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Challenges of palliative care for children with cancer in Iran: a review

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Abstract

Pediatric palliative care is a holistic caring approach for children and families that begins with diagnosis of a life-threatening illness and continues until death; it aimed to relieve pain and other symptoms in physical, mental, social and spiritual aspects. In spite of available evidence concerning optimal outcomes of the provision of palliative care, establishment of a palliative care system for children has hardly been feasible so far due to a number of challenges. Therefore, this review study aimed at identifying the challenges of the provision of pediatric palliative care along with the relevant solutions. The identified challenges were classified into two categories including structure-based challenges (i.e. lack of a clear structure in the health system and classification of services, shortage of specialized staff, insufficient home care services, absence of health care tariffs along with insurance coverage of palliative care services) and process-based challenges (i.e. absence of guidelines, lack of educational programs for family, family attitudes and beliefs, communication barriers, and lack of access to opioids). Thereafter, the solutions for each challenge are provided in accordance with the available literature separately. Given the significance of palliative care for children with cancer and in order to improve the quality of life of the children and the families, it appears necessary that policymakers and managers take account of the challenges as well as the feasibility and the implementation of provided solutions.

Key words: Neoplasms, Palliative care, Pediatrics

Introduction

Progress in medicine has raised the number of children living with chronic or life-threatening illnesses (1, 2). Statistical reports reveal that 600,000 to 1,600,000 children below the age of eighteen are living with life-threatening conditions (3-5). Cancer is one of the common chronic diseases threatening the lives of children in developing countries (6).

The prevalence of this disease in children and adolescents is reported to be approximately 22.9 per 100,000 for males and 21.3 for females (7). In Iran, cancer is the second leading cause of death for children below the age of fourteen(8).

Compared with other chronic diseases in children, cancer has its exclusive effects (9) due to having an uncertain and challenging nature, unexpected outcomes along with psycho-social and emotional disturbances over the course of diagnosis, treatment, and follow-ups(10).

Children with cancer suffer from a wide range of symptoms as well as side effects induced by the illness and treatments (11), contributing to various adverse effects on their quality of life and their families' (12). The previously mentioned factors along with high costs of treatment and social and psychological outcomes of the disease require the patient and the family to receive holistic palliative care(13).

Today, seven million children need to receive palliative care annually (14); the pediatric palliative care, as a well-known specialized expertise, has provided relevant guidelines and instructions in this area by international and national organizations (15).

Pediatric palliative care, as a holistic and active care of the body and spirit of the child and the family, begins with the diagnosis of a life-threatening illness and continues until death (16). The goal of this caring approach is to reduce the consequential adverse outcomes that influence physical, psychological (e.g. anxiety, depression, guilt), social (e.g. isolation), functional (e.g. financial stress), and spiritual aspects of target groups and to improve their quality of life.

This caring approach continues until after the child's death in order to provide support to the family so that they will cope with the process of grief more efficiently(17). The palliative care has other goals such as facilitating the decision-making skills in the patient, the family, and the health care team as well as establishing an inter-disciplinary cooperation among the professionals and personnel for taking care of the patient (18, 19).

Pediatric palliative care is a patient-centered approach that should be applied in conjunction with respect towards the family in a variety of ways, such as parent and child participation in the plan of care, the parents' understanding of the child's health condition, taking account of the values and preferences of parents, and designing a care plan in accordance with their values (20) Also, attention should be paid to the children's stages of development and participation in accordance with their experiences of the disease, developmental capacities, and intellectual level along with psychological, spiritual, and cultural characteristics (21).Ultimately, the option of palliative care for children with life-threatening illnesses should be available to all children and their families equally(22) and include a wide range of groups, including pregnancy, infancy, childhood, and adolescence (23) and proceeds with the child' death and the parents' grief (21).

In parallel with the previously mentioned goals and requirements for the delivery of pediatrics palliative care, it should be noted that the provision of palliative care for children is different from the adults due to following rationales; Children are being affected by a wide range of diseases that vary in terms of the complexity as well as the process and duration of treatment. In addition, evaluation of the severity of pain and quality of life in children is more complex (24). Besides, communication with children about the disease, treatment, and death is under influence of their developmental stages (25-27) . In other words, children in every age group have different understanding of the illness and death and thereby can hardly be treated by a similar protocol (25).

