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The Need of Palliative Care for the Patients in The Age Group 0-18 and an Analysis of the Practices

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ABSTRACT

It is seen that the cancer mortality and morbidity is increasing among the children all around the world. Each year, more than 500.000 children need to deal with serious health problems. But lately, with the innovations in the medicine and technology, children with cancer have longer lifetimes. The increase in the incidence of cancer and the lifetimes of the children with cancer has increased the importance of the children rights and the palliative care and the need for this care. Palliative care is different for the age group 0-18 than it is for the adults. In each group, the objectives of the palliative care are the same but the care and treatment needs are different. It is difficult to determine how the children will react to the treatment since their physical, emotional and cognitive development is still going on, and this period also changes their understandings on the illness and death. Children need a special kind of palliative care that consists their schools, friends at school and their other social environments. It must be known that each child has the right to receive palliative care, the medicines and complementary treatment methods for their pain and other symptoms regardless of their families' financial capabilities. Children should not be kept in the adult care units and their parents should be informed and helped so that they can stay with their children. Each family should have the opportunity of having a complementary pediatric palliative care group at their homes, which consists a nurse, pediatrician, social works expert, psychologist and a religion officer.

Keywords: Palliative Care, Patient rights, Child, Age group 0-18

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INTRODUCTION

Each year, 130 million people born around the world, and 15% of these people born premature and 5% of them are below 1000 grams when they born. Each year, 4 million babies die during their infancy, and 20% of these babies lost have congenital anomalies that are restricting their lives. Each year, more than 500.000 children need to continue their lives with serious health problems (Carter, 2004; Unal & Zenciroglu, 2016).

In Europe, an increase in the cancer morbidity and mortality is seen. In America, 12.400 new children are being diagnosed with cancer each year and around 2000-4000 children die from cancer (Elcigil, 2006). In the developed countries, cancer is the second most prevalent cause of death and in our country, it is in the top four reasons for the children mortality (Cavusoglu, 2008). According to the 2002 Data of the National Institute of Statistics, cancer is the second cause of mortality in our country for the people above 5 years who lost their lives. Today, 75% of the children that are diagnosed with cancer are recovered and 25% of the children go through the terminal period and lose their lives because recurrence or having no response to the treatment (Akgun, Kostak & Akan, 2011). But lately, with the improvements in the medicine and technology, children with cancer have longer lifetimes. Cancer incidence and the increase in the lifetimes of the children with cancer has increased the need for palliative care (Elcigil, 2006).

Children having right to recover the health they lost at the highest level and in a well-regarded way and if it is not possible, to protect their life qualities and let them die in an honorable way is the most basic right that they have (Republic of Turkey Ministry of Health, Accreditation Standards in Health, 2015). In this period, children and their families need to be provided the care that they need (Isil and Karaca, 2009).

The Definition of Palliative Care

The term “palliative”, comes from the Latin word “palliare” and English word “palliate”, and these words mean “covering, easing or eliminating” (Unal and Zencircioglu, 2016).

The term “palliative care” is used interchangeably with the terms supportive care, hospice care, care in the last days of life/terminal care and such. If the term palliative care is going to be examined from the point of its relations with these terms, in the base of the palliative and supportive care, there is the importance given to treatment and care equally, and by this, patient taking the utmost advantage of the care and live in a better way along with the effects of the illness. As another term, care in the last days of life, giving the patient who cannot be treated and has a terminal disease a good quality of life in his/her last days in life and meeting the needs of the patients’ families in these days; but palliative care means the caring period that starts with the diagnosis of the patient and his/her family and ends with the patient’s

death in an honorable way. To this extent, palliative care recognizes death as a normal process, and includes the controlling of the symptoms and comorbid diagnoses, a hospice care that includes meeting of the physical, psychological, social and moral needs and providing a peaceful death and in addition, the patient's family being supported morally and materially in the illness and the mourning period (Borasio, 2011; Elcigil, 2012; Kahveci and Gokcinar, 2014; Kabalak, 2014). In palliative care, both life and death are seen as normal phases. Death is neither delayed nor accelerated, the aim is to make it easier from life to death (Kabalak, 2014).

World Health Organization (WHO), firstly defined palliative care in 1989 as "A practice implied on patients who are in their last days of their lives when the treatment approaches are coming to an end.", considered two types of care as "curative" and "palliative", and declared that at the point one ends, the other one starts (Surmeli and Akcicek, 2016; Elcigil, 2012). In 2002, the definition of palliative care has been renewed by WHO. Then, palliative care is defined as "An approach that is improved by treating and evaluating the pain, physical, psychosocial and spiritual problems at the early stage that the patients and families who are having problems that are threatening the life of the patient." (Madenoglu Kivanc, 2017).

