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A Comparative Study of the Situation of Bereavement Care for Children with Cancer in Iran with Selected Countries

Maryam Pakseresht[1], *Shahram Baraz[2], Maryam Rassouli[3], Nahid Rejeh[4], Shahnaz Rostami[2]

[1]Ph.D. Student in Nursing, School of Nursing and midwifery, Ahvaz Jundishapur University of Medical Science, Ahvaz, Iran. [2]PhD in Nursing, Assistant Professor, Nursing Care Research Center in Chronic Diseases, School of Nursing and Midwifery, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran. [3]PhD in Nursing, RN, Associate Professor, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, Iran. [4]Associate Professor, Elderly Care Research Center, Faculty of Nursing and Midwifery, Shahed University, Tehran, Iran.

Abstract

Background

Death of a child with cancer is one of the most painful events that results in traumatic reactions of bereavement. Care should be taken into account during the bereavement period. The present study aimed to develop bereavement care in Iran and comparing it with Jordan, England, Australia and Canada, which have achieved the desired situation in the above area.

Materials and Methods

In this comparative study, the necessary data was made to databases of reputable and sovereign centers of the countries and palliative care programs. After accessing the pioneering patterns of world-wide palliative care, Iran's palliative care program, which came from children's service centers and access to the databases of those centers, was also examined.

Results

In the developed countries of Canada, England and Australia, a wide range of bereavement care is provided in care facilities. for example following the death of a child, in Canada family members are covered by all the bereavement care, in Australia formal caregivers increase their relationship with parents and are available to listen to feelings and in England all family members are supported. Jordan provides significant services in this regard such as visits at the bereavement ceremony, however, it is provided limitedly only in one center in Iran.

Conclusion

In the developed countries, pediatric palliative care is well developed. But in some developing countries, including Iran, there are only a few of these services for dying children and their families. As a result, the traumatic results emerge in social and family life activities.

Key Words: Bereavement, Cancer, Child, Death, Palliative care.

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Corresponding Author:

Shahram Baraz, PhD in Nursing, Assistant Professor, Nursing Care Research Center in Chronic Diseases, School of Nursing and Midwifery, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran.

Email: shahrambaraz@ajums.ac.i

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1- INTRODUCTION

Cancer is one of the main causes of child mortality in the developed and developing countries (1). The incidence of this disease in children and adolescents is approximately reported as 15 cases per 100,000 people (2). In Iran, this disease accounts for approximately 4% of children under 5 and 13% of deaths in children aged 5-10, among which leukemia is increasing in terms of prevalence and mortality (3, 4). Although progress in treatment for child cancers has increased by approximately 80%, cancer, after the car accidents, remains the second leading cause of mortality among children and adolescents aged 5-14 (5).

This disease has become of great significance among the chronic diseases of childhood, because it has a high prevalence and greatly affects the lives of the children and their family (6). Because of its challenging nature and its uncertain consequences, cancer has always been associated with high levels of ambiguity and emotional and psychological upheaval for both the child and the family since its initial diagnosis and during the treatment follow-ups (7), and patients suffer with a wide range of symptoms and side effects of the disease and related treatments in physical, mental, psychological and social dimensions (8), thus, exposure to these conditions has adverse effects on the quality of life of the patient and the family (9, 10).

The presence of symptoms and complications of the disease and the related treatments, the imposition of huge therapeutic costs, and the changes and psychological and social consequences of the disease, require the patient and the surrounding people to have a comprehensive care in the form of "supportive and palliative care" (11). This type of care supports the family and the surrounding people if the child dies. Thus, bereavement care is one of the components of supportive and palliative care (12). The death of a child is one of the most painful events that results in traumatic reactions of bereavement (13). Bereavement is the process of mourning accompanied by a severe feeling of loss and discomfort that occurs with death, and is a process in which life continues without the physical presence of a beloved one (14). For parents, the break of attachment relationship with the child leads to severe anxiety and other negative emotions. Parents may feel guilty due to their inability in protecting the child. The research emphasizes bereavement as an injury that causes adverse psychological and health consequences (13).