Communication with children about death is a daunting task for both parents and care providers (26, 27). On the other hand, children are incapable of making decisions(28) and complete involvement in their care(29). Therefore, the application of palliative care demands the collaboration of both parents and the health care team (28). Continuation or discontinuation of treatment in children is a difficult moral challenge(29) due to psychological and emotional conflicts of the parents and children that shift the attempts toward therapeutic treatments and away from palliative care (30).

From the health system's perspective,; however, the use of palliative care in parallel with the necessary therapeutic approaches can decrease the number of unnecessary procedures, reduce length of stay in hospital, decrease the need for hospitalization in intensive care units, facilitate pain management in children (31, 32), and improve communication among the parents and the health care team(33, 34). Other advantages of this caring approach includes preparing parents for the death of their loved one, facilitating their coping responses to the grief, empowering them with the sense of control over a terrible situation (35), reducing the care burden and parents' mental stress (36, 37), increasing collaboration between the family and the health care team, and improving the quality of life of the child (38).

Given the special attention of the WHO world health organization to pediatric palliative care in the region and the desirable outcomes attributed to this type of care for children and their families, establishing a pediatric palliative care system appears to be a priority of the health system in Iran country. So far, no action has been taken in this direction due to numerous challenges of the implementation of these caring approaches (39). Therefore, the present study intended to review the current situation of palliative care in the world and Iran, to introduce these challenges as barriers to the implementation of pediatric palliative care, and therefore, to facilitate the establishment of this caring system in Iran.

Current Status of Pediatric Palliative Care

In spite of the desirable outcomes of pediatric palliative care, available evidence suggests that the provision of palliative care to this age group has been overlooked in plans of care.

A systematic review study concerning the status of palliative care in different countries, based on a four-scale classification system recommended by the International Observatory on End of Life Care (IOELC), revealed that two thirds of the studied countries failed to provide palliative care, 19% were at the second level (i.e. establishing the preliminary requisites of the palliative care), 10% were at the third level (i.e. providing regional palliative care), and a very small number of high-income countries were at the fourth level. In the fourth-level countries, palliative care is regarded as part of the medical team's tasks that possess relevant educational institutes and academic curricula and impact their health policies (40). Access to the pediatric palliative care in low- or middle-income countries is limited. However, 160,000 children under the age of fifteen have been diagnosed with cancer annually in these countries (41, 42), with most of them diagnosed when their disease has progressively deteriorated and could hardly be cured; only about 20% of them will be cured in comparison with high-income countries, where 80% of the children can possibly be cured (41, 43-46). Connor, as cited in Caruso Brown , declared that evidence in the first global atlas of palliative care revealed nearly 1.2 million children under the age of fifteen were in need of palliative care annually, with 98% of them living in low-income or middle-income countries (43).

Despite the fact that, in Iran, cancer has been the second leading cause of death for children under the age of fourteen(44), and children with cancer and their families have a low quality of life, there is no pediatric palliative care unit, and only in oncology units, some services are being provided by oncologists, nurses, social workers, and psychologists (47).

A review of literature on the reasons for unsatisfactory provision of pediatric palliative care led to the discovery of several barriers in different studies that should be addressed. Therefore, the present study classified these challenges into two structure-based and process-based challenges and ultimately provided some strategies that have been presented in previous studies (Table I).

Structure-based challenges

According to the studies carried out in Iran, several challenges regarding necessary requisites of the provision of palliative care were found. These challenges are discussed below.

1- Absence of a defined structure in the health system and classification of services:

The provision of palliative care has been undertaken in a variety of ways. Designing a caring model in this regard is of pivotal importance as a guide to track the progress of related activities (48). Since there are various ways to provide pediatric palliative care, setting similar and pre-arranged goals can hardly be feasible (49). Therefore, designing and implementing a suitable model requires taking into account the specific circumstances and health care policies of every society (50). In Iran, the health system's policies are based on the idea that every individual must have fair access to the health care services through the classification of services and referral system (51). In regards to the palliative care; however, these is no classification of services in Iran. Thus, the regionalization system can offer access to the palliative care services and its development(52). On the contrary, the absence of such system can lead to confusion, high costs, low quality of life, and dissatisfaction in patients(50) .

