

## Determining the Burden of Mothers with Children Who Have Cancer

Ayfer Elcigil\*, Zeynep Conk\*\*

### Abstract

**Background:** The developments in cancer treatment have changed the perception of cancer to be a chronic illness which reoccurs at certain intervals where the patient needs appropriate interventions and careful monitoring. This has in turn affected families as they respond to the ongoing needs of the child who is living with cancer.

**Objectives:** The purpose of this study was to determine the burden on mothers of children who have cancer and the related effects on the family unit.

**Method:** This qualitative descriptive study used in-depth interviews to provide study data. The data collecting was continued until a saturation point was reached which was 23 mothers. The interview form was composed of semi-structured questions to explore the burden of care of mothers with children diagnosed with cancer within the previous twelve months. The tape-recorded interviews were transcribed verbatim and data were analyzed using qualitative content analysis. During the planning for the research, four main themes had been established from the literature and according to the perception of the researchers: emotional, economical, social and physical burden. Analysis revealed the raw data was compatible with these previously determined themes. One other theme, labelled "coping strategies", was also derived from the data during analysis.

**Results:** The primary results of the study showed that, as the children were experiencing difficulty with adjusting to taking their treatment, the mothers had trouble coping with the side effects their child was experiencing. Mothers described experiencing intense stress while providing child care and being unable to deal with it effectively. This in turn had an adverse effect on inter-family relations in most cases. Mothers also did not engage in their previous social activities and reported that their social relations diminished. Mothers indicated that they were generally more comfortable talking with mothers experiencing the same problem.

**Conclusion:** It is suggested that the nurses provide information and support to the mothers and the child in relation to side effects and best ways of coping with them. The nurses should support the mothers in maintaining their previous lifestyle as much as possible. Establishing support groups and encouraging the mothers to join such groups is urged.

**Key Words:** Childhood Cancer, Family Burden, Nursing.

### Çocuğu Kanser Olan Annelerin "Aile Yüğü" nün Belirlenmesi

**Giriş:** Kanser tedavisindeki gelişmeler kanserin kronik bir hastalık olarak algılanmasını sağlamıştır. bu değişim çocuklarının gereksinimlerini Karşılamaaya çalışan aileleri de etkilemiştir.

**Amaç:** Bu çalışma çocuğu kanser olan annelerin yükünü belirlemek için yapılmıştır.

**Yöntem:** Derinlemesine görüşme yönteminin kullanıldığı niteliksel bir çalışmadır. Veriler 23 anne ile görüşülmüştür. Veriler doyum noktasına gelinceye kadar toplanmaya devam dilmıştır. Verilerin toplanmasında çocuğu kanser olan annelerin son bir yılda yaşadıklarını belirlemek amacıyla yarı yapılandırılmış görüşme formu kullanılmıştır. Teybe kayıt edilen verilerin tüm dökümü yapılmış ve içerik analizi kullanılarak veriler analiz edilmiştir. Görüşmeler bittikten sonra verilerin ham dökümleri araştırmacı tarafından yapılmış ve dökümleri yapılan ham veriler daha önceden belirlenen ve çalışma sonunda da doğrulanan temalara göre sınıflandırılmıştır. Daha sonra tüm bu veriler yorumlanarak rapor haline getirilmiştir.

**Bulgular:** Çocukların tedaviye uyumlarında ve annelerin tedavinin yan etkileri ile baş etmede güçlükler yaşamaktadırlar. Ebeveynlerin stres düzeyi tanıyı ilk duyduklarında çok yüksektir. Ebeveynler bakım sürecinde yoğun stres yaşamakta, stresle etkili şekilde baş edememekte ve bu aile içi ilişkileri çoğu kez olumsuz olarak etkilemektedir. Ebeveynler çocuğa karşı aşırı hoşgörülü ve koruyucu olduğunu ifade etmektedirler. Anneler eski sosyal aktivitelerini yerine getiremediklerini ve sosyal ilişkilerinin azaldığını söylemektedirler. Anneler genellikle benzer sorunu olan annelerle daha rahat konuştuklarını ve bunun kendilerini rahatlattığını belirtmektedirler.

**Sonuç:** Elde edilen sonuçlar doğrultusunda hemşirelerin aileye ve çocuğa tedavinin yan etkileri ve bunlarla nasıl baş edecekleri konusunda bilgi vermeleri, ebeveynlere stresle baş etmelerini sağlayacak programlar düzenlenmesi, ebeveyn destek grubunun oluşturulması önerilmektedir.