Palliative Care in the World and in Turkey

Palliative care implications are first being practiced on travelers who have terminal illnesses and pilgrims and they are voluntary actions based on religion (Surmeli and Akcicek, 2016). Later on, in 1842, hospice centers for the patients at the terminal phase were opened in France. Hospice are the institutions that the patient and the companion can stay together, similar to homes and near the hospital campuses (Surmeli and Akcicek, 2016; Namara and Feudtner, 2012). In the medieval age, hospices continued on giving care services on religious rules to the patients who were in the terminal phases of their illnesses, and in 18th- 19th centuries, they started to give care services to patients who have one or two common diagnoses rather than giving service to travelers. In 1879, one of the Irish religious institutions, "The Irish Religious Sisters of Charity" opened the "Our Lady's Hospice" in Dublin, and thousands of patients who were in terminal phases who were diagnosed with cancer or tuberculosis. The same religious institution has established hospices similar in different countries (Surmeli and Akcicek, 2016).

The first modern hospice was "St. Christopher's Hospice" which was established in Britain in 1967, by nurse Dame Cicely Saunders, for the adult patients. Numbers of these hospices has increased since the time they were established first. In 1963, after the presentation of Saunders in the Yale University in the USA about the principles of the care of patients who are dying, the development of the hospices and palliative care centers in the USA has started.

In Canada, Montreal, the first palliative care center was established inside the Royal Victoria Hospital in 1975 (Surmeli and Akcicek, 2016).

In Germany, 1983, Cologne University has established its first palliative care center inside the surgery service. In years 1991-1996, Germany Ministry of Health has started a model work for the palliative care, and palliative care centers have increased in a short time period. Until 2009, more than 4200 nurses and doctors have received palliative expertise training and until 2010, palliative centers in 220 hospitals were opened and 170 hospice centers were established (Yilmaz, 2015).

The hospice system in the developed countries provide the routine care of the patients at the terminal phase in their homes, daily visits at home, nursing services at home and hospitalization if needed (Kabalak et al., 2012).

Until mid-1980's, palliative care has been defined as hospice care (Meghani, 2003; Elcigil, 2006) and throughout the years, it has changed and because it was started for the cancer patients in America, until the early-1990's, the term palliative care has been used for the care of the patients who were dying of cancer (Madenoglu Kivanc, 2017). In addition, patients who have chronic illnesses such as coronary failure and lung illnesses has started to get the advantages of the palliative care (Currow, 2009), and immediately after that, palliative care services has started to be rapidly developing in the countries such as Scandinavian countries, Britain and Canada and in mid-1990's, it became a special field. In 1999, Britain, 236 palliative care centers, 400 public palliative care service centers, 138 hospital care support service and 209 hospitals have established palliative care and support groups (Bag, 2012).

Today, San Diego in the USA and the Catalan region in Spain are the regions that have the most advanced palliative care centers. In these regions, all the service types of the palliative care can be seen (<http://www.acibademhemsirelik.com/e-dergi /82/ makale. asp>).

In Turkey, when we look at the historical development of the palliative care, it is known that in the Ottoman and Seljuk eras, educated doctors and health personnel has provided health services in "Darussifas" which were financed by the foundations. In Darulaceze, which was founded in 1895 and has 650 bed space today, with the incomes from the benefactors, people in every religion, race, language, sex and class, all the patients, almsmen and orphans were provided services (Surmeli and Akcicek, 2016).

As the first step of the palliative care, Republic of Turkey Ministry of Health has started the "Care at Home" service in 2010. The first palliative care center for the adult patients has been opened in the Ulus Public Hospital (Kabalak et al., 2012). In addition, Department of Battle with Cancer had evaluated the current situation in the country and prepared a project named "Palya-Turk". Palya-Turk project basically was built on the family doctor system and

primary nurse care and was supported by the Cancer Early Diagnosis Scan and Training Centers and non-governmental organizations. Palya-Turk project is a project that is going to be kept on with the help of the public support and the non-governmental organizations' cooperation. Within the scope of the project, there are first-base trainings, medicine and branch trainings and certificated trainings. Palya-Turk project includes the first, second and third nase palliative care centers (Yilmaz, 2015). Within the National Cancer Control Programme 2009-2015 published by the Department of Battle with Cancer, palliative care was defined, aims on the institutionalization were determined (Gultekin et al.,2010; Ozgul et al.,2012).