2. Absence of specialized human resources:

The knowledge and attitude of the health care team toward palliative care is another factor in the implementation of this caring approach. In other words, insufficient knowledge and expertise as well as misconceptions about palliative care can result in the cure-centeredness of this caring approach (48, 53, 54). In addition, the care providers might also believe that the provision of palliative care is merely limited to the situations in which there is no cure for an illness(55) and the children with recurrent and/or refractory diseases (56), or the children whose death is coming(57). A study investigated the general practitioners' perspectives on the optimal time of referring the patients to seek palliative care services and showed that 44.2% considered the end stages of life and only 15.4% considered time of initiating treatment as the optimal time(55). Knowledge, attitudes, and skills of healthcare team regarding palliative care appear to have an impact on the implementation of palliative care (58). The lack of training in this area is regarded as a barrier (59-65) through which no specialized team will be available to provide palliative care(66, 67).

Care providers need to receive training for palliative care, and the lack of standard educational content for nursing and medical students in this area can cause the staff to feel they are unprepared in clinical contexts(68). National studies revealed that palliative care providers had insufficient knowledge about this caring approach, its philosophy, and the techniques of symptom management(69, 70).The lack of training can cause health care staff to provide palliative care through the trial-and-error technique in order to identify an appropriate method (71).

Nonetheless, palliative care is expected to be provided by a team of experts, including at least one physician, nurse, social worker, and clergyman (72) There is no clergyman among the palliative care team in Iran in order to provide the patients and their families with spiritual care (62). In some institutes; however, only one person is assigned to give palliative care consultations in the place of a specialized palliative care team (66, 67).

Over last few years, palliative care centers have been established in the two large cities of Isfahan and Tehran, Iran (73). Thus, the palliative care education has not yet been introduced to nursing academia and curricula in Iran as a clinical training course. Nursing curricula merely contains 2-4 hours of theoretical teachings on the death and the techniques of delivering care to near-death patients. Recently, a one-unit course has been added to the curriculum of postgraduate nursing education (61).

3. Lack of home care services:

Parents of children with cancer, on the one hand, tend to take care of their children at home to meet their basic needs. On the other hand, they need access to informational and assistance resources. This situation can provide them with the chance to continue their lives without any change in their roles.

Currently, most services are being provided in hospitals and families must attend hospitals for necessary caring services. This can impose extra burden and costs on the families living in distant cities in particular(74). Nonetheless, the provision of home care services can empower the patients and their families (70).

The findings of a study in Iran showed that nearly one quarter of the nurses have received home care educations. Additionally, lack of necessary training and education has been a major hindrance to the provision of palliative care. Despite the fact that postgraduate courses in community health nursing has been introduced for several years in Iran, nurses still fail to practice home care services due to lack of a job description or a clearly defined position for these individuals(75) .

4. Economic challenges including the absence of health care tariffs, and insurance coverage of palliative care services:

The lack of financial resources is another barrier to providing palliative care services (76). Some families might be unable to seek palliative care services due to financial issues. Limited financial resources and inadequate investment in pediatric palliative care can hinder the development of this caring approach across the country and thereby lead to unfair distribution of services among individuals(77). The costs of palliative care services, in some countries like Cyprus and Lebanon, are being covered by insurance and charity institutes. In Jordan, palliative care services are provided free of charge and are covered by private insurance institutes and non-governmental organizations (NGOs)(78). In Iran, the NGOs such as the Mahak institute are offering their financial support in this regard.

Process-based challenges

In addition to the challenges that seem to arise from the structures governing the health system of the country, various studies have also pointed to some requirements for the provision of palliative care which are mainly considered as process-based challenges.

1. Absence of guidelines and instructions:

The lack of clear and documented policies and instructions is among the most important challenges of the palliative care provision (79).

In Iran, no specific palliative care plan exists and care providers act solely on the basis of their experience and knowledge rather than clinical guidelines. In many countries, different guidelines related to the symptom management in accordance with available resources, plans, and care plans are designed(80). In Iran, there are only a few guidelines concerning the spiritual care; only pain management protocols are designed and are being used in some institutions(81) .

2- Lack of educational programs for the family:

Public awareness of the palliative care and related information at the community level is an important indicator of the evaluation of palliative care systems. This awareness includes informing individuals about the rights of patients with cancer, introducing relevant institutions and organizations, and public education about the early detection of cancer. In Iran, the lack of public awareness about palliative care and cancer-induced stigma are obvious issues that might be attributed to the poor performance of the health system for raising public awareness. Additionally, the available educational programs are not based on the type of illness (68).

