

## Experiences of Jordanian Mothers and Fathers of Children with Cancer

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**Abstract:** Previous studies investigating psychological stress of parents of a child with cancer have shown inconsistent findings about parental perceived stress whose children have cancer and most of these studies were established in Western communities (with none in the Arab world). Additionally, the majority of published research focused on mothers. Therefore, the aim of this study is to explore perceived stress in mothers and fathers (couples) parenting a child with cancer in Jordan. Such an exploration may contribute to the existing literature and improve overall family survivorship experiences following childhood cancer in Jordan. This qualitative study used semi-structured interviews of 12 mothers and 12 fathers parenting a child with cancer in Jordan. Parents of children of various cancer diagnoses were interviewed and the ages of children were between six months and 14 years. Most mothers admitted that being with the ill child most of the time and therefore away from other healthy children, relatives and friends was the main cause of stress. However, most fathers said that employment status and financial burden were their main causes of stress after their child's health status. Most of the interviewed couples commented that they were sharing the life situation with their partners, helping and supporting each other to overcome the challenges. Results of this study highlight the importance of recognizing the psychological needs of Jordanian mothers and fathers of a child with cancer not only at the time of diagnosis but also during the cancer journey.

[Ahmad Saifan, Rami Masa'Deh, Carol Hall, Jacqueline Collier. **Experiences of Jordanian Mothers and Fathers of Children with Cancer.** *J Am Sci* 2014;10(8):29-39]. (ISSN: 1545-1003). <http://www.jofamericanscience.org>. 4

**Keywords:** mother; father; parent; child; cancer; stress

### Introduction

The life-threatening nature of childhood cancer and its invasive treatment present both practical and emotional stresses for family members (Warner, et al., 2011). The sources of such distress are varied and a number of potential stressors have been suggested. For example, it was suggested that parents are psychologically affected by their child's diagnosis of cancer (Norberg, Lindblad, & Boman, 2006). Reviewed studies found that parents may live with uncertainty about the effectiveness and side-effects of the treatment (Eiser & Upton, 2007). Parents might have to change their roles and responsibilities inside the family unit taking into consideration the requirements of the new situation (Rajajee, Ezhilarasi, & Indumathi, 2007). Additionally, the burden of care during the treatment phase can result in detrimental effects on employment and financial difficulties (Miedema, Easley, Fortin, Hamilton, & Mathews, 2008).

It is well acknowledged that mothers and fathers of children with cancer have also been found to have different stressors and different levels of perceived stress (Dockerty, Skegg, & Williams, 2003). For example, mothers of a child with cancer reported higher levels of anxiety and were reported to be at higher risk of post-traumatic stress disorder than fathers (Bayat, Erdem, & Gul Kuzucu, 2008; Kazak,

Boeving, Alderfer, Hwang, & Reilly, 2005). This can be explained by the findings of Yeh (2002) who highlighted a cultural aspect to the consideration of stress perception and suggested that the difference of stress among gender may be because expressing stress is more socially acceptable for women than for men. This also is further supported by many studies investigated parental experiences when having a child with cancer which report that the cultural background of the parents has an effect on their stress levels when caring for a child with cancer (Bozo, Anahar, Ates, & Etel, 2010; Johns, et al., 2009). In Jordanian culture, it has been reported that fathers are usually responsible for financial status of the family while mothers are mainly responsible for housework and care for their children (Jordanian Higher Council for Youth, 2009). These social-based gender roles may have an impact on how Jordanian parents may react when caring for a child with cancer.

Although culture, religion and the nature of marital relationship between couples are very important factors affecting how parents of children with cancer respond to stress, understanding parental stress of mothers and fathers of a child with cancer in an Arab Muslim community has not been a focus of research, as most of the published studies in this field were conducted in Western countries. The role of religious practices in improving healthcare outcomes

was investigated by Astrow, Puchalski, & Sulmasy (2001). Allowing patients and their relatives to practice their religious and spiritual beliefs was viewed crucial in improving the patient's life and maintaining the religious connection of their families (Astrow, et al., 2001). Religion is an essential factor in shaping the life of Jordanian population. Al-Hassan & Hweidi (2004) explained that the majority of Jordanians are Muslims who believe that illness and wellness is God's will, and their faith is within God's hands only. This makes Jordanians more religious, than usual, at times of illness and death (Al-Hassan & Hweidi, 2004).

