

The Difficulties Experienced by the Parents of Children with Cancer

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Brief Report

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ABSTRACT

The purpose of the mini-article is to describe the needs and difficulties of parents living with a child with cancer. Background Cancer is caused by a group of abnormal cells that develop rapidly and spread throughout the body, which is difficult to control. Malignant cancer can spread quickly enough to nearby tissues, and some abnormal cells can divide and migrate to distant areas of the body through the circulatory and lymphatic systems. Children with cancer have certain difficulties and needs that are associated with pain, nutrition, weakness, infection, and hyperthermia. All these needs require satisfaction and support not only from the medical person, but also from the child's family. One of the most difficult aspects of being parents of a child diagnosed with cancer is to balance their normal family life with the child's health needs and treatment requirements. Cancer is a serious disease that covers all parts of family life and creates many stress factors for family members. Families mostly feel that everything has changed in their lives with the cancer diagnosis and are obliged to make a number of adjustments in their lives including financial needs. Their normal family life suddenly appears to be interrupted by treatments, hospital appointments and hospitalizations. The shock after diagnosis, the painfulness of therapy, the associated disruption of family and social development, and the constant uncertainty of relapse or relapse of the disease affect not only the sick child, but also all family members.

INTRODUCTION

Childhood cancer - is a growing public health concern worldwide, that affects the lifestyle of the child and their family. Cancer from the moment of diagnosis and throughout the entire period of the disease to the terminal stage leads to the development of stress and the need to adjust the lifestyle of the patient and his surroundings. In addition to the suffering of the child, cancer affects the family, causing stress and lack of readiness of parents for home care, including pain managing, providing medical services and creating comfortable conditions. The problem of cancer impacts negatively upon a range of psychological and psychosocial aspects of the child's family. Family members may experience certain states of psychological distress and have physical health problems ^[1].

Changes in the Daily Life of Families Caring for Children with Cancer:

One of the main challenges for parents of children with cancer is to balance the child's treatment needs and a normal family life. The normal way of life is replaced by hospitals, medical examinations and intensive therapy. In addition, one of the family members must quit work in order to care for a sick child. These problems, in turn, can lead to a financial crisis, difficulties in family relations, and a decrease in tolerance within the family culture ^[2].

Parents of children with incurable diseases often need advice on how to cope with a child's lack of appetite, inability to follow a drinking regime, pain, and personal support, as they experience need and difficulty after diagnosis ^[3].

One of the experiences of parents of children diagnosed with cancer was a change in daily life, which was characterized by restrictions on certain leisure activities, a decrease in caring attitude towards themselves, increased financial expenses without social assistance, the presence of feelings of grief, sadness, fear, loneliness and misery ^[4].

One of the most effective methods of children's therapy with cancer is home care, the burden of which falls on the shoulders of parents. A study of the experience of parents with children with cancer showed that most of them changed their bed linen 1-2 times a week, aired the child's room and kept the bedspreads and curtains clean, which is a measure of protection against infection during chemotherapy.

In addition, the age of mothers also has certain significance in the provision of medical care, mothers aged 35 and older explained that the care and treatment of children takes more time, and communication with other healthy children had a more positive context. This indicated that the older the age, the more experience of caring for and establishing positive relationships with other children ^[4]. There is also a negative side, such as stressful relationships within the family, separation from the spouse and strained relationships, insufficient time for other family members ^[5].

Mothers stressed that they need to be tougher towards their children and their spouse, and changes were highlighted on the father's side that included the need to quickly understand and focus on doing everything necessary to treat the disease. The art of care for the family is a complex activity that requires hygiene, technological skills and training included in the activities of a nurse. Due to a severe diagnosis, mothers of children with cancer experience difficulties with insufficient support from medical staff, which requires their involvement to ease the burden of care and increase family satisfaction ^[6].

