PERCEIVED STRESS IN PARENTS OF CHILDREN WITH CHRONIC DISEASE: A COMPARATIVE STUDY

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Abstract

Background: Cancer, diabetes, asthma, congenital heart diseases and cerebral palsy are the most prevalent paediatric chronic illnesses in the world, and Jordan has particularly high prevalence. Most studies agree that parenting a child with a chronic illness is a stressful event, but few of them compared parental stress in relation to different diagnoses. Therefore, this study investigates parental stress levels when having a child diagnosed with cancer and compares these levels to those of parents with a child suffering from other chronic illnesses.

Methods: A survey of 600 participants parenting a child with a chronic illness (i.e. 305 parents of children with cancer and 295 parents of children with other chronic illnesses). Participants answered the Arabic version of the Perceived Stress Scale 10-items and Characteristics Check List Questionnaires.

Findings: There were no significant differences in the socio-demographic characteristics of parents of children with cancer and those parenting children with other chronic illnesses. Parents of children with cancer reported significantly higher stress levels than parents of children with other chronic illnesses ($p<0.001$), with a medium effect size (0.02). In the cancer group, the highest mean stress level was for those parenting children liver cancer and the lowest was for parents of children with lymphoma. In the other group, parents of children with cerebral palsy had the highest mean stress score and parents of children with asthma had the lowest.

Conclusions: These findings indicate the need to assess families of a child with chronic illness in Jordan to recognise their psychological needs and offer continuous psychological support.

Keywords: parent, child, paediatric cancer, chronic illness, stress

Introduction

According to the World Health Organization (WHO), chronic non-communicable diseases are one of the leading causes of death worldwide, representing 35 million deaths in 2005 and over 60% of all deaths (WHO, 2014). Among children, chronic diseases such as cancer, asthma, diabetes, epilepsy and/or heart disorders are increasing globally, as well as in Jordan (WHO, 2014). The diagnosis of any of these disorders has a major effects not only on the ill child but also on their parents (Cousino & Hazen, 2013).

The effect of having a child diagnosed with a chronic illness on the parents may vary according to the seriousness of the disease, the sign and symptoms, the side effects of the treatment, and the duration of the illness (Cousino & Hazen, 2013). For example, paediatric cancer is one of the chronic and non-communicable diseases that has a high mortality rate compared to other paediatric chronic illnesses (IARC, 2014). The signs and symptoms of cancer depend on the location of the tumour (e.g. lung cancer is characterised by coughing, and oesophageal cancer causes dysphasia). Moreover, there are systematic general symptoms for cancer, such as unintentional weight loss, fever and changes in skin integrity; and of metastasis, such as enlarged lymph nodes, liver or spleen, pain, fracture and neurological symptoms (Abo-Obead, Batiha, Al-Jauissy, Alhalaiqa, & Albashtawy, 2014; NHS, 2015; WHO, 2014; Wilkie & Ezenwa, 2012). Options for paediatric cancer treatment are based on many factors such as the type of cancer, location, grade and child's health (NCI, 2015; WHO, 2015). Childhood cancer treatment may include a combination of chemotherapy, radiation, surgery and aggressive targeted therapy (NCI, 2015). The previous treatment options, signs and symptoms may affect the quality of life of ill children and their parents.

Parents of children with cancer expressed negative experiences and stressors that affected their whole lives (Saifan, Masa’Deh, Hall, & Collier, 2014). Physical stressors such as tiredness, back pain, sleep disturbances, fatigue and cardiac disease were highlighted (Harding, et al., 2012). Some researchers highlighted financial stressors when having a child with cancer, related to decreased working hours, losing income and increased expenditure (Masa'Deh, Collier, Hall, & Alhalaiqa, 2013). Additionally, social stressors and psychological problems such as isolation, social withdrawal, anxiety and depression were highlighted (Rami Masa'Deh, Jacqueline Collier, & Carol Hall, 2012; Patiño-Fernández, et al., 2008).

Several studies investigated the stress level among parents of child with cancer and found that those parents had high levels of stress (Barbarin, Hughes, & Chesler, 1985; Boman, Lindahl Norberg, & Bjork, 2003; Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Patiño-Fernández, et al., 2008). Other researchers focused on stress levels among parents of children diagnosed with chronic diseases such as diabetes mellitus, epilepsy, celiac disease, asthma and sickle cell, finding that those parents had very high stress levels associated with their children’s diagnoses (Cousino & Hazen, 2013; Gupta, 2007). Being a parent of a child with chronic illness involves two dimensions; love and labour (Braithwaite, 1996; Connelly, Anthony, & Schanberg, 2012). Love is the affective aspect of caring involving emotion and comfort, while labour is the task, function and activity concerned with the role that helps the family to adapt with the situation (Connelly, et al., 2012).