Around 200 cases of childhood cancer are diagnosed in Jordan each year (Jordan National Cancer Registry, 2008). Due to improvements in childhood cancer treatment, the overall survival rate of all childhood cancers combined has improved for the last decade (Jordan National Cancer Registry, 2008). This improvement increases the need to understand parental experiences which in turn will be helpful in the management of stress and may improve the quality of life for childhood cancer parents. Therefore, the aim of this study is to explore perceived stress in mothers and fathers of a child with cancer in Jordan. This paper considered the first to examine such stressors in an Arab-Muslim community and therefore contributes to the existing literature. The results will enable healthcare providers to understand the stressors that affecting mothers and fathers. Thus, nurses can provide care for both mothers and fathers taking into concern their culture, religion and social background.

## **1. Methodology**

### **a. Setting the Context**

Participants were selected from King Hussein Cancer Centre (KHCC), as biggest cancer specialist centre in Jordan. Statistics showed that this centre treats the majority of childhood cancer cases over the country (i.e. more than 90% of the overall childhood cancer cases are treated there) (Jordan National Cancer Registry, 2008).

### **b. Theoretical Framework**

The stress and coping model was developed by Lazarus and Folkman (1984). It is a robust universal framework which accounts for how individuals cope with stress. According to this model, stress arises when individual demands exceed the available resources. The fundamental concept of this model is that people who are facing a stressor (such as parenting a child with cancer) assess the stressor and also assess their personal resources to deal with it. Therefore, the way an individual parent appraises the event of parenting a child with cancer plays a vital role in determining the magnitude of the perceived stress.

The stress and coping model by Lazarus and Folkman (1984) attains the main aim of this study of investigating the individual differences in perceived stress between mothers and fathers of a child with cancer in Jordan. Therefore, the meaning of stress is identified by this stress and coping model and will be adopted in this study.

### **c. Ethical Considerations**

The study was approved by the research ethics committee at the cancer hospital concerned and permission to proceed with the research was gained (see Appendix A).

The researcher informed the participants both verbally and in writing about their right to withdraw from the study at any time without giving a reason, causing no penalty or loss of benefits to them or their ill children. Mothers and fathers were interviewed separately and a study number was given to each participant in a way that enabled the researcher to link couples together. Data gained from the study was kept in an approved secure place of storage only accessible by the researchers. The researcher gave the participants full information about the purpose of the data they contributed and advised them that the data will be destroyed seven years after the completion of the study. Findings from the quantitative survey have been reported previously (Masa'Deh, Collier, & Hall, 2012; Masa'Deh, Collier, Hall, & Fadwa, 2013).

### **d. Data Collection Procedure**

An interview reply slip attached with the package (invitation letter, information sheet and the consent form) allowed the participant to respond, demonstrating their desire to be considered in the study. Survey respondents could agree to continue further with the interview by ticking the box in the reply slip, writing their contact details and posting it back to the researcher. This provided consent from the participant to enter the study. Moreover, the researcher secured written consent for the study which included consent for using quotes before conducting the interview. The participant's information sheet included information clarifying the nature of study.

The researcher contacted the couples who agreed to be interviewed and arranged with them for a convenient time and place of the interviews. The researcher (interviewer) was trained to conduct this kind of interview. With the permission of the participants, all interviews were undertaken in a special room prepared for research purposes and were audio-recorded. The interviews were conducted using the Arabic language (the official language in Jordan). Each interview took between 50 and 70 minutes. Only the participant and the researcher were present at the interview time (none of the participants asked to be accompanied with someone during the interview).

Hence, the researcher believed the parent's responses were independent of each other.

At the beginning of each interview, the researcher introduced himself to the participants and answered any questions they may have had. Then, the researcher started the interview by asking the participants general question regarding their experiences of having a child with cancer. The researcher showed an interest in their stories and views, and established that what has been said was completely confidential and their responses would be coded and maintained anonymously. All interviews began with a general question, for example; 'Could you please tell me about your experience of having a child with cancer?' This broke the ice and encouraged participants to talk about their demands and resources and provided background information about their present condition. Interviews were guided by a provisional interview schedule (Appendix B). Additionally, the whole study was guided by the consolidation criteria for reporting qualitative interviews (Tong, Sainsbury, & Craig, 2007).

#### e. Participants and Sampling

Mothers and fathers (married couples) parenting a child diagnosed with cancer in Jordan were approached. Parents were considered eligible if they were:

- Parenting a child diagnosed with any type of cancer;

- Attending for his/her treatment or follow-up in KHCC; and
- Are able to speak, understand, read and write Arabic language.

Parents were considered not eligible and were excluded from the study if:

- They had hidden the medical diagnosis from their ill child and/or siblings and/or relatives and friends; and
- They were parents of a dying child or with a life expectancy of only few weeks.

