2017) estimated that the rate of pediatric patients' need of palliative care in England is 20.1 per each 10,000 children between 0 and 19 years old (29). Pediatric palliative care is part of child health care services at the National Health Service (NHS), and free extended services (30) are available to children and their families in the form of home care (31, 32).

**3-1-1. The introduction of palliative care** in medical and nursing schools: The official medical education in pediatric palliative care started in England in 2009. The 2-year postgraduate course, medical palliative care/pediatric care, has been designed in some universities in order to develop palliative care for infants and children in various fields, including home care (30).

**3-1-2.** Designing curriculums or adapting the existing ones: Pediatric palliative care curriculum, with emphasis on health care education in a variety of areas, including home care, for children with malignant and non-malignant diseases, was approved in 2015, in order to improve the knowledge, attitude and practice of care providers (33). A palliative

care program for children on long-term mechanical ventilation was also developed in 2014 which includes a discharge program, home care, the introduction of caregiving staff, and evaluating the quality of home care (34). There are no nursing specific curriculums for pediatric palliative care in the UK. However, nurses can access related fields. The Royal College of Nursing has defined a collection of nursing competencies and abilities for pediatric palliative care. But the first step in training nurse specialists in pediatric palliative care is to provide its academic curriculum (30); no evidence has been found of developing such a curriculum. Palliative care for children is provided by Community Children's Nursing (CCNs). These nurses work in pediatric palliative care teams as key workers and play an important role in preventing the hospitalization of children in hospitals and addressing their needs (30).

3-1-3. Designing palliative care guidelines and standards and incorporating palliative care in licensing exams: The National Association for Children's Palliative Care in England developed supportive and palliative care standards and guidelines (NICE guideline) for infants, children and young people in 2016. This guideline is designed to plan for and manage the children (0-17 years of age) with life-threatening diseases and to involve children and their families in decisions, in order to improve end-of-life care and support for children. Home care, hospice care, home visit, symptom management and care plans are included in this guide (35). In England, the Specialty Certificate Examinations, computer-based, multiple choice tests of professional competence in a number of specialized disciplines, such as specialist palliative medicine, provide a summative assessment of doctors' clinical knowledge and decision-making skills (36). Community Children's Nursing in England evaluates the professional competence for palliative home care and end-of-life care (37).

#### 3-2. Canada

Canada is a large country with a population of 34 million people, of which 18% are children under the age of 19. Around 3,500 deaths are recorded per year in this age group, a large percentage of whom are the children under 1 year of age. In this country, there are 4,000 children with life-threatening diseases who benefit from palliative care (38). Canadian Home Care Association defines children with special health care needs as children who are in need of a network of health, training, and social services at home and in the community throughout their lives. These children have a wide range of physical, evolutionary, psychological, congenital or acquired problems. Therefore, home care is particularly important to them (39). In almost all Canadian provinces, receiving home care and community care is accepted as a legal right for children and their families (40).

**3-2-1. The introduction of palliative care in medical and nursing schools:** In Canada, palliative care is not a compulsory course in all medical schools (41). Pediatric palliative care is presented at one university (42).

**3-2-2. Designing curriculums or adapting the existing ones:** Complex care core curriculum for pediatric post-graduate

trainees is designed according to the competence, skills and knowledge required for planning basic care, emergency and discharge, as well as the impact of chronic disease on child and family and its effects on the objectives of the programs of this university for pediatricians (42). The headlines of nursing home care education include awareness of the uses of communication technology at home, issues, ethics, special and critical circumstances. responsibility, and accountability (43). Palliative and end-oflife care toolkit in Canada is an online resource for instructions, learning and supporting undergraduate nursing students. This toolkit lists 9 competencies for endof-life care, among which are home care and care for people of all ages, including children (44).

3-2-3. Designing palliative care standards and guidelines and incorporating palliative care in the licensing exams: Children's hospice palliative care guideline, the guide, along with clinical principles and norms deal with pediatric palliative care in hospices (45). Hospice Palliative Care Nursing Certification Exam and Community Health Nursing Certification Exam are Canadian licensing exams in palliative and home care for nurses. Child care competencies are included in both exams (46). In medical education, palliative care and endof-life care are taught and evaluated according to the undergraduate curriculum (47).

# 3-3. Australia

About 4 million children under the age of 15 are living in Australia. Although there are no accurate statistics regarding the number of children in need of palliative care, most of these children are suffering from non-malignant conditions, such as congenital anomalies and neurodegenerative conditions. Very few of these children have access to specialized care, and some of them lose their lives during infancy and the first year of their lives due to severity of conditions (48).

