CHILDHOOD CANCER AND ITS EFFECT ON THE MARITAL ADJUSTMENT OF THE PARENTS

A THESIS SUBMITTED TO
THE GRADUATE SCHOOL OF SOCIAL SCIENCES
OF
THE MIDDLE EAST TECHNICAL UNIVERSITY

BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE
IN
THE DEPARTMENT OF PSYCHOLOGY

DECEMBER 2003

Approval of the Graduate School of Social Sciences

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ABSTRACT

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December 2003, 87 pages

The main purpose of the study was to investigate whether illness-related factors predict marital adjustment in parents of children with cancer. The sample consisted of parents of hospitalized children, parents of children receiving outpatient treatment, and parents who brought their children for their routine controls ith a total of 105 mothers and fathers. The data were gathered by administering the Dyadic Adjustment Scale and Demographic, Illness- and Caregiver- Related Information form. Findings suggested that number of previous hospitalizations and support from spouse predict marital adjustment in

parents of children with cancer. However, when the subscales were analyzed seperately, different predictors emerged. Number of previous hospitalizations predicted Dyadic Consensus, relapse and support from spouse predicted Dyadic Satisfaction, and currently receiving treatment and support from spouse predicted Dyadic Cohesion. No predictors for affectional Expression could be found. When only the parents of children currently receiving treatment are selected for analysis, the predictors do not change for Dyadic Satisfaction. However for Dyadic Cohesion, both parents as caregivers emerges as a predictor along with support from spouse. Single variables correlate significantly with the DAS Score, Dyadic Consensus and Affectional Expression. They are support from spouse for the DAS Score and Dyadic Consensus, and length of marriage for Affectional Expression.

Keywords: Childhood cancer and marital adjustment

ÖZ

ÇOUKLUK ÇAĞI KANSERLERİ VE ANNE-BABALARIN EVLİLİK UYUMLARI ÜZERİNDEKİ ETKİLERİ

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Yüksek Lisans Tezi, Psikoloji Bölümü

Tez Yöneticisi: Doç. Dr. Hürol Fışıloğlu

Aralık 2003, 87 sayfa

Bu araştırmanın temel amacı, kanserle ilgili değişkenlerin anne- babaların evlilik uyumunu yordayıp yordamadığını araştırmaktır. Örneklem (105 kişi), hastanede yatmakta olan, ayakta tedavi gören ve rutin kontrollerine gelmiş olan çocukların anne-babalarından oluşmaktadır. Veriler Çiftler uyum Ölçeği ve Demografik, Hastalık ve Refakatçiyle İlgili Bilgi Formu'nun uygulanmasıyla elde edilmiştir. Elde edilen sonuçlara göre evlilik uyumunu daha önceki hastane yatışlarının sayısı ve eşin desteği yordamaktadır. Alt ölçekler ayrı ayrı incelendiğinde, alt ölçekleri yordayan farklı değişkenler bulunmuştur. Eşler-arası

Fikir Birliğini (Dyadic Consensus) daha önceki hastane yatışlarının sayısı, Eşler-arası Doyumu (Dyadic Satisfaction) ise hastalığın tekrarlamış olması ve eşin desteği, çocuğun tedavi alıyor olması ve eşin desteği değişkenleri ise Eşler-arası Bağlılık (Dyadic Cohesion) yordamaktadır. Duyguların İfade Edilmesi'ni (Affectional Expression) yordayan bir değişken bulunamamıştır. Analizlere sadece tedavi görmekte olan çocukların dahil edilmesi durumunda Eşler-arası Doyum'u yordayan değişkenler farklılık göstermemektedir. Ancak Eşler-arası Birliktelik'I anne ve babanın refakatçi olarak kalması ve eşin desteği yordamaktadır.

Anahtar kelimeler: Çocukluk çağı kanserleri ve evlilik uyumu

To Life

ACKNOWLEDGMENTS

I would like to express my gratitude to my supervisor Assoc. Prof. Dr. Hürol Fışıloğlu, for his invaluable contributions, advice and guidance, but above all for his encouragement. Without his support, this thesis could not be completed. I would also like to express my sincere appreciation to Assoc. Prof. Dr. Belgin Ayvaşık and Prof. Dr. Ferhunde Öktem for their valuable suggestions, interest, and support in the project.

I would like to express my gratitude to Ankara University Medical School Hospital (Ankara Üniversitesi Tıp Fakültesi), Demetevler Oncology Education and Research Hospital (Demetevler Onkoloji Eğitim ve Araştırma Hastanesi), Oncology Hospital in Hacettepe University Medical School and, Hacettepe University İhsan Doğramacı Children's Hospital (Hacettepe Universitesi İhsan Doğramacı Çocuk Hastanesi for giving me permission to carry out this research and the participating wards for their interest in the study and for trusting me with their patients' parents. I would also like to thank the staff of those institutions for their help and interest in the project. I would especially like to thank Nurse Deniz Altuğ, Doctors Ayhan Pektaş and Erdem

Durmaz and Psychologist Candan Akçay for their invaluable help and support during the data collection process.

I would like to thank my friends and colleagues Yonca Toker, Gülay Dirik, Başak Ok, Olga Hünler, Sinan Ulu and Şehnaz Yıldırım for their help and emotional support throughout the thesis process. I would also like to thank my friends Duygu Kayadelen and Nihan Tanışel for offering help and always being there for me. Support and friendship of these people mentioned above have been invaluable in the process of this thesis.

I would like to thank my parents for their support in the thesis process. I would also like to express my admiration and appreciation for their patience with me during the process.

Last, but not the least, I would like to express my gratitude to all the patients and their family members I got to know in the process of this thesis for their interest in the project and sharing their experiences and feeligs with me. I admire and am very much inspired by their strength.

I hereby declare that all information in this document has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

Date: Signature:

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CHAPTER I

INTRODUCTION

Cancer actually refers to a wide range of diseases (100 - 200 types depending on the source) with different distribution and incidence patterns - across genders, age groups and races-, treatment and prognosis. What they all have in common is that all forms of cancer involve out of control growth and spread of abnormal cells (Cancer Research Institute, n.d.).

Cancer is the leading cause of death by disease in children of ages one and twenty (National Cancer Institute, 2002) and it is the cause of death for more children than asthma, diabetes, cystic fibrosis (a lethal chronic illness) and AIDS combined (National Childhood Cancer Foundation, n.d.). There was an increase in childhood cancer incidence of as much as 10% for all types combined (National Institute of Health, n.d.). The incidence rate of cancer in the year 1998 was 152 cases per 1,000,000 children as opposed to 114 cases in the year 1975. In the year 2001 “approximately 8,600 children were diagnosed with cancer and about 1,500 children died” of it (National Cancer Institute, 2002) and

about 1/3 of the children currently diagnosed with cancer will not survive five years (Chesney & Chesler, 1996).

Unfortunately, incidence and prevalence statistics in Turkey are inadequate and unreliable because of the lack of one central source of information, non-referred, non-reported and mis-diagnosed patients, and lack of access to the available data (Büyükpamukçu et al., 1998; Hayran & Fırat, n.d.). Hayran and Fırat (n.d.) suggest that cancer is the fifth leading cause of death in children whereas Bilir (1994) claims that cancer is the third leading cause of death, infections and accidents being the first and second causes respectively. According to the death statistics of State Institute of Statistics (2001), 411 children between the ages 1-14 died of cancer. It accounts for 2% of the deaths in children ages 1-14, 1.6% of people from all ages who died of cancer and 0.2% of the deaths in the whole population. The type of cancer that killed the most number of children was leukemia with 134 children and it accounts for 33% of children who died of cancer between the ages 1-14.

On the bright side, the survival rates for childhood cancer have also dramatically improved with advances in medical technology. From less than 30% survival chance in the 1960's cancer survival rates have by about 42% to a five-year survival rate of almost 70% in all sites combined. Mortality rate of cancer in most sites have dropped by about 50% (National Cancer Institute, 2002).

Increasing survival rates for childhood cancer has qualified cancer as a chronic illness rather than the terminal illness status it had before. This has shifted the focus of both families and the researchers from 'dying form' cancer to 'living with' it. Still, 70% survival rate means 30% of children still die from the disease and this is a risk parents must face and "the diagnosis of cancer in one's child is accepted as one of the most severe stressors that parents can experience" (Kazak, 1997).

Steinglass (2000) has pointed out four main perspectives that have emerged in the literature on families and medical illness; d*eficit perspective*, which emphasizes how pathologies in the family environment leads to illness; *resource perspective* that views family as a resource for coping with illness; *clinical course* perspective, which suggests that family eventually organizes its life around the illness and the illness becomes the central theme in the family life; *impact perspective,* which focuses on the impact illness has on the family. Studying the effect of having a child with cancer on the parents, this study will be looking at the parents of cancer from an impact perspective.

Psychological upset, financial burden, lack of emotional support and negative effects of the illness on parental employment, finance and family relationship were found to be the sources of distress in parents of children with cancer (Patistea, Makrodimitri and Panteli, 2000; Sloper, 1996). Hope, social

support and marital relationship were found to be the most helpful resources for parents in the initial period after the diagnosis by Patistea et al. (2000).

The findings on whether marital adjustment of parents of children with cancer or chronic illness is significantly different than that of parents with healthy children is controversial. Taanila, Kokkonen and Jarvelin (1996) identified the risk factors for marital adjustment of parents of children with a chronic illness as higher level of education, insecurity at onset, heavy daily demands for care of the child, unequal distribution of tasks between the spouses and a lack of time for leisure activities. Protective factors for the marital relationship were found to be adequate information, a realistic notion of the illness or disability and practical advice for everyday life.

No studies on marital adjustment in parents of children with chronic diseases in Turkish culture could be found. However, Bekdemir (1996) found that increasing length of child's stay in hemodialysis, presence of another patient in the family other than the ill child and expressed psychological disorders/problems after the child's disease were negatively correlated with scores on Family Assessment Device with "Affective Involvement" being the most adversely effected sub-scale followed by "Roles" and "Affective Responsiveness". In another study, Erdem (1999) found the quality of life of parents of children with cancer to be affected by the stage and length of disease, type of treatment provided, parents' perceptions about disease, parents'

satisfaction with the knowledge regarding the disease and treatment, differences in family relationships depending on cancer and getting support in coping with cancer. In accordance with her findings, Peykerli (1994) has found that first relapse affected both depression and affection in family relations more adversely than the initial diagnosis.