Kumari et al (2011) investigated the stress in parents of children with bronchial asthma in India and compared them to the stress level in the normal parenting population. A higher level of stress was found among study group compared to the control (Kumari, et al., 2011). Another study found that parents of children with celiac disease suffer from high stress level caused by the nature of the disease and the symptoms associated with the disease (Epifanio, Genna, Vitello, Roccella, & La Grutta, 2013).

In Jordan, Masa'Deh et al. (2012) found that parents of children with cancer had higher stress levels compared to parents of children who did not have any serious illness (Barbarin, et al., 1985; Rami Masa'Deh, et al., 2012). However, none of the reviewed studies compared the stress level between parents of child of cancer and those parenting a child with any other chronic disease. Therefore, the purpose of this study was to explore the level of stress in parents of children diagnosed with cancer in comparison to those who have a child diagnosed with another chronic disease.

Research Question

Is there a significant difference in the mean stress levels for parents of children with cancer and parents of children with other chronic illnesses?

Methods

Ethical Considerations

This cross-sectional survey was conducted in Jordan. Ethical approval was gained from the Jordanian Ministry of Health (JMoH) and the Institutional Review Board (IRB) of the Applied Science Private University. It was explained to the participants that participation is voluntary and that they have the right to withdraw at any time without giving a reason, causing no penalty or loss of benefits to them or their ill children. The participants were given full information about the purpose of the data they will present and signed informed consent after their questions have been answered and explained. After the data was collected, it was stored in a secure place and was only available to the researchers and not used by anyone else.

Settings

As per ethical approval, parents of a child with chronic illness being treated at Ministry of Health hospitals in the three main Jordanian cities (Amman, Irbid and Zarqa) were approached. These cities cover more than 75% of the Jordanian population (Jordanian Department of Statistics, 2010). The six largest hospitals in these cities were involved in this study.

Participants

The population of this study was parents known to have a child diagnosed with any type of chronic illness in Jordan. Participants were divided into two main groups, parents of children with cancer and parents of children with other chronic illnesses.

Inclusion criteria:

a) Parents with a child diagnosed with any type of chronic illness and attending for his/her treatment in any of the selected hospitals; and
b) Parents should be able to speak, understand, read and write Arabic.

Exclusion criteria:

a) Parents of a dying child (as stated by the parents).
b) Parents diagnosed with a psychiatric illness.

Sampling

Using a non-random convenience sampling allowed the researcher to approach all those who attended any of the selected hospitals during the data collection period(i.e. February 2015 to august 2015). The sample size was calculated using Sample Power software, which determined that a sample size of 500 would have power of 80.0% to yield a statistically significant result at α level of 0.05.

Data Collection Procedure

Two research assistants in each selected hospital were assigned and carried out the data collection process. The research assistants were trained in conducting research, authorized to carry out such kind of research, assigned by the Jordanian Health Ethical Committee to work in this study. The researcher clarified and explained each point about the project to the research assistants. In order to decrease the recruitment bias, it was important that the researcher and the research assistants agree on a recruitment script in order to recruit in an identical manner. Additionally, regular meetings were held between the researcher and the research assistants.

The participants were asked to call either of the two research assistants within a week after having been given the information sheet. The research assistants' contact details and phone numbers were clearly outlined in the information sheet. Parents could call them with any enquiries they had about the study, and those who wanted to participate could arrange with any of the research assistants on a time and place to sign the informed consent. By signing the consent, the participants accepted to willingly take part in the study and they were thus administered the questionnaires.

Measures

The Arabic Version of Perceived Stress Scale 10-Items Questionnaire (PSS10)

The PSS10 has been used in Arabic language in Jordan by several studies and been shown to be valid and reliable (Al-Hassan & Wierenga, 2000; Hamdan-Mansour & Dawani, 2008; Hattar-Pollara & Dawani, 2006; Masa'Deh, et al., 2013).

The questions used in the PSS10 questionnaire measure participants' feelings regarding whether they have enough resources to meet the demands placed upon them (Cohen & Janicki-Deverts, 2012). The questions are designed to be quite simple and general in their nature, and are judged over a broad spectrum in order to relate to participants with varying social circumstances (such as parents of a child with chronic illness) (Cohen & Janicki-Deverts, 2012). Because the questionnaire is short and easy to complete, participants have little difficulties or burden in participation.

The items of PSS10 are answered using a five point Likert-type rating scale, ranging from never (0) to very often (4). It can generally be competed in under four minutes (Cohen & Janicki-Deverts, 2012). The total score is obtained by reversing the scores of the four positive items (4, 5, 7, 8), and then adding up all scores. Higher scores indicate higher stress levels.

Characteristics Checklist

A participant characteristics checklist was developed in Arabic language by the researcher and included the following information: participant's gender, status as the primary caregiver of the ill child, participant's education level, participant's employment status and age. Also, perception of family finances, age of the ill child, sex of the ill child, type of illness and number of children in the family were included in the checklist. These factors were developed after reviewing the literature relating to the effect of childhood chronic illness on the parents.