For instance, Stroebe's et al. study (2005) showed that bereaved people are more susceptible to suicide (15). Li et al. also found in 2005 that bereaved people, especially a mother, is subject to psychiatric admission (16). In fact, the risk of mother admission may continue to more than 5 years after the child's death. Danish researchers found that the mortality rate of mourning parents is more than non-mourning parents. Therefore, mourning affects social performance and family quality of life (17). Supportive and palliative care in the area of bereavement focuses on the empathy, recognition of the strengths and sources of family support, investigation of family adaptation and the provision of emotional, practical, social and spiritual support to the family (12).

Support in bereavement aids in the family grief process. It also creates an opportunity for the family to share their feelings with those who understand their feelings. There are plenty of supportive groups, people and resources that aid this process. In addition to the family, the children who understand the diagnosis of their disease and its constraints will experience a sense of sadness and loss. All family members, including the parents and siblings find a feeling of loss at the time of diagnosis.

Therefore, there should be a care plan that can assist the family and the surrounding people to have an appropriate respond to the loss or the grief (14). Based on the World Health Organization (WHO), more than half of the countries in the world are making efforts to provide supportive and palliative care (18). Nevertheless, in 2014, the Organization acknowledged the limited access to these care services in many parts of the world (19), in which the provision of these services in the Middle East countries was introduced as a necessity (20). Iran is no exception to this, given the young population of the country and the high incidence of mortality due to child cancer in children (21).

Although the supportive and palliative care is one of the requirements of the health system, there is still no plan in Iran to provide supportive and palliative care for the child and family and treatment centers do not provide such services to patients and their families (18, 22). There are only a few centers for providing these services that do not have purposeful or well-documented plans, or do not follow a particular care model, and patients and their families usually do not receive the necessary care and training as well as cares associated with social, psychological, physical and or spiritual needs (18).

Since one of the best practices to improve the quality of care is the audit of the provided care, investigation of the current state of bereavement care in the country and its comparison with the experiences of the countries that have achieved the desired situation in this regard can be a step towards the development of this kind of care in Iran. The purpose of this study was to describe and compare the bereavement care process in children with cancer and family in Jordan, England, Australia and Canada with Iran.

1-2. Conceptual framework

The conceptual framework of the present study is based on the square of care, in which the child and the family are placed in the center of the square as a care unit. Clinical activities conducted in children's palliative care include two parts where child and family care (disease management, physical care, symptom and pain management), psychosocial, spiritual, social, evolutionary, practical, end of life, and loss/grief and bereavement) are located on the left side of the square. The care provision trend is located on the top of the square. Practical activities that support the effective palliative care of childcare include two parts, which consists of supportive activities on the right side of the square, and government at the bottom of the square (**Figure.1**) (23).

2-MATERIALS AND METHODS

This study is a comparative study, which describing and explaining the similarities and differences of situations among large scale social units such as regions, nations, societies and cultures (24). The research community comprised the supportive and palliative care system in four countries of Jordan (within the same region with Iran and with similar health conditions), England (providing pediatric palliative care as a comprehensive approach and in the physical, emotional, social and spiritual dimensions), Australia (development of service delivery models innovatively and specifically), and Canada (significant growth of clinical, research, pediatric palliative care education over the last 20 years) which were eventually compared to Iran's supportive and palliative care system.

For this purpose, in order to obtain the necessary data in the field of bereavement care, we referred to the databases of valid and governmental centers of the mentioned countries, including the King Hussein Cancer Center (25), Cancer Care Ontario (26), and the Australian Government/the

Department of Health (27), European Association for Palliative Care (28) and using the keywords of pediatric cancer, palliative care, cancer care in children, guide to Palliative Care, bereavement care, grief, Loss and palliative care programs were studied in line with the bereavement care in children with cancer. The time range of the search was from June 2017 to October 2017. After providing and accessing the palliative care documented patterns of the world the palliative Care Program of Iran was also examined, which was obtained from child-care centers and referring to the databases of those centers. Based on the study purpose, the present study was conducted on around the axis of bereavement care and analysis of data by comparing the common aspects and differences in the palliative care system in selected countries on the mentioned axis.