**Anahtar Kelimeler:** Kanser, Çocuk, Aile Yüğü, Hemşirelik.

Cancer is a chronic, long-term illness that affects not only the child but also the family as a whole. Björk and Wiebe (2005) and McCaffrey (2006) have suggested that childhood cancers can be considered as a family disease. Parents describe the diagnosis and treatment of a child with cancer as one of the most stressful times in their lives (Hoekstra-Weebers, Jaspers, Kamps & Klip, 2001; Lindblad & Boman, 2007; Matziou et al., 2008; Norberg, Sawyer, Antoniou, Rice & Baghurst, 2000; Sloper, 2000).

The stress begins immediately after the diagnosis and continues through the treatment (Frank, Brown, Blount & Bunke, 2001; McGrath, Paton & Huff, 2005; Northouse, 2005; Sloper, 2000; Yeh, Lee, Chen & Li, 2000). Caring for a child with cancer brings an enormous physical, psychological, social and economic burden upon the family (Kazak et al., 2001; Wells et al., 2002), with the period of a child's cancer treatment often described as a struggle by

\* Assistant Professor, Dokuz Eylül University School of Nursing, Inciraltı/ Izmir, E mail: [ayfer.aydin@deu.edu.tr](mailto:ayfer.aydin@deu.edu.tr)

Tel: +90 232 4124753

\*\* Professor, Ege University School of Nursing

the families (Kelly & Porock, 2005; Björk, Wiebe & Hallström, 2009).

The "Burden of Care" is the reflection of the undesirable events and difficulties brought about by the disease upon the members of the family. The difficulties for families are categorized as consisting of objective burden of care, such as financial needs, housekeeping, and work activities and subjective burden which refers to the psychological reactions that family members experience, such as communicating with siblings of the ill child, dealing with the reactions of others and concerns about the child's future and depression (Norberg et al., 2007; Ow, 2003). The burden of care for the family is related to the frequent and long treatments and hospitalizations, medical problems of the children, and the ever-present risk of relapse (Frank et al., 2001; Ow, 2003; Sloper, 2000). The burden is often experienced most by mothers, since they often take on the major responsibility of caregiving. Providing emotional and physical care for their child not only increases the mother's workload but may cause her own physical health to suffer. In a recent study, mothers reported higher levels of stress than fathers (Norberg et al., 2007). Individuals who have difficulty with fulfilling the responsibilities related to care report physical symptoms such as insomnia, fatigue, headache, backache, loss of appetite, digestive problems, and palpitations (Martinson & Liu-Chiang, 1997).

It has been determined that both children and their families experience many psychological problems. Various studies have shown that mothers display symptoms such as hopelessness, despair, anger, stress, anxiety, and depression (Bayat, Erdem & Kuzucu, 2008; Best, Streisand, Catania & Kazak, 2001; Frank et al., 2001; Norberg et al., 2007; Sawyer et al., 2000; Sloper, 2000). In the last decade approximately 20 studies, the majority conducted in the US, have addressed posttraumatic stress symptoms (PTSS) and/or posttraumatic stress disease (PTSD) in parents of survivors of childhood cancer (Bruce, 2006).

Having a child with cancer may cause the mothers to be socially isolated because cancer diagnosis requires long and expensive treatment and care plans. Also, there can be repeated hospitalizations, or the child may receive care at home. The relationships within the social environments of these parents may be limited because of the treatment requirements and burden of care related to the illness. Most studies have shown that during the course of the disease, mothers primarily participated in the child's care. Working mothers often quit their jobs and could not participate in social activities or have time for themselves, resulting in high levels of anxiety and depression (Hoekstra-Weebers et al., 2001; Sloper, 2000).

Another most important problem for families caring for children with cancer is the economic burden that the mothers face. Mothers experience additional stress due to anxiety concerning job losses and economic difficulties related to the illness and treatment. Expensive treatments, frequent hospitalizations, short social security coverages and insufficient income of the mothers create overpowering difficulties faced (Eiser & Upton, 2006).

