

Maternal Distress Among Jordanian Mothers Caring for Children with Cancer in Jordan

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Abstract

Objectives: The purpose of this study was to investigate the psychological and mental health among the Jordanian mothers caring for children with cancer.

Material and Methods: A descriptive correlational design utilized to collect data from 37 women caring for their children who are diagnosed with cancer.

Results: The analysis revealed that mothers of children with cancer had a moderate level of depression and stress, and a severe level of anxiety. There was significant correlation among the three variables ($r > .80$, $p < .001$). Anxiety level was significantly different in relation to marital status ($F_{1,4} = 4.37$, $p = 0.007$). Only 38% of the children know their illness. The results also showed that there is a negative and significant correlation between the level of child's knowledge about his illness and stress (BTAU= $-.29$, $p = .03$) and anxiety (BTAU= $-.34$, $p = .01$).

Conclusion: The study infers that mothers of children with cancer are suffering multiple psychological and mental health problems. Informing children with cancer about their illness appeared to be a significant contributor in lowering the children's anxiety level. Thus, health care professional should collaborate to enhance information exchange and target mothers of children with cancer in their psychosocial programs that will reflect positively on the psychological status of the mothers and children diagnosed with cancer. The study also concludes that mental health counseling for mothers and children diagnosed with cancer is an essential component of the quality of health care that requires more attention in research and practice.

Keywords: Anxiety, Cancer, Children, Depression, Maternal Stress.

(*J Med J 2010; Vol. 44 (4):404-412*)

Received

August 2, 2009

Accepted

February 22, 2010

Introduction

Despite the great improved outcomes of cancer treatment over the past three decades, children

with cancer and their parents continue to experience significant distress throughout the course of diagnosis and illness, and beyond.

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One of the issues emerged in the literature of pediatric psychology is the experiences of mothers caring for children with cancer and the duration and consequences of their distress through their child's course of treatment.

Several investigations have examined self-reported parental distress immediately or after the child's cancer diagnosis. The average follow-up assessments among studies ranged from 6 to 20 months postdiagnosis.¹⁻⁵ Some of these studies have indicated high symptomatic levels of distress during the initial two to eight weeks of cancer treatment and declining in the levels of distress as treatment progresses at twelve to twenty months post cancer diagnosis. Other investigations, however, have suggested that parental distress following cancer diagnosis remains stable or mildly decreases over the course of therapy (e.g., 3-6 months, 6-18 months).²

Perhaps, of greater importance than the duration of elevated distress among parents of children with cancer, is whether and how such elevations are associated with clinical and psychosocial problems. For example, several qualitative studies of families impacted by childhood cancer suggested that parents are concerned about role strain during active treatment.⁶⁻⁷ The results of these studies suggested that parents were concerned about the impact of cancer diagnosis and treatment on their parenting behavior. Consistently, investigations using quantitative self-report measures have also supported these concerns. Previous studies showed that a 7-year follow up investigation revealed that parents of children with cancer or other illnesses indicated were more lax, more overprotective, and less emotionally responsive to their children than were parents of healthy children.⁸⁻¹⁰ Therefore, the literature emphasized the role of childhood illness on the psychosocial and mental wellbeing among parents. The need for such investigations is still a priority in the developing countries that lack the evidence-based research and indices that examine the parenthood experience of children illness. Thus, this study came to address this issue among the Jordanian mothers. Particularly, this study examined the psychological and

mental health among Jordanian mothers with children diagnosed with cancer.

Review of Literature

The literature provides some evidence that there is an improvement in clinical outcomes in relation to parents' experience during their children's diagnosis and treatment of the disease. However, parent and children's distress has been found to be positively associated, and mothers of children with cancer experienced more internalizing difficulties than parents of healthy children which may leave children with cancer more vulnerable to internalizing difficulties.^{1, 11} In addition, studies found that about 95% of families coping with pediatric cancer report some symptoms of distress, and parents who experienced high levels of distress were less able to help their children cope with the treatments of cancer.¹² While Sloper⁵ and Robinson et al.¹³ found strong association and evidence of high level of distress among parent of children with cancer, Hoven, Emma et al.¹⁴ reported that parents in the complicated cancer category significantly had higher disease-related fear, anxiety, depression, loss of control, late effects-related uncertainty, and poor self-esteem compared to parents of children with acute lymphoblastic leukemia.