**3-3-1.** Introducing palliative care in medical and nursing schools: The formal education on pediatric palliative care at the Royal Australasian College of Physicians is the only pediatrics curriculum in Australia which is held in cooperation with Sydney Pain Management Center. Preparations for training nurses specialized in pediatric palliative care are made in Australia (48).

3-3-2. Designing curriculums or adapting the existing ones: Palliative Medicine Advanced Training Curriculum has been developed in 4 sections in order physicians to prepare for pediatric palliative care as advanced training in palliative care for adults and children (49). The integration of a palliative care program into the nursing undergraduate curriculum and the topics related to providing palliative care for children with life-threatening disease in various care settings, including home care, has been addressed in this program (50).

3-3-3. Designing palliative guidelines and standards and incorporating palliative care into licensing exams: National palliative care standards in targeted Australia have standard application in vulnerable populations, including infants, children and adolescents life-threatening disease with (51). Australian national competency standards in various practical fields such as home care are defined by Australian Nursing and Australian Midwifery Council. Competency Standards for Palliative Care Nurses, National Framework for Cancer Nursing, and Palliative Care Nurse Practitioner Candidacy Overview are courses that assess the competency of palliative care nurses. Some of these courses have independent curriculums, too (47).

### **3-4. South Africa**

South Africa is a country with limited resources, but has been successful in creating a national palliative care program for children. The prevalence of children immunodeficiency with Human virus/Acquired deficiency immune syndrome (HIV/AIDS), and the community-wide poverty have affected the palliative care needs in children, and as a result, home care programs are of great importance in this country (52). It is estimated that 801,155 children require palliative care, but the coverage of these services is limited, with minimal access (53). Children under the age of 5 face death in Africa more than anywhere else around the world (54). There are already 160 specialized palliative care programs in this country, of which 20 (13%) are childspecific (55).

**3-4-1.** Introducing palliative care in medical and nursing schools: There are 8 medical schools in South Africa, at half of which palliative care is presented as a compulsory subject and in the other half as an optional one. There are also 53 nursing schools in this country, in which no palliative care courses are offered either as a compulsory subject or as an optional one or as a part of other courses (55).

3-4-2. Designing curriculums or adapting the existing ones: There were no formal palliative care courses for doctors until the year 2000. In 2001, due to the doctors' urgent need for providing palliative care education, a cooperation was formed between University of Cape Town and Cardiff University in England, and formal education of doctors in the field of palliative care was formed through a medical curriculum adapted to the South Africa culture, and with emphasis on childcare, home care, family dynamics, family and non-nuclear Human immunodeficiency virus/Acquired immune deficiency syndrome (HIV/AIDS) patients. This curriculum was adapted for doctors in

South Africa and the issues they face (56). The main purpose of this program was to train family doctors, pediatricians, internists and oncologists, and it was integrated into their primary education program (57). The palliative care curriculum consists of two programs of Postgraduate Diploma and Masters of Philosophy in Palliative Medicine (MPhil) (56). Educational modules related to the pediatric palliative care are limited in medical and nursing undergraduate curriculum. In spite of efforts made in this country, there is still a need to strengthen in-service and pre-service training in the medical and the nursing curriculum in order to ensure the coverage of pediatric palliative care services. Evaluation of the curriculum showed that communication was considered as the main competency in providing pediatric palliative care, while it somehow been ignored in the has curriculum. Therefore, it has been considered in the development of the curriculum in this country (58).

The development of a support and training package of home-based palliative care for children with AIDS as well as its initial feasibility and evaluation was done in South Africa in 2015 for home care and community care providers, and pediatric palliative care was integrated with home care programs (16). A palliative care curriculum with emphasis on home care in villages was also developed in 2012 as a doctoral dissertation (59). The informal training of volunteer care givers at community level was done in response to the increased need for palliative care and in order to access more patients, and also as a result of inadequate number of doctors and nurses (57).

**3-4-3.** Designing palliative guidelines and standards and incorporating palliative care into licensing exams: Guidelines, treatment standards, and the list of essential medicines were revised in 2013 in South Africa. Chapter 20 of this guide, with the title of *palliative care and pain control in pediatrics*, has focused on issues such as pain assessment, pain assessment scales, and controlling pain and other symptoms at the hospital level (60). There are no tests specific for pediatric palliative care in South Africa. However, some improvements have been made in introducing palliative care at different levels. But there are still limitations in medical and nursing education (58).

