

RESEARCH ARTICLE

Hopelessness and Depression Levels of Parents of Children with Cancer

Melahat Akgun Kostak*, Gulcan Avci

Abstract

The purpose of this descriptive study was to determine the hopelessness and depression levels of parents of children diagnosed with cancer and undergoing cancer treatment and factors affecting these levels. The study was carried out with parents of 44 children receiving treatment in a paediatric haematology clinic of a university hospital. Data were collected using a survey form, the Beck Hopelessness Scale (BHS) and the Beck Depression Scale (BDS). The mean BDS score of the mothers and fathers was 18.3 ± 11.30 and 15.2 ± 11.33 , respectively. The mean BHS score of the mothers was 6.45 ± 4.40 , whereas the mean BHS score of the fathers was 5.88 ± 4.27 . The results showed that the levels of hopelessness and depression among the mothers were higher than among the fathers ($p < 0.001$). There was a positive relationship between the hopelessness and depression scores of the mothers and the fathers ($p < 0.05$), and the levels of hopelessness and depression scores of the fathers increased as those of the mothers increased. A weak financial situation of the family increased the hopelessness and depression levels of the fathers. The hopelessness and depression levels of the mothers who were supported by their families and relatives were decreased compared to those without such support ($p < 0.05$). The results show that the parents of children with cancer face many psychosocial and spiritual problems. Using simple screening tools, nurses can identify at-risk parents and direct them to support services. We conclude that actively encouraging families to avail themselves of support resources and supporting them financially would positively affect the levels of depression and hopelessness of parents of children with cancer.

Keywords: Child with cancer - mother - father - depression - hopelessness - support

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Introduction

Cancer may lead to mental disorders and serious compliance problems in families while leading to physical and psychological stresses in children (Han, 2003; Fotiadou et al., 2008; Klassen et al., 2011). Compliance must be good to deal with problems related to the disease and to enable successful treatment (Han, 2003). Although cancer is a chronic disease, advancements in health care technology, prolonged periods of remission and relapse and increased survival times of children with cancer mean that the importance of compliance has increased, as well as the importance of the parents and children in the treatment process (Mu et al., 2001; Han, 2003).

Chronic disease in a child affects all aspects of family life and every member of the family (Al-Gamal and Long, 2010; Ozono et al., 2010; Peek and Melnyk, 2010; Çavuşoglu, 2013). In particular, families of children diagnosed with cancer are confronted with severe trauma (Norberg and Boman, 2008; Björk et al., 2009; Fayed et al., 2011; Klassen et al., 2011). Social relationships, daily routines of families and the work status of parents are negatively affected in such cases (Fotiadou et al., 2008;

Elcigil and Conk, 2010; Ozono et al., 2010; Klassen et al., 2011). A diagnosis of cancer results in feelings of intense fear and despair, both by the child and their family (Cernvall et al., 2013). Parents and siblings of a child with a chronic disease have been reported to be affected spiritually (Wijnberg-Williams et al., 2006a; Baykan, 2010). Studies have reported increased levels of depression, anxiety and hopelessness in children with cancer and in their parents and siblings (Çavuşoglu, 2001; Mu et al., 2001; Toros et al., 2002; Barrera et al., 2003; Hung et al., 2004; Norberg et al., 2005; Wijnberg-Williams et al., 2006a; Bayat et al., 2008). The levels of depression and anxiety of children with cancer and their parents were higher than those of children with another chronic disease and healthy children, and the levels of depression and anxiety of mothers were higher than those of fathers in a study conducted in Turkey (Toros et al., 2002; Tuna et al., 2012). Another study reported that parents of children with cancer experienced a higher level of stress than the parents of children with disabilities (Hung et al., 2004). Baykan et al. (2010) found that the life satisfaction of parents of children with a chronic disease was low, and Çavuşoglu, (2001) found that the levels of depression were higher

¹Department of Nursing, Faculty of Health Sciences, ²Clinic of Pediatrics, Faculty of Medicine, Trakya University, Edirne, Turkey
*For correspondence: akgunmel@yahoo.com

among children with cancer than among healthy children.

