Effects of Childhood Cancer on Family Life and Child with Cancer

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Abstract
Childhood cancer is the second cause of death among children all over the world. Although there have been positive advances in prognosis and treatment of childhood cancer, still all family members are negatively affected by it. The quality of life is decreased because of stress.
and anxiety. These complications affect three groups of a family member. The first group are the parents of the child who are affected by their child's cancer. The second group are the child's siblings whose lives are dramatically changed due to their brother/sister's disease. And the last group are the sick children themselves who are not only physiologically affected by cancer but also psychologically. Therefore, the aim of this article is to review the effects of childhood cancer on the lives of these three groups.

Keywords: Childhood cancer, family challenges, distress

1. Introduction

1.1 Background

In the world, approximately 175,300 new cancer cases are reported for children aged between 0-14, in 2008. And it is the second cause of death (after accidents) in children between 5 and 14 years old (1). The most common types of cancer in the childhood are acute lymphoblastic leukaemia and Central Nervous System tumors, respectively with 26% and 21% (2). Progress in medication and treatment has resulted in 84% 5-year survival rate for young children diagnosed with cancer (3).

1.2 Statement of the problem

In spite of all positive advances in prognosis, all members of the family can be negatively affected during cancer diagnosis and long period of treatment (4). Family’s quality of life is negatively affected by an increase of stress and anxiety (5) and family experiences role changes in the family with diagnosis of cancer. While mother stays at hospital with the sick child, father attends to the needs of other children at home and do house chores (6, 7). For the whole family, a new period very different from the past begins. This period can be painful and stressful for family (8). At any time during their child’s disease and therapy, symptoms of acute stress and posttraumatic stress may surface in parents. These symptoms may abrogate their capacity to care for their children and themselves. Parents need to handle both their own emotions and the emotional response of their children to disease and treatment difficulties. After diagnosis, anger is the initial response and
increased levels of anxiety and depression follow, which are observed for a few years more. In addition, families anticipate the loss of their child during the course of treatment and experience psychological distress, which is also seen for many years following successful treatment of their child (4).

A mixture of guilt, injustice and incomprehension forms their feelings. They accuse themselves for being ignorant, responsible for missing regular medical exams and not enforcing a healthier diet and lifestyle(4). Importantly, siblings experience increased psychological distress as a result of diminished parenting time and attention during the therapy of child diagnosed with cancer (9, 10). Child diagnosed with cancer is the individual who is influenced most strongly from this period. Long hospital admissions, heavy treatment, disruption of school life, being unable to spend time with peers, fear of death, uncertainty and hopelessness may exert adverse effect on the child.

The diagnosis of the disease alters the functioning of the family system in various aspects. The family’s information on the disease, availability of family resources, and family’s experience in coping with a similar issue should be considered by the medical staff while assessing the abilities of the family in confronting cancer (4).

1.3 Objectives

This paper states that even the survivor rate of childhood cancer has been increased, the family’s quality of life has been negatively impacted by diagnosis of cancer. This essay is structured as follows: firstly, it focuses on changes of the roles of family, secondly, explains the effects on siblings, finally, effects on the child with cancer.

Effects of Childhood Cancer on Parents
A constant absence of the mother in the home due to companion for child with cancer has revealed some role changes in the family. While mother usually stays with the sick child at hospital, father is at home with other children doing house chores. Sometimes grandparents move in with the family to support them. A serious change has taken place in the house. In addition, if the mother is working, she may be forced to quit her job. Father has to take leaves from job frequently. Family may be faced with dire straits economically.

Moreover, Parents are cut from their social lives and their lives pass between home and hospital. Moreover, it has shown that 60% of caregivers had to abandon their hobbies and stop seeing their friends (11). Indeed, the mothers were shown to be less satisfied with their marriages and experience more depressive symptoms, anxiety and somatization in comparison to fathers in a Taiwan-based study of 164 families (12).

In addition, parents have to learn complex treatments and monitor side effects of drugs, provide transport to medical care establishments, provide emotional support by sharing their feelings of mortality, uncertainty, fear and hope and hence they take a new role as a medical caregiver that may lead to feel exhausted (13). As a result, some relationships are getting weaker, while others are getting stronger by these stressful conditions during cancer diagnosis and treatment (7, 12, 14).

Generally, parents report that they can cope with this period successfully and their marriage is stronger than before (7). On the other hand, stressful issues imposed a negative effect on the couples’ relationships. As expected, some mothers express their concerns of a weakened relationship with their partner due to stressful conditions originating from the child’s illness. Fathers express uneasiness due to role changes because they do expect to be the primary caretaker concomitant with increased home duties, which are difficult for them to cope with (14). In almost half of the couples,
intimate relationship and sexuality became worse. This is related to the physical and emotional energy spent in the sick child’s care, leaving no space or time for leisure or sexual activities (14). The disruption and changes of family integrity and functionality can also lead to some psychiatric disorders like depression and anxiety disorders in parents. In addition, parents of child may not be able to cope with their feelings such as anger, sadness, helplessness and loneliness (15).

Some parents mentioned that they have to cope with these feelings along with the active phase of the illness, but these feelings may overburden after they return home. A correlation has been found between posttraumatic stress symptoms after 5 years of final treatment, mothers’ anxiety trait and duration of treatment (16). Generally, it is thought that women usually feel more responsible for their child’s disease and experience more difficulties in adjusting their child’s illness and greater stress than fathers. On the other hand, not only mothers but also fathers might be affected by this period.

