

Pediatric Palliative Care in Iran: Applying Regionalization of Health Care Systems

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Abstract

Background: Establishing palliative care services is a priority in the health system of Iran. Considering the necessity of integrating these services into the health system, this study aimed to explore the stakeholders' perceptions about the provision of a conceptual framework for palliative care services for children with cancer according to the health system in of Iran. **Methods:** The present qualitative study was conducted through in-depth semi-structured interviews held with 29 participants including palliative care specialists, policy-makers, health care providers, the parents of children with cancer selected through purposive sampling, between August 2016 and February 2017. Interviews continued until saturation of data. All interviews were recorded, transcribed and analyzed using MAXQDA10 software. **Results:** The codes extracted from interviews produced the main theme "classes of palliative care services" with the two main categories "comprehensive care" including, strengthening family shelter, maintaining the child in a familiar environment, achieving stability and "establishing social justice" including, easy access to services, financial relief and quality care. **Conclusion:** Presenting a framework based on level of palliative care services, the findings of this study paves the way for integrating these services into Iranian health system.

Keywords: palliative care- pediatric- regionalization- health system

Asian Pac J Cancer Prev, **19** (5), 1303-1311

Introduction

Cancer is the second leading cause of death among the children under the age of 14 in Iran. It is fatal in 1,037 out of every 1567 children with cancer which is a high rate in comparison with advanced countries (Globocan, 2015). Due to the increasing incidence of the disease by 2020, and considering the young population of Iran (World country Index, 2015), securing health for this group is one of the most essential needs of Iran's health system.

Despite medical advances, the development of therapies, and consequently the increase in survival rates, children with cancer continue to suffer physically, psychologically, socially and spiritually from a wide range of symptoms associated with the disease and the side effects of the treatment (Lee et al., 2011). It affects the quality of life not only for the child, but also for the whole family as the primary care provider (Valizadeh et al., 2014). In such a situation, one of the essential objectives of the health care system is to provide palliative care services (Rassouli and sajjadi, 2014), services that are required to be applied as major components of the health

care systems of all countries and must be presented as comprehensive services in the global action plan published in 2014 according to the World Health Organization. (WHO, 2016). The Program of Action for Cancer Therapy (PACT) of the international Atomic Energy Agency and the WHO experts recommendations on the matter confirm this necessity as well (Rassouli and sajjadi, 2014). This policy is only carried out through governmental support and is very important in countries with limited resources (Connor and Sepulveda, 2014). In Iran, health care system is managed by the governmental sector and the need to integrate this program into the health care system is well-understood by the policy-makers. This is a fact confirmed by the establishment of the Palliative Care taskforce in the Ministry of Health and Medical Education and also the draft of palliative care action (Rassouli and sajjadi, 2016a).

The provision of palliative care in the world is carried out in a variety of ways. Designing it as a health care model is essential which can be used as a guide for the development of related activities (Bacon and Adams, 2005). Therefore, considering the variety of palliative care

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models for children it is not possible to set a set of fixed and predetermined goals for it (Cancer Research Center, 2012) and the detection and application of the appropriate model requires considering the specific conditions of each society and consequently, the policies of the health care system of that society (Rassouli et al., 2017). The structure of the Iranian health care system, based on the principle of “fair access to health care services for all”, is presented through classifying services and the referral system (Asadi-Lari et al., 2004). It seems that in such a situation the classification of palliative care services will also become meaningful and useful in Iran’s health system and leads to the development of palliative care service as a “road map” (ACI Palliative Care Network, 2013). On the contrary, the lack of such classification can lead to confusion in patients at different levels of care procedure, high costs, lower quality of life and patient dissatisfaction (Rassouli et al., 2017).

The development of accessible, affordable and qualified palliative care is proposed as classified palliative care services in countries such as Australia, England, New Zealand, Scotland and Canada (Department of Health; State of Western Australia 2008; Bycroft et al., 2012; Geraldine et al., 2009; Ministry of Health NSW, 2011) and is provided at primary, secondary and tertiary levels in most countries (Geraldine et al., 2009). Classifying palliative care, considering the health system of each country, provides a framework to identify a pathway to present a health care system from early stages of diagnosis to end-of-life care services. It also provides integration between different levels which leads to a persistent care based on the needs of the child and the family (Bycroft et al., 2012).