Opposing the general trend of studies focusing on either diseases specifically or under a very general umbrella term of 'chronic illness', Rolland (1994) proposes that the medical classifications are created and useful for understanding and treating physical illnesses. However, he claims, that for a better understanding of the psychosocial effects of these diseases, a classification based on "key biological similarities and differences with distinct psychosocial demands for the patient and family" (Rolland, 1999) will be more suitable. The model he suggests – Family Systems-Illness Model – comprises of two dimensions: psychosocial typology of illness and time phases of illness.

Psychosocial typology of illness emphasizes four characteristics of the illnesses; o*nset* (acute or gradual), c*ourse* (constant, relapsing or progressive), o*utcome* (fatal, non-fatal or shortened lifespan / possibility of sudden death), i*ncapacitation* (impairment of cognition, sensation, movement, stamina, disfiguring conditions, social stigma). Time phases of illness are listed as crisis, chronic and terminal. *Crisis phase* starts at the time of diagnosis, or even before, if the symptoms were present pre-diagnosis. *Chronic phase* is the adjustment

phase when the patient and the family learn to live with the disease. *Terminal phase* is the phase 'when issues related to death and dying predominate" (Rolland, 1994)

Few studies focusing on the illness-related factors such as treatment-type, treatment-length and hospitalization could be found. Barbarin, Hughes and Chesler (1985) found that husbands' marital quality was correlated with wives' time spent at home as opposed to hospital with husbands' perceived support dropping with increased time spent at the hospital by wives. Hilbert, Walker and Reinheart (2000) found no effect of incapacitation and Banis, Suurmeijer and van Peer (1999) suggested that parental interpretations (i.e. subjective meaning of illness) may be more important than the objective factors. Peykerli (1994) compared psychosocial adjustment and depression levels of families of children with leukemia in diagnosis, first relapse and terminal phases with those of families of children with acute rheumatic fever and has found first relapse to affect both depression and affection in family relations more adversely than the initial diagnosis.

According to Rolland's Family Systems-Illness Model, cancer falls under different categories depending on its type. For example, lung cancer with CNS metastases would fall under incapacitating and progressive diseases with gradual onset, progressive course, and fatal outcome along with AIDS and bone marrow failure, whereas lung and liver cancers would still be under the same

category of progressive diseases with fatal outcome, however they would be under the nonincapacitating diseases with acute onset, along with acute leukemia. Again, incurable cancers in remission would be classified under nonincapacitating diseases with acute onset and fatal outcome, however, they would be under the category of relapsing diseases. Considering the controversial findings on the psychosocial effects of illness on families, and the relatively few number of studies on the effect of illness-related factors and time dimension, it seems to be that these might be the missing variables needed for a better understanding of differences both between different illnesses and within the same diagnosis.

The present study investigated the marital adjustment of the parents of children diagnosed with cancer. The study focused on the effects of illness-related factors such as gradual versus acute onset, time since diagnosis, treatment received, extent of hospitalizations, incapacitation, expected outcome and course of illness.

The main goal of the study was to investigate which variables among the following predict marital adjustment in the parents of children with cancer; the *cancer- related* (if the diagnosis was made suddenly or took some time to be arrived at, time since diagnosis, the reason why they are at the hospital, current treatment, previous hospitalizations, what type of treatment was received before, if the child can meet his/her basic needs such as eating or getting dressed by

himself/herself, whether there was a relapse, the course of cancer, parental rating of the child's health status), *caregiver-related* (if the reason is hospital stay, then, if someone is staying at the hospital with the child and who, how long the child has been in the hospital, if the child has been hospitalized before then whether someone stayed with the child in the previous stays and if so who, if the non-caregiving parent can visit and with what frequency, source of support) and *demographic* (gender, age, education, marital status of the respondent, age and education of spouse, length of marriage, number, age and gender of children, if there is anyone else living with them, if there is some other person such as a relative that requires their care, city of residence, gender and age of the child with cancer). The other goals were to investigate whether different variables predict marital adjustment of the parents of children in the treatment phase and if gender, education, course, incapacitation and reason for being at the hospital effect marital adjustment in parents of children with cancer.

1.1 Significance of the Study

The present study is the first – to the author's knowledge –to have used Family Systems-Illness Model as a framework for research purposes. It may serve as a step toward appreciating the different aspects of illness and the changes throughout the treatment process that color the experiences of the

parents rather than taking the illness as a stable factor. It is also important in the sense that it employs criteria other than medical diagnosis.

The study is also a first to investigate the effects of having a child with cancer on the marital adjustment with the focus on illness-related factors. It may shed some light to the controversial findings in this area. Since those studies have taken the diagnosis as their sole criteria, some critical factors related to the experience of parents to illness that determine the outcome may have been overlooked.

Finally, this study seems to be a first to have studied marital relationship in the parents of children with cancer -or any other chronic illness- in the Turkish culture as no such study could be found.

1.2 Implications of the Study

The present study may have important implications for the health care team members who work with parents of children with not only cancer but other chronic illnesses as well to the extent it generalizes. Since positive marital adjustment is a resilience factor for healthy individuals and for coping, it may serve an important function at this extremely stressful period of their life. Knowing the critical factors for the parents' marital adjustment may help

identifying couples at-risk and allow for taking preventive measures. It is suggested that crisis can strengthen the relationship if the couple can be responsive to each other's needs as well as help insecurities surface. Therefore such an intervention may not only preserve the marriage but also actually help them improve. Marital adjustment of parents is also important for their children's well being -both ill and healthy- therefore indirectly benefiting from an intervention to the marital dyad.

This study may also serve to emphasize the necessity of cooperation among different professions in the medical setting. Despite working with the same population and within the same physical space, health care and mental health professionals seem to work quite separately without much flow of information. An integration of medical aspects of the illness and its psychological effects on the patients and their families as this study aims to do may provide a more holistic picture of the patient and their families by pointing out the other half of the picture for both medical professions and the mental health professions.

On a more global level, this study may have an implication on the health care policies. Currently, only the ill child is regarded as the patient and the well being of the child is regarded as the only focus. However, the well being of the family members –especially the caregiver- effect the ill child as much as the ill child effects the family. Therefore a perspective of taking the family as a unit is

emerging. This study may point to the consideration of the parents' needs and well being.

CHAPTER II

REVIEW OF THE LITERATURE

2.1 Cancer and Families

Historically, the studies – and the attention of the health care professionals – on children with chronic illness focused exclusively on the ill child. However, with the realization and growing awareness of the importance of both the family factors on the clinical course of the illness and the impact illness has on the family, family variables started being taken into account as well.

Increased survival rates have transformed cancer from a terminal illness to a chronic one. This shift has placed the focus on "gaining a better understanding of how the child, parents and the family unit adapt and recover both during the active treatment phase and in long-term survival" as McCubbin, Balling, Possin, Frierdich, and Bryne (2002) have put it.

The changes in survival rates and treatment has also altered the experience of the patients and their families. It also has presented them with new

challenges such as more potentially toxic, intensive and often painful treatment regimens which can take up to several years, distressing side-effects, longer hospitalizations, uncertainty about survival, possibility of relapse in remission and possible after-effects of treatment (such as amputations). Additionally, there are stressors caused by the chronic nature of the disease such as disrupted normal family routines, alterations in the parent-child relationship and sibling care, parental and occupational role changes, concerns about long term effects on the child and the family. Not surprisingly, "the diagnosis of cancer in one's child is accepted as one of the most severe stressors that parents can experience" (Kazak, 1997).

2.2 Parents of Children with Cancer

This section will focus on the effects of having a child with cancer on the parents. Studies on these parents' distress, social support, hope, wishful thinking, coping and marital relationships will be examined.

2.2.1 Distress

The findings on distress of parents of children with cancer has been controversial. Some studies have found parents of children with cancer to be

significantly more distressed than parents of healthy children whereas some found no such difference. For example, Yeh (2002) noted that parents, whose children were diagnosed within two months, reported higher levels of depression anxiety, global stress and marital dissatisfaction. Supporting this finding, Sawyer, Antoniou, Toggod, Rice and Baghurst (2000) found that psychological problems of parents were significantly more than those of parents of healthy children at the time of diagnosis. However, this difference did not exist in the follow-ups, which were conducted annually for the next four years. On the other hand, Sloper (2000) found high levels of distress in parents of children with cancer at 6 months post-diagnosis. The change in distress level was found to be little in the follow-up at 18 months post-diagnosis. Grootenhuis and Last (1997b) also reported finding no effect of time since diagnosis on the emotional reactions of parents.

There also are studies suggesting milder differences between the two groups. Dockerty, Williams, McGee and Skegg (2000) reported a significant difference between parents of children with cancer and parents of children from the general population on the General Health Questionnaire scores. However, he comments that the difference is significant though small and suggests that this implies the resiliency of parents of children with cancer. Along the same line with Dockerty et al. (2000), Wright (1993) reported that parents of children with cancer evaluated their quality of life as good though it was worse in comparison with their quality of life pre-diagnosis. Sloper (1996) reported that 55% of

mothers and 41% of fathers scored above cut-off indicating high levels of distress and Sloper (2000) found 51% of mothers and 40% of fathers had high level of stress. These findings mean 45% of mothers and 59 % of fathers were below the cut-off and 49% of mothers and 60% of fathers did not experience high levels of distress.

On the sources of distress, Patistea et al. (2000) reported psychological upset and financial burden to be the most difficult factors for the parents during the initial period after diagnosis. Likewise, negative effects on parental employment, finance and family relationships and, lack of emotional support were found to be the factors associated with higher levels of distress by Sloper (1996).

In their study, Morrow, Carpenter and Hoagland (1984) reported age to be a significant factor in psychological adjustment. In the domains of domestic environment, sexual relations, extended family relations, personal psychological distress and total psychological adjustment, younger parents were found to have greater difficulties in psychologically adjusting than parents who were older than 30 years of age.