This literature reflects studies conducted primarily in the USA and Europe. There is only one published study that examined the impact of childhood cancer on mothers in Turkish culture (Bayat et al., 2008). This quantitative study was conducted to determine the depression, anxiety (state and trait), hopelessness, and perceived social

support levels of 94 parents of children with cancer followed up at a university hospital. A positive relationship was found between depression and hopelessness scores and between state and trait anxiety scores for both mothers and fathers. Also, a negative relationship was found between social support and depression scores and between hopelessness and social support scores. It was found that when increased social support scores, hopelessness and depression levels decreased in mothers.

Although this quantitative study contributed to understanding the effects on parents of caring for their children with cancer, it did not describe their experience within the Turkish context. This study was conducted with the aim of determine thing the "burden of care" of mothers with children diagnosed with cancer. This research is crucial for Turkish health care professionals in order to develop culturally-sensitive interventions.

## Method

### *Study Design*

A qualitative descriptive design was used. It was chosen because of the limited amount of knowledge in this field so the exploratory nature of the qualitative descriptive design was appropriate. Data were collected through in-depth interviews with mothers who have children diagnosed with cancer.

### *Participants*

A purposive sample of mothers recruited from a paediatric oncology unit of university and governmental hospitals participated in this study. Mothers were eligible for selection if: (1) their child was diagnosed at least three months prior to the study but no more than one year, (2) chemotherapy had started and (3) the mothers were the direct care givers. Recruitment continued until a data saturation point was reached (Strauss & Corbin, 1990). Twenty-three mothers participated in the study. Seven of the mothers were between the ages of 19-29, ten mothers were between the ages of 30-39 and 6 mothers were 40 years and over. About half of the mothers (16 mothers) had elementary school education, five were middle-school, and only two were university graduates. The large majority of the mothers were housewives. Only two of the mothers were employed. More than half of the mothers (13 mothers) indicated their economic situations as poor.

The age breakdown of the children whose mother's were interviewed were: 4 children at the age of 0-3 years, 6 children at the age of 4-6 years, 7 children at the age of 7-12 years and 6 children at the age of 13-18 years. More than half of the children had Acute Lymphoblastic Leukemia (14 children), 8 had suffered from malignant tumors and one had been diagnosed with Non-Hodgkin lymphoma. Ten children were diagnosed 3-6 months and 13 children were diagnosed 7-12 months prior to the study.

### *Data Collection*

An interview form was prepared in keeping with the aim of the research under the guidance of literature. The interview form was composed of semi-structured questions designed to explore "the burden of care" of mothers with children diagnosed with cancer. The interviews began with the broad question: "How does your child's illness affect you and your family members?".

Other questions included:

How does your child's illness affect you and your family members (your sick child, siblings and your husband) socially?

How does your child's illness affect you and your family members physiologically?

Do you have any health problems after your child have this illness ?

How does your child's illness affect you and your family members psychologically?

How does your child's illness affect you and your family members financially?

Interviews took place in a quiet and empty patient room in the hospitals. They lasted for 45-60 minutes and they were tape recorded.

#### **Data Analysis**

At the end of the interviews, the records were transcribed verbatim and an analysis immediately carried out. Data were analyzed using qualitative content analysis. The data was first separately coded by both researchers and then compared. To ensure the power of the analytical process, the two investigators read and interpreted the interview transcriptions independently (Morse & Field, 1995).

Following the coding stage, the data was then classified according to the themes. Sub-themes under the main themes were developed. Later, all the information was interpreted in a report. During the planning for the research, four main themes had been established from the literature and according to the perception of the researchers: Emotional, economical, social and physical burden. It was seen that the raw data was compatible with the previously determined themes. The other main theme of "coping strategies" was derived from the data by the two researchers. The results of the study were defined on the basis of these five principal themes.

#### **Research Ethics**

Written permission was obtained from the institutions where the interviews were held. In addition, the purpose of the study was explained to the mothers and their consent was sought for their interviews to be taped. The interviews were conducted with the mothers alone and no children were present. All the information was kept confidential.

### **Results**

Mother's views on burden of care experienced with children who have cancer revealed the themes as social, emotional, physical and economical burdens with coping strategies described within each of these themes.

#### **The Physical Burden**

Mothers stated that trying to cope with the side effects of the treatment and taking care of the child in the hospital had caused their workload to increase. This, then had an adverse effect on their own physical health.

#### **Coping with Symptoms /Coping with Side Effects of the Treatment**

Most of the mothers interviewed indicated that their children suffered from the side effects of the chemotherapy which led to great difficulties in coping with the different problems that arose. The feeding problems and diarrhea experienced by the child led to feelings of fatigue and stress for the mothers.