Those excluded parents might have different stressors affecting them and different ways of social support.

The sampling method used a convenience sample and all those families meeting the study criteria, who attended KHCC during the data collection period (four months) were approached. A total 42 mothers and 35 fathers agreed to proceed with the interview. However, when arranged in couples, those mothers and fathers created a total of 19 couples. After that, seven couples withdrew (3 couples did not answer their phones, 2 couples did not attend at the allocated interview time twice and 2 fathers were out of Jordan). As a result, the study involved 24 interviews with 12 couples parenting children with cancer in Jordan. The aim of including couples was to explore stressors that affect both parents in a family setting. The following table presents the profile of the participants.

**Table 1. Respondents' profile**

ID	Age of the mother	Age of the father	Number of children	In/out hospital	Time since diagnosis in months	Child's sex (age in years)	Child's diagnosis
1	38	40	6	At home	9	F (9.17)	Leukaemia
2	37	48	5	At home	28	M (14.00)	Brain tumour
3	31	32	2	At home	33	M (4.50)	Leukaemia
4	45	55	4	In hospital	13	M (2.00)	Leukaemia
5	35	44	4	In hospital	24	M (9.00)	Leukaemia
6	25	28	1	At home	4	M (1.25)	Testis
7	41	49	6	At home	9	F (1.25)	Eye
8	25	31	1	At home	5	M (0.83)	Eye
9	36	37	4	At home	4	M (0.67)	Others
10	39	42	4	At home	152	F (13.00)	Others
11	45	53	12	At home	44	M (10.50)	Leukaemia
12	20	34	2	At home	8	M (2.83)	Leukaemia

#### f. Data Analysis Process

Data gained from the interviews was analysed manually by the researcher. Thematic analysis as identified by Boyatzis (1998) was used to analyse the data. The process of thematic analysis as applied in this study is explained in the next steps:

- Transcription: the data were prepared through transcription of all interviews. Transcription was done by the researcher immediately after the end of the

interview and was checked for any transcription errors.

- Coding: this happened in several stages; listening to the recordings repeatedly, and reading through the interview transcript 4-5 times, then writing of initial codes using a colour coded system. This step was done by the researcher and another coder in the following way:

➤ The researcher and the coder coded the same transcript independently, repeating the process.

➤ They met to compare and discuss differences in the codes and any problems with coding structure.

➤ They returned to the transcripts in few cases to recheck and discuss the initial codes until agreement was reached.

- Translation: all previous steps were completed in the Arabic language. After that, English translation of the initial codes was undertaken by the researcher. Verification of the translation was achieved through back translation by two professional bilingual people (whose mother language is Arabic) with medical backgrounds (both translators are postgraduate nurses), followed by a comparison between the translated and the original transcribed text in a method described by Tran (2009). Finally, the researcher sat with the two professional linguists and discussed the translation until agreement on meaning was reached.

- Data display: there were many different codes across the data set. The researcher started to consider how codes combined to overarching themes. This technique provided the researcher with a way of drawing and verifying conclusions. Based on thematic analysis, a manual technique was then used to establish key themes. The researcher clarified themes in relation to the coded extracts, refined the specifics of each theme and gave clear definitions and names for each theme.

- Themes and categories: the thematic map was used to demonstrate the relationship between themes and codes.

- Representing the data analysis: related quotes were presented under each theme. After that, the results developed a complete understanding of the issue under the study.

Double coding was done in order to attain sufficient reliability to proceed with the analysis and interpretation. Also, it is useful to ascertain the degree of similarity and consistency of judgment between the independent coders. This helps the researcher determine the degree of difficulty in ascribing codes to the themes and may suggest revisions or recycling it before continuing the analysis of the research.

## 2. Results and Discussion

The core issues discussed with informants concerned the stressors of parenting a child with cancer. Differences between mothers and fathers in their perceived stressors are explored and discussed under each theme and quotations from selected interviewees' transcripts are presented as examples.