In Iran, in spite of the fact that the health policy makers pay attention to this issue and have considered it in the National Palliative Care Action Draft Plan, the classification of palliative care services and establishment of the referral system are considered as challenges (Khoubbin Khoshnazar et al., 2016), and the children and their families still have a low quality of life and their access to resources is limited (Rassouli et al., 2017). Therefore, providing a conceptual model for the provision of these services is necessary in Iran, and its applicability requires considering and applying the beneficiaries’ views in which the child and the family play an important role as a care unit. On the other hand, considering the standards of palliative care in Europe, based on providing care services according to the needs of the patient and the family (the Committee of the EAPC task force, 2007), and considering satisfaction as one of the results of these services, it is necessary to identify the needs of the child and the family to provide care based on their needs (Ann et al., 2014). To this end, using the beneficiaries’ opinions based on available resources and service delivery models can be helpful (Bacon and Adams, 2005). This study aims to explain the beneficiaries’ perceptions on providing a conceptual framework based on the health care service delivery system in palliative care for children with cancer in Iran.

Materials and Methods

This qualitative research uses content analysis and is carried out between August 2016 and February 2017 for 7 months.

Participants consist of 29 health care providers whom are chosen purposefully, including the parents of children with cancer referring to Mofid hospital (as a cancer referral center for pediatric services in Iran), nurses, Pediatric oncologists, and psychologists,... with more than one year of working experience with children with cancer, as well as the policymakers and cancer experts at hospital, university and the Ministry of Health’s levels.

The data was collected using semi-structured in-depth interviews in a relaxing environment preferably chosen by contributors mostly in Mofid children’s hospital. Rest of the work was done in the authorities’ and experts’ office on scheduled appointments. Data collection was done through semi-structured interviews. Separated interview frameworks were designed for parents, care-providers and policy-makers. In the beginning of the interview, questions were asked to familiarize the participants with the interviewer and create a relaxing atmosphere of sincerity. Then the questions became more specialized and were in line with the purpose of the research. The main question for parents was “What is your experience of caring for a child with cancer? What are the basic care needs?” For care-providers and experts, the main questions focused on the structure of the health system, different levels of health care and their relationships, deficiencies and opportunities of each one; questions such as “What is your experience of caring for a child with cancer? What is your opinion on palliative care services for children? How to integrate these services into the health system? How are the priorities set? What are the deficiencies?”

Besides, during the interview, while trying to minimize interference in the interview process, the interviewer used follow-up questions such as: “What did you mean by that? What else? Can you make your point clearer?” To direct the interview in a way that would help him or her grasp the views and profound experiences of the interviewees completely. All the interviews were recorded by the digital audio recorder and were transcribed at the earliest possible time after each interview after listening to it several times, carefully mentioning emotional reactions such as smiling, sighing, sobbing or keeping silent. Interviews lasted for 50 to 60 minutes on average and choosing the participants continued until data saturation (Streubert and Carpenter, 2011).

Data analysis

In order to analyze the data, conventional content analysis method was used considering Graneheim and Lundman (2004) approach. Parallel to the interviews, they were transcribed by the researcher. The text was read several times in order to get a profound and correct understanding of it and then was broken into the smallest possible meaningful code units. Similar initial codes were placed on a more comprehensive level and finally the main levels were specified. All the coding sessions of the interview texts were also managed using the qualitative

data analysis software (MAXQDA10).

To assess the accuracy of the qualitative data, the four benchmarks of Lincoln and Guba (1985) were used: to validate the Credibility, researcher had long-term engagement with the participants checking with their experiences and ensuring adequate interview time.

To investigate the Dependability, the researcher used a combination of data collection methods (field notes) along with external observers.

Conformability of research findings was achieved through recording the participants' words, writing them down and having them reviewed by the expert's observers and the participants.