*He was alright when he came here. He had two cycles and the diarrhea started and hasn't stopped since. There's diarrhea, vomiting, loss of appetite; he didn't eat, he just drank water. I couldn't keep up with it. I couldn't eat, I couldn't even go to the toilet. He's constantly going—every minute .*

#### **Adverse Effects on Mothers' Physical Health**

Mothers reported problems with their own physical health as they were trying to cope with the child's sickness and the emerging problems during the treatment. Mothers complained most frequently of symptoms such as headache, backache, aching neck, loss of appetite, menstrual irregularity and insomnia.

*I've been extremely tired. I've lost my appetite, I've had a lot of headaches. I even went to a neurologist because I was losing sensations in my hands. He said it was because of stress. My forgetfulness is at an extreme. You forget things, sometimes when I'm home, I even forget what I was going to do. Sometimes I forget what the doctors said.*

*I don't sleep. Even at 2 or 3 o'clock in the morning I don't feel like sleeping. You think you'll forget while you're sleeping but no, even in your dreams you're still there. We don't want to sleep .*

#### **The Emotional Burden**

##### **Changes in Mothers' own Disposition and Behavior**

Mothers have said that besides their physical health, their psychological well-being is also adversely affected. Mothers say that they are more nervous, easily angered with the most small events and they are much more sensitive.

*I'm extremely nervous. I can't take the smallest thing. I get nervous when my son does something I told him not to do. Sometimes I get angry at the girls, too. They complain that*

*I've become too nervous and edgy.*

##### **Changes in the Husband's Disposition and Behavior**

Mothers say that their husbands as well are more tense and nervous compared to the days prior to the sickness. Seeing their husband grieving and crying for the child makes the mothers very sad.

*My husband's behavior has changed too. He is also very nervous. He gets upset when he's at home, he gets nervous. My husband is worse than I am. He was never such a nervous person. He's worse than me. He forgets things .*

##### **Changes in the Child's Disposition and Behavior**

It is also seen that besides the mother and father, the child too experiences changes in disposition and behavior. Children who were quiet and well-adjusted before are seen to be more agitated with the sickness.

*M.... has become a nervous child. When you try to do a chore, he yells and won't let me out of his sight. He's either very restless or he's yelling. He wants me to be by his side always. He used to be so quiet, he had toys and he would play the whole day. He was never stubborn. Now he's very stubborn and very nervous.*

##### **Changes in Relationships**

###### **Changes in the Relationship with the Spouse**

The mothers interviewed said that both they and their spouses had become more edgy and tense after the diagnosis was made. They said that they directed their anger at their spouses most of the time, stressing that this had a detrimental effect on interfamilial relationships. A large majority of the mothers said that everything had changed and that their marriages were not as they were before, stating that the child had become the focus of attention.

*Yes, we're not like husband and wife anymore. We're just friends. Everything revolves around our child. When I used to cook, I used to say, 'What do you want me to cook for you today?' Now I cook whatever my child*

wants. We cook and eat whatever it is he wants. Maybe this is wrong but life is moving on, you can't help it. You want to live each day to its fullest. If he wants to play for instance I leave everything. I don't cook, I tell them 'let's go out to eat.' Everything has changed.

#### **Changes in the Relationship with the Child**

Mothers have said that their own attitudes and that of the father's changed after the child's diagnosis. They expressed the fact that they allowed the child to do many things that had been restricted in the past.

*You always want to put on a smiling face in front of your child. You always say yes, you can never say no. It pains me how much I have to be careful about this. I also have to act the same way to my other child. Right now I'm a calmer mommy who says yes to everything and I'm happy about that.*

#### **Changes in Relationships with Other Family Members**

Mothers have said that their healthy children have also been affected and they have experienced certain difficulties as well. The mothers say that their healthy children are both sad about their sick sibling and also jealous because of all the attention paid to the afflicted one. This, they say, has caused them to fail in their schoolwork.

*The child wears a mask so he doesn't contract germs. My five-year-old son thinks he's going to catch a germ from his sister. We separated all their belongings. She doesn't use the things we use. My son still isn't used to this. He keeps thinking he's going to catch something. You always have to watch out and hide things. The siblings are very upset. Their schoolwork has gone down. They're trying to look after themselves. Their lessons have suffered a bit. One of them says, 'Mommy, I can't seem to forget. My mind is constantly back here at home.'*

#### **The Social Burden**

Almost all of the mothers interviewed said that they were experiencing significant changes in their social lives. Mothers who previously had good relations with their neighbors and liked to go visiting said that they were not seeing their friends as often as before or engaging in their previous activities ever since their child's diagnosis.