### a. Stressors of Parenting a Child with Cancer in Jordan

#### i. Treatment.

Treatment of cancer was found to be stressful for the interviewed parents. In all interviewed families, the ill child had undergone at least one of the treatment options (i.e. surgery, chemotherapy, radiotherapy, bone marrow transplantation or alternative treatment). Firstly, parents have to understand the treatment plan which is a long journey in most of the cases with the child undertaking various invasive procedures such as central line insertion and bone marrow aspiration which were found to be stressful for them. Moreover, cancer treatments regularly include side-effects which could be a main source of stress for parents. This finding is in accordance with many previous studies which have acknowledged that treatment options of paediatric cancer are aggressive and are often followed by serious side effects which might even be life-threatening at times (Colletti, et al., 2008; McGrath & Phillips, 2008; Pöder, Ljungman, & von Essen, 2010). The following extract is an example on the effect of treatment of children with cancer on their parents as stated by one mother:

*...My son's hair was long but it fell down because of the drug. Sometimes people ask why he shaves like this, they do not know about the drug side-effects. Other children do not like him because of his appearance.... The medication caused vomiting, diarrhoea and this was increasing the pressure on me...The first five days after each dose of chemotherapy I do not sleep. One time he suffered from cramping and this increased my fear. I felt like he might die from the side-effects of the medication. (Mother6)*

In the current study, parents were not only affected by the short-term side-effects but also with the long-term side-effects of the treatment on the child. There was a belief that cancer treatment could have an effect on the child's future. Several participants were worried and anxious that the child would not return to normal as a consequence of the treatment. For example, some parents said that even if a child recovered from cancer, the treatment may affect their growth and development stages. They also recognised that this treatment may have a long-term effect on the general health and may deprive the ill child of being able to have children in the future. The last issue was raised by a couple parenting a child with testicular cancer and illustrated in the next quote. Chao-Hsing (2003) and Anclair et al. (2009) explored the same issue and found that parents of children with cancer were affected by the unexpected future outcomes and consequences of the treatment of their children. In this study, one mother said:

*...Sometimes I feel worry about my child's future as he might not able to get married and have children because of the side-effects of the treatment! As you know, he has cancer in his testis. I hope he could continue his life normally!...I think that cancer treatment in general has long-term effects on the child future. (Mother6)*

Due to the well acknowledged side-effects of the medical treatment, some parents looked for alternative medicine. Although all parents in the current study admitted that they do not believe in alternative medicine as a cure, some of them used several kinds of herbs and/or a particular type of acupuncture to treat their ill child. The idea which was clearly stated by parents behind the use of such alternative therapy was that even if this alternative medicine did not have any benefit, it would not cause harm. For example, one father commented on this:

*...I did my best and knocked on all doors looking for a cure to my son. I tried some herbs. If this herbal treatment does not work, I guess it will not harm him. It is only herbs, not chemotherapy!...I am sure that any alternative medicine will not be as harmful as the medical treatment. (Father3)*

Although there are insufficient studies examining the use of herbs to treat children with cancer and its effect on the parents, such herbal treatment was found to be popular in China. A Chinese study found that parents of a child with cancer searched for alternative and herbal medicine to treat their child. Some of the Chinese parents tried a combination of alternative and/or herbal treatment combined with the standard medicine (Chao-Hsing, 2003). In this Chinese study, one mother reported that she decided to stop the standard medicine and just rely on the herbal medicine (Chao-Hsing, 2003). However, the alternative and herbal treatments are considered to be part of the main traditional medicine in China and more popular compared to Jordan.

## **ii. New roles and responsibilities.**

Most of the interviewed parents commented on the role change after their child was diagnosed with cancer. In particular, mothers experienced huge compromises in their ability to function in their roles as mother of their other children, spouse and housekeeper. They were unable to perform basic caring tasks for other children including taking them to school, preparing food and so on. Mothers in Jordan are normally responsible for the households and caring for the children (Jordanian Higher Council for Youth, 2009). These cultural gender roles may be compromised when having a child with cancer.

Caregiver parents faced role conflict between their parenting role and the demand of the hospital situation (i.e. mother in majority of the cases vs. nurse). All the mothers in the study were physically

close to their ill child and they spent all the time with the ill child either in the hospital or even at home. Mothers lived full-time in the hospital with their ill child in the weeks or months during the treatment and returning home only for brief periods, often for only a couple of hours at a time. Primary caregiver parents (i.e. mothers) had concerns about feeding their ill child, infection, cleanliness and remembering tablets (nurse roles). The next quote is an example of how an interviewed mother raised this issue:

*...I am responsible for helping my ill child in lots of things. For example, help him to eat, drink, take care of his hygiene and clean or sterilize everything as his immunity is very low. I am also responsible for giving him some medications in different times during the day and night. (Mother6)*

The new roles of mothers of children with cancer have been raised in many previous studies (Ångström-Brännström, Norberg, Strandberg, Söderberg, & Dahlqvist, 2010; Bjork, Wiebe, & Hallstrom, 2005; Chao-Hsing, 2003; Enskar, Hamrin, Carlsson, & von Essen, 2011; Svavarsdottir, 2005). One study, based on interviews of 20 mothers with a child with cancer in the United Kingdom, found that mothers had to feed their ill child, convince him/her to accept treatment and some medical procedures, answer the ill child's questions, be physically close to the ill child and provide comfort and support. However, 30% of those mothers were single, separated or divorced which could be one reason behind the mothers being the primary caregivers and responsible for everything in this study (Young, Dixon-Woods, Findlay, & Heney, 2002) and this may not be the case within couples.