DIFFICULTIES FACED BY FAMILIES OF CHILDREN WITH CANCER

Financial Situation

The first difficulties for family with child with cancer are financial waste. Cancer treatment carries a financial burden on the entire family. The daily cost of treating childhood cancer is huge. This includes direct and indirect costs of treatment. New methods of treatment and diagnosis are quite expensive, and these costs are borne by the family of the sick child, the health sector and society as a whole. These expenses are classified as medical and non-medical expenses. Medical expenses include hospital expenses, diagnostic research expenses, and medication expenses. Non-medical expenses include expenses related to transportation, food, and accommodation. Costs incurred by families are called expenses out of pocket expenses. Because of the burden of cancer, sometimes parents may face reduced working hours or loss of work, resulting in a loss of income. In addition, self-employed parents sometimes have to close their businesses ^[7].

Done studies show that more in-depth research into the experience of parenting children with cancer, found that financial difficulties are one of the important factors that contribute to poor mental health among parents of children with cancer. Families with children with cancer have additional expenses that are not covered by insurance and the health care system. Additional expenses lead to financial difficulties in the family. During this period, social assistance provided by friends, relatives and their environment will be very useful, which reduces the development of depressive symptoms in parents ^[8].

As well as protecting the financial stability of families of children with cancer has the potential to alleviate the psychological stress of both parents and their children ^[8].

Lack of Knowledge

The second difficulties for family with child with cancer are insufficient knowledge of parents about the existing disease.

During cancer treatment, parents of children face various types of needs and difficulties, due to the fact that this disease affects several body systems. One of the most common problems during cancer treatment is symptoms associated with a violation of the gastrointestinal tract. Very often children experience problems of malnutrition. In this regard, parents need to be informed about diet and nutrition, including the categories of foods that children should eat and how to use them. The lack of this type of information causes alarm in families, as children need to eat properly and get the necessary nutrients. Parents need more complete nutrition education before, during, and after treatment. Families experience difficulties with a lack of knowledge about food and its interaction with medications, foods that children should avoid for cancer, and cooking rules, especially when white cell levels are low ^[9].

In addition, fathers and mothers of children with cancer actively participate in the care and treatment of the child both in the hospital and at home, where they face unfamiliar situations. At the initial stage after the diagnosis, parents feel insecure due to the fact that they have insufficient information about the possible difficulties they will have to face after starting treatment. Family members are afraid that they will face a number of new responsibilities that they have not faced before. Therefore, parents noted the need for clear and detailed information about the disease of their children. The educational information provided for the child's first discharge after treatment is useful for better preparing them for the situations they will experience at home, as well as reducing the stress and number of re-admissions of children and adolescents ^[10].

Pain Managing Situation

Another important difficulties was that the complexities of parents' experience is managing the pain and symptoms of children with cancer at home. Pediatric cancer patients are at increased risk of relapsing pain throughout treatment, as treatment requires multiple painful procedures, and chemotherapy drugs can lead to iatrogenic pain. Parents of children with cancer after switching from outpatient treatment to home care provide therapy aimed at reducing pain. More often, parents use analgesics with a lower dose, extending the time of reception and replacing analgesics with non-medicinal methods such as massage, cold. The use of pain medication by parents may be affected by barriers related to socio-economic variables, but the main role is played by the parent's beliefs about pain management and their impact on pain management at home. To better assess pain in children, parents need to communicate more with medical staff and benefit from it. Determining the degree of pain and providing appropriate pain relief is a necessary measure in home care and is a complex process for the family. Therefore, there is a need for special events that include providing complete information about analgesia and training parents and children who are oriented to their characteristics ^[11].

Where the child's family is responsible for pain management, parental involvement is an important element of caring for children with cancer ^[12]. Data from one study found that parents regularly monitor and evaluate the localization and severity of pain experienced by their children, as the pain they feel affects their quality of life ^[13].

Based on parents' experience, family involvement can support their children emotionally and financially. On the other hand, mothers face some obstacles to take care of their child at the end of life. For example, the absence of a nurse who visited children at home to provide care for the child at home, mothers could not cope with their child's pain at home and experienced difficulties in terms of costs and transportation when the child was in pain at home and had to be taken to the hospital. Mothers tried to do everything to please their child, because they knew that they had had a difficult experience with various treatments and medications. Parents felt depressed because their child didn't have long to live and was tired, and they continued to try to please their children by providing everything their child wanted. Some parents have shown that they tried to take care of their child by doing whatever they wanted, always staying close, watching, entertaining and supporting their child. Mothers also left their jobs to take care of their child; some were willing to close their store to focus on their sick child and ease their condition ^[14].