3- Families' attitudes and beliefs:

With the occurrence of a life threatening illness, parents seek treatment options and endeavor to take the recommendations of the nurses and physicians into consideration(82) . The majority of parents deny poor prognosis of their children, have unrealistic expectations from available technology, and hold optimistic beliefs about healing their near-death child(83). This denial can be attributed to the emotional bond between parent and child that appears to be stronger in Middle Eastern countries, including Iran(73) . In the Middle East, cancer is a taboo due to the lack of knowledge and awareness of families(84) . On the other hand, the inevitable and non-curable nature of death are the concepts that are commonly attributed to the adults (85).

Parents consider children as symbols of passion in life with a long-term survival perspective (86). This point of view can result in unconscious denial of the child's problem among parents and thereby stop them from the acceptance of bitter facts, such as incurable disease or coming death (87). Benini quoted a statement from the WHO(world health organization) and explained that holding beliefs about healing every disease through modern medicine and considering death as an outcome of the failure of treatment and/or human errors can be barriers to the acceptance of palliative care. In other words, the parent's cultural beliefs about treatment and disease influence their decision-making roles concerning the acceptance of palliative care(88) .

In parallel with culture, religion has also a significant impact on the development of palliative care (89). Iran is an Islamic country, and their spiritual beliefs are integrated into their poets and stories. In this regard, death is perceived as a significant event and a transition from one stage of life to another (i.e. material phase to spiritual stage) (90). It is believed that death is under the control of God and discontinuation of treatments is against the God's will and thereby must be avoided by individuals. From the religious perspective, discontinuation of treatments is regarded as disappointment with God and a wrongdoing (91). These religious beliefs complicate the decision making matter for parents to initiate palliative care (92).

4. Communication barriers:

Trust is a key element of communication that reduces stress and anxiety, increases satisfaction, and boosts morale. In order to achieve patients' trust, the members of health care team need to have a friendly behavior and to treat the patients in accordance with ethical standards over the course of treatment (93). Dealing with children and parents demands a therapeutic communication that is based on their understanding and communication abilities (94).

Communication with parents of near-death children seems to be impossible and risky(95). Holding this perspective by physicians and nurses can postpone their interactions with parents(35) . In addition, the lack of training on how to communicate with parents and their children can lead to the caregivers' reluctance to establish communications (59). In a study by Iranmanesh et al., Only 22.5% of health care teams were instructed about the end-of-life cares, with no instruction on palliative care strategies; this led to their lack of proper skills for communication with parents and children (62). However, the quality of communication among therapeutic teams and parents can influence treatment choices and strategies (60).

5- Lack of access to opioids:

Several studies have pointed to the opioid-related challenges as a common obstacle on pediatric palliative care (40, 84, 96-98). A group of factors limiting the usage of opioids in palliative care includes lack of national policies on access to opioids, lack of legal documentation on how to use them, poor performance of the Ministry of Health (MOH) in documentation and the use of opioids, strict rules about opioid prescriptions, taboo and stigma of the opioid usage in Iran, fear of drug addiction and its side effects, misconceptions about opioid-induced death, lack of adequate information on the main effects of opioids, and lack of education on the proper use and choice of opioids (77).

Given the structure-based and process-based challenges thathave been introduced so far as barriers to the provision of palliative care, some solutions on how to tackle the previously mentioned obstacles are presented below. Since challenges are classified into two structure and process challenges, it seems that offering relevant solutions in the same sequence and order maintains a reasonable conceptual link between the subjects.

Recommended solutions for structure-based challenges

1. Defining structures related to palliative care, including the classification of services and establishment of a home care model

Establishment of palliative care demands the identification of health system structures in the country in order to provide palliative care services that are compatible with the system structures without spending too much time and money(44) .

According to the WHO's recommendations, the most appropriate places for the provision of palliative care in countries with limited financial resources are hospital-based clinics (96) which seems to be appropriate for a country like Iran as well (70). On the other hand, it can provide all children in need of palliative care with the opportunity to receive care at community level and at home. Given the positive attitude of policymakers toward the development of home care services and its social and economic benefits to the patient, family, and health system, this caring approach has been taken into consideration in Iran (99) in order to arrange programs and establish relevant centers.