Most of the daily care was done by mothers though some fathers provided occasional support. Yeh (2002) investigated stress in couples of parents of a child with cancer and showed that the majority of the mothers were the primary caregivers. Chinese mothers chose to stay with their ill child in the hospital (Yeh, 2002). In the current study, the other parent had to care for the other children, household and continue their employment responsibilities to maintain income (i.e. fathers in the majority of the cases). Interviewed fathers said that they had to do things they had never done before. For example, they were cleaning their houses, preparing food, helping children in the shower, washing clothes, vacuuming and ironing, because the mothers were with their ill child in the hospital. Although cultural differences between countries can affect the parental roles inside the family, the roles of the interviewed fathers of a child with cancer in Jordan were found to be similar to those which have been identified in the previous literature (Brody & Simmons, 2007; Jones, Pelletier, Decker, Barczyk, & Dungan, 2010). The following

extract highlights the new parental roles as described by the participant:

Beside to my normal daily work, I was cleaning the house, taking care of the children, preparing food and arranging some of the household issues...I never done this before my child diagnosed with the disease, my wife was doing all of the house duties. I am now learning how to do such new things. This has increased the burden on me. (Father4).

Most fathers in the current study were found to have role conflict between being at the hospital with the ill child and managing other duties (i.e. work, household and taking care of other children). Some of them stated that a parent whose role is to maintain income can at times find it difficult not being with the child in the hospital and therefore the ill child most probably demonstrates a stronger bond with the caregiver parent. The similar issues have been raised in previous literature (Clarke, 2005; Hill, Higgins, Dempster, & McCarthy, 2009). Therefore, fathers at times may want to be involved in the caring roles of their ill child.

Interestingly, having other children in the family was found to affect interviewed mothers and fathers of a child with cancer in Jordan in different ways. Some fathers described that having many children was stressful and an extra responsibility or burden on them as they became the ones who are responsible for taking care of the healthy children particularly when mothers are at the hospital with the ill child. Mothers had different views about the number of children in the family. On one hand, interviewed mothers who have one child commented that having only one child (i.e. the sick child who generally has priority) was very stressful. Those mothers said that if they lose the ill child then they will lose everything they have. They also believed that having other children would make the marital relationship stronger; this is a common belief among Jordanian women in general (Jordanian Higher Council for Youth, 2009). Again, this highlights a cultural issue where women in general consider having children make the marital relationships more secure. However, there are insufficient studies examining the effect of having only child who is diagnosed with cancer on the marital relationships. On the other hand, some mothers found having other children was stressful, as they could feel guilty for leaving them alone and staying with the ill child most of the time. This last issue was raised by previous studies which showed that mothers feel guilt when they could not provide the same attention for other healthy children (Bjork, et al., 2005; Patistea, Makrodimitri, & Panteli, 2000).

Interviewed mothers and fathers appreciated the help and co-operation of the other parent with managing the new roles and responsibilities. They also

stated that they had to share everything to be able to carry on. For example, one father pointed out this issue:

We are flexible in terms of our tasks, roles and responsibilities. My wife and I were helping each other in caring for the ill child. Everyone does some tasks. We have to share things and co-operate so we can maintain the balance. (Father10)

Parental co-operation in the context of a child with cancer is aligned with previous studies which found that mothers and fathers share the responsibilities of caring for the ill child, other children and managing financial status in order to overcome this situation (Bjork, et al., 2005; Patistea, et al., 2000). Moreover, a qualitative study which explored the experiences of single-parent families caring for a child with cancer found that it was exhausting for those single parents to care for the ill child alone, arranging medical procedures, hospitalisation and undertaking the economical burdens (Huang, Mu, & Chiou, 2008). Due to the nature of the family structure and the marital relationships in Jordan combined with a very low divorce rate compared to many other countries, the results regarding single parents may not be comparable to the context in Jordan. Nevertheless, sharing responsibilities between two parents could possibly make the situation easier.