Along with covering a wide range of participants in terms of age, occupation, and academic status, the researchers also tried to provide an comprehensive, detailed and step-by-step description of the way the research was conducted, to generalize the process for other researchers and contexts and to improve the Transferability of research for providing the ability to transfer the findings for evaluation and judgment by others.

In order to observe ethical considerations before initiating the interview, contributors were asked to sign an informed consent form. They were also asked for permission to be recorded for note-taking purposes. They were assured that while publishing the results their personal information would remain confidential. They were also informed that they could withdraw from the research at any step at their discretion. Besides, Moral approval was obtained from Shahid Beheshti University of Medical Sciences with the code number of IR. SBMU. RETEBH.REC.1395.240.

Results

The group of participants in this study included 9 parents, 8 mothers and 1 father with children with cancer, who were interviewed for 60 minutes on average. In addition, 20 health policy-makers with expertise in cancer, radiotherapy, cancer surgery, epidemiology, as well as health care-providers including pediatric Oncologists, pediatric cancer fellows, nurses, psychologists, social workers and nutrition experts were interviewed for an average of 50 minutes.

In the analysis process of the interviews, after removing repetitive codes and integrating similar cases, 1985 codes were obtained which were categorized as a content under the title of "level of care" in 2 main levels, 6 sub-levels, and 17 sub-sub-levels.

"Classes of palliative care services "

Meeting the needs of the child and family requires a leveling of palliative care services. This theme was expressed with the two categories including comprehensive care and the establishment of social justice.

1- Comprehensive Care

According to the participants, family environment as the original refuge is at the center of care and is protected

by different layers of care so that any defect or insecurity in this shelter will inevitably lead the family to the next layers of care in order to gain stability and to keep the child in the family environment. This category consists of two subcategories, including "Strengthening family shelter", "Maintaining the child in a familiar environment", "Achieving stability".

1-1 Strengthening Family Shelter

Participants believe that family is a pivotal pillar in children's palliative care which is specified through two sub-levels: "empowerment" and "family support-seeking".

Due to the lack of independence in sick children, the participants referred to the important role of family in care-providing and emphasized its empowerment. In this regard, a healthcare policy-maker said: "Having a child with cancer is equal to at least 3 people suffering from the disease, so the treatment procedure should be based on family. We should teach the mother how to take care of the child, and teach the father how to help her take care of the child well."

Participants in the research also referred to the crisis of disease and its consequences as a reason for the family's support-seeking in order to prevent the collapse of its integrity, mentioning the necessity of family members' supporting each other, the treatment team and other people involved in the procedure. In this regard, "being understood" was a necessity which was repeated in codes. It seemed that those mothers who had more support were more successful in maintaining the family's integrity. As one of these mothers puts it: "My husband never worked much and used to sleep a lot, but since Zahra got sick and we needed more money, he has changed a lot. He is better now. I never thought he felt he had any emotions before, but now things have changed. He's very supportive now."

1-2 maintaining the child in a familiar environment

According to the participants, due to the family's involvement in the process of diagnosing and treating the disease, they face challenges such as long-term hospitalization, treatment costs and changes in parents' roles. Contributors think that such challenges can be best managed by taking care of the child at home which will be possible through preparing sub-levels of "access to primary care", "access to information resources", "Continuity of roles", and "volunteer angels".

Due to the variety of needs in the child and the family, participants pointed out access to primary care provided by public care-providers while highlighting its benefits for family, besides considering it cost-effective for the health system. "We need to take our services into the community so that all people can have access to it," said a palliative care specialist, "instead of an incurable patients' having to refer to the hospital to get an opioid during the last days of his life."

The family identified the necessity of access to reliable sources of information as an important need during their child's illness period. Otherwise, without having access to trainings from official sources (physicians, nurses, etc.), they will have to gather information from informal sources

Table 1. Theme, Main Categories, Sub- Subcategories

Main theme	Main category	Sub-categories	Subcategories	
Classes of palliative care services	Comprehensive care	Strengthening family shelter	empowerment	
			family support-seeking	
		Maintaining the child in a familiar environment	access to primary care access to information resources Continuity of roles volunteer angels	
		Achieving stability	care-providing from diagnosis restoring calmness on a turbulent path reaching a warm shelter Helping the child to fly	
	Establishing social justice	Easy access to services		provide care settings provide care 24-hour providing professional service
			Financial relief	insurance coverage of services participation of NGOs
		Quality care	satisfaction quality of life	

such as the internet, mass media and even other patients.