Several other studies on parental distress report gender differences in predictors of distress. Sloper (2000) found that for both mothers and fathers, appraisal of strain of illness and family cohesion predicted distress in parents of

children with cancer. Additional factor predicting distress in mothers was their ability to deal with the strain of illness predicted distress and at 6 months post-diagnosis, use of self-directed coping strategies. Whereas for fathers, it was employment problems at 6 months post-diagnosis, and number of hospital admissions at 18 months post-diagnosis. In another study, Hoekstra-Weebers, Jaspers, Kamps and Klip (1999) took measures at the time of diagnosis and at 12 months post-diagnosis and found trait anxiety to be the strongest predictor of both mothers' and fathers' future distress. Also for fathers, choosing social support-seeking as a coping style and dissatisfaction with support, and for mothers, number of pleasant events experienced pre-diagnosis were found to be predictive of future distress. For short-term, dissatisfaction with support in fathers and assertive behavior of mothers were found to be predictive of higher distress. Another finding on dissatisfaction with support comes from Hoekstra-Weebers, Jaspers, Kamps and Klip (2001). Support was found to be predictive of both concurrent and future distress fathers but not so for mothers. For fathers, dissatisfaction with support and negative interactions were found to be risk factors whereas for mothers, there was no persisting effect of support. However, in comparison of mothers who adjusted well and mothers who remained clinically distressed, the former were found to be receiving more support and less dissatisfied than the latter.

2.2.2 Social Support

Morrow, Hoagland and Carnrike (1981) found that psychological adjustment of parents of children with cancer was most frequently correlated with perceived support. Similarly, hope, social support and marital relationship to be the most helpful resources for parents in the initial period after the diagnosis by Patistea et al. (2000). Hoekstra-Weebers, Jaspers, Kamps and Klip (2001) reported that parents of children with cancer perceived most support during diagnosis. Although the quantity of support decreased in time, parents were equally satisfied with the support they received. In contrast, Morrow, Hoagland and Morse (1982) found no difference between parents of children who were at different stages of treatment in terms of patterns of social support.

On sources of support, Morrow et al. (1982) report that spouse, the medical community and parents from a mutual help group were rated as the most helpful sources of support by the parents of children with cancer. Despite more than half of the parents that mentioned emotional support and counseling as what they needed most during their child's illness, mental health professionals were seen less frequently and were perceived as less helpful. Morrow et al. (1984), however, reported differential sources of support to be beneficial for parents of different groups. While for parents whose child was not undergoing treatment, relatives seem to be the sole source of support that helps, parents of children in treatment seemed to have several sources of support. For

parents who have lost their child to cancer, no source of support was found to be helpful in adjustment difficulties.

2.2.3 Hope

Grootenhuis and Last (1997a) found that the factor that most strongly correlated with negative emotions for both mothers and fathers was the lack of positive expectations about the course of illness. In relation to that, Grootenhuis and Last (1997b) reported parents of children who have relapsed to feel more helpless and uncertain, and fear about child's chances of survival more in comparison to parents of children in remission.

Grootenhuis and Last (1997a) found a gender difference that, feelings of uncertainty in mothers was related to having a child with relapse and predicted feelings of helplessness and uncertainty, but for fathers, it was related to reported feelings of depression of the child. Also Grootenhuis and Last (1997b) noted that mothers reported more depression and anxiety if their child has relapsed, but no such relationship was found for fathers.

2.3.4 Coping

Goldbeck (2001) found that parents of children with cancer developed more rumination, defense and information seeking, and less support seeking strategies in comparison with parents of children with epilepsy or diabetes. Goldbeck (2001) also reported that, coping dissimilarity within couples on social support seeking and religion were associated with higher quality of life for parents of children with cancer. However, coping dissimilarity in information seeking was found to be correlated with a decrease in the child's quality of life.

On the effect of coping style of parents on the marital relationships, Wittrock, Larson and Sandgren (1994) report that though engaged coping was found to be related with lower levels of anxiety and depression and higher levels of marital satisfaction for parents of childen with flu, for parents of children with cancer, no such relation could be found. However, disengaged coping was found to be associated with greater levels of maladjustment in both groups of parents alike.

2.4 Marital Relationship

There are many concepts in defining the marital relationship; marital quality, marital satisfaction, marital adjustment and marital stability to name a few. With so many concepts, there are many different definitions and measures as well which pose the question of which definition to use. Bucker and Fowers (n.d.) reviewed the literature and found that the most commonly used concepts were marital satisfaction and marital adjustment followed by marital distress, conflict, quality and communication. They note that 'the most important thing in the marital research literature is whether spouses experience personal satisfaction in their marriages" and they suggest that communication/emotion model of marriage is the predominant model. According to this model, good communication experiences lead to positive affect and intimacy, which leads to positive marital cognitions, thus have lower chances of being violent, and, as a result, they have positive evaluations of their marriage and are likely to remain together. According to Spanier and Cole (1976) marital adjustment is 'the functioning and success of the marital partners, and it encompasses the concepts of marital satisfaction and happiness" (cited in Russel & Allgood, 1990) and Dyadic Adjustment Scale (Spanier,1976) poses an example for this model with the subscales dyadic consensus, dyadic satisfaction, dyadic cohesion and affectional expression.

2.4.1 Marital Relationship in Parents of Children with Chronic Illness

There are relatively few studies on the marital relationship of the parents of children with cancer. Therefore the findings of parents of children with chronic illnesses will also be reviewed in this section.

The studies on the effect of childhood chronic illnesses on the marital adjustment of the parents has been inconclusive. In their review of the literature, Sabbeth and Leventhal (1984) concluded that marital distress was increased in the parents of children with various chronic illnesses. However, there was no increase in the divorce rates of these parents. This is against the expectations since lower levels of marital satisfaction predicts divorce potential which in turn predicts likelihood of divorce for up to 7 years later (Devine & Forehand, 1996).

It is suggested that having a child with chronic illness may increase the costs of leaving the relationship therefore, parents may stay in a relationship despite increased marital distress (Eddy & Walker, 1999). However, in their study of parents of children with chronic childhood illnesses, Eddy and Walker (1999) found no difference in either marital stability or satisfaction in parents of children with chronic illness in comparison to parents of healthy children.

Holmbeck et al. (1997) and Quittner et al. (1998) also found no difference in the marital relationships of the parents of children with chronic

illnesses, spina bifida and cystic fibrosis respectively, in comparison with parents of healthy children despite their reports of distress on other areas. Mothers of children with spina bifida scored lower in perception of competency as a parent and adaptation to change and higher in social isolation. And greater role strain on measures of role conflict, childcare tasks, and exchanges of affection was found in the parents of children with cystic fibrosis in comparison to parents of healthy children.

Taanila et al. (1996) reported the risk factors for lower marital satisfaction to be higher level of education, insecurity at onset, heavy daily demands for care of the child, unequal distribution of tasks between the spouses and a lack of time for leisure activities. Protective factors were found to be adequate information, a realistic notion of the illness or disability and practical advice for everyday life seemed to be the protective factors for the marital relationship. It was also noted that 20% of the parents reported the child's disability to have contributed positively to the marital relationship. 25% of the parents reported that some areas of their marital relationship was impaired and only 7% of the parents reported that they had drawn apart from each other.

Dahlquist et al. (1993) studied 67 married couples who were parents of children with cancer. Marital distress was reported by 25% of mothers and 28% of fathers. General emotional distress, discrepancy between couple's state

anxiety levels and the couple's use of sensitizing coping strategies were found to be predictive of marital distress.

Hoekstraweebers, Jaspers, Kamps and Klip (1998) also found increased marital dissatisfaction in the parents of children with cancer. Psychological distress was found to be associated with marital dissatisfaction 6 and 12 months post-diagnosis. However there was no association at diagnosis. This finding suggests that passage of a certain amount of time is necessary for the child's illness to affect the parents' marital relationship. There was no mention of the onset of the illness, whether the symptoms were ongoing or the parents were not suspecting anything and that the diagnosis was totally unexpected and sudden. It might be hypothesized that parents of those children will already have experienced psychological distress and the marital relationship of parents of children who were not diagnosed but were showing the symptoms will already be affected by the illness of the child.

Hoekstraweebers et al. (1998) also reported a gender difference. The marital distress was found to be related to the father's coping behavior for both mothers and fathers. Marital distress of both mothers and fathers was also associated with discrepancies in coping within couples.

However, Dahlquist, Czyzewski and Jones (1996) found contradicting results. In the study that investigated emotional distress, coping style and marital

adjustment, data were taken from 42 couples who were parents of children with cancer at 2 and 20 months after the diagnosis. For both mothers and fathers, depression and spouse's marital satisfaction predicted marital adjustment at follow-up. An additional predictor for fathers was child health status. Coping style was found to be related with marital adjustment at 2 months post-diagnosis but not so at the follow-up. There was no change of marital adjustment scores in both mothers and fathers over time.

2.5 Related Studies in Turkish Culture

Findings on the marital relationship of mothers and fathers of children with cancer, could only be found in one study. Güdek (1999), asked parents if there had been any change in their marital relationship since the diagnosis of their child's cancer. 72% of parents reported change in the marital relationship. This was significantly higher than 2% in the control group, which consisted of parents of children with no chronic illnesses. 2.8% of the parents of children with cancer reported this change to be very bad, 22.2% said it was bad and 75% reported it was better. Considering the percentage of parents who reported change and those who reported that the change was for the better, 52% of parents have reported their relationship has changed for the better after the diagnosis of their children with cancer.

Unfortunately, Güdek (1999) did not mention if there were any gender differences in the percentages reporting the change for better. It might be an area that can be explored further. In the study on not the parents of children with cancer but on the spouses of patients with cancer, Anuk (1997) found that there was a positive correlation between negative evaluation of their spouses and anxiety and depression levels of the female patients whereas no such correlation was found for male patients or the spouses of the patients of both genders. Gender difference has also been found in other populations. For example, Kastro (1998) compared couples with either one of the spouses diagnosed with depression and couples with neither of the spouses diagnosed with depression. The findings suggest that women in both groups evaluated marital adjustment level and affectional expression more negatively than their spouses. On the other hand, Binici (2000) found wives to significantly score lower in the professional help group. There were no significant gender differences in the marital adjustment levels of husbands and wives who did not apply for professional help.

In contrast to the finding of Güdek (1999) suggesting change on a positive direction, Çolak (1992) reported change of family functions in the negative direction at 6 months post-diagnosis in the families of children with leukemia. He did not report such a change at 4 months post-diagnosis. One possible explanation may be critical timing of the study.