Hope is the expectation that good things will happen in the future rather than bad things. Hope is an important variable for families to cope with stress and achieve positive health outcomes (Folkman, 2010). Hope is very important for the psychosocial adjustment of the parents of children with cancer (Fotaidou et al., 2008; Folkman, 2010). However, the role/effect of hope in the caregiving provided by mothers and fathers of chronically ill children has not been thoroughly addressed in the literature (Fotaidou et al., 2008; Fayed, 2011). Some studies suggested that optimistic/hopeful parents adjust themselves better to stresses, such as cancer, that they experience less depression and that the adjustment of the parents affects treatment-related morbidity, quality of life and treatment outcomes (Han, 2003; Foitadou et al., 2008; Fayed, 2011).

The most important source of support for children with cancer is their families. However, the majority of the research regarding the effect of chronic disease on the family has focused on mothers and the relationship between the mother and child (Han, 2003). Studies conducted in Turkey mostly focus on mothers because they are the primary caregivers and are responsible for taking care of the child and taking the child to hospital, (Öztürk et al., 2005; Elçigil and Conk, 2010). Research on how having a child with a chronic disease affects fathers in Turkey is limited, and there is little information on (Öztürk et al., 2005; Elçigil and Conk, 2010; Tuna et al., 2012).

Parents' levels of depression and hopelessness negatively affect their ability to meet the complex health care requirements of a child with cancer. They also affect the child's adjustment to the diagnosis and the treatment of the disease and the child's social, emotional and behavioural adaptation (Fotaidou et al., 2008; Peek and Melnyk, 2010). Paediatric oncology nurses have an important role in determining parents at risk of mental disorders. Early determination of at-risk parents and the provision of consultancy and support to such parents are important for the adjustment of the children and the parents. To ensure timely and appropriate care, the levels of depression and hopelessness, in addition to the contributing factors, must be identified. The purpose of the study was to determine the hopelessness and depression levels of the parents of children diagnosed with cancer and undergoing cancer treatment and the factors affecting these levels. The study addressed the following questions: Is there a statistically significant relationship between the hopelessness and depression levels of the parents and personal characteristics (age, marital status, education level, family type, employment status, income level, sources of support, having information about the disease etc.)? Is there a statistically significant relationship between the hopelessness and depression levels of the parents (age, gender, year of illness, disease stage etc.) and the child's characteristics (age, gender, year of illness, disease stage etc.)? Is there a statistically significant relationship between the hopelessness and depression levels of the fathers and the mothers?

Materials and Methods

Design and sample

This descriptive and cross-sectional study was performed at a university hospital in Edirne, Turkey. The study was carried out between January and June 2011 with the parents of 44 children who volunteered to participate in the study. The children were undergoing treatment in the hospital's paediatric haematology clinic (a total of 88 parents, 44 mothers and 44 fathers).

Ethical considerations

Permission from the Ethics Committee of the Medical Faculty of Trakya University and the institution where the study was conducted were obtained prior to the study. Parents were informed about the study, and their verbal consent was obtained.

Data collection tools

The data were collected using a survey form, the Beck Hopelessness Scale (BHS) and the Beck Depression Scale (BDS).

Survey form: The survey form was developed by the researchers in line with the literature (McCaffrey, 2006; Norberg and Boman, 2008; Fayed et al., 2011; Klassen et al., 2011; Çavuşoğlu, 2013). The survey form consisted of 24 questions. Fifteen of the questions referred to the demographic characteristics of the parents and the children (age, gender, education level, economic status, employment status, family type, place of residence, number of children, number of siblings etc.), and nine of the questions centred on aspects of the child's disease (diagnosis, stage, age of diagnosis, received information about the disease, support resources etc.).

Beck Depression Scale (BDS): A quadruple Likert-type scale consisting of 21 questions was used to measure the severity of symptoms associated with depression. Each question was scored between 0 and 3, and the total score ranged from 0 to 63. The cut-off score of the scale was determined as 17 in the Turkish validity and reliability study (Hisli, 1989). The scale was classified as follows: a score of 0-10 denoted no depression, a score of 11-17 denoted a mild level of depression, a score of 18-23 signified a moderate level of depression, and a score of 24 and above denoted a severe level of depression. The Cronbach's alpha validity coefficient of the scale in the study of Hisli et al. (1989) was 0.75. The Cronbach's alpha validity coefficient was 0.90 for mothers and 0.92 for fathers.