One of these mothers said, “I did not know anything about what Zahra must or must not eat. Every week, I used to write a list of meals and ask the doctor to merely mark the ones she was allowed to eat, without any explanation. I just read all the items and understood them by experience. No one explained them to me.”

Family members’ roles as parents, spouses or members of the community change with the development of the child’s illness and the family’s integrity faces challenges due to the family members’ inability to perform their roles or even changes in relationships. To solve such problems, they need to “Continuity of roles”.

“When I took my daughter to the hospital, I had to leave my 2-year-old son with my mom,” said the mother of a 4-year old girl with cancer. “He was always sick. Once when I was at the hospital for a week, when I got back, I found he was suffering from heat rash. I felt pity for him since I could not mother him properly. I hugged him and whimpered”

Participants acknowledged that besides all the usual resources, there were some support groups that unexpectedly gave them a hand and facilitated child care in difficult circumstances. Emotional support, supplying equipment for care-providing at home, celebrations with the presence of celebrities, giving presents, playing with children and reading stories for them were among what these volunteers known as Volunteer Angels did. “Every year, just before new year’s Eve, they hold a big party in the hospital, with the presence of celebrities like TV actors popular with children, such as Uncle Pouring, and the Wicks.” A mother said, “Children become very happy, everyone plays, laughs and dances. It really boosts their morale.”

1-3 Achieving stability

At different stages of the child’s illness, from diagnosis

to the end, little by little, family faces various challenges and new needs appear which gradually prepare them to deal with more complex conditions. Participants professionally acknowledged the necessity of responding to these needs during this arduous period which was specified through the sub-levels of “care-providing from diagnosis”, “restoring calmness on a turbulent path”, “reaching a warm shelter” and “Helping the child to fly”.

Almost all participants referred to an initial shock, turbulence, disappointment and crisis in their lives after the child’s being diagnosed with cancer and regarded starting care-giving, along with the professional announcement of the bad news, and taking part in the therapeutic decision-making at the onset of the disease as an effective way to overcome this shock. “The day doctor told us that my daughter had cancer, I just cried and stared at him. He asked me if I had understood and had at all listened to what he had said. I was just shocked,” said the mother of a 6-year-old child about her reaction after hearing about her child’s disease.

Another contributor talked about the family’s desperation as a result of not being involved in the therapeutic decision-making process. She said: “When I was told about my son’s medical diagnosis and his illness, I had millions of questions about the illness, treatment procedure, his doctor, etc. I did not know what they were going to do. No one even answered me. It was very hard and terrible. It seemed I was wandering in a limbo.”

On the other hand, according to participants, the illness and treatment process is accompanied by ups and downs that disturb family’s peace, so the family needs physical, mental, social and spiritual cares in order to restore peace on this turbulent path.

“Lots of things happened to us in these last 6 months of visiting hospital. Once his cells drop; another time, his mouth ulcerates. He was down due to all these incidents which had made him depressed.” Says a mother, “We

are exhausted too; we don't know what to do anymore. We went on pilgrimage, we traveled. To sum it up, it's extremely tough. I don't know, maybe it's a divine test."

Although the participants considered hospitalization of their child inevitable in some circumstances, they referred to problems such as long admissions in the hospital, and the parents and the child's being away from home and feeling home-sick. They felt the importance of some solutions such as designing consultation systems to accelerate the discharge process and help the child return home earlier to restore peace reaching this warm shelter. "We always come to the hospital for a three-day treatment, but we are forced to stay there for at least one week," a mother said, "This time my son didn't accept to come here for he knew they'd get him to stay there for another week. I wish doctors could do something about it. Every time we bring him by force. Maybe it's the fear that has negative effects on his cells and his morale. You know how important it is to have high spirits" When the treatment ends, the ineffectiveness of the process, makes the family confront problems that lead to symptoms such as fear, feeling guilty, denial, etc. Participants pointed out the importance of caring for the needs of the child and the family at this stage by fulfilling the last wishes and helping the child to fly. "One of my patients, a 14-year-old girl, had a wish on her last days." One of the nurses stated describing one of her experiences, "She wanted to go home, to stay and die near her sisters. She used to paint their yard every day. She asked everyone to send her home, but his father was still in Tehran searching for expensive drugs believing he was doing the right thing for his daughter. What always bothers me is that the girl's dying wish was never fulfilled."