In the same study, Çolak (1992) found that state anxiety levels of parents of children with leukemia dropped in time though it still remained higher than that of parents of children with diabetes. On the anxiety levels of parents of hospitalized children, Er (1998) found significant effect of age of the mother with greater anxiety in the families of younger mothers. However no significant effect of child's anxiety levels, type of illness and number of hospitalizations were found.

One of the factors predicting the anxiety level of the parents seems to be lack of information. In a study carried out with mothers of children with acute lymphoblastic leukemia, Yazıcı (1989) noted that 70% of the mothers were uninformed about the treatment. When mothers were informed about the aim of chemotherapy, its necessity, side effects and preventive measures over the course of 5 weeks, their anxiety levels were found to significantly drop in comparison to the control group who were given routine care.

Yağan (2001) studied possible changes in other areas as well as anxiety. Cancer patients' spouses or first degree relatives were found to score significantly higher on state anxiety, depression, paranoid thinking, phobic anxiety, obsessive-compulsive and general psychological symptoms than spouses and first degree relatives of patients with diabetes. Another significant difference was found between somatization levels, depression, obsessive-compulsive and general psychological symptoms of caregivers and relatives and

spouses of cancer patients who are not caregivers. Caregivers also scored significantly higher on state anxiety regardless of the illness of the patient.

Another study on the care-giving spouses was by Babaoğlu (2001). In this study, predictors of psychological and social problems of spouses of terminal cancer patients were investigated. Age of the patient, type of cancer, age, income level, the number of children, duration of marriage, number of people assisting in care-giving and daily duration of care-giving were found to be predicting both social and psychological problems. In addition, time since diagnosis, duration of hospital stay, educational level, occupation and perceived level of emotional sharing with spouse determined the extent of social problems. Additional predictor of extent of social problems was gender. On the other hand, Anuk (1997) found no significant effect of gender on anxiety and depression levels of the spouses.

There are several studies focusing on the effect of illness on family functioning. Bekdemir (1996) found that increasing length of child's stay in hemodialysis, presence of another patient in the family other than the ill child and expressed psychological disorders/problems after the child's disease were negatively correlated with scores on Family Assessment Device with "Affective Involvement" being the most adversely effected sub-scale followed by "Roles" and "Affective Responsiveness".

In another study, Çolak (1992) found communication to be the most affected dimension in the families of children with cancer. When mothers and fathers were evaluated separately, mothers were found to be affected most in the communication dimension and fathers in general functioning. In comparison to parents of children with diabetes, mothers of children with cancer were found to be more affected in problem solving and fathers to be more affected in behavior control and general functioning scores.

Additionally, Sefil (2001) also found that cancer disrupts family functioning by increasing problem behavior in the child and affecting especially problem solving, role allocation, behavior control and general functioning. However, differential effects of child's gender were found. Problem solving, role allocation, expressing affection, behavior control and general functioning were affected in families of boys whereas families of girls were affected in the problem solving and role allocation areas only and they report positive change on expression of affection. The order of birth of the ill child was also found to be effective with second or later child being more disruptive on the family structure.

Erdem (1999) studied the illness-related factors affecting the quality of life of the parents of children with cancer. Quality of life of parents of children with cancer were found to be affected by the stage and length of disease, type of treatment provided, parents' perceptions about disease, parents ' satisfaction with

the knowledge regarding the disease and treatment, differences in family relationships depending on cancer and getting support in coping with cancer. Peykerli (1994) found that first relapse was found to affect both depression and affection in family relations more adversely than the initial diagnosis.

CHAPTER III

METHOD

3.1 The Participants

The sample consisted of 66 mothers and 39 fathers, all of whom were married. These parents' children were either being treated for cancer (n = 71), or their child was once diagnosed with cancer and had come for the regular check-up (n = 34). Participants were recruited from the Pediatric Hematology - Oncology - Immunology Ward of the Ankara University Medical School Hospital (Ankara Üniversitesi Tıp Fakültesi), Pediatric Oncology Ward of the Demetevler Oncology Education and Research Hospital (Demetevler Onkoloji Eğitim ve Araştırma Hastanesi), Pediatric Oncology Out-Patient Clinic of Oncology Hospital in Hacettepe University Medical School and, Hacettepe University İhsan Doğramacı Children's Hospital (Hacettepe Universitesi İhsan Doğramacı Çocuk Hastanesi). Quota sampling (Kumar, 1996) was used as a sampling procedure.

The age of the parents ranged from 20 to 55 (M = 33.6, SD = 6.83) and their spouses' age ranged from 20 to 59 (M = 34.8, SD = 6.85). The length of their marriage ranged from 2 years to 40 years with the mean of 12.1 years (SD = 6.28). The education level of the parents was illiterate (N= 4), literate (N=2), primary school graduate (N= 42), secondary school graduate (N=11), high school graduate (N= 23) and university (N= 23). Twenty-six of the parents were residents of Ankara and 79 came from other cities for treatment.

The age of the mothers ranged from 20 to 55 (M = 31.76, SD = 7.13). The length of their marriage ranged from 2 years to 40 years with the mean of 12.0 years (SD = 6.70). The education level of the mothers was illiterate (N= 3), literate (N=1), primary school graduate (N= 39), secondary school graduate (N=6), high school graduate (N= 9) and university (N= 8).

The age of the fathers ranged from 28 to 48 (M = 36.7, SD = 5.02). The length of their marriage ranged from 3 years to 22 years with the mean of 12.3 years (SD = 5.57). The education level of the mothers was illiterate (N= 1), literate (N=1), primary school graduate (N= 3), secondary school graduate (N=5), high school graduate (N= 14) and university (N= 15).

The mean age of ill children was 6.6 (SD = 4.20) and it ranged from 3 months to 17 years. Forty-six of these children were female and 59 were male. Of the 71 children who were receiving treatment, 55 (24 females, 31 males)

were hospitalized and 16 (6 females, 10 males) received their treatment in the outpatient clinic. Mean age of hospitalized children was 8.1 years (SD = 4.16) and that of children receiving treatment in the outpatient clinic was 4.7 (SD = 3.43). Mean age of children who came in for check-up (16 females and 18 males) was 5.87 (SD = 3.99).

3.2 The Instruments

Dyadic Adjustment Scale (DAS) (Appendix A) was used for measuring marital adjustment. Demographic, Cancer- and Caregiver-Related Data Form (Appendix B) was used for gathering demographic information and information related to the child's diagnosis, treatment and caregiver.

3.2.1 The Dyadic Adjustment Scale (DAS)

The DAS (Spanier, 1976) is used to assess dyadic adjustment of married and cohabiting couples and is one of the most frequently used measures for marital adjustment (Russell & Allgood, 1990). It consists of 32 items, most of which are likert-type with responses from 5 to 6 points. The remaining 2 items are yes/no type questions.

Four factors, namely Dyadic Satisfaction, Dyadic Cohesion, Dyadic Consensus and Affectional Expression emerged as a result of factor analysis. The Cronbach alpha's for the subscales ranges from .73 to .97 and the entire scale has an alpha of .96. The subscales can be used and scored separately. The possible total scores range from 0 to 151 with higher scores indicating a perception of better adjustment in the relationship.

The DAS was translated into Turkish and its reliability and validity studies were carried out by Fışıloğlu and Demir (1997). Alpha coefficient of the Turkish version was .90 and its split half reliability coefficient was .85 with an alpha of .89 for part one and .73 for part two. Construct validity was .82. Factor analysis of the Turkish form yielded the same four factors of the original form.

3.2.2 The Demographic, Cancer- and Caregiver-Related Information Form

The Demographic, Cancer- and Caregiver Related Information Form was formed by the researcher based on related literature and studies and inquired the following demographic information; gender, age, education, marital status of the respondent, age and education of spouse, length of marriage, number, age and gender of children, if there is anyone else living with them, if there is some other person such as a relative that requires their care, city of residence, gender, age and diagnosis of the child with cancer. The cancer- and caregiver-related

information inquired in the form are the diagnosis of the child, if the diagnosis was made suddenly or took some time to be arrived at, when the child received the diagnosis, the reason why they are at the hospital, if the reason is hospital stay, then, how long they have been in the hospital, if someone is staying at the hospital with the child and who and for how long, what kind of treatment the child is receiving now, if the child has been hospitalized for this diagnosis before, if so, how many times and what type of treatment was received, if someone stayed with the child in the previous stays and if so who, if the non-caregiving parent can visit and with what frequency, if their child can meet his/her basic needs such as eating or getting dressed by himself/herself. Then the parents are asked to rate their child's health by giving a number from 1 to 10, 1 being poorest health and 10 being totally healthy and to name who they have received support from in the process of treatment. The parents were also asked about the course of the child's illness: if the child has been constantly getting better or worse or has had ups and downs.

3.3 Procedure

The study was conducted with the parents at the hospital whose children were diagnosed with cancer and are receiving treatment or whose children are in remission and came for the routine check-up. The procedure followed for getting in touch with the parents differed depending on the hospital. In Ankara

University Medical School Hospital, the researcher asked the nurses in the ward which of the patients were diagnosed with cancer. In Demetevler Oncology Hospital, all patients were receiving treatment for cancer so the parents were contacted directly at either the child's room or at the recreation room. In Hacettepe University İhsan Doğramacı Children's Hospital, the researcher was asked to wear a white coat and an ID card enabling access to the wards out of the visitation hours and into the patients' rooms. Mostly the nurses to whom the researcher was introduced prior to the research or the nurses and doctors who got to know about the researcher and the study were asked which patients were diagnosed with cancer. In the cases that that medical staffs were absent, the researcher briefly explained the research and asked about the patients diagnosed with cancer to the available medical staff members. In Hacettepe University Oncology Hospital, Pediatric Oncology Clinic, the researcher directly approached the caregivers in the waiting area.

Once the contact was made with the caregivers, the researcher introduced herself and briefly explained the study and asked the caregiver if they are the parent of the child. If the answer was positive they were asked if they would like to participate in the study. If the parent accepted, effort was made to talk in relatively quiet and private parts of the ward as possible, which was in the most cases the room of the interviewed parent's child. In the cases of the child being in the room, the canteen or the doorway of the room was used. First the Demographic, Cancer- and Caregiver-Related Information Form was

read to the parent and the information was noted down by the researcher. Then the DAS form with identical number on the interview sheet was given to the parent. The parents were asked if they would prefer the questions being read to them. Some parents asked the interviewer to read them the questionnaire since they were illiterate or in some cases they found it too hard to concentrate. In that case, the questionnaire was read aloud and the interviewer marked the answers. If they preferred filling the form on their own, the instructions were explained, and a few questions were reviewed together. Then the parents were asked when it would be possible to get the form back and if there is a possibility their child might be discharged soon.