*We don't go anywhere. I used to go out. Now when I go home I just want to close the door and just sit. I would sit there for 10 days if they let me. I don't feel like going anywhere. Even if I do go, my mind is always on my child. I feel like somebody's stealing the attention I should be paying him... I feel like just thinking. Thinking about what I can do, what I should do.*

#### **The Economic Burden**

The majority of the families defined their economic situation as poor and said that it has gotten worse after their child's diagnosis. Parents stated that frequent hospital visits, long stays in the hospital, the increasing expenses of the child's care were not compatible with the earnings of the mothers which caused great economic difficulties. Some mothers said that they had been forced to sell some of their belongings or ask for loans from friends in order to cover the costs.

*Transportation costs a lot. We keep going back and forth. We've borrowed (money) from friends, we've sold our belongings.*

#### **Coping Strategies**

Mothers interviewed said they tried to cope with their situation through talking with their husbands, talking with other mothers experiencing similar problems, smoking and praying. More than half of the mothers said that they and their husbands had increased the number of cigarettes they were smoking. Nearly all of the mothers said that other mothers at the hospital going through the same difficulties were supportive to each other and talking helped to ease their discomfort.

*I feel so much better when I talk to other mothers here. We share the same fate, we're always together. For instance, we always call up and talk to the mothers who've left the hospital because their treatment has ended. We miss them. We've shared our food together, shared a lot of troubles together. Talking with them makes a lot of difference, it feels good.*

#### **Discussion**

The mothers providing care and support to their child with cancer in this study reported many factors that accounted for their feelings of stress and burden, including the painful interventions and side effects of treatment with which their child had to cope, worries about the child's recovery, feelings of inadequacy regarding the care process, staying in the hospital for long periods, and being unable to make time for the other members of the family. These stressors are similar to those reported in previous studies, such as the illness and treatment process, frequent and long treatments and hospitalizations, medical problems of the children, and the ever-present risk of relapse (Frank et al., 2001; Hoekstra- Weebers et al., 2001; Sloper, 2000). Parents trying to cope with these many challenges described postponing meeting their own needs. This finding is similar to other studies, where mothers described not being able to meet their own needs, resulting in physical problems such as sleep disturbance, loss of appetite, fatigue, headache and headache (Essen, Enskar & Skolin, 2001; Fotiadou, Barlow, Powell & Langton, 2008; Yiu & Twinn, 2001). In an early Chinese study, Martinson and Liu-Chiang (1997) reported that mothers had a high incidence of flu, sleep disorders, appetite loss, fluctuations in weight, headache and dizziness. The mothers interviewed described psychological problems also. They said they were more easily agitated, felt anger at the slightest impetus and felt more sensitive and fragile. Other studies have shown that during the course of the disease, the mothers had anxiety and stresses (Bayat et al., 2008).

Besides the stated changes mothers experienced, there were also attitudinal and behavioral changes within the affected child. Children who had previously been quiet and well-adjusted became edgy. This type of change is known to be a characteristic of children who suffer from a chronic or life-threatening disease that forces them to endure long bouts of treatment and hospitalization (Svavarsdottir, 2005; McCaffrey, 2006). The interviews also emphasized that children became over-attached to their mothers regardless of their age. Even adolescents did not want to leave their mothers behind at home which made things even harder for the mothers. The mother's tendency for not being able to leave the children by themselves and the mother's perception that the children would not be unable to look after themselves prevented the mothers from attending to their household duties and social activities. This in-

evitably increases the mother's emotional burden (Svavar-dottir, 2005).