In fact, fathers hardly accept their weaknesses and vulnerability, expressing fear and inner conflicts to keep their social image of strength and courage. Fathers do not express their anxiety and doubts to their partner, avoiding to appear weak as they were expected to keep the family together. After the diagnosis of child with cancer, some couples might experience communication problems, especially those who do not have close relationships and hardly accept and adapt the new situation. Moreover, some partners avoid sharing information with the other on child’s condition for emotional protection, which leads to communication problems, drifting the partners apart. Hence, inadequate communication leads to conflicts and disagreements, abrogates feeling of closeness in difficult times (17).

Different surveys have claimed that the rate of divorce is higher in families with child having chronic disease other studies report that in these families’ divorce rate is not higher
than other families, and that spouses develop their role and relations in spite of all adverse factors (18-20). It has been illustrated that along with these, prolonged chronic stress, sense of burden, depression and anxiety paves the way for health problems (21) Altered appetite, headaches, fatigue, pain, insomnia and high blood pressure may be seen in caregivers (22). Also, Importantly, chronic stress abolishes immune system, negatively affecting specific immune responses (23).

Therefore, It has been stated that adaptation of parents to disease is a complex process and in this process there is a strong relation between social supports such as being informed on disease, seeing other sick children, and talking with other parents and feeling well, behavior towards children and adjustment of child to disease (24). In addition, division of labor, supporting and respecting each other, being open and frank, receiving support from psychologist and psychiatric when feeling burnout and reserving some time for social activities will relieve the couples.

**Effects of Childhood Cancer on Siblings**

If parents put their child with cancer on center of the family, they will become not able to see needs of other siblings. Unfortunately, the parents cannot be at the hospital and home at the same time. As mentioned before; the change of family roles does not affect only relationship between child with cancer and parents, but also affect relationship between parents and healthy siblings. The relationship between siblings is more significant than between children and parents. There is a close bond between siblings, thus when one of the children has a serious illness such as cancer, the healthy sibling can be negatively affected. Sibling may feel sad, guilt and worry that a brother or sister may die.
Parents spend an important part of their time on care and management of ill child, which leads the other siblings to feel forgotten and neglected, resulting in experience of emotions such as anger and jealousy to be experienced between siblings (20).

It has been established that parents focusing on sick child show interest on health problems of other children rather than their social and emotional lives, and do not usually notice their emotional problems and restrict the social activities of healthy children (25). Therefore, other children may feel themselves more alone, unhappy and hopeless. It has been previously shown that siblings of cancer survivors are at higher risk for having depression, posttraumatic stress, tobacco and alcohol use, as well as they experience disturbed academic and social functioning (9, 26). Moreover, childhood cancer families present with higher risk of somatization in siblings, concomitant with increased worry and notice of bodily sensations (27). Parent should manage time to make a balance between siblings and child with cancer. It may protect the siblings from possible negative effect of this period Also, parents can receive training and help from psychiatrists, child development specialists and education consultants for displaying the most proper attitude to children and healthy children.

**Effects of childhood cancer on child with cancer**

Cancer is a disease of physiological system but it also presents with psychological and psychosocial problems. Radiotherapy and chemotherapy, painful interventions, leaving family and school, feeling of threat to body wholeness, physical changes, and limited physical capacity negatively affect psychology and psychosocial conformity of the child. Children increasingly feel anxious and depressive and sleep, eating disorders, separation anxiety disorder, treatment refusal, oppositional behaviors against family and medical
team can occur in children. Children may feel guilty and perceive disease mostly as a punishment (28). They can ask some questions such as

“I am a good child why God chose me?” “They say God loves the children, why doesn’t he love me?” “I do not pray anymore. It has no use. God has forgotten me!” (29).

Also the disease enforces adolescents to give up their future plans due to the sense of uncertainty related to cancer diagnosis. This destabilizes the family, brings a sense of lack of goals as well as anger and unhappiness. Depressed boys were demonstrated to have more behavioral disturbances, although emotional symptoms were more common with girls (30). Even though parents are the prominent source of emotional support for children with cancer, their distress positively correlates with distress in children. For example, children of depressed mothers present with various internalizing and externalizing symptoms at a greater degree than those displayed by children of non-depressed mothers (31). Unfortunately, clinicians and other medical staff focus on the physiological aspects of the disease, ignoring the psychosocial needs of child and the parents. However, it was established in the study of Last and AMH’, that children with cancer who receive adequate information on their diagnosis and its prognosis are less depressed than children receiving inadequate information on diagnosis. In view of these findings, it may be accepted that discussion of the disease and its course by health team and family with the child may be an approach creating less stress for the sick child. In addition, in order to determine compliance problems to treatment and psychological problems, psychiatric consultation services should be offered regularly (32). It has been reported that for
parents, siblings and children with cancer, group therapies are useful especially for sharing emotions, accepting the situation and finding the power to cope with it (33, 34). In conclusion, so that children with chronic diseases especially cancer, which is fatal, and their families, can cope better with stress during medical help, can adjust to disease and be influenced from the disease at minimum level, adequate communication and collaboration should be present between different department in the hospital, patients and their relative should receive accurate information, and psychiatric support should be offered to whole family.

**Conclusion**

Healthy development process of the children is one of them most important expectations of all parents. Cancer is a difficult experience both for a family as a system and for its individual members. Starting with the diagnosis, cancer affects patients and their caregivers physically, socially, psychologically and spiritually, creating a challenging situation. The issues to be exposed during the course of this experience may create burden, depression and anxiety, negatively affecting both psychological and physical status of family caregivers. Family members who were using more positive coping strategies can experience less emotional exhaustion. No doubt, cancer is traumatic for all members of family.

**References**