#### 3-5. Iran

Due to the policymakers' lack of awareness on priorities and the necessity of these services, there is no official structure for providing children's palliative care services in Iran (11). The Home Care Regulations (61), and home-based palliative care services for adult cancer patients were approved in 2016 by several medical centers in the cities of Isfahan and Tehran (8).

**3-5-1.** Introducing palliative care in medical and nursing schools: А fellowship course in palliative medicine was launched by the Ministry of Health Medical Education at Tehran and University of Medical Sciences, in 2009. This 15-18 month course focuses on the indicators of quality of life, signs and symptom control, social and spiritual support, and the provision of care for incurable patients (8). There is no palliative care post graduate program in the nursing curriculum.

**3-5-2.** Designing curriculums or adapting the existing ones: Caring for infants with special health needs based on the nursing process, caring for dying infants and home care as infant care are included in the curriculum of pediatrics master's program (62). A two-unit course, called nursing care at home, is integrated in the nursing undergraduate curriculum with emphasis on common diseases in Iran, with an approach to training the patient and the family in self-care and

lifestyle (63). The nursing master's curriculum of community health nursing has also emphasized providing home care, home visits and home follow-ups for patients (64). Evaluating the system of continuous education and in-service training for nurses and physicians indicated that no codified program has ever existed in the field of pediatric palliative care.

**3-5-3.** Designing palliative guidelines and standards and incorporating palliative care into licensing exams: Due to the lack of establishment of a pediatric palliative care system in Iran, it is necessary to develop the structure, guidelines and standards of this type of care to achieve the desirable status and improve the quality of life for the child and family. There are no licensing exams in the field of palliative care in Iran.

#### **4- DISCUSSION**

The purpose of this study was to describe and compare the status of palliative home care in children with chronic diseases in the selected countries. The conducted studies show that pediatric palliative care and home care are in their early stage in Iran. In order to reach the desired level and integrate health care into the health system, training employees at different levels is essential. Considering the educational settings of World Health Organization framework, colleges. curriculums, guidelines, and then licensing exams will be discussed in the selected countries. The purpose of pediatric palliative care education is to train physicians and nurses competent in providing care for children with lifethreatening diseases (65). Education is referred to as the basis and the first step in providing this type of care (66). Among the investigated countries and based on the principles of World Health Organization Public Health framework, the road map of pediatric palliative care in England offers

the best educational conditions. Home care is one of the choices of children and their families for palliative care in this country (30). Palliative care in medical schools at undergraduate level is a mandatory course only in the UK. Despite palliative care education being mandatory in England; evidence suggests that there is not sufficient training during undergraduate programs, especially on bereavement care as a part of palliative care. This issue has also been identified and confirmed in Canada and Western European countries (67). In Iran, the study of Pakseresht et al. has also shown that there is a lack of attention to this concept in education and clinical practice (68). Investigating the curriculums revealed that in England, Canada, Australia, and South Africa, pediatric palliative care exists as specialist courses for doctors, and providing home care for children with life-threatening disease is a part of their specialized curriculums. There are also fellowship courses of palliative medicine for physicians in Iran. However, in this curriculum, palliative care for children is only briefly addressed (69).

Therefore, it is not surprising that the emergence of palliative care in Iranian accompanied system is health by insufficient education, specialists and care providers' unawareness, especially nurses and doctors (21), and the lack of general knowledge and awareness on services of this type of care (70). Therefore, using the successful experiences of leading countries designing appropriate programs, in curriculums at the postgraduate level and adapting curriculums according to the culture (26), pattern and disease burden as well as holding educational workshops in Iran can help overcome this barrier in palliative education. Pediatric care curriculum in England can be a useful model for other countries, and even for other related professions in education. This model has been developed by a group of

family doctors with work experience in pediatric palliative care (30). The program is adapted in many countries, such as South Africa (57). In Iran, the use of the curriculum of developed countries and its adaptation to the culture and diseases burden can be beneficial. There were no independent and academic specialized curriculums for pediatric palliative nursing care in any of the investigated countries, and home care and pediatric palliative care were part of other specialist curriculums of palliative care. In Iran, there are sporadic and limited home care and pediatric palliative care in the curriculum of undergraduate and postgraduate pediatrics students; therefore, this fact should be specifically considered while revising the curriculums, according to the increasing prevalence of chronic diseases in children (7), and the advantages of home care (23).