The level of distress experienced by mothers after the children's diagnosis had an influence on later psychological adjustment of the children. This is due to the impact of maternal distress on the capacity of mothers to care for their children during the treatment course.

The impact of an ill child extends to the whole family and affects the wellness of family members. The entire family's normal life and activities are disturbed when there is a life-threatening diagnosis of a child with cancer, which impose stressors of varying duration, predictability and impact.^{12,15-18}

Previous literature on parent adjustment capabilities vary depending on the stage of illness of their child. Anxiety is elevated at diagnosis but declines for most parents as treatment is initiated,

and family members accommodate to the new situation by time. Studies found that parents of children with newly diagnosed or in active cancer therapy reported higher levels of anxiety than parents of children off active cancer therapy, in remission, or parents whose child has relapsed.¹⁹⁻²¹

However, the impact of children's illness seems to be different among parents in relation to the gender of the caring parent. A study found that depression and anxiety levels are higher among mothers than fathers with children with cancer.²²

Another issue rose here, is that the occurrence of one psychosocial disturbance may contribute to and affect positively the occurrence of another psychosocial problem.

Bayat et al.²³ found a positive relationship between depression, hopelessness, and state and trait anxiety scores for both mothers and fathers. Also, they found a negative relationship between social support and depression scores and between hopelessness and social support scores. Depressive symptoms reported for parents of children with cancer may include feelings of hopelessness, guilt, helplessness, decreased energy and insomnia¹⁹⁻²¹, and those symptoms were found to be at high levels shortly after the child's diagnosis with cancer.^{21, 24-26}

In Jordan, no previous study examined this issue, and little research was found discussing the children illness and its impact on the family life. Therefore, it's a research priority in Jordan to address the effect of children's illness on their mothers' psychosocial well being. The *purpose* of this study was to investigate the psychological and mental health among the Jordanian mothers caring for children with cancer. The research questions were:

1. What is the psychological and mental health status of Jordanian mothers caring for children with cancer?
2. Is there a relationship between the child's knowledge about his/her cancer diagnoses and their mothers' psychological and mental health status?

Methods

Design: This is a descriptive correlational study conducted in Amman, Jordan. Data were collected using a semi-structured self report questionnaire. After obtaining ethical approval from the Scholarship and Research Committee at the Faculty of Nursing, the research team (PI and research associate) first met the women whose children were diagnosed with cancer. The researchers described the study and explained the purpose of the study, answered women's questions and assured confidentiality of the study and that participants' rights are protected. Researchers requested women's participation and informed them that they will be asked questions related to their psychosocial and mental health status. A description of the study was provided. The questionnaires were administered at the hospitals where their children are admitted and are receiving healthcare. About 15 minutes were required to fill out the survey. The researchers explained and read the instructions prior filling the survey. Upon signing the consent form, the survey was filled using a semi-structured interview. A total number of 37 women agreed to participate in the study during the designed period of the data collected that lasted for three months.

Sample and Setting: A total of 37 women agreed to participate in the study. The inclusion criteria were: 1) women who have a child diagnosed with cancer. No exclusion criteria were identified to enhance variability of the collected data and participation. Confidentiality was maintained and data were kept in a closed cabinet at the Faculty of Nursing, University of Jordan.

Instrumentation: For the purpose of this study, the instrument was translated into the Arabic language. All original norms were applied for the translated scales. A translation and back translation were carried out by linguistic professionals, and a pilot testing of the instrument was carried out to check for understanding, clarity, and the time required for filling the questionnaire.