The mothers also supported the view that cancer affected each one of the family members. They stressed that they generally directed their anger toward their husbands and that this adversely affected interfamilial relations. They expressed that their marriages were not as before and that much of their attention was focused on the child. The separation of the parents during the child's hospital stay also caused stress. While the mother and the child are in the hospital and the father and the other children have remained at home can cause stress among the family members and also compromises the marriage (Van Dongen-Melmana, Van Zuurenc & Verhulstb, 1998; Young, Dixon-Woods, Findlay & Heney, 2002; Björk et al., 2009). The mothers interviewed said that they and their husbands experienced a change in attitude and behavior toward their affected child after the diagnosis of the illness; they became more tolerant and protective than before; there were changes in their previous child rearing and discipline practices. Mothers discovered that accustomed rules were waived because they did not wish to appear strict and heartless. If their child went into remission, parents feared that they would have a relapse. They were on constant watch. Afraid of losing their child, parents did everything the child wanted and become very protective. These responses are similar to those reported by Hersh and Wiener (2001) and Mu et al. (2001). Other studies have shown that "dealing with fears of their child's cancer spreading" is a primary problem for parents (Hoekstra-Weebers et al., 2001; Kerr, Harrison, Medves, Tranmer & Fitch, 2007; Santacroce, 2002; Sawyer et al., 2000).

The mothers also reported that their healthy children were affected by the situation. They reported findings similar to those in other studies, where healthy siblings exhibited anger, jealousy, deterioration of schoolwork, anti-social behavior, depression and other negative manifestations (Simms & Nicki, 2002). Siblings of a child with cancer have been reported to suffer from internalizing (emotional) problems as well as externalizing (behavioral) problems. In a metaanalysis of the literature on the psychological effects of a chronic or life-threatening illness on siblings, internalizing problems appeared to be the most prominent (Sharpe & Rossiter, 2002).

The mothers interviewed expressed that their social lives have been heavily affected, so they did not engage in the social activities that they used to and did not socialize with their neighbors since the child's diagnosis. Other studies have shown that during the course of the disease, working mothers had to quit their jobs; they could not participate in social activities, go off on a weekend or have time for themselves (Hoekstra-Weebers et al., 2001; Sloper, 2000). When the mothers go back home after weeks and sometimes even months of stay in the hospital they see to the needs of the other family members and do household tasks. Mothers revise their lifestyles continuously in order to be able to provide comfort for their child. They may not be able to set aside time for social activities and they may not be able to see their friends for long periods of time.

The child's sickness affects the family's relations with friends and neighbors and may cause the mothers to become socially isolated. The most striking reason the mothers interviewed did not get together with their neighbors anymore was the demoralized feeling they had while

with their neighbors. The neighbors were unable to give them any support which made them not wanting to see them. The emotions created with both parents in relation to their child's cancer diagnosis was very much affected by the neighbors, friends, other members of the family and the immediate environment's reactions. Even though the mothers during the interviews expressed that they did not wish to get together with their neighbors due to various reasons, almost all of them spoke to the other mothers on the hospital floor, sharing the difficulties they face and supporting each other. Literature also has shown the benefits of the "support groups" formed by patients or their families. The opportunity of sharing experiences allows the parents to form emotional and social bonds, to feel that they are not alone, which helps to relieve the feelings of inadequacy and despair (Hallström & Elander, 2007).

A large majority of the families defined their economic situation as poor and said that it got worse after their children's sickness was discovered. Parents experiencing economic problems also had high levels of stress. The lengthy treatment of the sickness, its failure to be cured, the relapses and the long hospitalization periods create emotional, social and economic losses for the patient and the family, bringing a significant burden to the family budget and hence to the country's economy (Dockerty, Skegg & Williams, 2003; Eiser & Upton, 2006).

It was seen that the mothers interviewed were trying to cope with their situation through talking to their spouses, to other mothers with similar problems, smoking and praying. Previous research has shown that childhood disease imposes changes on coping strategies, lowering the ability to retain mother's social relationships (Sloper, 2000; Clarke, Davies, Jenney, Glaser & Eiser, 2005). The qualitative study carried out by Yiu and Twinn (2001) showed that the support they received during this period was very important to parents of children with cancer in terms of coping with their situation. Parents said that they received support from their families and from health personnel but that the biggest support came from their spouses. In another study with the Chinese parents of children with cancer, it was also pointed out that mothers received the most support from their husbands (Martinson & Liu-Chiang, 1997).

### Limitations of the Study

This study provided valuable data concerning the topic under investigation but it has some limitations. The small sample size was limited by the number of parents with cancer children, being treated which may not be representative of the general population. Most of the mothers were in low socioeconomic status.