One of the problems with pediatric palliative care education, which is especially considered as a deficiency of the pediatric palliative care curriculum in South Africa, is to communicate with the children and their families (58).Fellowship doctors in their PICU courses have described caring for children with serious diseases as the dark side (71), i.e. accepting the inevitable suffering when the child's life is threatened (72). They have also difficulties regarded the in communication and interactions with children and parents as an issue. They believe that teaching communication skills to medical students in dealing with these issues is one of the solutions to overcome them (67). Effective communication is the key to success in pediatric palliative care, which has been less frequently addressed in formal medical curriculums (73).Enhancing the communication with parents and children, especially in their late stages of life, reduces the care burden of the disease (74), and due to caregivers and children's preference for home care in such circumstances (75), providing proper care for the children and their families can be ensured by establishing a suitable channel of communication for care providers (67). In Canada and England, palliative care in the community is provided by community nurses and children's community nurses (30, 76). In South Africa, community health workers are responsible for providing palliative care for children, especially for those with AIDS (16). Similarly, community health nurses in Iran are trained through a course of community health nursing in nursing master's program in many nursing schools. Despite the fact that this curriculum addresses topics such as home visits, home care and patient follow-up, since the position and the role of community nurses have not been defined in the society, and due to the absence of a clear job description, and in general, because of the lack of necessary infrastructures, this potential is not used and graduates of this field are employed at clinics and educational centers (77).

In order to provide content of the palliative home care curriculum for children with AIDS in South Africa, various home care texts from 1979 to 2011 have been reviewed. The studies indicate that the existing references put emphasis on palliative home care for adults and that the appropriate educational content for employees, as service providers, is limited Therefore, the provision (16). of appropriate educational content in the field of home care, based on the employees' needs, can help establish and maintain this care in the community, regarding its benefits for the child, the family and the health system (77). The purpose of developing these guidelines is to increase the effectiveness and the quality of service and justice in the health system (78). which determines the pathway for providing services with regard to the resources, the principles and the objectives of each country's health system (11). In

England, pediatric palliative care guidelines are specifically designed with regard to the pediatric home care program (35). Pediatric palliative care guidelines exist as parts of other guidelines in Australia and Canada, (45, 51), and at hospital level in South Africa (60). However, guidelines for pain relief in cancer children, developed by the WHO, are translated and implemented in some countries (32). There are no such standards in Iran, due to the lack of the establishment of a pediatric palliative care program, and also due to the absence of codified medical and nursing curriculum. The development of specialized guidelines in the field of pediatric palliative care and home care can ensure better health care and access to appropriate services. Professional licensing exams were also investigated in the selected countries. In England, Australia and Canada, there are some exams for entering this profession or examining professional competency (35, 36, 43-46).

In Canada, a list of competencies necessary for the provision of palliative care is provided, and these competencies are assessed through exams (45). In Iran, registration and nursing nursing competency assessment have been started by the Deputy of Nursing in Ministry of Health. In Iran, non-professionals without caregiving skills and competency are hired to provide home care and palliative care due to various reasons such as the lack of defined specialized competencies for staff, the absence of professional training in patient management at home, the lack of proper supervision of these services, and the need to reduce costs (79). Therefore, conducting professional licensing exams and skill assessments with regard to expertise and the supervision of care providers can prevent such issues and service quality. It is ensure also recommended that short-term and longterm training courses and workshops be organized for nurses and doctors to create competencies. Home care is a new issue in Iran (80). In order to establish a homebased care program, in-service training will play an important role in the development of the program. Also, the integration of home-based care and pediatric palliative care programs in the medical and nursing curriculum is essential. It is hoped that by training human forces, the integration of these care services into the curriculum of related disciplines and developing an interdisciplinary curriculum, the challenges to pediatric palliative care will be overcome.

#### 4-1. Study Limitations

The small numbers of studies conducted on palliative care and home care in Iran, especially in the field of pediatrics, and the home care programs' being nascent and limited were among the limitations of this study.

### **5- CONCLUSION**

Due to the increase in chronic diseases in children and the possibility of managing some of the symptoms at home, attention is paid to home care in educational courses, especially in medical and nursing postgraduate programs. In this regard, the establishment of appropriate educational infrastructures in medical and nursing disciplines is very important. Additionally, it is recommended to conduct qualitative and quantitative studies in order to examine the views of different groups on home care and the manner of teaching it, and to evaluate the effectiveness of the related educational courses.

# 6- CONFLICT OF INTEREST: None.

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