### **iii. Isolation and self neglect.**

Previous studies have showed that the relationship between parents of a child with cancer and their surrounding environment has been seen to be limiting. Parents of children with cancer reported that they feel lonely and isolated because of the treatment requirements and burden of care related to the child's illness (Fletcher, Schneider, & Harry, 2010; Maurice-Stam, Oort, Last, & Grootenhuys, 2008; Rajajee, et al., 2007). Although there was a belief among the interviewed parents that relatives and friends were supportive and contacted them regularly and more often than before to ask about the child's condition, most of the interviewed parents acknowledged that they felt isolated. The relationships with other people in the family, work and friends were found to be decreased as there was no adequate time for socialising.

Most interviewed mothers in the current study stated that they could not take their ill child out for normal visits or parties and to crowded places as they were worried that the child might become infected; this subsequently led to being less engage in social events. Mothers in a similar UK qualitative study said that they spent most of their time with the ill child and therefore, they could not socialise with family and friends in the way they had done previously (Young, et al., 2002). With regards to the interviewed fathers,

although men in Jordan are usually actively involved in social activities (Jordanian Higher Council for Youth, 2009), fathers in the current study were found to be away from social events. The following quote reflects the social life of Jordanian parents of a child with cancer.

*...Before my child got the disease, I was going out with my friends almost every weekend. I used to spend a lot of my time with them...after my child was diagnosed with cancer I did not go out with my friends as before. I need to stay close to my son...going out with people requires good spirit and smiling. I can't smile while I am busy-minded all the time thinking of my son. (Father8)*

James et al. (2002) and Fletcher et al. (2010) all showed that mothers and fathers of children with cancer acknowledged that they did not have sufficient time for socialising. Mothers and fathers together need to be able to take care of the ill child, other children, work and managing financial balance. All these requirements need time and effort which may deprive parents from being involved in the social events.

In the current study, due to the fact that the specialist cancer hospitals in Jordan are located in the main cities, some families were staying away from their homes and close to the hospital while others had to travel to obtain medical care, leaving parents in both cases away from their social environment. Some interviewed fathers but not mothers, commented on the distance to the hospital. Fathers said a long distance to the hospital was considered stressful and time consuming for them.

Having a child with cancer was found to be time consuming for both parents which affected not only the parental social relationships but also might affect the parental own needs. For example, few interviewed mothers (but not fathers) admitted that they experienced a negative impact on their physical health and a lack of self caring (such as weight changes) as they were stressed and had no time for themselves. In a world in which the role of mothers is constructed as being selfless, it was clearly difficult for mothers to give attention to their own needs. Some of them admitted that they were no longer taking care of their appearance as they had been before, they did not have time and ability to do so. Mothers stated that they spent the majority of their time with the ill child either in hospital or at home. However, if they had time to go out, then they would care for themselves. The following quote explains this issue:

*...Because I am the primary caregiver for my ill child, I do not have time to care for myself. A mother of a child with cancer is always busy taking care of the ill child. It has been ages since I looked at myself in the mirror. I do not care of myself like before, such as my hair and nails. I spend most of my time with my*

*child, why should I care about my appearance! I do not care about myself as much as my child's health. (Mother4)*

Although some previous studies concerning mothers of children with cancer did not raise the issue of maternal self neglect, James et al. (2002) conducted a study which included primary caregivers of a child with cancer and found that 29/151 participants stated that there were negative impacts of having a child with cancer on the parents' physical health. For example, lack of attendance to own body needs, as well as weight and mood changes were seen the most by those parents. Thus, it may be important that nurses and healthcare providers refer parents of a child with cancer to a psychological specialist in the event of self neglect.

#### **iv. Siblings and general family issues.**

At least one parent in each interviewed couple commented that there was an effect of having a child with cancer on siblings and therefore on the parents. Some parents illustrated that the academic achievement of the siblings was found to be affected by the situation. Siblings may also feel shame, guilt, or fear of illness. For instance, this concern was raised by a father:

*The behaviour of my healthy children and their achievement in the school has changed, to the worse of course! Those are children; they need someone to be always around taking care of them. I do not know where I should be! with my ill child or next to my other children. (Father4)*

In the context of the available studies, similar finding was found in various studies which focused on the effect of having a child with cancer on the siblings (Alderfer, et al., 2010; Rajajee, et al., 2007). For example, a study investigated the impact of having a child with cancer on siblings two years after the onset of illness. This study found that the siblings of children with cancer are generally negatively affected by this situation and reported that school performance of siblings of a child with cancer have been found to be affected by their brother/sister's illness (Houtzager, Grootenhuis, Caron, & Last, 2004).