### Conclusion and Implications

This study adds to the existing evidence about the stressors and responses of mothers of children undergoing treatment for cancer. Specifically it describes the experiences of Turkish mothers and parallels the findings of studies from other countries. Physical and psychological burdens are described and the effects on other family members confirmed. This study did not explore specifically what mothers would find helpful, as they managed the multiple issues facing them and their family. However, some suggestions were provided and others extrapolated from the findings. An important nurse's role is providing knowledge and support as parents learn to deal with how to take care of their

child and come to the realization of, and try to live with, cancer. Nurses are seen as key providers of information to patients and families after a diagnosis of cancer (Chelf et al., 2001). It is also important to continue to assess parents' supportive care needs throughout the cancer journey as individuals experience varying degrees of needs that differ from one another and that may change over time. For any intervention to be effective, it needs to be based on the parents' specific concerns as determined through the assessment of their unique situation and then through the modification of the intervention based on that assessment.

Our study also revealed that mothers' attitudes towards both their sick and healthy children change where the mothers experience a loss of control over what to do. Information needs to be offered about cancer and the psychosocial effects of treatment on the sick child and his siblings. Guidance as well must be provided as to how to react in the situation. Our participants did describe the importance of relationships with other mothers. They also spoke about the need for good information and for support that involved the whole family. Nurses can be helpful as they encourage such informal support. Perhaps starting a more formal parent support group would be useful. It is most essential that any interventions that are implemented be carefully evaluated. Our study has again confirmed the many issues facing children with cancer, their mothers and other family members. Now attention should be directed to determining effective interventions for families on their journey.

## References

- Bayat, M., Erdem, E., & Kuzucu, E. G. (2008). Depression, anxiety, hopelessness, and social support levels of the parents of children with cancer. *Journal of Pediatric Oncology Nursing*, 25, 247 - 253.
- Best, M., Streisand, R., Catania, L., & Kazak, A. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology*, 26, 299-307.
- Björk, M., & Wiebe, T. I. (2005). Striving to survive: families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 22, 265-275.
- Björk, M., Wiebe, T., & Hallström, I. (2009) An everyday struggle—swedish families' lived experiences during a child's cancer treatment. *Journal of Pediatric Nursing*, 24: 423-432.
- Bruce, M. (2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review*, 26, 233–256.
- Chelf, J. H., Agre, P., Axelrod, A., Cheney, L., Cole, D. D., Conrad, K., et al. (2001). Cancer-related patient education: An overview of the last decade of evaluation and research. *Oncology Nursing Forum*, 28, 1139-1147.
- Clarke, S. A., Davies, H., Jenney, M., Glaser, A., & Eiser, C. (2005). Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psycho-Oncology*, 14, 274–281.
- Dockerty, J. D., Skegg, D. C. G., & Williams, S. M. (2003). Economic effects of childhood cancer on families. *J. Paediatric Child Health*, 3, 254–258.
- Eiser, C., & Upton, P. (2006). Costs of caring for a child with cancer: a questionnaire survey. *Child: Care, Health and Development*, 4, 455–459.
- Essen, L., Enskar, K., & Skolin, I. (2001). Important aspects of care and assistance for parents of children, 0-18 years of age, on or off treatment for cancer. Parents and nurse perceptions. *European Journal Of Oncology Nursing*, 5, 254-264.
- Fotiadou, M., Barlow, J. H., Powell, L.A., & Langton, H. (2008). Optimism and psychological well-being among parents of children with cancer: an exploratory study. *Psycho-Oncology*, 17, 401–409.
- Frank, N. C., Brown, R. T., Blount, R. L., & Bunke, V. (2001). Predictors of affective responses of mothers and fathers of children with cancer. *Psycho-Oncology*, 10, 293-304.
- Hallström, I., & Elander, G. (2007). Families' needs when a child is long-term ill: A literature review with reference to nursing research. *International Journal of Nursing Practice*, 13, 193–200.
- Hersh, P. H., & Wiener, L. S. (2001). Psychiatric and psychosocial support for the child and family. In: Principles and Practice of Pediatric Oncology (eds Pizzo A. Poplack D.G. ). Lipincott Williams Wilkins Publisher.
- Hoekstra-Weebers, J., Jaspers, J. P. C., Kamps, W. A., & Klip, E.C. (2001). Psychological adaptation and social support of parents of pediatric cancer patients: a prospective longitudinal study. *Journal of Pediatric Psychology*, 26, 225-235.
- Kazak, A., Prusak, A., McSherry, M., Simms, S., Beele, M., Alderfer, M., et al. (2001). The psychosocial assessment tool (PAT): pilot data on a brief screening instrument for identifying high risk families in pediatric oncology. *Families, Systems and Health*, 19:303-317.
- Kelly, K.P., & Porock, D. A. (2005). Survey of pediatric oncology nurses' perceptions of parent educational needs. *Journal of Pediatric Oncology Nursing*, 22, 58-66.
- Kerr, L., Harrison, M., Medves, J., Tranmer, J., & Fitch, M. I. (2007). Understanding the supportive care needs of parents of children with cancer: an approach to local needs assessment. *Journal of Pediatric Oncology Nursing*, 24, 279 - 293.
- Martinson, I. M., & Liu-Chiang, C. Y. (1997). Distress symptoms and support systems of Chinese parents of children with cancer. *Cancer Nursing*, 20, 94-99.
- Matziou, V., Perdikaris, P., Feloni, D., Moshovi, M., Tsoumakas, K., et al. (2008). Cancer in childhood: Children's and parents' aspects for quality of life. *European Journal of Oncology Nursing*, 1-8.
- McCaffrey, C. N. (2006). Major stressors and their effects on the well-being of children with cancer. *Journal of Pediatric Nursing*, 21:1.
- McGrath, P., Paton, M. A., & Huff, N. (2005). Beginning treatment for pediatric acute myeloid leukemia: The family connection. *Issues in Comprehensive Pediatric Nursing*, 28, 97–114.
- Morse, J. M., & Field, P. A., (1995). *Nursing Research: The Application of Qualitative Approaches*. Second Edition, Nelson-Thornes.
- Mu, P., Ma, F., Ku, S., Shu, H., Hwang, B., et al. (2001). Families of Chinese children with malignancy: The factors impact on mother's anxiety. *Journal of Pediatric Nursing*, 16,287-295.
- Norberg, A. L., Lindblad, F., & Boman, K. (2007). Support-seeking, perceived support and anxiety in mothers and fathers after children's cancer treatment. *Psycho-Oncology*, 15, 335-343.
- Northouse, L. L. (2005). Helping families of patients with cancer. *Oncology Nursing Forum*, 32, 743-750.
- Ow, R. (2003) Burden of care and childhood cancer: Experiences of parents in an asian context. *Health and Social Work*, 28, 3, 232-240.
- Santacroce, S. (2002). Uncertainty, anxiety, and symptoms of posttraumatic stress in parents of children recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 19, 104-111.
- Sawyer, M. S., Antoniou, G., Rice, M., & Baghurst, P. (2000). Childhood cancer: A 4-year prospective study of the psychological adjustment of children and parents. *Journal of Pediatric Hematology/Oncology*, 22, 214- 220.

- Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, 27, 699–710.
- Simms, S. H., & Nicki, V. J. (2002). Sibling support in childhood cancer. *Paediatric Nursing*, 14, 20-23.
- Sloper, P. (2000). Predictors of distress in parents of children with cancer: A prospective study. *Journal of Pediatric Psychology*, 25, 79-91.
- Strauss, A. L. & Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Newbury park: Sage publications
- Svavarsdottir, E. K. (2005). Caring for a child with cancer: a longitudinal perspective. *Journal of Advanced Nursing*, 50(2), 153–161.
- Wells, D. K., James, K., Stewart, J. L., Moore, I. M., Kelly, K. P., et al. (2002). The care of my child with cancer: A new instrument to measure caregiving demand in parents of children with cancer, *Journal of Pediatric Nursing*, 17, 201-210.
- Van Dongen-Melmana, J. E. W. M., Van Zuurenc, F. J., & Verhulstb, F. C. (1998). Experiences of parents of childhood cancer survivors: A qualitative analysis. *Patient Education and Counseling*, 34, 185–200.
- Yeh, C. H., Lee, T. T., Chen, M. L., & Li, W. (2000). Adaptational process of parents of pediatric oncology patients. *Pediatric Hematology and Oncology*, 17, 119-131.
- Yiu, J. M., & Twinn, S. (2001). Determining the needs of Chinese parents during the hospitalization of their child diagnosed with cancer: an exploratory study. *Cancer Nursing* 24, 483-489.
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualizing mothers of children with cancer. *Social Science & Medicine* 55 1835–1847.

**Dergiye geliş tarihi: 25.06.2008**

**Kabul tarihi: 10.10.2010**