Beck Hopelessness Scale (BHS) This scale was used to determine the hopelessness levels of the parents. The validity and reliability study of the scale was performed by Seber, (1993). It consists of 20 questions, which are scored from 0 to 1. Individuals can score between 0 and 20 on this scale. It is assumed that the hopelessness level of an individual is high when the scores on the scale are high. A score of 0 to 3 indicates a minimal level of hopelessness, 4-8 a low level of hopelessness, 9-14 a moderate level of hopelessness and 15 and above a high level of hopelessness. Seber et al. (1993) found the Cronbach's alpha validity coefficient of the scale was 0.86. The Cronbach's alpha validity coefficient was 0.84 in this study.

Data collection

The survey form and the scales were completed by the researchers during face-to-face interviews separately with the mothers and /fathers in a room. It took 15-20 minutes to fill in the form.

Statistical analysis

The data obtained were analysed using SPSS 11.0 (Statistical Package for Social Science for Windows) package program. Descriptive statistics of the parents' and children's demographic characteristics (age, gender, education level, economic status, employment status, family type, place of residence, number of children, number of siblings etc.), children's characteristics associated with the disease (diagnosis, stage, age of diagnosis, received information about the disease, receiving support etc.) and the results of the BDS and BHS scores were calculated. Relations between the children's and parents' socio-demographic and clinical characteristics and the results of the BDS and BHS were analysed using the Student's t-test, the Mann-Whitney U test, the One-Way Anova and Kruskal-Wallis variance analysis. Pearson's correlation coefficient (r) was used to document the relationship between the mothers' and fathers' scores of the BDS and BHS. A value of $p < 0.05$ was considered statistically significant.

Results

The mean age of the mothers and fathers participating in the study was 33.3 ± 5.8 and 36.9 ± 5.2 years, respectively. The mean age of the children diagnosed with cancer was 8.1 ± 3.9 years, the mean age at the time of diagnosis was 6.3 ± 4.2 years, the mean duration of the disease was 1.9 ± 1.4 years, and half of the children were female (54.5%). The majority of the children (61.4%) were diagnosed with ALL (acute lymphoblastic leukemia), and 59.1% were receiving chemotherapy. Among the families, 65.9% were middle income, and 22.7% were low income. A total of 90.9% of the parents stated they were informed about the disease, 68.2% said they had adequate knowledge about their child's disease, and 63.6% said they had access to support resources (Table 1).

The results showed that 36.4% of the mothers and 25.0% of the fathers in the study group had symptoms of severe depression, 18.2% of the mothers and 4.5% of the fathers had symptoms of moderate depression and 11.4% of the mothers and 6.8% of the fathers had a high level of hopelessness, 9.1% of the mothers and 13.6% of the fathers had a moderate level of hopelessness. The

depression scores of the mothers (54.6%) and those of the fathers (29.5%) were higher than their cut-off scores.

The mean BDS score of the parents was 16.75 ± 11.37 , and the mean BHS score was 6.17 ± 4.32 . The mean BDS score of the mothers and the fathers was 18.34 ± 11.30 and 15.15 ± 11.33 , respectively. The mean BHS score of the mothers was 6.45 ± 4.40 , and it was 5.88 ± 4.27 for the fathers. A statistically significant difference was found between the levels of hopelessness and depression of the mothers and the levels of hopelessness and depression of the fathers ($p < 0.001$). The levels of hopelessness and depression of the mothers were higher than those of the fathers (Table 2).