In the current study, mothers made more comments compared to fathers regarding the communication with their children. Some of them found it hard to communicate with the child in the same way prior to the child's illness. They did not know how to transfer the information about the disease to the ill child, siblings, other family members and friends. Parents also stated that it is easy to tell people about good news but not bad news. Mothers found it hard to answer all questions posed by their ill child and to be open with siblings especially when they were very young. Only one interviewed couple in the current study preferred not to tell the siblings

about the seriousness of the disease as the siblings were too young and may not be capable of understanding the situation. The same issue was raised in similar study where parents of children with cancer reported that it is hard to explain and discuss the situation with people in the same family and siblings, particularly if their siblings are too young (Patistea, et al., 2000). For example, one mother said:

*...In the beginning, I did not tell my other children about my son's illness. I thought that they would not understand or accept it. However, one time, one of my daughters asked me about the situation because I used to leave them a lot and she noticed changes in the appearance of her ill brother. Therefore, I sat down with them, told them about disease and explained to them the situation...it is not easy to explain such things to your children; I do not want this to negatively affect them as well. (Mother9)*

In this study, although almost all fathers took care of their healthy children when the mothers were with the ill child in the hospital, grandparents were very helpful. The extended family dominates the Jordanian culture and grandparents usually offer help in caring for their grandchildren (Al-Hassan & Hweidi, 2004). Interviewed mothers who had a toddler or a baby stated that they cannot trust anyone to care for their healthy children apart from the grandparents. In previous studies, some authors found that the biggest change for the siblings was that they received far less attention from their parents. In many of the affected families, siblings were taken care of by grandparents or friends (Alderfer, et al., 2010; Bjork, et al., 2005; Rajajee, et al., 2007; Trute, Worthington, & Hiebert-Murphy, 2008). However, the degree of the participation offered by grandparents in such a situation may differ across different cultural background. For instance, one father commented on the family life when having a child with cancer:

*...I have three daughters and my youngest son is sick. When his mother stayed with him in the hospital I took my daughters to their grandparent as no-one can take care of them as before....It is chaos; I have to go to my ill child, work and go to see my other children when possible. Life is like a mess. (Father9)*

Although grandparents may offer help in the context of children with cancer, many parents in previous studies stated that siblings' needs were not met like before. Parents' attention was focused on the ill child (Alderfer, et al., 2010; Dang-Tan & Franco, 2007). Almost all mothers and fathers in the current study described the situation as disrupted and noted deterioration in the quality of family life. More than half of the interviewed fathers admitted that their feeling of guilt were associated with being away from the ill child as they are caring for other children and doing their normal daily work. In contrast, mothers

described feelings of guilt caused by them being away from other healthy children whilst caring for the ill child. Mothers and fathers commented that they did not know where they should be, with the ill child or with their other children. In a previous study, unlike this current study, maternal feelings of guilt were associated with issues regarding their prenatal care whereas paternal feelings of guilt and self blame were associated with delay in seeking medical help for the child's symptoms (Patistea, et al., 2000).

With regards to the parental relationship with the ill child, more than half of the interviewed parents said that they had a conflict between meeting the child's demands and good parenting. Although mothers wanted to keep their ill child happy as much as they could, they also wanted to discipline them if necessary. Mothers explained that they want the child to be happy, recover from the disease and also to grow up with good behaviour. This concern was raised by mothers more than fathers. The next quote reflects this issue.

*...I was in a conflict between keep the ill child happy and to rear him, I want him to be good when he grows up. I do not want him to recover from the disease and acquire bad habits or attitude. Sometimes I had to be serious with him, scream, make discipline and act like any normal relation between mother and son but when I do so I blame myself for what I did. It is hard to do it, the fact that he has cancer and rearing him is a bit complicated and that's really made me tired sometimes. (Mother5)*

#### v. Financial issues

Finance was one of the main themes that emerged from all interviewed families. In the current study, fathers commented more than mothers that having a child with cancer has a negative financial effect. The new situation could cause interruption of work and parents might be unable to go to work as before. Loss of income in some cases was caused by a reduction or termination of employment which affected the financial status of the family. This is in accordance with previous studies (Dockerty, et al., 2003; Eiser & Upton, 2007; Gravestock, McDowell, & Vale, 2011; Limburg, Shaw, & McBride, 2008). For example, Eiser & Upton (2007) found that fathers of children with cancer reported higher stress levels than mothers related to the medical expenses and financial management issues, whereas mothers reported higher stress levels than fathers related to the time spent with the ill child.