The Depression, Anxiety, Stress Scale (DASS-42) was used to measure depressive symptoms, anxiety and stress among mothers with children diagnosed with cancer. DASS-42 is a self-report inventory of 42-items that was designed to measure factors of depression, anxiety, and stress in individuals during negative emotional state.²⁷⁻²⁸ Each sub-scale contains 14 items, divided into subscales of 2-5 items with similar content. Mothers were asked to rate their answers using the Likert scale of 4 points ranging from 0 (not applied to me) to 3 (applied to me). The depression sub-scale measures the domains of dysphoria, hopelessness, and devaluation of life, self-depreciation, and lack of interest/involvement, anhedonia, and inertia. The sub-scale of anxiety measures the domains of autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The stress sub-scale measures the domains of difficulty in relaxing, nervous arousal, and being easily upset/ agitated/ irritable/ over-reactive and impatient.

Potential Covariates: Age, family history of cancer, place of living, her child's sex, age, medical diagnosis, time since diagnosis, type of treatment, and if the child knows about his diagnosis with cancer.

Data Analysis: Data were screened and examined for patterns of missing values. Depressive symptoms, stress and anxiety were described by using the central tendency measures (means, and medians) and the dispersion measures (standard deviation and ranges). Pearson correlation coefficient (r) was used to examine the relationship between Depressive symptoms, stress and anxiety. Chi-square is used to examine the differences in relation to demographic factors.

Results

Demographic Characteristics: The total number of participants in the study was 37 mothers and their 37 children. About 57% (n= 21) of their children were males and 43 % (n = 16) were females. The mean age for their children was 11.2 years (SD= 2.6). About 47% (n= 17) of their children were diagnosed with Acute Lymphocytic Leukemia (ALL), 10.8% (n= 4) were diagnosed with brain tumor, 10.8% (n= 4) were diagnosed with osteosarcoma, and 8.1 % (n= 3) were diagnosed with Acute Myelocytic leukemia. The time since diagnoses of the children ranged from 0 (less than a month) to 30 months (mean= 12.5 months, SD= 9.0). In addition, 80% (n= 30) of the children are receiving chemotherapy and 16% (n= 6) are just taking medication.

These data were normally distributed (Kolmogorov-Smirnov Z= 0.632, p = 0.819 for the depression subscales, Kolmogorov-Smirnov Z= 1.128, p = 0.157 for the anxiety subscales, and Kolmogorov-Smirnov Z= 0.807, p = 0.533 for the stress subscales), and were all analyzed parametrically.

Mothers' Psychological and Mental Health Status

As shown in table (1), mothers have a moderate to severe level of psychosocial disturbances. The analysis showed that mothers have a moderate level of stress (mean= 22.5, SD= 10.1), moderate level of depression (mean = 18.4, SD= 11.2), and high level of anxiety (mean= 16.2, SD= 9). The mothers' scores indicate that they tend to be at higher marginal level of the stress and depression sub-scales. Moreover, the analysis showed that 34% (n= 14), 39% (n= 15), and 45% (n= 17) of the mothers have a severe level of stress, depression and anxiety, respectively. This indicates that the larger proportion of women is either moderately or severely suffering from psychosocial disturbances represented by stress, anxiety and depression. The high score and the severe positive skewness of the distributions infer that women are experiencing a psychosocial consequences related to their children illness.

Table (1): Psychosocial Status of Mothers with Children Diagnosed with Cancer (N= 37).

Variable	Mean	SD	P25	P75	Range		Implication of scores
					Min	Max	
Stress	22.5	10.1	15.3	32.0	2	39	Moderate
Depression	18.4	11.2	9.3	27.8	1	40	Moderate
Anxiety	16.2	9.1	10.0	23.3	2	36	Severe

In addition, and through examining the correlation among the three major variables; stress, depression and anxiety, the analysis showed that there is a significant and positive correlation among the three variables. Stress had strong and positive correlation with depression ($r = .90, p < .001$) and anxiety ($r = .80, p < .001$). Also, depression had a strong and positive correlation with anxiety ($r = .85, p < .001$). This indicates that the mother who has a high level of anxiety is more likely to have a high level of stress and depression. The results infer that mothers' experiences of caring of their children who are diagnosed with cancer seem to affect their psychosocial stability and wellness. The analysis showed high levels and correlation among stress, depression and anxiety which indicates that mothers' abilities to manage their children's illness is compromised, and therefore, they were unable to maintain their psychological and mental functioning and wellness.