2- Establishment of Social Justice

The second main level in the present study is the "establishment of social justice". Frequent commuting to receive treatment, heavy costs for family, waiting for services, dissatisfaction with the treatment system and frequent absences from their workplace were among the problems experienced by family members, which led to the formation of these 3 sub-levels: "easy access to services", "financial relief" and "access to quality care".

2-1 Easy access to services

Participants believed that to have easy access to services, the existence of the care provision settings in which specialists are available 24-hours a day is a must. This sub-class consists of provide care settings, provide care 24-hour and providing professional service.

Providing care at home, at the clinic and at the hospital were approved by the participants respectively, whose realization, as they believe, depends on the integration of services into the health care system. "Integrating services in the health system is one of the principles of health management meaning that such services should also be provided by the care team in the country and are not something apart from the rest", said a policy-maker in palliative care. The child and the family's gets confused in various care fields, delays in the treatment process, spending too much time to access services, etc. were

among family problems. Participants noted the importance of coordination between different treatment levels in order to receive 24-hour care. "We have to determine where and when the patient goes after diagnosis. Then the family should be referred to other sectors according to their needs," said a palliative medicine expert, "We have to provide a guideline to be able to do so."

Due to their lack of knowledge about palliative care and the lack of pediatric palliative experts, participants considered the professional provision of services to children so important and highly effective in developing these services. "We need to educate people with general and specialized degrees at different levels of health system. In other words, the providers of the service themselves should be classified", said a palliative medicine expert.

2-2 Financial relief

According to participants, one of the main pillars of providing proper services is financial relief which is specified as sub-levels of insurance coverage of services and the participation of NGOs. Losing jobs, lack of financial support, depletion of family's cash reserves, and high costs of non-medical treatments were among families' experiences. In order to overcome such challenges, participants referred to the key role of major insurance organizations and NGOs. "My husband was a driver at a car rental agency. After my son became sick, we sold our car. At first, it was fine since we spent that money for Ali's treatment. But as we ran out of money, serious problems raised. It was during those days that I literally found out what it means not to be able to make ends meet," said a mother.

2-3 Access to quality care

The provision of services on one hand, and its quality as an important component in the effectiveness of services on the other hand, were among the concerns of participants which were described as two subsidiary sub-levels of satisfaction and quality of life. "My son's doctor is really bad-tempered and impolite. I don't even dare to ask him a question. I'd like to take my son to some other doctors. I'm not satisfied with his doctor," said a mother.

Discussion

Providing a suitable platform for the establishment of palliative care in each country requires the identification of overall structure of health system in that country. By considering this fact, the pathway for applying palliative care services can be specified in the context of the existing system without having to spend too much time or paying high costs (Rassouli et al., 2017). Therefore, this study was conducted in an attempt to specify the beneficiaries' perception of providing a conceptual framework based on service classification system as a general plan in the health system on the palliative care for children with cancer in Iran.

The experiences of many countries show that the provision of services in appropriate fields and based on the classification of the child and the family's needs is an important principle in designing the palliative care model

for children (Bycroft et al., 2012). The results of this study consistent with previous experiences showed in the Iranian beneficiaries' opinion, the classification of palliative care service is a key component in offering such services.

One of the main categories that specify the necessity of classification in the present study is named "comprehensive care". Comprehensive care refers to a set of services in a specific order, focusing on the child and family, offered in order to maintain the child's presence in the atmosphere of the family, and to provide a relative stability in the care process.