In this current research, with a few exceptions, mothers were already housewives. This is consistent with the general Jordanian population where the majority of mothers are housewives (Jordanian Department of Statistics, 2008). Although one interviewed mother stated that she left her job to be

able to care of the ill child, she was happy to do so. This mother said:

*...My ill son is the most important thing to me; I try to do everything to make him happy. I like to stay with him a lot providing love and care that he needs. I left my job to be able stay with my child in the hospital and even when he is at home. I am not regretting that, I want to spend my time with him. (Mother5)*

All fathers admitted that their work pattern was negatively affected by their child's illness. However, only one father left his job completely to stay with the ill child. This father stated that the child wanted him to be around all the time, otherwise he would work. Previous literature showed that high anxiety and depression levels for parents caring for children with cancer were caused by parents losing their jobs due to being the primary caregivers for the ill child (Rajajee, et al., 2007; Sloper, 2000). This might not be necessary similar to the situation in Jordan as most of the interviewed primary caregiver mothers in this study were already housewives and the one who lost her job expressed no negative effect of that on her.

Poorer finances when having a child with cancer was not only caused by reduced income but also by the increased expenses for some families and follow-up care including transportation, accommodation, meals, child's needs, some medications and procedures which are not covered by the insurance were found to affect the financial status of the fathers. For example, some fathers clarified that they bought lots of toys for their ill child and meals to the mother while they were in the hospital. Fathers also commented on the travelling cost, whilst others preferred to rent a house for the family or stayed in a hotel beside the hospital without returning to home for weeks or months. Due to the long stay this caused financial burden on the family. A few fathers commented that they had to get loans either from banks or from relatives in order to be able to cover these expenses. For example, a father commented on the financial issue:

*...After my daughter has got the disease I borrowed money to buy the car as it is the easiest way to come to the hospital because we live 73 km away and the car can help better than transportation in the emergency cases....You know petrol is very expensive so it costs me a lot of money when I come for a medical visit. Moreover, I do bring her everything she wants like food, games, toys, etc...all of this cost a lot of money. (Father7)*

None of the interviewed families were found to be affected by the direct costs of the treatment, as all of them were receiving treatment for free, paid by the government. Those families were very thankful to the government because they were required to pay nothing. A Canadian study focusing on the financial

aspects of parents of children with cancer found that having a child with cancer may cause a short-term financial burden to the whole family even though the medical financial expenses of parenting a child with cancer in Canada were covered by the government or an insurance company (Limburg, et al., 2008). Although previous studies highlighted the financial cost of having a child with cancer on the family (Dockerty, et al., 2003; Eiser & Upton, 2007; Miedema, et al., 2008), Limburg et al. (2008) reported that parental financial burden is significant in the first year of diagnosis and found that the financial status of approximately 80% of parents of a child with cancer in their study improved after one year of diagnosis.

In the current study, financial issues were raised by both parents but fathers seemed to be affected by the financial aspect much more than mothers as culturally, and from a religious point of view, they considered that maintaining financial balance is a father's responsibility. This issue was also raised by some mothers who explained that the financial balance is one of the fathers' responsibilities and stated that fathers were trying to do their best to maintain enough income for the family. Mothers commented that they felt sympathy with the fathers as they were trying to do their best in order to financially overcome the situation. The next quote is an example of how a mother described the effect of having a child with cancer on the financial status.

*...Although the treatment is covered by the government, we have been financially affected by the disease. Transportation, frequent clinic visit that cost a lot of money. We do buy her everything she wants such as buying clothes, games, and take them to play in fun fairs to meet all her requests. Moreover, also we buy things for her brothers and sister as we cannot buy for her and not for other children. It is hard to my husband to manage all of these. (Mother1)*

### 3. Conclusions

Like most of the previous studies, Muslim mothers and fathers were found to be stressed when having a child with cancer. Each parent was found to face various stressors and/or they perceived stressors differently. The cancer treatment period was found to be very stressful for the parents. More mothers compared to fathers perceived having a child with cancer as time consuming and therefore they did not have enough time to take care of other siblings, socialise with other people and/or even for themselves. Although all interviewed parents acknowledged that the cost of treatment is paid for by a third party, the financial cost of having a child with cancer was raised by most of the interviewed parents. Fathers commented more than mothers on this aspect. Fathers acknowledged that the financial cost of having

a child with cancer is not only the direct treatment costs but also about many different other costs. They also acknowledged that the financial effect starts on the pre-diagnosis periods and often lasts during the treatment period. Jordanian culture and religion are very similar to some surrounding countries. Therefore, the findings of this research may also benefit parents of children with cancer in the neighbourhood countries. Due to the fact that religion may be considered a type of support, future research is needed to investigate parental resources when having a child with cancer.

#### Acknowledgment:

The authors are grateful to the Applied Science Private University, Amman, Jordan, for the financial support granted to cover the publication fee of this research article.

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5/16/2014