In the Faculties of Medicine in Turkey, the palliative care branch is not established yet. In the palliative care units in Turkey today, oncologists, geriatrists, practitioner doctors or family doctors are working (Surmeli and Akcicek, 2016). In a research conducted in 2009 by Ministry of Health Department of Battle with Cancer, there are 10 palliative care centers and 72 pain centers in Turkey. As 2014 on, there are 8 palliative care service providing health centers only in Izmir (Ege University Faculty of Medicine, Dokuz Eylul Faculty of Medicine, Katip Celebi University Faculty of Medicine, Tepecik Research and Training Hospital, Seferihisar, Buca Seyfi Demirsoy, Bayindir and Selcuk Public Hospitals). Having these centers increasing in numbers shows the importance given and the need in this field (Surmeli and Akcicek, 2016).

Palliative Care in Age Group 0-18

The American Academy of Pediatric (AAP) has defined palliative care for pediatric patients as “Without taking the place in consideration (hospital, home...), providing the best living quality for the patient and the family according to their values” (<https://www.openpediatrics.org>).

Palliative care is different for the age group 0-18 than it is for the adults. In each group, the objectives of the palliative care are the same but the care and treatment needs are different. Children need a special kind of palliative care that consists their schools, friends at school and their other social environments (Liben et al., 2008). It is difficult to determine how the children will react to the treatment since their physical, emotional and cognitive development is still going on, and this period also changes their understandings on the illness and death (Akgun Kostak and Akan, 2011).

Health workers who provide palliative care should know the psychosocial, physical and emotional needs of the child, evaluate them the provide the suitable care. In addition to meeting the needs of the child and the family for having the best life conditions they can

have, they are also responsible of optimal comfort level of the child to be provided (Liben et al.,2008; Lanken, 2008).

In March 2006, a group of health workers from Europe, Canada, Lebanon and the USA met at Trento, Italy in the International Meeting of Palliative Care of Children in Trento (IMPaCCT) to discuss the current state of the pediatric palliative care. In this meeting that continued for 3 days, the common definition of the pediatric palliative care was created and the minimum standards were reached on a consensus by having the best practices determined. IMPaCCT recommends these standards to be implied in European countries (EAPC, 2007).

Children that Need to Receive Palliative Care

Children that need to receive palliative care can be categorized into 4.

1st group: Cases that the prospect of recovery is possible, but failure is also possible. After the treatment trials, life-threatening conditions can occur. e.g.: Cancer, liver or kidney failures.

2nd group: Cases that the early death is inevitable but making the life longer and child joining normal activities is possible. e.g.: Cystic fibrosis, muscle dystrophies.

3rd group: Cases that there is no prospect of curative care, the treatment is done with palliative care up to a few years. e.g.: Batten disease.

4th group: Cases that there are no prospects of recovery, but are not progressive. May cause early deaths. e.g.: Cerebral palsy, Cerebrospinal trauma (Algier, 2005; EAPC, 2007).

Palliative Care Levels

A three-stage expertise is recommended in palliative care.

Level 1- Palliative care approach: The system that all the clinicians in the health centers and all other health workers imply the palliative care principles.

Level 2- General palliative care: As being considered as mid-level, patients and families are being part-time care services provided by the doctors that are not palliative care experts but have provided palliative care services and supporting health personnel.

Level 3- Expert level palliative care: For the more complex patients that need more care, services given by the palliative care experts, supporting health personnel who have been trained on palliative care within the hospitals, palliative care centers and hospices (Kahveci and Gokcinar, 2014).

Palliative Care Team and its Features

An efficient palliative care requires a teamwork with interdisciplinary communication and coordination (Yilmaz,2015; Elcigil, 2012). Palliative care should be conducted by the people who have received special trainings, the applicants should update their knowledge and abilities often and should provide a family-centered care service (Kabalak et al., 2012; Elcigil, 2012). Families are both the part of the care team and the family itself, and they need

help too (Kabalak et al.,2012). Palliative care team should have home visits, should train the family on the care of child, should cooperate with the family and should provide psychosocial help for the family first (Kabalak et al., 2012). Health personnel who work in the palliative care team should listen to family carefully, should respect the experiences, decisions and the abilities of the family, should have a good communication with the family and the children, should defend the patient and the family, should be able to bring the development potential and the living quality of the child to the highest level and should make plans for the possible problems that can occur for the child (Elcigil, 2012).

At least one doctor and one nurse who have palliative care expertise, one social services expert, one child therapist or psychologist and one religious officer should be in a palliative team. Pediatric oncology patients should be given palliative care at home by a pediatric oncology palliative care team (Saruc, 2013).

Palliative Care Principles

The Need for Information for the Patient and the Family:

Information should be given by the palliative care team after the diagnosis is definite and in a way that the patient and the family can understand. This information given should consist the diagnosis, how the treatment will be conducted, current status and the implications that will be done (Ishibashi, 2001). If possible, the information given to the patient and the family should be supported with the written, audio, visible materials (Elcigil, 2012).