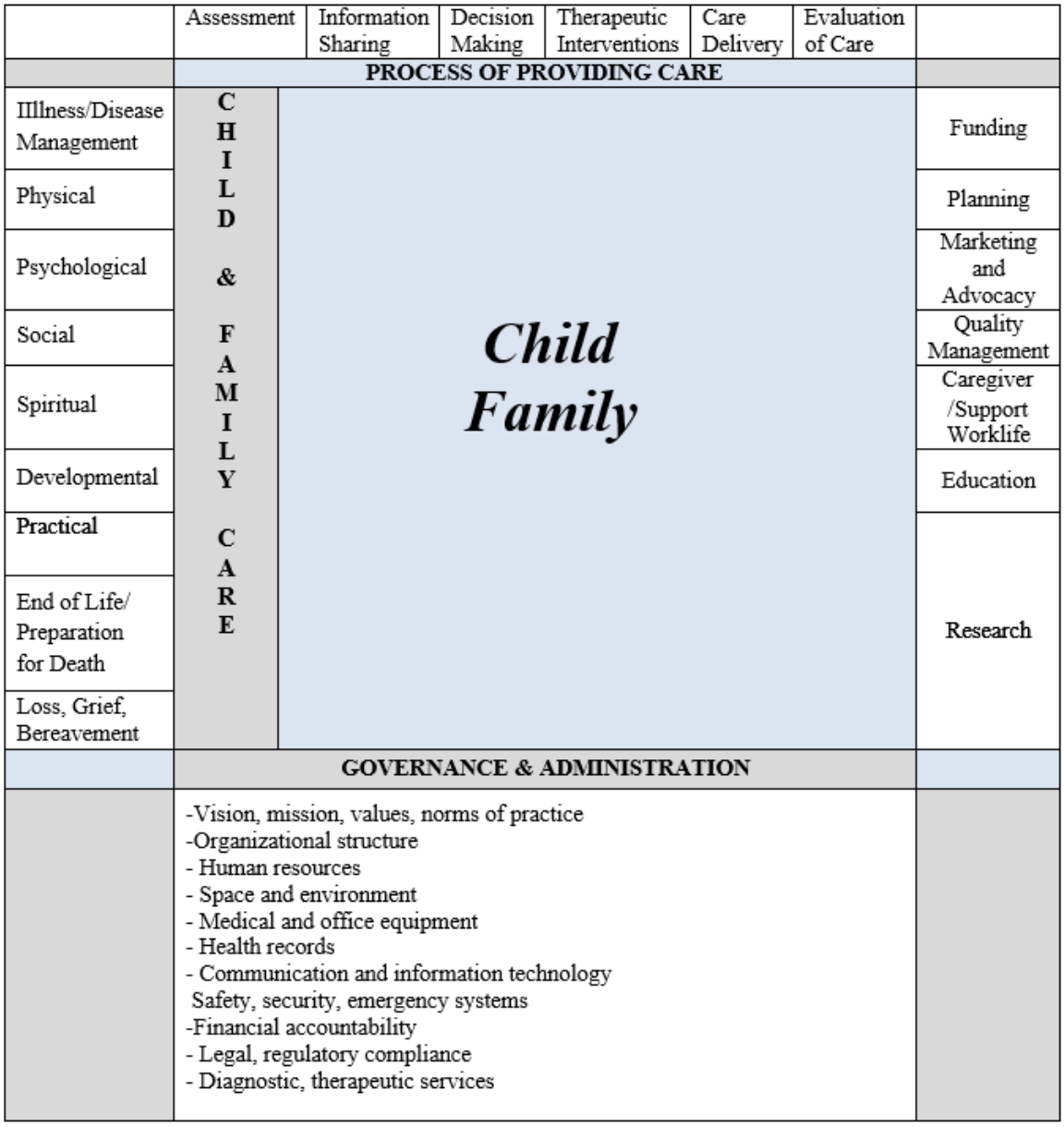

Fig1: The Process of Providing Care (23).