Developing cancer in children creates a crisis that shakes up the family, making family members find themselves dealing with a range of unfamiliar tasks such as physical, emotional and therapeutic care in such a way that they persistently seek help and support to protect and strengthen their refuge. Their request for help is expressed as demands in order to satisfy their needs for information and psychosocial and economic support (Rassouli et al., 2017). Over time, mothers gradually feel they are not heard while they expect empathy and need the support of their husbands and families more and more everyday (Nikfarid et al., 2015). Despite the necessity of providing family-based care in the country's health system and emphasizing the empowerment of care-givers and its impact on maintaining the patient's survival at home, neglecting the needs of the family by care-providers is one of the permanent complaint-raising issues (Nemati et al., 2017).

An obvious wish of the participants in the research was keeping the child at home by satisfying the child's basic needs and solving the problems through having access to information resources and getting help from volunteers, and thus being able to keep on living without yielding to changes in their family roles. Such a wish raises in situation in which services are mostly provided in hospitals, forcing the family to travel long distances to receive proper treatment, which not only causes a financial burden, but also increases the care-giving pressure on them and leads to psychological distresses (Rosenberg et al., 2013). And all this is still happening while the world is moving towards providing services at the community level, putting emphasis on the principle of social justice (WHO, 2016), which is provided in different countries in terms of care classification (Khoubbin Khoshnazar et al., 2016). In Iran, despite the policy-makers' emphasis, providing services at the community level is very basic and there exist some flaws such as lack of proper structure, lack of family participation and legal, security and financial issues (Hemati et al, 2016).

In seeking a way to keep the child at home, families referred to the importance of information sources and their ongoing efforts to seek out information, specifically from the doctor. Despite the nurses presence and their being in touch with the child and the family, perhaps their lack of knowledge in this field is what causes families to try to seek information from the doctor (Hamooleh et al., 2013). This kind of care is not included in the formal nursing educational program, but considering the importance of having expert forces in providing this kind of care, the educational planning for the required majors in this field is

a priority in the country (Sajjadi et al., 2015). Focusing on giving care to a child with cancer, as well as its emotional burden, has caused mothers to feel depleted about their other roles. Their duties toward their other children, as mothers, their duties toward their parents as children, as well as the duties they had as a wife, were among the duties these mothers believed were being neglected by them. These findings are consistent with a study on the Jordanian mothers with children suffering from cancer, some of whom believed that having a sick child had caused imbalances in their family structure and procedures (Rami Masa' Deh et al., 2012). Seeking assistance from volunteers as family mediators and service providers in providing palliative care is common around the world and is considered an important resource in developing countries (WHO, 2016). In this study, it was the same, as mothers highlighted the role of volunteers and talked about them and their generous services enthusiastically. In a study, researchers have referred to the unrivaled role of volunteers in care-providing to the child and family's satisfaction (Candy et al., 2015), which can be considered in accordance with the prevailing conditions of the country, regarding its cultural and religious background, and the existence of many charity associations (Rassouli and sajjadi, 2016a).

Having a child suffering from cancer makes the family confront a turbulent path, which leads to consistent encounter with conflicts, forcing them to try to find a way to reach stability. Issues such as cancer diagnosis in a culture with cancer stigma, fear of unknown therapies, physical, psychological and spiritual distresses, approaching the child's death and fear of losing him or her, create a set of challenges from the stage of cancer diagnosis to the death of the child and afterwards, which the participants in the research referred to as causes of family instability. Managing such challenges requires a specification of the care-giving process from the earliest stage of the disease in order to create peace in the family, and to lead them towards having a warm refuge and fulfilling the child's last wishes, all during the turbulent cycle of the disease.

The process of care provision in different countries varies according to their resources and the goals of their health system (WHO, 2007). In the UK, for example, the palliative care process in children is presented in the three phases of diagnosis, living with cancer and end-of-life with 6 standards, which is also used in other countries such as Australia, New Zealand, Scotland as a standard framework (Ministry of Health NSW, 2011; Geraldine et al., 2009; Bycroft et al., 2012). In Canada, palliative care is regarded as a package from the stage of diagnosis, and symptom management is carried out according to full review of the patient, family and care providers based on relevant guidelines (Ontario Palliative Care Network).