2- Preparation of the specialized staff:

An important strategy in policy-making is the adoption of an interdisciplinary approach and formation of a professional team comprising the nurses, physicians, psychologists, social workers, and nutritionists (68). Therefore, it seems necessary that the teamwork strategies be integrated and supported in the society through formal education (100). The health care team should also possess sufficient knowledge and skills to meet physical, mental, social and spiritual needs of the children and the families (101) Therefore, training the health care team can raise their awareness, change their attitude (102, 103), and make them professional and qualified in the palliative care context(104). Therefore, it is recommended that an educational program consisting of an interdisciplinary philosophy of palliative care, the implementation principles and benefits, communicative skills with family, symptom management essentials, collaborative strategies, legal and ethical concepts about discontinuation of treatment, available supportive resources as well as death, grief process, and coping mechanisms should be taken into account (105).

Considering that a palliative care program is one of the priorities of the WHO(world health organization) (62) , the revision of medical and nursing curriculum should also be taken into consideration(106). Consequently, an interdisciplinary complementary program such as the Masters course in palliative care should be provided (107). The training of supporters and volunteers as well as the provision of necessary educational resources for palliative care organizations are also highly emphasized(68) .

3- Allocation of funds:

Allocation of funds is another important concept for the provision of palliative care. Palliative care centers, whether for children or adults, are dependent on institutional support because they can hardly provide sufficient financial returns and be self-administrated. Therefore, attracting more NGOs can provide more financial support and reduce the economic burden of palliative care on families (62). One example of an NGO is the Mahak institute .Also, due to measures taken in the field of tariffs for home care services, the insurance companies will also be considered as funding sources.

Recommended solutions for process-based challenges:

1- Provision of guidelines

Provision of clinical practice guidelines based on available resources can be an effective way to implement palliative care. Every palliative care system should possess written and specific policies for palliative care and update them continuously in order to provide evidence-based services (108). The literature suggests that the palliative care guidelines can be developed through the Delphi technique of research with participation of specialist and review studies (109-112). These guidelines should include the following items; a model of palliative care provision, time management, knowledge, skills, human resources, pain management, nurse's role, spiritual care, consultant, social worker, and access to opioids (110). Given the increasing number of postgraduate students in nursing, it might be possible to enlist universities to participate in the development of guidelines as well.

2- Providing educational programs for the family, changing their attitudes toward palliative care, and establishing effective communication

In addition to the provisioning of the necessary prerequisites and preparation of specialized and skilled personnel, preparation of parents for the acceptance of palliative care is of pivotal importance. In this regard, the parents' insistence on continuation of treatments and their attitudes toward palliative care are important challenges (54).

Therefore, communication with parents demands establishment of a trust-based, intimate(113) and responsive relationship among children, parents and healthcare team(114). Establishing communication with parents of near-death children is a daunting task. One of the main needs raised at this level is the need for religious and spiritual counseling. It seems necessary that adequate time be allocated to these types of counseling services prior to making decisions for palliative care so that the decisions are in accordance with the religious and spiritual beliefs of parents (115). Also, attention should be paid to the culture of parents as well (116).

Raising public awareness concerning palliative care to overcome cultural and social barriers can also be an important factor in palliative care acceptance by parents(117). Public perspectives toward palliative care is complex(118) and its change requires relevant knowledge (119). Therefore, it is recommended that a plan be introduced for the introduction of palliative care to the public (120) and be implemented through the participation of media and social networks.

3-Distribution of medications and application of opioids

To manage the challenges of using opioids in palliative care, the government should properly incorporate drug usage requirements into its plans and regulate the use of opioids by monitoring the availability of drugs for therapeutic purposes(121) Also, the provision of training programs concerning the application of opioids and its availability to physicians, nurses, pharmacists, and top government officials who play an important role in supplying medications seem to be effective measurements(122). Since in some countries, including Iran, the usage of opioids is under the influence of attitudes and culture, and the fear of drug addiction is one of the major challenges (123) that stem from knowledge deficiencies(124) , raising awareness of parents concerning the opioids and their usage purposes can facilitate their acceptance of the application of opioids to their children.

Conclusion

Today, pediatric palliative care is a well-known and progressive need that is associated with some challenges related to parents, palliative care providers, and health care system. It seems necessary that these challenges be addressed prior to the establishment of pediatric palliative care. The authorities and managers of palliative care should take the preliminary steps by planning and setting goals in order to develop educational programs for the palliative care providers and the public. Additionally, the provision of financial resources and funds seems to be essential for establishment of designed programs. Taking advantage of the experiences of successful countries and the countries with similar socio-economic status in particular can also be a useful solution to overcome palliative care challenges in developing countries such as Iran.

Conflicts of interest

There are no conflicts of interest.

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