There was a statistically significant positive correlation between the hopelessness ($r = 0.483$, $p = 0.001$) and

Table 1. Characteristics of the Parents (44 Mothers, 44 Fathers)

Characteristics	n (%)
Mother's age, year (mean \pm SS*)	33.3 \pm 5.8
Father's age, year (mean \pm SS*)	36.9 \pm 5.9
Mother's educational level	
Elementary school	18 (40.9)
Middle school	7 (15.9)
High school	13 (29.5)
University	2 (4.5)
Mother's employment status	
Employed	5 (11.4)
Unemployed/housewife	39 (88.6)
Father's educational level	
Elementary school	14 (31.8)
Middle school	11 (25.0)
High school	12 (27.3)
University	5 (11.4)
Father's employment status	
Employed	41 (93.1)
Unemployed	3 (6.9)
Family type	
Elementary	36 (81.8)
Extended	8 (18.2)
Family's economic status	
Low	10 (22.7)
Middle	29 (65.9)
High	5 (11.4)
Family's place of residence	
Inner-city	19 (43.2)
Upstate	25 (56.8)
Received information about the disease	
Yes	40 (90.9)
No	4 (9.1)
Level of information on the disease	
Comprehensive	30 (68.2)
Not comprehensive	14 (31.8)
Support resources available	
Yes	28 (63.6)
No	16 (36.4)

*Mean \pm SS: mean \pm standard deviation

Table 2. Comparison of the BDS and BHS Scores of the Mothers and Fathers

	Mother X \pm SS	Father X \pm SS	p
BDS	18.34 \pm 11.30	15.15 \pm 11.33	<0.001*
BHS	6.45 \pm 4.40	5.88 \pm 4.27	<0.001*

*t-test

Table 3. Correlation (Spearman) Coefficients between the Mothers' and Fathers' BDS and BHS Scores and the Significance (p) Levels of the Variables

Variables	Mother BDS		Mother BHS		Father BDS		Father BHS	
	r _s	p	r _s	p	r _s	p	r _s	p
Mother BDS	-	-	0.641	<0.001	0.349	0.020	-	-
Mother BHS	-	-	-	-	-	-	0.483	0.001
Father BDS	-	-	-	-	-	-	0.589	<0.001
Father BHS	-	-	-	-	-	-	-	-
Time elapsed since diagnosis	-0.062	0.688	-0.283	0.063	0.031	0.843	-0.092	0.551

Table 4. Comparison of the Mothers' and Fathers' BHS and BDS Scores According to Specific Characteristics

Characteristics		Mother	Father	Mother	Father
		BHS (Mean±SD)*	BHS (Mean±SD)	BDS (Mean±SD)	BDS (Mean±SD)
Economic status	High	5.20±6.09	3.00±2.82	16.40±11.58	3.40±1.51
	Middle	6.51±4.25	5.10±2.87	16.68±10.79	15.03±10.70
	Low	6.90±4.30	9.60±6.0	24.10±11.88	21.40±11.67
	p	0.350**	0.017**	0.304**	0.003**
Support resources	Yes	5.42±3.83	5.10±3.68	16.71±10.51	14.03±11.38
	No	8.25±4.86	7.25±4.97	21.18±12.41	17.12±11.33
	p	0.036 [†]	0.122 [†]	0.183 [†]	0.328 [†]
Received information about the disease	Yes	6.20±4.33	5.52±3.86	18.12±11.80	15.22±11.29
	No	9.0±4.83	9.50±6.95	20.50±3.69	14.50±13.52
	p	0.152 [†]	0.192 [†]	0.953 [†]	0.798 [†]

*Average±standard deviation, **Kruskal-Wallis variance analysis, [†]Mann Whitney U variance analysis

depression ($r=0.349$, $p=0.020$) scores of the parents. The level of hopelessness of the fathers increased as the level of hopelessness of the mothers increased, and the level of depression of the fathers increased as the level of depression of the mothers increased (Table 3). There was a statistically significant positive correlation between the scores of hopelessness and depression of the mothers ($r=0.641$, $p<0.001$). The levels of depression of the mothers increased as their hopelessness levels increased. There was a statistically significant positive correlation between the scores of hopelessness and depression of the fathers ($r=0.589$; $p<0.001$). The levels of depression of the fathers increased as their hopelessness levels increased (Table 3).