For getting the DAS forms back, different procedures were followed in different hospitals. If the child was not expected to be discharged in a few days, the researcher asked if it was all right if she picked the form in a few days. If there was a chance that the child might be discharged soon, parents were also given an envelope. They were asked to put the form in the envelope and leave it to the nurse familiar with the study and the researcher (in İhsan Doğramacı Children's Hospital) or the secretary (in Demetevler Oncology Hospital) or if neither is possible, they were asked if there is someone else they could leave the form to such as one of the caregivers in the ward they are close with.

3.4 Analysis of Data

Data were analyzed by using the appropriate programs of the Statistical Package for the Social Sciences (SPSS) (Nie, Hull, Jenkins, Steinbrenner, & Brent, 1975). A correlation matrix was formed for all variables and their subscales to investigate the correlations between each variable of the present study. Four multiple regression analysis were performed. First, DAS was taken as the predicted variable. The variables with significant correlations with the DAS Score were entered into the regression equation. These variables were; education, support from spouse, support from nuclear family, support from extended family and relapse. Then the subscales were taken as predicted variables one by one. Education, length of marriage, and support from nuclear family were entered into the regression equation for Dyadic Consensus. For Dyadic Satisfaction, support from spouse, support from nuclear family, support from extended family and relapse were entered into the equation. Finally, support from spouse, support from nuclear family, support from extended family, relapse and whether the child is receiving treatment now were entered into the regression equation where Dyadic Cohesion was the predicted variable. No regression analysis was performed for the subscale Affectional Expression because only one variable was significantly correlated, which was education.

In addition, to examine the effects of hospitalization, course of the illness, parents being apart, perceived support from spouse and incapacitation on

the DAS Score and the scores on the subscales, Analyses of Variances were performed. Also, to examine the effects of gender, Multivariate Analyses of Covariance was performed with education being the covariate.

CHAPTER IV

RESULTS

In this section, the descriptive statistics of the study variables, the correlation matrixes and the results of the regression analyses are presented.

4.1 Descriptive Statistics of the Study Variables

The mean and the standard deviations of the variables used in the analyses are presented in the following table.

Table 1. Means and Standard Deviations for the Demographic Variables of the Study

	M	SD
Demographic Variables		
Age of the Respondent	33.59	6.83
Length of Marriage	12.09	6.28
Age of Spouse	34.80	6.85
Number of Children	2.31	1.16
Number of People Living in the Same House	4.61	1.49
Age of the Child Diagnosed with Cancer	6.62	4.20

Table 2. Means and Standard Deviations for the Cancer-Related Variables of the Study

	M	SD
Cancer-Related Variables		
Time Since Diagnosis (months)	12.37	15.26
Parental Perception of Child's Health Status	6.36	2.95
Number of Previous Hospitalizations	4.22	6.09
Number of Previous Treatments	1.43	.98

Table 3. Means and Standard Deviations for the Dyadic Adjustment Scale and Subscale Scores

	M	SD
Dyadic Adjustment Scale		
Affectional Expression	54.82	1.70
Dyadic Consensus	39.93	8.07
Dyadic Satisfaction	10.18	5.40
Dyadic Cohesion	14.31	4.19
DAS Score	119.25	14.76

4.2 Predictors of Marital Adjustment in Parents of Children with Cancer

The main goal of this study was to investigate which of the demographic, cancer- and caregiver-related variables predict marital adjustment in parents of children with cancer. To see which variables predict marital adjustment,

Multiple Regression Analysis was carried out. The variables significantly correlating with the DAS were included in the analysis.

Number of previous hospitalizations, relapse and support from spouse were the variables that correlated significantly with the DAS Scores. Pearson correlation coefficients of these variables are presented in Table 4.

Table 4. Pearson Correlations of Variables Significantly Correlated with DAS Scores

	DAS Scores
Number of Previous Hospitalizations	.22*
Relapse	.21*
Support from Spouse	.28**

* p<.05
** p< .001

Multiple regression analysis was carried out with the variables above. The total variance explained by the variables was 14.3% ($F(3,99) = 5.335$, p<.01). Number of previous hospitalizations and support from spouse were the predictors of the DAS Scores (Table 5).

Table 5. Results of Regression Analysis for DAS Scores

Predictor Variables	Beta	t	Partial R	R^2 Change	F Change
Number of Previous Hospitalizations	.21	2.14*	.20	.14	5.34
Relapse	.18	1.86	.18		
Support from Spouse	.21	2.09*	.20		

* p <.05

In order to examine possible differences in the predictors for different subscales, separate regression analyses were also conducted with each subscale except for Affectional Expression Subscale as it did not correlate with any of the variables significantly.

When Pearson correlation coefficients were examined, length of marriage and number of previous hospitalizations were found to be the variables that correlated significantly with the Dyadic Consensus Scores (Table 6).

Table 6. Pearson Correlations of Variables Significantly Correlated with Dyadic Consensus Scores

	Dyadic Consensus
Length of Marriage	.20*
Number of Previous Hospitalizations	.25*

* p<.05

When these variables were entered in the regression, the model explained 8.8% of the variance ($F(2,101) = 4.803$, $p = .01$) and number of previous hospitalizations was the only significant predictor (Table 7).

Table 7. Results of Regression Analysis for Dyadic Consensus Scores

Predictor Variables	Beta	t	Partial R	R^2 Change	F Change
Length of Marriage	.17	1.71	.16	.09	4.80
Number of Previous Hospitalizations	.22	2.21*	.21		

* p<.05

Dyadic Satisfaction was found to correlate significantly with relapse and support from spouse (Table 8).

Table 8. Pearson Correlations of Variables Significantly Correlated with Dyadic Satisfaction Scores

	Dyadic Satisfaction
Relapse	.26**
Support from Spouse	.30**

** p< .001

When the regression analysis was carried out with these variables, both were found to be significant predictors of Dyadic Satisfaction Scores and the variance explained by the model was 12.3% ($F(2,102) = 7.038$, $p = .001$) .

Table 9. Results of Regression Analysis for Dyadic Satisfaction Scores

Predictor Variables	Beta	t	Partial R	R^2 Change	F Change
Relapse	.21	2.22*	.21	.12	7.04
Support from Spouse	.24	2.51*	.24		

* p <.05

Finally, Dyadic Cohesion was correlated significantly with relapse, currently receiving treatment and support from spouse (Table 10).

Table 10. Pearson Correlations of Variables Significantly Correlated with Dyadic Cohesion Scores

	Dyadic Cohesion
Relapse	.21*
Currently receiving Treatment	-.29**
Support from Spouse	.25*

* p<.05
** p< .001

Regression analyses were carried out with the variables in Table 10. Currently receiving treatment and support from spouse were found to predict Dyadic Cohesion. The model explained 15.3% of the variance (F (3,101) = 5.880, p = .001)

Table 11. Results of Regression Analysis for Dyadic Cohesion Scores

Predictor Variables	Beta	t	Partial R	R^2 Change	F Change
Relapse	.10	1.07	.10	.15	5.88
Currently receiving Treatment	-.27	-2.79*	-.26		
Support from Spouse	.21	2.20*	.21		

* p <.05

4.3 Predictors of Marital Adjustment in Parents of Children in Treatment Phase

In order to examine possible differences in the predictors of marital adjustment when only parents of children in the treatment phase are studied, regression analyses were run excluding the parents of the children in remission.

When Pearson correlation coefficients were examined, support from spouse was found to be the only variable that correlated significantly with the

DAS and Dyadic Consensus Scores of parents whose children are in the treatment phase (Table 12). Affectional Expression also correlated significantly with only one variable, which was length of marriage. (Table 13).

Table 12. Pearson Correlations of Support from Spouse and DAS and Dyadic Consensus Scores of Parents of Children in the Treatment Phase

	DAS	Dyadic Consensus
Support from Spouse	.39*	.28*

* p< .05

Table 13. Pearson Correlations of Support of Spouse and Affectional Expression Scores of Parents of Children in the Treatment Phase

	Affectional Expression
Length of Marriage	.23

* p< .05

When Pearson correlation coefficients were examined, relapse and support from spouse were found to be significantly correlated with Dyadic Satisfaction (Table 14).

Table 14. Pearson Correlations of Variables Significantly Correlated with Dyadic Satisfaction Scores of Parents of Children in the Treatment Phase

	Dyadic Satisfaction
Relapse	.30*
Support from Spouse	.41**

* p<.05
** p< .001

When regression analyses was carried out with these variables, the model accounted for 20.6% of the variance (F (2,69) = 8.694, p = .000) and both relapse and support from spouse significantly predicted Dyadic Satisfaction.

Table 15. Results of Regression Analysis for Dyadic Satisfaction Scores of Parents of Children in the Treatment Phase

Predictor Variables	Beta	t	Partial R	R^2 Change	F Change
Relapse	.23	2.04*	.22	.21	8.69
Support from Spouse	.35	3.13*	.34		

* p <.05

Finally, when Pearson correlation coefficients were examined, both parents as caregivers and support from spouse significantly correlated with Dyadic Cohesion (Table 16).

Table 16. Pearson Correlations of Variables Significantly Correlated with Dyadic Cohesion Scores of Parents of Children in the Treatment Phase

	Dyadic Cohesion
Both Parents as Caregivers	.27*
Support from Spouse	.28*

* p<.05

When the variables above were entered into the regression analysis, the model explained 15.8% of the variance (F (2,70) = 6.381, p<.01) and both variables were found to predict Dyadic Cohesion.