The purpose of this study was to describe and compare the bereavement care process in children with cancer and family in Jordan, England, Australia and Canada with Iran. Based on the survey done by the International Organization for Surveillance on End-of-Life Care, approximately 160 countries are actively providing palliative care or developing a framework for deploying such services. In the 2006 report of this study, countries in the world were divided into four groups according to the level of palliative care, but in the recent report, the 3rd and 4th groups were divided into two subgroups a and b. Group 1 without any palliative care activities, Group 2 is capacity building activity, Groups 3 and 4 are divided into two levels: 3a Provide palliative care sparingly, 3b Provide Palliative care generally, 4a Countries where palliative care and hospice care services are in the pre-integration phase in the provision of services, and 4b Countries with palliative care and hospice in the stage of advanced integration in the mainstream delivery system England, Canada and Australia are in group 4a. In this group, specialized palliative care services are provided to end-stage patients and their families, such as symptom treatment and pain management, end-of-life programs such as providing family service at the bereavement stage and the provision of Hospice services; the professional and the general people are well aware of palliative care, unlimited access to morphine and all other types of antipyretic drugs, formal palliative care centers are developed in these countries, and have a national palliative care community as well as academic associations with other universities (29, 30). Jordan is known to be one of the countries with Level 3 Palliative Care. Limited training was provided for experts, but other key aspects, such as the National Palliative Care Strategy, drug supply policies, and training on a large scale are developing. In these countries, home care is the most common type of palliative care (31). In 2011, Iran was ranked up to 3b group. In this group, palliative care is sporadically developed and not well supported. Funding is heavily dependent on financial support of a single source (such as government), and non-governmental organizations do not play a significant role (29, 30). After examining the status of supportive and palliative care in Iran and four countries of Canada, Australia, England and Jordan in the study area, the results were presented as follows.

3-1. Canada

Families of children with life-threatening illnesses have access to specialized hospital and community services with the presence of skilled people in the bereavement care. Following the death of a child, members of the family are covered by the bereavement care, including providing information, peer support, supporting through trained volunteers, group support and advocacy counseling through professionals. The care plan is developed based on the assessment of the family's abilities and needs and discussion with them. Formal caregivers support the patient and the family during the process of grief by regularly contacting with the family or holding a birthday party for the child or holding a child's death anniversary. Formal caregivers provide a variety of support and resources to address the continuing physical, emotional and spiritual needs associated with sadness and loss for the family. Cultural leaders of the community may voluntarily participate in the bereavement care. The access to care with the bereavement quality is on the shoulders of a series of care team members who communicate with the family and are skilled in the bereavement care. Families receive bereavement care and support for at least one year. The caretakers respectfully deal with the subject of death, and they will contact the family two or four weeks later by telephone or a letter.

Team members have access to instructions for making appropriate, timely and evidence-based calls. Caregivers are trained to aid families develop their knowledge, skills, and perspectives, study their needs, and identify people who need more support and counseling Formal caregivers work with children and families facing progressive and life-threatening illnesses, and offer support for sadness and bereavement as part of their own task and based on the basic needs of the family (12).

3-2. Australia

Formal caregivers increase their relationship with a dying child and parents, and are available to listen to feelings, frustration, anger, guilt, regret, discomfort and hopelessness. One of the fears of families is that their children are forgotten, thus, there will be a contact with families at significant times, such as the birth of a child, the anniversary of death, and other significant times. Siblings of the deceased child may be afraid. For this reason, the provision of a diary can sometimes be helpful, because their feelings can be discovered through their drawings or writings. Because grief for child may last for months, caregivers should identify local bereavement services for family access. There are various bereavement support models, including individual, two-person, or group counseling. People are different, and for each person there is a support method (32). A wide range of bereavement support, including professional counselors, community-based social support groups, spiritual careers and church-based support groups, hospital-based support groups, Internet-based bereavement support groups, bereavement care of parents and the siblings (14).