In Iran, despite the successful experiences such as compiling a clinical guide to "spiritual services for cancer patients" and drafting a "service package of palliative care for cancer" to standardize care, there are still no special care plans designed for these patients and these services are provided based on the experience and knowledge of care providers regardless of any clinical guidelines (Rassouli et al., 2017). Khoshnazar et al., (2016) considered the lack

of guidelines for care provision as a structural challenge of providing palliative care in Iran .

The first step in the care chain is providing professional services at the very beginning of the illness that is critical due to the shock and distress caused by the diagnosis of childhood cancer. In the UK, this stage of care is presented through two standards: “delivering the bad news professionally” and “participating in the therapeutic decision-making” (Widdas et al., 2013). In Canada, at the earliest stage of the disease, the diagnosis is explained to the patient and the family based on their perception and therapeutic options are shared with them (Ontario Palliative Care Network). Regarding the cancer stigma in Iran (Zamanzadeh et al., 2013) and mothers’ taking it as a bad omen (Nikfarid et al., 2015), it is essential to deliver the news of cancer diagnosis in a professional way.

Passing through the crisis of diagnosis and progressing through the process of disease, the family faces various physical, psychological, social and spiritual distresses which necessitate receiving specialized services in various fields. In Iran, despite the existence of different specializations, there is no integrated care provision system, and individual experts work on their own. In a study, Tahmasebi (2013) refers to the inappropriate relations of doctors with one another in managing a cancer patient at the end of life, which leads to ineffective interventions and keeping the patient in the emergency department . One of the solutions offered by the Ministry of Health has been the provision of integrated and multidisciplinary services is designing an interdisciplinary curriculum (Irajpour et al., 2015).

Long-term hospital admissions, which result in the child and the family’s being far from home, can be avoided by designing a supportive consultation system to accelerate hospital discharge and make it possible for the child to return home earlier and restore peace in the family. Discharging a child from the hospital is economic not only for the family, but also for the health system (Nikbakht -Nasrabadi et al., 2016). In developed countries, hospitalization is necessary only for fulfilling complex needs and receiving specialized services, and they try to direct the child and the family to community-based care by providing them with full support (The Scottish Ministry of Health , 2012). In Iran, the family inevitably refers to emergency rooms and ICUs for special care which imposes a large financial burden on both the family and the health system (Rassouli and sajjadi, 2014).

The end of cancer tragedy for the family is the child’s death. Returning home is the last wish of an Iranian child with cancer facing death, which is in contrast to the family’s request. The family insists on receiving services until the very last day hoping for recovery which perhaps is a way to get rid of the feeling of guilt in parents having its roots in the culture (Fallahi et al., 2017). It’s a standard of care for the patient to choose the place of his/her death but Iran possesses the second place from the bottom on the world’s list of countries regarding the quality of death index, while Iraq is the last on this list (Suresh et al., 2015). Supporting the family after the child’s death is also very important in terms of grief management and mourning care, and there are valid guidelines for it around

the world (Widdas et al., 2013). There are no guidelines designed in this regard in Iran and there’s only Shervin Charity Foundation which provides care for families during this phase as group therapies which are managed by volunteer psychologists (shervin chariety, 2017).

Supporting the child and the family requires the all-round provision of their needs. And the other main class of this paper is “establishment of social justice”. Frequent commuting to the hospital for receiving treatments, spending the family budget, waiting in line for services, dissatisfaction with the treatment system and frequent absences from work were among the common issues experienced by family members which led to the formation of three sub-classes of “easy access to services”, “financial relief” and “receiving quality care”.

Access to services will become possible by providing a variety of care-providing settings such as care-giving at home, hospitals, hospices, clinics, etc. which makes it possible for families to choose one according to their needs. Home and hospice care were the most popular choices for care in other countries (Khanali et al., 2017). However, families in this study referred to hospital care after outpatient cares since they were afraid of their child getting sick as a result of lack of family support and their inability to be involved in care- giving. They wished to receive treatments at home along with family members with the support of a care provision team while preserving the family’s integrity. And this will require a 24-hour care.