Table 17. Results of Regression Analysis for Dyadic Cohesion Scores of Parents of Children in the Treatment Phase

Predictor Variables	Beta	t	Partial R	R^2 Change	F Change
Both Parents as Caregivers	.28	2.60	.28	.16	6.38
Support from Spouse	.29	2.60	.29		

* p <.05

4.4 Effect of Gender on the Marital Adjustment of Parents of Children with Cancer

To examine if there is any gender difference in the Dyadic Adjustment Scale Scores and in the subscales, five one-way analyses of variances were conducted. No effect of gender was found on the marital adjustment of parents of children with cancer on any of the subscales or the total score. $F(1,104) = 1.103$, $p = .296$ for Dyadic Consensus, $F(1,104) = 1.300$, $p = .257$ for Dyadic Satisfaction, $F(1,104) = .134$, $p = .715$ for Affectional Expression, $F(1,104) = .690$, $p = .408$ for Dyadic Cohesion and $F(1,104) = .014$, $p = .905$ for DAS Score. The mean scores for subscales and the DAS Score are presented in Table 18.

Table 18. Mean DAS and Subscale Scores for Males and Females

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Female	66	119.12	55.46	39.47	10.13	14.05
Male	39	119.48	53.75	40.71	10.26	14.75

Considering the differences in education of the mothers and the fathers, analysis of covariance was conducted with education of the respondent as a covariate and gender difference was found in DAS Scores ($F(1,104) = 3.985$,

p<.05), and the subscales Dyadic Satisfaction (F(1,104) = 4.013, p<.05) and Affectional Expression (F(1,104) = 7.065, p<.05).

Table 19. Corrected Mean DAS and Subscale Scores for Males and Females

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Female	66	116.84	53.98	39.01	9.82	14.03
Male	39	123.33	56.25	41.49	10.79	14.80

4.5 Effect of Education of the Respondent on the Marital Adjustment of Parents of Children with Cancer

In order to examine the effect of education of the respondent on the DAS and subscale scores, one-way ANOVAs were conducted with the total and subscale scores. Significant differences were found in the subscales Dyadic Consensus (F(3,104) = 7.051, p =.000) and Affectional Expression (F(3,104) = 6.116, p =.001). Significant difference was also found in DAS Score (F(3,104) = 3.465, p<.05). In order to find the source of difference, post-hoc comparisons were conducted. According to the results of Scheffe, parents with higher education score lower than parents who are primary school graduates or less on DAS and the subscales Dyadic Consensus and Affectional Expression. Secondary and High School graduates did not differ significantly

from either group. The mean scores for DAS and the subscales are presented in Table 20.

Table 20. Mean DAS and Subscale Scores for Education of Respondent

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Primary School Graduate or less	44	123.78	58.09	40.74	10.83	14.91
Secondary School Graduate	16	117.42	54.27	39.57	10.11	14.27
High School Graduate	21	117.14	53.43	39.20	9.40	14.15
Higher Education	24	112.64	49.66	38.97	9.27	14.11

4.6 Effect of Course of Cancer on the Marital Adjustment of Parents of Children with Cancer

To examine any difference in the Dyadic Adjustment Scale and subscale scores of parents whose children's condition is steadily improving and those who are not, one-way ANOVAs were conducted. No difference was found on the DAS Scores ($F(1,91) = 3.445$, $p = .067$) or the subscales ($F(1,91) = .405$, $p = .526$ for Dyadic Satisfaction, $F(1,91) = 1.330$, $p = .252$ for Affectional

Expression and $F(1,91) = 1.223$, $p = .272$ for Dyadic Cohesion), except Dyadic Consensus ($F(1,91) = 4.633$, $p < .05$). The mean scores for the DAS and the subscales are presented in Table 21.

Table 21. Mean DAS and Subscale Scores for Parents Whose Child's Condition is Steadily Improving and Those Who Are Not.

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Steadily Improving	62	117.66	53.76	39.81	9.95	14.14
No Steady Improvement	30	123.62	57.50	40.58	10.37	15.16

To investigate the difference on DAS and its subscales' scores between the parents of children whose condition have not changed, have worsened and parents who are unsure of the child's condition, one-way ANOVAs were conducted. No difference was found between the parents. ($F(2,29) = 1.574$, $p = .226$ for DAS Score, ($F(2,29) = 1.170$, $p = .326$ for Dyadic Consensus, $F(2,29) = .433$, $p = .653$ for Dyadic Satisfaction, $F(2,29) = .692$, $p = .509$ for Affectional Expression and $F(2,29) = .403$, $p = .627$ for Dyadic Cohesion. The mean scores for the DAS and the subscales are presented in Table 22.

Table 22. Mean DAS and Subscale Scores for Parents whose Child's Condition Has Not Changed, Has Worsened and Parents Who are Unsure of the Child's Condition

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
No Change	12	119.12	55.08	39.57	9.97	14.50
Worsened	5	126.61	59.00	41.21	10.55	14.95
Unsure	13	126.62	59.40	41.38	10.89	15.84

4.7 Effect of Incapacitation of the Child with Cancer on the Marital Adjustment of Parents

In order to investigate the differences in the scores of parents whose children are too small to be self-sufficient on, incapacitated and capable on DAS and its subscales, one-way ANOVAs were performed. Significant difference was found in Dyadic Consensus (F(2,96) = 5.409, p <.01) and DAS Score (F(2,96) = 3.671, p <.05) and no difference was found in Affectional Expression (F(2,96) = 1.946, p =.149), Dyadic Satisfaction (F(2,96) = 2.303, p =.106) and Dyadic Cohesion (F(2,96) =1.414, p =.248). In order to find the source of difference, post-hoc comparisons were conducted. According to the results of Scheffe, parents of children who are too small to be self-sufficient scored significantly lower on Dyadic Consensus than parents of both capable and incapacitated children. They also score significantly lower on DAS than

parents of incapacitated children. The mean scores for the DAS and the subscales are presented in Table 23.

Table 23. Mean DAS and Subscale Scores for Parents whose Child is Capable, Incapacitated and Parents whose Child is Too Small to be Self-sufficient

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Capable	39	120.42	55.95	39.02	10.19	15.27
Incapacitated	35	122.57	56.44	39.11	10.44	14.16
Too Small	23	112.25	50.04	41.53	9.57	15.27

4.8 Effect of Reasons for Being at the Hospital on the Marital Adjustment of Parents of Children with Cancer

To examine if there is any difference in the Dyadic Adjustment Scale and subscale scores of parents whose child is hospitalized, is receiving outpatient treatment and is in remission, one-way ANOVAs were conducted. No difference was found on the DAS Scores (F(2,96) = .766, p = .468) or the subscales (F(2,96) = .695, p = .501 for Dyadic Consensus, F(2,96) = .511, p = 602 for Dyadic Satisfaction, F(2,96) = 1.031, p = .361 for Affectional Expression and F(2,96) = 2.093, p = .129 for Dyadic Cohesion). The mean scores for the DAS and the subscales are presented in Table 24.

Table 24. Mean DAS and Subscale Scores for Parents Whose Child is Hospitalized, Receiving Outpatient Treatment and is in Remission

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Hospitalized	55	117.44	54.58	39.52	9.97	13.37
Outpatient Treatment	16	118.16	56.76	40.81	10.67	14.37
In Remission	26	122.60	53.70	39.12	10.03	15.31

4.9 Effect of Time Since Diagnosis on Marital Adjustment

In order to investigate the effect of time since diagnosis on marital adjustment, one-way ANOVAs were performed. Five categories were created for time since diagnosis. The categories were; up to 3 months, up to 6 months, up to 1 year, up to 18 months, and more than 18 months. No significant differences were found in any of the subscales (F (4, 100) = 1401, p =.239 for Dyadic Consensus, F(4, 100) =.037, p =.997) for Dyadic Satisfaction, F(4, 100) = 1.567, p =.189 for Dyadic Cohesion) except for Affectional Expression (F(4, 100) = 3.355, p =.013). There was also no significant effect of time since diagnosis on the DAS Score (F(4, 100) = .576, p =.681)

Table 25. Mean DAS and Subscale Scores for the Categories of Time Since Diagnosis

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
Up to 3 months	24	119,4549	54,8611	40,0974	10,6909	10,1811
Up to 6 months	16	114,1912	50,8685	39,5059	8,8607	13,8055
Up to 1 year	32	120,2460	56,6711	40,0500	10,3718	14,9561
Up to 18 moths	14	119,9786	54,8675	39,7737	10,3410	13,1531
More than 18 months	19	121,0328	54,9612	40,0064	10,2099	14,9964

4.10 Effect of Suddenness of Diagnosis on Marital Adjustment of Parents of Children with Cancer

To examine the effect of suddenness of diagnosis on the marital adjustment, one-way ANOVA's were conducted. There was no significant difference between the two groups in any of the subscales (F (1, 92) = .618, p =.434 for Dyadic Consensus, F(1,92) =.447, p =.505) for Dyadic Satisfaction, F(1, 92) = .166, p =.684 for Affectional Expression, F(1, 92) = 1.534, p =.219 for Dyadic Cohesion) or the DAS Scores (F(1, 92) = .144, p =.705).

Another set of ANOVA's were performed with the parents of children who were diagnosed up to 3 months ago, considering the possibility

that the effect of suddenness of diagnosis might wear off with passage of time. However, even in that group, no differences were found between parents whose children were diagnosed in a short period of time and those who were not in any of the subscales F (1, 20) = .550, p =.467 for Dyadic Consensus, F(1, 20) = .383, p=.543 for Dyadic Satisfaction, F(1, 20) = .781, p =.387 for Affectional Expression, F(1, 20) = .328, p =.573 for Dyadic Cohesion) or the DAS Score (F(1, 20) = .444, p =.513).