The analysis also showed that illness group; number of children and young people in the home, and gender of the child were not significantly correlated with the mothers' self-reported measures of anxiety, depression and stress. The Analysis of Variance (ANOVA) also indicated that the mothers' level of distress did not differ by disclosure of cancer diagnosis to the children. The only significant association was between mother's level of anxiety and mother's marital status ($F_{1,4} = 4.37, p = 0.007$).

Relationship between Mothers' Psychological Health and their Children's Illness

As shown in table (2), families tend not to be honest and clear about the child's diagnosis of cancer with their children. The analysis showed that only 37.9% (n= 13) of the children know everything about their illness including diagnosis and treatment while 24.4% (n= 8) know that they are sick with tumor and nothing more than that.

Table (2): Level of Child's Knowledge about His Diagnosis (N = 37).

Variable	N	%
Everything including his diagnosis and treatment	13	37.8
Knows that he has virus in the blood	6	16.0
Knows that he has anemia	1	2.7
Knows that he is sick with just or a mass	8	24.3
Knows that his lymph nodes or glands are affected	2	5.4
Knows that he has kidney stones	1	2.7
Nothing at all	6	16.0

This would question the correlation between mother's psychological status and level of knowledge her child has about his illness. Using Mann-Whitney U test, the analysis showed that there is no significant difference in mothers' stress, depression, and anxiety level in relation to child's knowledge about his illness (yes versus no). However, using Kendall's tau b (BTAU) (see table 3) to examine the correlation between the child's level of knowledge and mother' level of stress, depression and anxiety, the analysis

showed that there is a negative and significant correlation between the level of child's knowledge about his illness and stress (BTAU = $-.29, p = .03$) and anxiety (BTAU = $-.34, p = .01$); whereas the relationship with depression was not statistically significant. This indicates that mothers with children who don't know their illness have a higher level of stress and anxiety than among mothers who have children who accurately know about their illness. The results infer that mothers' stress and anxiety are high

when their children know nothing about their illness. One explanation is that mothers might suffer and develop maladaptive techniques while providing care for their children that resulted in increasing their level of anxiety and stress. Although the correlations were significant, the magnitudes were low that may affect the clinical implication of the results. Regarding other demographic data, the analysis showed that there was no significant correlation between the age of the child, time since child's diagnosis, and mother's level of stress, anxiety and depression. Moreover, the level of stress, anxiety and depression was not statistically different in relation to child's gender, type of treatment that the child receives, and child's diagnosis.

Table (3): Correlation among Child's Knowledge about His Illness and Mothers' Level of Stress, Anxiety and Depression (N= 37).

<u>Variable</u>	<u>Kendall's tau-b</u>	<u>P-value</u>
Knowledge X Stress	.29	.03
X Depression	.23	.08
X Anxiety	.34	.01

Discussion

The study aimed at exploring the psychological and mental health status of women caring for their children with cancer. The study results showed that mothers have a moderate to severe level of psychosocial disturbances; a moderate level of depression and stress and a severe level of anxiety. The results correspond with previous international studies which showed that parents of children diagnosed with cancer usually experienced feelings of sadness, worry, loneliness, and distress.^{2,5,27} Feelings of despair and hopelessness and fear of the unknown can induce anxiety and depression among parents. This eventually will increase parents' sense of helplessness and interferes with their coping.

In this study, significant correlations were found among stress, depression and anxiety which indicates that the mothers' abilities to manage their children's illness is compromised, and therefore, it can be hypothesized that mothers were unable to maintain their psychological and mental functioning and wellness.