In this study, the child and the family’s confusion in various care settings, delayed therapeutic procedures and spending too much time to access services were among the family issues mentioned and participants felt the need for coordination between different levels of a 24-hour care system. This kind of care is one of the principles of pediatric palliative care which is applied in many countries (the Committee of the EAPC task force, 2007) and will be achievable by integrating such services at different levels of the health system (Ministry of Health NSW, 2012). Establishing coordination between different levels of care and the referral of the child and the family in order to receive specialized services can be managed by creating a positive attitude in different disciplines and designing a referral system between different centers (Harrop et al., 2013). In Iran, despite the existence of the national Family Physician Plan and a referral system, there are still problems such as improper referrals, lack of confidence in mid-level practitioners and the lack of sufficient information flow in the country (Rassouli et al., 2017). On this basis, it’s obvious that the optimal implementation of palliative care requires the knowledge and awareness of service providers, which has been referred to as an important factor in the development of palliative care services by participants. Iran is ranked 78th out of 80 in the global ranking of access to expert forces and the availability of training courses (Suresh et al., 2015). Available evidences also indicate that the level of service providers’ knowledge is low in this field (Sajjadi et al., 2015).

Another important factor in the development of palliative care is the provision of financial resources. Losing job, lack of financial support, depletion of family’s

cash reserves and high costs of non-medical treatments were among the experiences of participants specified by the sub-level of financial relief. In most countries, these resources are provided by government and charities (Rassouli and sajjadi, 2016b).

Australia, Ireland, the United Kingdom and Denmark pay 80% of all patient care costs and, are ranked first in the world while in Iran the lack of insurance coverage is a big challenge (Khoshnazar et al., 2016). In this regard, Iran is ranked 56th in the world (Suresh et al., 2015). However, the healthcare reform plan has been effective for the country and has increased patient satisfaction and reduced many of their costs (Khoshnazar et al., 2016). Given that a major part of hospices and home care costs in the UK is provided by charities, it seems that this kind of service in Iran is also possible regarding its cultural and religious background, as many organizations are already offering such services in various fields including Mahak charity Institute which supports the children suffering from cancer (Mahak charity, 2017).

In addition to providing funds for service development, it is also necessary to ensure the quality of the care provided through these services which is measured by various indicators and using its results is essential for better resource management in countries with limited resources (Knapp et al., 2010; Woitha et al., 2012). In this regard, assessing the quality of life in children with cancer and their families as the main outcome of palliative care can provide information on the pressure of illness and the negative effects of mal-treatment on children and their families (Woitha et al., 2012). The quality of life in cancer patients in Iran, as well as in other developing countries, is facing many challenges due to different factors and from different aspects. Various studies conducted in the country describe the quality of life in children with cancer as unsatisfactory and sometimes even poor (Rassouli et al., 2017; Valizadeh et al., 2014) and despite numerous studies on the quality of life in cancer patients and their families from the viewpoints of the patient, the family and that of care providers, and examining the various factors associating with it, there is still no data on the direct impact of such care procedures on the quality of life in children and their families due to the lack of provision of codified services in the form of palliative care (Rassouli et al., 2017). In other words, by providing palliative care and paying attention to it from all different aspects, improving the quality of life in cancer patients will be possible.

Final conclusion

In the health system of Iran, services are provided at three levels: primary, secondary and tertiary levels. The research findings also highlighted the integration of palliative care services in the health system. Thus, care at the community level can be provided at home, at the primary and the secondary levels of health care system, as well as outpatient treatment at the closest center to one's home i.e. provincial and urban health centers. Specialized services are provided at the third level of health care systems i.e. specialized hospitals, supported by a team of experts 24-hours a day.

The establishment of a palliative care system in Iran is an obvious necessity and so far serious efforts have been made to design and implement it. However, there is still a long way to go to reach the desired level, but thanks to the existence of initial structures for the establishment of this system within the country's health system and the potential processes and opportunities created by medical universities, NGOs and charities, there's hope that such a system will be realized in the not too distant future and its impacts on improving the quality of life in children with cancer and their families will be sensible and significant.

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