3-3. England

It is very significant for families to ask what they want to ensure preserving the whole family. All types of support must exist for the family during this lifetime. Sometimes professional approaches that are too reliant on opinions may provide inadequate support for the family. For instance, group support is good for some, not everyone. Support for the husband and wife is beneficial because the desire for communication in parents during child care is affected by the death of the child (33). It should be noted that support for other siblings and other family members, including grandparents, is socially, functionally, emotionally, psychologically, socially and spiritually, significant to adapt to the death of the child (34). The basic principles of bereavement care include confidentiality, respect, equality and diversity, quality and safety (35).

3-4. Jordan

Palliative care services continue until death. The palliative care group at King Hussein Hospital believes that the sadness of losing loved ones remain long after his death, thus, the palliative care group makes visits at the bereavement ceremony and carries out spiritual care for the family. At this center, some strategies are provided such as talking about the loss, self-forgiveness, good eating, and doing exercise to families to adapt with the bereavement (36). Also, protecting mourning friends and families is done by not judging the person, believing and accepting that even in the same circumstances, the adaptation method of friends and other family members is different with another person, avoiding the imposition of opinions to others, accepting to help people, arranging a group of friends to share family tasks, such as cooking or fetching children from school, helping the individual to renew interest in past activities and entertainment (37). Bereavement care is done at no cost, 24 hours a day, and at all days of the week (38).

3-5. Iran

As regard death is a central concept in Islam, and 98% of Iranians are Muslims, to cope with stresses induced by disease and the prospect of death, most Iranian people turn to religion to elevate the patient's mental state. Such an approach is highlighted by the Iranian Palliative Care Association, which views religious counseling as one of the objectives of palliative care in order to raise the patient's and family members' spirits. Accordingly, what raises Iranian patients' hopes in most circumstances includes pilgrimages to Mecca and other religious sites, sacrificing animals to cure the patient, praying and taking part in religious ceremonies, and helping people in need to satisfy God so as to heal the patient (18). However, there is no evidence of religious advisers to help bereaved families in service centers.The only case found was providing counseling to families of deceased patients at the Mahak Charity center (39).

4- DISCUSSION

Bereavement is the condition of losing someone or those we love (40). Given the significance of child death as a traumatic experience for parents, parental bereavement research is less than expected (13). Child death can change life and make family members sad for a long time, especially parents, and make them in need of support or advice for living and adapting to conditions. Given that different families, communities and cultures show different grieves and bereavement (40), the use of other countries' experiences in bereavement care can promote the process of providing bereavement services for parents and the surrounding people. The present study was conducted aiming at the comparative study of bereavement care in children with cancer in Iran with the selected countries. A brief overview of the findings of the present study on the general situation of palliative care in selected countries shows that in the palliative care countries such as Australia and Canada, much effort has been devoted to the development of palliative care and coverage of services in spite of the low mortality rate Children and the geographic extent of these countries are underway (41, 42). In England, as a pioneer in the introduction of palliative care, a significant portion of the function of the clinics, as well as education and research, is devoted to pediatric palliative care (43). In developing countries, including Jordan, palliative care is considered a newly created specialty that faces many challenges (44). In Iran, there is still no plan for providing these services in a coherent way, even for adults (18). Based on the results of the present study in the Australia, during the interview with mournful employees and parents, it was found that most children in need of palliative care were willing to receive care at home; however, the children's ward lacked a social and specialized infrastructure for this kind of care (41).