A statistically significant difference was found between the financial status of the family and the scores for hopelessness ($p=0.017$) and depression ($p=0.003$) of the fathers. There was a significant difference between the depression scores of the fathers with a middle level of financial income ($p=0.001$) and the depression scores of the fathers with a low level of income ($p=0.003$). There was a difference between the hopelessness scores of the fathers with a high level of income and with a low level of income ($p=0.040$) and between those of the fathers with a middle level of income and with a low level of income ($p=0.026$) (Table 4).

There was a statistically significant difference between the hopelessness scores of the mothers who stated that they were supported by their families and relatives and the mothers who stated otherwise ($p=0.036$) (Table 4). The hopelessness scores of the mothers who stated that they had support resources during the disease were low compared to those who did not have such support.

The age, gender, disease stage (treatment/remission) of the child, time elapsed from diagnosis, parents' ages, total number of children in the family, educational level and availability of disease-related information did not affect the levels of depression and hopelessness of the parents ($p>0.05$) in this study.

Discussion

Depression and hopelessness are the most common psychological problem encountered in families for children with cancer, and affect the child's adjustment to

the diagnosis and treatment of cancer. The results indicated that mothers' and fathers' depression and hopelessness were more strongly related to each other. The mean BDS score of the parents was 16.75 ± 11.37 , and the mean BHS score was 6.17 ± 4.32 in this study. The average BDS score of the mothers (54.6%) was higher than the cut-off score. Half of the mothers and one-third of the fathers had moderate-to-severe symptoms of depression, and about one-fifth of the mother and fathers experienced a moderate-to-severe level of hopelessness. A study conducted in Turkey reported that 11.7% of parents with children with a malignant and chronic disease had moderate symptoms of depression and that 9% had severe symptoms of depression (Tuna et al., 2012). The same study found that 20.7% experienced a moderate level of hopelessness and that 6.3% experienced a high level. The higher levels of depression and hopelessness in this study may be due to it including only parents of children with a malignant disease. Sloper, (2000) reported that 51% of mothers and 40% of fathers of children with cancer experienced a high level of sadness, and Rocha-Garcia et al. (2003) reported that 47.1% of families experienced grief and only 51% of them were hopeful. Elçigil and Conk, (2010) reported in their qualitative study that parents experienced a very high of stress upon hearing that their child had cancer and that mothers in particular were incapable of fulfilling their social activities, and their social relations decreased. Klassen et al. (2011) reported that parents experienced depression after their children received a diagnosis of cancer. They also found that the depression affected their abilities to cope with daily routines and that they took drugs to enable them to cope. Hope is very important to cope with stress and achieve positive health outcomes. Physical well-being and lower levels of depression and anxiety are among the characteristics of hopeful/optimistic individuals. One study reported that optimistic mothers of hospitalized children experience less stress and that they are more active and use effective coping strategies in the early period of hospitalization (Fayed et al., 2011). Nurses should be aware of the grief experienced by families, and parents should be provided with supportive initiatives to maintain their hopes and beliefs and to cope with depression.

In the current study, the BDS and BHS levels of the mothers were higher than the levels of the fathers.

Similarly, the BDS levels of mothers of children with cancer and another chronic disease were higher than the levels of fathers in another study conducted in Turkey (Toros et al., 2002). Two other studies also reported that the levels of depression of mothers were higher than those of fathers and that mothers felt more anxiety than fathers (Winjberg-Williams et al., 2006a; 2006b). Lawoko and Soares, (2002) also found that the levels of hopelessness and depression of mothers of children with a chronic disease were higher than those of fathers. Essen et al. (2004) found the quality of life levels of fathers were higher than those of mothers. In common with the results of the previous studies, the current study also found that mothers have a greater risk than fathers of negative psychosocial outcomes. According to Norberg and Boman, (2007), among family members, mothers appear to be the closer than fathers to their children, and they assume more responsibility for the care of the chronically ill child. Thus, they experience more depression and hopelessness. Mothers get little respite from caregiving because they are always with their chronically ill child, both at hospital and at home. In contrast, fathers, who must continue to work to uphold their financial responsibilities, receive support from external resources (e.g. work colleagues, other family members), so they experience less depression and hopelessness.