Table 26. Mean DAS and Subscale Scores of Parents Whose Children were Diagnosed Suddenly and Those Who Were Not

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
All Parents						
Sudden	59	118,5948	53,9984	39,6678	10,0752	14,8534
Not sudden	35	119,8269	55,3817	40,4627	10,2229	13,7596
Up to 3 Months						
Sudden	12	122,5510	56,8868	41,0000	10,3179	14,3463
Not sudden	10	117,3923	53,7025	39,3338	10,9383	13,4176

4.11 Effect of Perceived Health Status of the Ill Child on Marital Adjustment

In order to investigate the effect of perceived health status of the ill child on marital adjustment, one-way ANOVAs were performed. Four categories were created for time since diagnosis. The categories were; 1-3 points, 4-6 points, 7-9 points and 10 points. No significant differences were found in any of the subscales (F (3, 59) = .432, p =.731 for Dyadic Consensus, F(3, 59) =.807, p =.495) for Dyadic Satisfaction, F(3, 59) = .309, p =.819 for Affectional Expression, F (3, 59) = .009, p =.999 Dyadic Cohesion). There was also no significant effect of time since diagnosis on the DAS Score (F(3, 59) = .576, p =.681)

Table 27. Mean DAS and Subscale Scores for the Categories of Perceived Health Status

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
1-3 points	5	124,5549	57,2000	42,8000	9,9549	14,6000
4-6 points	16	121,5593	55,8303	41,0158	10,4859	14,2273
7-9 points	24	119,1353	55,4385	39,1829	10,2134	14,3005
10 points	18	118,9223	53,4975	40,6215	10,5213	14,2820

4.12 Effect of Spousal Support on the Marital Adjustment of the Parents of Children with Cancer

To examine any difference in the Dyadic Adjustment Scale and subscale scores of parents who report support from their spouses and those who do not, one-way ANOVAs were conducted. No difference was found on the subscales Dyadic Consensus (F(1, 103) = 3.861, p = .052) and Affectional Expression (F(1, 103) = .007, p = .932). However, there were significant differences in the subscales Dyadic Satisfaction (F(1, 103) = 10.234, p = .002) and Dyadic Cohesion (F(1, 103) = 6.883, p = .010). Support from spouse was found to have an effect on the DAS Scores as well (F(1, 103) = 9.041, p = .003). The mean scores for the DAS and the subscales are presented in Table 25.

Table 28. Mean DAS and Subscale Scores for Parents Who Report and Do Not Report Spousal Support

	n	DAS	Dyadic Consensus	Dyadic Satisfaction	Affectional Expression	Dyadic Cohesion
No support	44	114.34	53.02	38.03	10.20	13.08
Spousal support	61	122.79	56.12	41.30	10.17	15.20

CHAPTER V

DISCUSSION

The main goal of the study was to investigate the predictors of marital adjustment in parents of children with cancer. The variables examined were; cancer- related, caregiver-related and demographic variables.

The other goals were to investigate whether;

- different variables predict marital adjustment of the parents of children in the treatment phase
- females score lower on DAS than males
- parents with higher education will score lower on the DAS than parents with lower education
- parents of children getting better steadily score higher on DAS than parents of children who are not and parents of children who do not know
- parents of children who are incapacitated by cancer thus require constant care, children who do not and children who require care because of their age score differently on DAS

- parents of children who are at the hospital for different reasons score differently on DAS

5.1 General Evaluation of the Results

The main aim of the study was to identify which variables predict marital adjustment in parents of children with cancer. Number of previous hospitalizations and support from spouse were the only variables to do so. The correlation between marital adjustment and number of previous hospitalizations was positive. When only parents of children in treatment are included, number of previous hospitalization does not predict marital adjustment anymore. This finding was unexpected.

Barbarin et al. (1985) suggested that for husbands marital quality is related with the amount of time his spouse spends at home as opposed to the time she spends at the hospital, whereas for wives, marital quality is related to 'their husband's active involvement in the children's medical care and to their husband's seeking information about the illness and its treatment" (p. 478). Based on this study, it was expected that for both mothers and fathers, marital adjustment would be negatively correlated with the number of previous hospitalizations. One possible explanation could be that since number of previous hospitalizations increases as the time since diagnosis does, the increase

in marital adjustment could actually be due to increasing adaptation to living with the illness. Another possible explanation is, since worse parental perceptions of the child's health status and worse course of illness is associated with increased number of hospitalizations, survival of the child may be "assigned a higher priority by the couple than expressing or resolving their marital conflict" (p.478) (Barbarin et al., 1985).

The parents of hospitalized children were expected to score lower on DAS than the children receiving treatment in the outpatient clinics and children in remission since hospitalization involves longer time spent away from home, however, no significant differences were found between any of the groups. This may partly be due to the under-representation of the fathers who are not caregivers. Since those are the ones to report decreased marital quality when number of hospitalizations increase, under-representation of them may have masked the effect. Taking the findings discussed above in account as well, it could also be that parents in the Turkish culture could have different expectations from their spouses than the parents mentioned by Barbarin et al. (1985).

As for the gender difference, no gender difference was found initially. However, when the variables were examined, fathers were found to have significantly higher education levels than mothers. Since higher education was related with lower marital satisfaction (Taanila et al., 1996), level of education

was predicted to be a confounding factor. When education was controlled for, gender difference emerged as expected.

An interesting finding on the effect of education on marital adjustment emerged in comparison to the findings of Taanila et al.(1996). Parents who are primary school graduates or less had significantly higher marital adjustment than parents with higher education. The secondary and high school graduates did not significantly from either group. However, as Taanila et al. found this effect on marital satisfaction, Dyadic Satisfaction was expected to be significantly different in low and high education groups. No such effect was found for Dyadic Satisfaction. Instead, Affectional Expression and Dyadic Consensus were the subscales to show significant differences.

The course of cancer did not differentiate between the DAS or the subscale scores of the parents of children who steadily got better and who did not, except for Dyadic Consensus. Interestingly, Dyadic Consensus scores of parents whose child is getting steadily better was lower than parents whose child is not. This again may be due to the survival of the child getting a higher priority or attention than the marital relationship.

Hilbert et al. (2000) reported that extent of incapacitation did not have a significant effect on the negative aspects of caregiving. Also, Wallander, Pitt, and Mellins (1990) reported no relation between child functional independence

and mothers' adaptation. However, in this study, significant differences were found in the subscale Dyadic Consensus with parents of children too small to be self-sufficient scoring significantly lower than parents of both incapacitated and capable children. A more unexpected difference was found in the DAS Scores. Parents of incapacitated children had higher marital adjustments than parents of children who are too small to be self-sufficient whereas parents of capable children did not. When the three groups were examined, differences in age, length of marriage, ages of the oldest and smallest child, and age of the ill child were found. However, when controlled for those differences, the significant effect of incapacitation still remained.

Marital relationship of parents of children with chronic illnesses has been a controversial topic. In their review article, Sabbeth and Leventhal (1984) have concluded that parents of children with chronic illness do not tend to divorce more than parents of healthy children do. However, they suggest that in comparison with parents of healthy children, parents of children with chronic illness experience higher levels of marital distress. In support of their view, Lansky, Cairns, Hassanein, Wehr and Lowman (1978). found a divorce rate of 1.19% for parents of children with cancer which was slightly lower than 2.03% for divorce rates of married couples with children and Hoekstra-Weebers and Jaspers et al (1998) found increased levels of marital dissatisfaction in the year following the diagnosis of cancer with no gender difference in levels of

dissatisfaction and they found psychological distress to be the only predictor of dissatisfaction.

However, Eddy and Walker (1999) found no difference in terms of marital quality and stability between parents of children with chronic illness and healthy children. Quittner, Espelage, Opipaari, Carter and Nemr Eigen (1998) also found parents of children with cystic fibrosis do not differ significantly in marital satisfaction than parents of healthy children. Katz and Krulik (1999) suggest that despite fathers of children with chronic illness experienced a greater number of life events and reported lower self-esteem than parents of healthy children, the two groups did not differ on their marital satisfaction.

In this study, mean DAS Score of parents was 119.25 (SD =14.76). It is higher than the mean of the sample of Fışıloğlu and Demir (2000) which was 104.5 (SD =18.6). The means for mothers was 119.12 and for fathers it was 119.48 in this study as opposed to 103.7 for males and 105.2 for females in the study mentioned. This can be explained as "... if spouses can be responsive to each other in these situations, such a crisis can strengthen the couple's bond" (Walker et al., 1996, p.1033). Supporting this view, Taanila et al. (1996) have also reported 20% of the parents with a disabled child claimed the child's disability to have contributed positively to their marriage. This finding is also supported by Barbarin, Hughes and Chesler (1985) who noted that majority of the parents reported no change or change in a positive direction regarding their

feelings toward each other and that "their spouses had been a significant source of support during difficult times" (p. 478) and by Chesney and Chesler (1996) who noted that 56% of the parents reported having handled the illness "very well".

5.2 Implications of the Study

The findings of the study has implications in both research and practice of psychologists and other professionals in the health care field. First of all, these findings suggest that marriages are indeed resilient. Not only did the marriages stay intact, but they seem to have improved. Therefore, in working with parents of children with cancer, the marital relationship could be an important strength to draw upon. Also, given the scores parents of children with cancer scored on the DAS, further studies on the strengths and resiliences of these parents could be carried out including concepts such as post traumatic growth since studies on the negative effetcs of having a child with chronic illness (such as anxiety, depression, marital dissatisfaction and instability) seem to be disproportionately abundant in the literature on families of children with chronic illnesses

Secondly, the findings of the study partially support the view of Rolland (1996) that psychosocial typology is more important than the medical diagnosis

in our understanding of psychosocial effects of illnesses and that even the same medical diagnosis can have different effects on different families or family members. In this study, number of previous hospitalizations was found to significantly predict marital adjustment in parents of children with cancer, significant differences were found among Dyadic Consensus Scores of parents whose child is getting steadily better and those who are not, also among Dyadic Consensus and DAS scores of parents of incapacitated children and children who are too small to be self-sufficient. Additionally, significant effects of time since diagnosis was observed on the subscale Affectional Expression. However, no significant effects of reason for being at the hospital, onset and perceived health status of the child could be found. There may be two possible explanations; these factors may be more influential on the individual well-being of the parents than their marital relationship, or there may be moderator or mediator factors that were not measured in this study that determine the effect onset, perceived health status of the child and reason for being in the hospital have on the marital adjustment of the parents. In the future studies, possible mediator or moderator variables could be investigated.

Finally, Sabbeth and Leventhal (1984) note that "…only limited areas of marital adjustment actually have been explored in a systematic fashion" (p.766) and that "areas of marital adjustment to chronic childhood illness other than divorce and distress have been virtually ignored"(p.767). When DAS Scores are reported, usually only the total score is reported and studies examining the

subscales separately are few (eg: Baker et al., 2000; Martinez, 1996; Kolchakian & Hill, 2002) in the literature. However, different predictors for the subscales or different factors affecting the subscales could lead to different patterns of relationships between the variables which in effect could be useful in practice in specifying and targeting the problem areas.

5.3 Limitations of the Study and Suggestions for the Future Research

There were a number of limitations of this study. First limitation is the lack of information on social security and the financial state of the parents. Since financial burden, and negative effects of the illness on parental employment and finance were found to be the sources of distress in parents of children with cancer (Patistea et al., 2000; Sloper, 1996), it might be an important factor to control for.