While there is no right or wrong way to mourn in dealing with a child's loss, Australian care program helps families to recognize which response is right or wrong to this loss, and helps families find out when family members need counseling and support. In this program, normal reactions to this lack were stated for the child and parents and siblings (14). One of the gaps in children's palliative care in Australia is the lack of professional bereavement services. There are few professional bereavement services with a low number of child and family careers and limited access to long-term government financial services. Bereavement care should exist for all members of the family. There is also a need for appropriate bereavement services for indigenous families, however, there is little evidence in regard with providing the best service provision model (45). Therefore, based on the research, such

families will live in a state of chronic uncertainty and apprehension after their child's death (46). In Canada, despite the fact that research has shown that parents are constantly in need of bereavement care as a component of care, but only in four palliative care programs for children bereavement follow-ups are done for families experiencing loss of children. In hospitals without extensive bereavement plans, some follow-ups may be carried out for families who are being cared in certain settings, such as the intensive care unit or the cancer ward. There is a huge variety in bereavement programs that can include a set of contacting plans by phone or letter, groups for grief support (siblings or parents) or meetings with professional people to discuss the child's death or the results of an autopsy (42). Therefore, it can be said that in Australia and Canada, despite the advancement of children's palliative care programs, there is no bereavement care for families whose children are died at home, which is a challenge for these countries and needs more attention. In England, there is a wealth of evidence from quality surveys to show bereavement care at the Cancer Research Center.

There are documents also of guidelines for demonstrating the need for flexible and available bereavement services when needed, as well as temporary studies on guidelines and development of bereavement care standards. However, in England, there are challenges including the manner of dealing with the reactions of acute grief from family members and the current needs, satisfaction and preservation of the tissue after death, transferring the child to house after death, especially when death occurs in the hospital (47).

Nevertheless, among the selected countries the England enjoys standards of bereavement care, which was published in 2001 and is considered as an outstanding event (35). In the Middle East, there is only one comprehensive pediatric palliative care unit in Jordan, and its introduction as one of the most advanced countries in the Middle East regarding the supportive and palliative care in 2006 confirms this claim (48, 49).The goal of palliative care identified by the World Health Organization is to improve the quality of patient and family life. But in Jordan, the family of patients is usually not among the care providers as the goal of medical and nursing care, and the needs of the families of patients are usually overlooked (50), which is inconsistent with the definition provided by the World Health Organization. Therefore, the promotion of palliative care requires a change in the culture in which the family together with patients is considered for care (51). With the current state of affairs in Jordan, bereavement care with the main purpose of family has been somewhat overlooked. In Iran palliative care for adults is provided by a multidisciplinary team. On children, there is no reliable information (52).

Contrary to the progression of the primary health care program and the efforts of other elected countries in providing supportive and palliative care for the child and family, in Iran a developed program for providing specialist palliative care services does not exist yet as health care services do not provide specifically designed end-of-life palliative care to patients and their families (53). Also there is no palliative care system for children, and only the cancer sectors offer the same services in the country and due to the lack of sufficient evidence in assessing the need for these services, the policy makers of the country are unaware of the necessity and priority of such services (22, 54).

5- CONCLUSION

In the developed countries of Canada, Australia and England, the pediatric palliative care is well developed. While

three quarters of adults and children in need of supportive and palliative care live in developing countries, in some of these countries, only a small number of these services are available for dying children and their families (55). As a result, traumatic results of bereavement emerge in social activities and family life (56). There is no reliable information available on pediatric palliative care in Iran, and only counseling to deceased patients has been reported at the Mahak Charity Center (52). Therefore, the development of supportive and palliative care for children and their families in Iran and the provision of bereavement care is considered one of the essential requirements of the health system, and there is a long way to reach the desired situation, which requires collective efforts and multidimensional support (18). In this regard, it is suggested that all child cancer centers provide families with appropriate bereavement care at the right time, which depends on having accurate information on the bereavement experience and the manner of managing it. Therefore, it is essential to educate care providers and put these trainings in the relevant curriculum. These services should also be tailored to the spiritual and cultural needs of each community.

6- CONFLICT OF INTEREST: None.

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