This study discovered that the level of hopelessness of the fathers increased as the level of hopelessness of the mothers increased, and the level of depression of the fathers increased as the level of depression of the mothers increased. Similarly, the levels of depression and hopelessness of mothers and fathers of a child with cancer were also found to be similar in another two studies conducted in Turkey (Bayat et al., 2008, Tuna et al., 2012). Al-Gamal and Long, (2010) also reported that the levels of grief of mothers and fathers were similar. Overall, there is consensus that fathers' lives are significantly affected by the chronic disease of a child, regardless of the extent to which they contribute to the child's care (Norberg and Boman, 2008; Çavuşoğlu, 2013). In this study, the levels of depression and hopelessness of the fathers were lower than those of the mothers. Nevertheless, 25.0% of the fathers had severe symptoms of depression, and their depression score (29.5%) was higher than the cut-off score.

In this study, the levels of depression increased as the levels of hopelessness of the mothers and fathers increased. Similarly, Bayat et al. (2008) reported a positive relation between the levels of parents' depression and hopelessness. Another study reported a negative relation between hope and anxiety and depression (Fotiadou et al., 2008).

In this study, the levels of hopelessness and depression were increased among the fathers with low income. A previous study reported that low-income families of a child with a chronic disease experience more grief than families with a higher level of income (Al-Gamal and Long, 2010). Rocha-Garcia et al. (2003) reported that 78.4% of families with a child with cancer face financial distress and that this prevents them using effective coping strategies. Thus, the disease places a greater burden on families. As traditional Turkish families have a patriarchal family structure, it is

the man's responsibility to take care of familial needs. Women are usually housewives in the patriarchal family structure. They do not work outside the home or may not be permitted to do so. In this study, only 10% of the mothers were employed, and the women were responsible for taking care of their children. The fathers were solely responsible for shouldering the economic burden of the family. Therefore, it is inevitable that the economic status of the family affects the levels of hopelessness and depression of the father.

A diagnosis of cancer in a child and the sequelae of the disease cause families to have a depressed perspective on life and to view the disease in negative terms. It is important to provide mothers and fathers with social support to help them to cope with the disease. Such support can act as an important buffer against stress. In this study, the levels of hopelessness of mothers who said they received support from their families and relatives were lower than those who did not have this type of support. Similarly, other studies found a positive correlation between hope and social support and a negative correlation between social support and depression (Norberg and Boman, 2007; Fotiadou et al., 2008). Studies have also shown a positive correlation between perceived social support and adaptation to a disease (Barrera et al., 2003; Han, 2003). In one study, parents of children with cancer reported that they received support from their families and health care staff but that the greatest support was provided by their spouses (Tuna et al., 2012). Wijnberg-Williams et al. (2006a) found that mothers tend to receive support from their families and friends and that fathers tend to receive support from their male friends and work colleagues. Al-Gamal and Long, (2010) found that social support has a positive impact on coping with cancer experience. Sloper, (2000) reported that familial cooperation is a very important source of support for mothers and fathers. The same study found that mothers receive support from other parents and health care staff during the time they spend in hospital but that working fathers cannot avail of such support because they are not in the hospital. Sloper, (2000) also noted that fathers of a chronically ill child are deprived of the support of their spouses during this period. As noted in a previous study, supporting families during cancer treatment can reduce the arduous and exhausting burden placed on parents (Björk et al., 2004). For this reason, nurses should ensure that parents have social support, and families should be provided with access to psychosocial care.

In conclusion, the current study found that the levels of hopelessness and depression of mothers are higher than those of fathers. The levels of hopelessness and depression of fathers are associated with the economic status of the family. Furthermore, the levels of hopelessness of mothers who receive support from families and relatives are lower than those who do not receive such support. Health care professionals should identify parents at risk for mental disorders (those with a poor economic status, inadequate social support) at an early stage and encourage them to obtain professional care and treatment services. Nurses, in particular, are well placed to do this because they spend a great deal of time with the families during the

lengthy period of the child's illness and are responsible for providing the child with holistic care. Putting families in touch with support services and ensuring they receive financial support can help to reduce the levels of depression and hopelessness of the parents of a chronically ill child.

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