The Need for Personal Evaluation for Each Child and Family:

Having an illness that threatens the life of the child is something unacceptable for the family. In such a case, the strengthening the living quality of the patient and the family, the reduction of pain, giving the opportunity for personal development and giving a care that is in accordance with the culture and the society they live in is important (Algier, 2005).

The Management of the Physical Symptoms of the Child

There are some physical and emotional symptoms seen in the patient child in accordance with the illness process. Children with cancer in the terminal phase generally experience pain, nausea and vomiting, tiredness, in appetency, diarrhea, constipation, dyspnea, death anxiety, stomatitis, spiritual distress. Most of these symptoms can be removed with standard nursing care methods. In a study conducted with the families that lost their children to cancer, 89% of the parents stated that in the last months of their children' lives, children have experienced pain mostly and this was followed by tiredness, dyspnea and in appetency (Michelson and Steinhorn, 2007; Lanken et al. 2008; Mon-Sprehe and Sprehe, 2008; Yilmaz et al. 2009).

Giving the Opportunity for the Emotional and Behavioral Needs of the Child to be Expressed

Child should be helped to understand the illness and the questions about death should be answered with intimacy. Older children may feel lonely because of not seeing their friends. Games, arts and music may be helpful for the children to express their fears and feelings (Elcigil, 2006).

Improving the Living Quality

In order to improve the living quality of the child and the family, child should be helped to maintain the daily life, and for this, symptoms that cause should be managed or helped to be managed (Martinson and Liu-Chiang, 1997).

Support for Families

Supportive care helps the child and the family to deal with the illness and the treatment. The support starts with the diagnosis and should continue until the treatment and the mourning phases are ended (Kuebler et al., 2005). Health, social services and voluntary organizations should cooperate to help the family in this issue (Elcigil, 2006).

The Care During Death

Palliative care team should make the environmental arrangements for the child to die peacefully, should provide an environment which the privacy of the child and the family is preserved and continue on having close relationships. Families generally want the death to be quick when they understand the treatment does not have effect anymore. This is an intense mourning period. Parents in this period can ask questions such as “Is he going to die?” “How do we know that she is dead?” “What is going to happen when she is dead?”. In addition, during the period, parents may worry about their child being in pain and not being with the child when the death comes (Elcigil, 2006; Elcigil, 2012).

It should be discussed with the family that where the child is going to die and they should be assisted while trying to decide. Families may be very worried and feared about this. Family might need more support in this period. If there is a religious ritual that the family wants to prepare, they should be helped (Elcigil, 2006).

Mourning Period

Family members have a period of sorrow starting with their child to be diagnosed with terminal disease and continuing with the child dying. In the following two weeks of the patient being lost, mostly a difficulty in believing in such an event is experienced. Trained health personnel should help the family who live in sorrow during the periods before death, during death and after death. Mourning is a normal period. Consultancy and assistance in the mourning period should be a part of the palliative care. Voluntary people might be asked for

help. Brothers and sisters might also need help. Meeting them with other mourning brothers and sisters might be helpful (Pavlish and Ceronisky, 2009; Kahveci and Gokcinar, 2014).

Legal Rights of the Children During the Palliative Care

Patient rights issue has become more in the agenda since the medical ethics is being more improved. The most important regulation on the patient rights is the Regulation on the Patient Rights which came into force in 1998 (Aydin, 2003). Even though the international principles for the palliative care are already defined, each country has their own sociocultural, economic, ethical and legal differences and implications should be done in accordance with these separately. Patients and the families of patient' decisions are important. Their informed consent must be taken. The decision on ending the supportive treatment should be taken with the family. Euthanasia and supportive death are not ethical (Kabalak et al., 2013).

Declaration of Children with Illnesses is published in the first conference of the European Association for Children in Hospital' in Leiden, May of 1988 and was edited in the 7. Conference in Brussels in 2001 (<http://www.kindundspital.ch/charta-d.pdf>).

Each child has the right to receive palliative care regardless of their families' financial capabilities (Larcher and Karnavale, 2012). Each child has the right to receive the medicines and complementary treatment methods for their pain and other symptoms (Cakici, 2010). Children should not be kept in the adult care units and their parents should be informed, courage and helped so that they can stay with their children in the hospital. There should not be an age limit for the visitors of the child patients. All the methods to remove the physical and mental problems should be applied. Children and their parents have the right to join every decision that is related to their health. Each family should have the opportunity of having a complementary, multidisciplinary pediatric palliative care group at their homes, which consists a nurse, pediatrician, social works expert, psychologist and a religion officer (EAPC, 2007)

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