Psychological Health Situation

A sick child is always a stress and a change of family attitudes. When a child is diagnosed with an incurable disease, the parents' stress increases twofold, which leads to finding guilt in other people, hostility and anger directed at the whole world, but also feelings of guilt?

In addition, families are subjected to stressful situations aimed at making decisions that parents of pediatric cancer patients should make - such as stopping cancer treatment, giving consent to refuse resuscitation or refusing life support ^[15]. Parents not only suffer the making of these decisions, but they also suffer when they come to accept these decisions in the future. While some parents learn to make their own decisions, some struggle and experience regret ^[15]. At the same time, the uncertainty of child survival leads to the preservation of life prospects ^[16]. Accordingly, parents will choose chemotherapy or other treatments for their child, even if there is no real chance of a cure ^[17]. Unfortunately, children who receive end-stage cancer therapy suffer more symptoms than those who do not receive treatment ^[18]. Moreover, at the end of life, parents experience both hope and hopelessness ^[16]. Hope can ease the fear of losing a child and help maintain a harmonious relationship between parents and children. In some cases, when the child's condition worsens, hope can also help transition to a peaceful end of life ^[16].

Parents of children with life-limiting diseases are immersed in a constant struggle for the child's life and face the difficult realities of life ^[19].

All over the world, parents of children with cancer suffer in the course of therapy and experience difficulties in caring for children at home, which creates certain needs, such as moving closer to a medical facility, receiving social support, and meeting information needs ^[20].

Anxiety and fear are at the heart of the complexities of caring for children with cancer. Parents may provide excessive care, which will negatively affect the child. One of the side effects of therapy for children with cancer is the development of fever, lack of appetite, vomiting, nausea, and difficulty feeding. With the development of these conditions, parents become guardians of children to prevent the development of infection and complication of the disease. Children's reactions to excessive care can be varied and interpreted as a loss of independence and influence future plans ^[20].

In modern medicine, the concept of "palliative care" is widely used, meaning a wide range of activities that improve the quality of life of seriously ill patients and their families. The goal of palliative care is to create such conditions that would allow the patient, as far as possible, to actively live the last days. This assistance is provided to all patients with an incurable disease of all ages in Republic of Kazakhstan. This assistance is aimed at addressing the spiritual, psychological and social needs of each patient and their family ^[21].

At the moment, research in the field of life experience of children with cancer, the dynamics of changes in the daily life of families with children with cancer in our country is not enough, as it requires a deep and detailed study. Research should be of high quality. Currently, we can study the structure and problems in the field of palliative care in the Republic of Kazakhstan.

Palliative care is aimed at solving the problems of a patient in the terminal stage of the disease, including cancer diagnosed in children. But the study of the difficulties and needs of parents of children with cancer from the beginning of diagnosis and the entire period of its development has not been studied in our country. In connection with the reform of the health care system of the Republic of Kazakhstan in the field of nursing, conducting qualitative research in the field of parental care of children with cancer will be an important direction in the development of nursing science. There are data on statistics of childhood cancer and palliative care, but the problems of parents and their needs when raising a child with cancer is no less important for the development of science in the health system.

CONCLUSION

This mini-article has shown that those parents of children with cancer from the moment of detection to the onset of the critical moment of the disease face a large complex of difficulties and care needs. This mini-article reflects only part and general aspects of the problems that parents have when raising and caring for a child with cancer. Studying the opinions and difficulties of parents of children with cancer is relevant and very important in order to improve the organization and provision of medical services at the

appropriate level in order to mitigate and meet the quality of life of the child and all members of his family. Literature data has shown that the life experience of parents of children with cancer includes changes such as changing the routine of normal life, the shock after diagnosis and certain difficulties in financial direction, daily routine, pain management, the psychological state or health of the parents, and insufficient awareness of the current state of the child and his disease in full. All this information shows the need to conduct research on this topic in the Republic of Kazakhstan and further develop guidelines and standards for providing assistance to such families from the health system, and especially from the nurse. Patient and family care, training, family counseling, and prevention are the direct services of nursing staff.

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