Some parents tried to protect their children by hiding their cancer diagnosis. Most parents told their child only about the diagnosis and treatment, but not when there is poor prognosis. Earlier studies suggested that families who talk with their children about the diagnosis, recurrences of disease, and death were those who already openly discussed the arrangement of matters within the family.²⁸ In this study, few mothers used an open approach to communicate cancer diagnosis with their children and this may be associated with the mothers being unable to face the reality of their child's disease. Indeed, their reluctance to talk openly with their children about their cancer diagnosis may be influenced by parents' difficulty in coping with the disease and therefore the mothers' stress and anxiety were high when their children knew nothing about their cancer diagnosis. On the other hand, another explanation could be that mothers might suffer and develop maladaptive techniques while providing care for their children that resulted in increasing their level of anxiety and stress.

Conclusion

The study has an implication for health professionals concerned about women's and children's health. The study found that mothers of children with cancer are suffering multiple psychological and mental health problems. This may affect the mothers' ability to manage illness-related stressors and perform their role as primary care givers for their children. Moderate to high level of depression, stress and anxiety will compromise the women coping capacity. No significant difference in mothers' level of stress, depression, and anxiety was found in relation to the child's knowledge about his/her illness. However, a higher level of anxiety and stress was found among mothers of children who have not told their children about their diagnosis.

The study implies that nurses working with families caring for children with cancer have to consider the possible psychological and mental health issues for those patients and their families beside their physical health. Following this ongoing assessment, nurses and other health professionals have to emphasize the role strain

that caregivers, here are the mothers, have during their caring experience. Caregivers are in need to have psychological and mental health care, and their psychosocial concerns have to be addressed during their children health care plans. Health care systems have to reorganize and modify care plans to include caregivers, especially mothers of sick children, in the treatment plan and their concerns have to be followed up after discharge. It's an urgent need to establish an interdisciplinary coalition among the Jordanian health care institution to address caregivers' psychological and mental health status, particularly mothers caring for children diagnosed with cancer.

One limitation of the study is that the study did not have adequate information about the demographics of mothers and thus a study that includes essential information about the mothers will be more informative in this area and will enable a better understanding in relation to differences in the level of stress and depression in regards to mothers and children demographics.

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الضغوط النفسية لدى الأمهات الأردنيات اللواتي يقدمن العناية لأطفالهن المصابين بداء السرطان

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الملخص: يُعدّ مرض سرطان الأطفال من الأمراض التي تؤثر في الأسرة في جميع نواحي الحياة، وهذه الدراسة تركز على مدى تأثير المرض في الأمهات من النواحي النفسية والعقلية، وفي مدى معرفة الطفل بمرضه وتأثيره في حالة أمه النفسية والصحية.

الهدف: تهدف هذه الدراسة إلى تعرّف مدى تأثير مرض سرطان الاطفال في الحالة الصحية والنفسية والعقلية للأمهات الأردنيات اللواتي يقدمن العناية لأطفالهن المصابين بالسرطان.

طريقة البحث: تم أخذ عينة تتكون من (37) أمّاً ممن عندهن أطفال مصابون بالسرطان، وذلك باستخدام العلاقة الوصفية بين المتغيرات.

النتائج: أشارت النتائج إلى وجود مستوى متوسط من الاكتئاب والضغط النفسي عند الأمهات، ومستوى حاد من القلق، كما وجدت علاقة إيجابية بين المتغيرات الثلاثة، كما تبين أن 38% من الأطفال كانوا على علم بتشخيصهم المرضي الذي أوجد علاقة سلبية مع درجة القلق والضغط النفسي لدى الأمهات.

الختامة: خلصت الدراسة إلى أن الأمهات اللواتي عندهن أطفال مصابون بمرض السرطان يعانون من مشكلات نفسية. لذلك يجب على المؤسسات الصحية أن تركز على النواحي النفسية للأمهات الأطفال المرضى، خاصة للأمهات الأطفال المصابين بالسرطان.

الكلمات الدالة: سرطان الأطفال، الامهات، القلق، الاكتئاب، التوتر النفسي.