Another limitation of the study was the imbalanced representation of the parents of children with cancer. The parents who refused to participate in this study, in most of the cases, were parents of children who had either been diagnosed recently or whose condition requires constant attention. Therefore the parents of children who were at the terminal stage or who just got diagnosed are not represented. It is also suspected that parents with higher distress tend to refuse participation more than parents who are not as much distressed. For this

reason, the findings may not generalize to rest of the parents of children with cancer and the DAS Scores may be elevated.

Thirdly, information on perceived health status of the child, incapacitation, caregiving conditions and source of support were gathered by the Demographic, Illness- and Caregiver Information Form in either single or few number of questions because of the researcher's concern not to overburden the parents with numerous and lengthy questionnaires and to ensure a better return rate. However, use of separate standardized measures such as the Child Health Questionnaire (CHQ) (Raat, Bonsel, Essink-Bot, Landgraf and Gemke, 2002) and The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Farlem, Zimet and Farley, 1988) may yield more detailed information in those areas.

Finally, information of biopsies performed and the child being neutropenic (low blood count) were not included in the data gathered. Especially neutropenic state of the child could be frustrating for parents since the child can not receive treatment for cancer until the condition is cleared out first and the child has to stay in the hospital for an indefinite time.

As for the suggestions for the future research, in addition to the suggestions above, investigating the cancer-related variables as moderators might be more appropriate in the future as none of the illness-related variables

predicted marital adjustment except number of previous hospitalizations and since factors such as time since diagnosis and support were found to significantly effect psychological well-being of the parents of children with cancer.

Secondly, though support from spouse predicted marital adjustment of the parents of children with cancer and was the only variable to significantly correlate with the marital adjustment of parents whose child is currently in treatment, it is not clear what kind and how much support is meant. Future studies could look into defining this support and what constitutes support for different genders.

Finally, this study could be replicated with other chronic childhood illnesses enabling comparisons between diseases. This would enhance our understanding on the applicability of psychosocial typology of illness and the differential factors that affect the marital relationships of parents of children with different illnesses, conversely, it may lead to few factors common in all or many illnesses. Either way, it would yield us valuable information both for practice and for theory.

5.5 Conclusions of the Study

The only predictors for parents of children with cancer were number of previous hospitalizations and support from spouse. Consistent with the literature, there was a gender difference in the marital adjustment of the parents with the mothers' being lower than the fathers' when controlled for education. There was also significant difference in education with parents with higher education having lower marital adjustment than parents with lower education. The course of cancer only affected Dyadic consensus with parents of children who are steadily getting better having lower marital adjustment than parents whose child is not getting better steadily. There was also a significant effect of incapacitation on the marital adjustment of parents. Parents of children too small to be self-sufficient had significantly lower marital adjustment than parents of incapacitated children, whereas parents of capable children did not differ from either group. Finally, there was no difference in marital adjustment of the parents of hospitalized children, children receiving treatment in the outpatient clinics and children in remission.

This study was -to the researcher's knowledge - the first to have investigated such an extensive number of cancer-related variables in predicting the marital adjustment of the parents of children with cancer. With the increasing incidence rates for childhood cancer, the need for research and understanding on the effects of childhood cancer on the child, the parents and

the family is growing. This study aimed to contribute to this growing need and hopefully has, despite its limitations.

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APPENDICES

APPENDIX A

ÇİFTLER UYUM ÖLÇEĞİ

Örnek Maddeler:

1- Ne sıklıkta boşanmayı, ayrılmayı ya da ilişkinizi bitirmeyi düşünür ya da tartışırsınız?

2-Eşinize güvenir misiniz?

3- Siz ve eşiniz ev dışı etkinliklerinizin ne kadarına birlikte katılırsınız?

Aşağıdaki olaylar siz ve eşiniz arasında ne sıklıkla geçer?

1- Birlikte gülmek.....

2. Birşeyi sakince tartışmak.....

Yazışma Adresi: Doç. Dr Hürol Fışıloğlu, Ortadoğu Teknik Üniversitesi Psikoloji Bölümü, Ankara

APPENDIX B

DEMOGRAPHIC AND CANCER-RELATED DATA FORM

Bilgi Toplama Formu

YER: *(görüşmenin yapıldığı hastane, servis)*

Adınız, Soyadınız:

Cinsiyetiniz:

Kadın Erkek

Kaç yaşındasınız?

Eğitiminiz:

Okur-yazar değil Okur-yazar İlkokul

Ortaokul Lise Üniversite

Medeni durumunuz: *(Evli misiniz?)*

Evli Dul Boşanmış

Kaç yıldır?

Eşiniz kaç yaşında?

Eğitimi:

Okur-yazar değil Okur-yazar İlkokul

Ortaokul Lise Üniversite

Nerede yaşıyorsunuz?

Kaç çocuğunuz var? Yaşları? Hangileri sizinle yaşıyor?

1.

2.

3.

4.

5.

Sizinle yaşamakta olan başka kimse var mı? *(Evde sizinle beraber yaşayan başka biri var mı? Siz, eşiniz, çocuklar...?)*

Sizin sürekli bakımınızı gerektiren bir rahatsızlığı/engeli olan var mı?

(Sizinle yaşamasa da sürekli baktığınız, ilgilenmeniz gereken birileri var mı?)

Tedavi görmekte olan çocuğunuzun;

Cinsiyeti: Kız Erkek **Yaşı:**

(Bu bilgiler daha önce çocuklarıyla ilgili bölümde alındıysa bir daha sorulmadı)

Çocuğunuzun aldığı tanı: *(Çocuğunuz hangi tanıyla tedavi görüyor?)*

Tanıyı alışı:

ani oldu

bir sürecin sonunda oldu *(Bir süre birşeyler ters gitti ama ne olduğu anlaşılamadı...)*

Tanıyı ne zaman aldı?

(Genelde bir önceki soruda tanı süreci anlatılırken bu sorunun cevabı verilmiş olduğundan bu soru tekrar sorulmadan cevabı not edildi)

Tanıyla ilgili ne dediler? Bir yüzde veya zaman verdiler mi?

(Bu soru Demetevler Onkoloji Hastanesindeki anne-babaların çoğunun sorulmadan bahsetmesi üzerine forma eklendi, fakat Hacettepe Üniversitesi Tıp Fakültesi Onkoloji Hastanesi'ndeki uygulama için uygun olmadığı gerekçesiyle ikinci kısmı çıkarılarak "Size tanıyla ilgili ne dediler? Size tanısıyla ilgili ne gibi bir açıklama yapıldı?" şeklinde değiştirildi.)

Aldığı başka bir tanı, tedavi görmekte olduğu başka bir rahatsızlığı var mı?

Bugün burada olma sebebiniz: Hastane yatışı

Ayakta Tedavi

Kontrol

Diğer (belirtiniz)

<u>*sebep hastane yatışı ise:*</u>

ne zamandan beri: _____

yanında biri kalıyor mu? kalıyorsa; kim? ne sıklıkta?

Şu anda görmekte olduğu tedavi:

Kemoterapi Radyoterapi Ameliyat

Diğer (belirtiniz)

Çocuğunuz daha önce aynı tanıyla veya bu rahatsızlıktan kaynaklanan sorunlardan dolayı hastanede yattı mı?

Yattıysa; kaç kez? _____

Ne kadar süre ile?

Ne tedavisi için?

Kemoterapi Radyoterapi Ameliyat Diğer

Onunla bu dönemde biri kaldı mı?

Kaldıysa, kim? _____

Ne sıklıkta, ne kadar süre ile? _____

Annesi/ Babası ziyarete gelebiliyor mu?

Ne sıklıkta? *(Ayda bir, haftada bir, her gün…?)*

Lütfen çocuğunuzun şu anki durumuna *en uygun* olanı seçiniz.

(Çocuğunuz kendi ihtiyaçlarını karşılayabiliyor mu? Yoksa bazıları için sizin yardımınız gerekiyor mu?)

Kendi ihtiyaçlarını kendisi rahatlıkla karşılayabiliyor.

Kendi ihtiyaçlarını karşılayabiliyor fakat çabuk yoruluyor.

Bazı ihtiyaçlarını karşılamak için yardıma ihtiyaç duyuyor.

[ ] yemek/içmek

[ ] giyinmek

[ ] tuvalet

[ ] yıkanmak

[ ] mobilite... merdivenlerden inip çıkmak, yürümek, tekerlekli sandalye

(İhsan Doğramacı Çocuk Hastanesi'nde dördüncü madde olarak "kendi ihtiyaçlarını karşılamak için yaşı küçük" eklendi)

Çocuğunuzun genel sağlık durumunu *1 çok sağlıksız 10 tamamen sağlıklı* olmak üzere 1 ile 10 arasında bir sayı vererek değerlendiriniz. ____

(Bu soru genellikle net anlaşılmadı. Bu durumda anne-babalara önce "Çocuğunuzun sağlık durumunu soracak olsam, bana ne derdiniz? İyi, çok iyi, çok kötü, şöyle böyle..." sorusu soruldu. Buna verdikleri cevaba göre bir sayı önerildi, örneğin "şöyle böyle diyorsunuz, yani on üzerinden beş-altı gibi mi, yoksa daha iyiye mi yakın dersiniz, mesela sekiz gibi ya da kötüye yakın, 3 gibi?". Bu şekilde açıklama yapıldığında genellikle bir sayı alınabildi. Fakat bu örnekten sonra da "bilmiyorum" diyen anne babaların formunda bu madde boş bırakıldı.)

Seyir:

(Çocuğunuz tedavi görmeye başladıktan sonra sürekli iyileşti ya da kötüleşti mi, bir iyileşti,bir kötüleşti mi, yoksa durumu hiç değişmedi mi?- Bazı anne-babaların "ne zamandır sonuçları almıyoruz, haftaya çıkacak sonuçlar, o zaman bileceğiz kitle küçülmüş mü yayılmış mı"şeklinde cevap vermeleri üzerine anne-babalara okunmamakla birlikte, bu seçeneklere ek olarak, "bilmiyorum" seçeneği olası cevaplara eklendi.)

Destek: Eş

Akraba

Anne-baba

Arkadaş

Kattaki diğer anne-babalar

Doktor/hemşire

Diğer