The whole research process was checked by distributing the research papers to the participants. The first twenty participants were considered as a pilot, and because there were no changes in the process, the information gained from those participants was included in the analysis and the researcher proceeded with the data collection.

In this study, 650 participants were invited to participate. Of those, 620 people signed the consent to participate. Parents who did not complete the questionnaires were excluded from the analysis. At the end, 600 participants fully completed, returned the questionnaires and were included in this study. In all of the six hospitals, the percentages of the approached/consented participants were close to each other (i.e. between 69% and 83%), suggesting minimal recruiting bias.

Data Analysis Process

SPSS version 21 was used to analyse the quantitative data. After coding the data, the researcher entered the survey data into the software. A significance level (P-value) of less than 0.05 was considered to be statistically significant, and two tailed tests were used in all statistical analysis techniques. Numbers in the results were rounded up to the closest two decimal points.

Descriptive statistics were computed to describe the participants and their ill children. Independent t test was used to compare stress levels of parents of children with cancer to those having children with other chronic diseases.

Findings

Using a convenience sample, 330 parents caring for a child with cancer and 320 parents of children with other chronic illnesses were invited to take part in this study. 310 parents of children with cancer and 300 parents of children with other chronic illnesses consented. Ultimately, 305 parents of children with cancer and 295 parents of children with other chronic illnesses completed and returned the questionnaires and were considered in the analysis. This represents more than 90% of the approached parents in the two groups.

Table 1 presents some characteristics of the participants and their children. It can be seen that approximately 50.5% of parents of children with cancer were mothers compared to 49.5% in the parents of children with other chronic illness. The mean age of the participants in the two groups was 37 years, and both groups have a mean of three children per family. More than 85% of the parents in the two groups had high school education and above. There is no significant difference in any of the socio-demographic characteristics between the two groups.

The cancer group involved children with different cancer diagnoses such as leukaemia, cancer related to central nervous system, lymphoma, bone, kidney, liver and cancer of the testis. The other group involved children diagnosed with diabetes mellitus, asthma, cerebral palsy, congenital heart disease and disability. Around 39% of children in the cancer group were diagnosed with leukaemia, and almost half of the children in the chronic illness group were diagnosed with diabetes mellitus.

Table 1 Characteristics of the parents and their ill children

Variable	*Parents of children with cancer N=305*	*Parents of children with other chronic illness N=295*
Parent age (yrs.)	37.48 (8.72)	36.48 (7.76)
Child age (yrs.)	6.45 (3.69)	6.17 (4.01)
No. children in family	2.74 (1.44)	2.95 (1.27)
Sex of parent:		
Male	151 (49.50%)	149 (50.50%)
Female	154 (50.50%)	146 (49.50%)
Sex of child:		
Male	175 (57.38%)	169 (57.29%)
Female	130 (42.62%)	126 (42.71%)
Parent employment:		
Employed	152 (49.84%)	151 (51.19%)
Unemployed	153 (50.16%)	144 (48.81%)
Parent education:		
Elementary school	26 (8.52%)	28 (9.49%)
High school	111 (36.39%)	109 (36.94%)
College and above	168 (55.08%)	158 (53.55%)
Child's diagnosis:		
Leukaemia	118 (38.69%)	
CNS	71 (23.28%)	
Lymphoma	35 (11.48%)	
Bone	24 (7.87%)	
Kidney	26 (8.52%)	
Liver	19 (6.23%)	
Testis	12 (3.93%)	
Non-cancer chronic illness types:		
Diabetes mellitus		150 (50.85%)
Asthma		20 (6.78%)
Cerebral palsy		20 (6.78%)
Congenital heart disease		60 (20.34%)
Disability		45 (15.25%)

*Values are Means ± SD or N(%)

As presented in table 2, an independent-samples t-test was conducted to answer the research question and to compare the total stress score for parents of children with cancer and parents of children with other chronic illness. Parents of children with cancer reported significantly higher stress levels than parents of children with other chronic illnesses. There was a significant difference in the stress scores of parents of children with cancer (M=23.35, SD=9.26) and parents of children with other chronic illness (M=20.84, SD=7.78); t(586)=3.60, p<.001. The mean difference between scores was 2.51 (95% CI: 1.14 to 3.88). The magnitude of the differences in the means was moderate (eta squared=0.02).

Table 2 Differences in total stress scores between parents of children with cancer and parents of children with other chronic illness

Variable	*Parents of children with cancer* *N=305* *Mean (SD)*	*Parents of children with other chronic illness* *N=295* *Mean (SD)*	*P-value*
Total stress score	23.35 (9.26)	20.84 (7.78)	<0.001

The mean of the total stress scores of parents in each diagnosis were checked and presented in table 3. In the cancer group, it was clear that parents of children with liver cancer had the highest mean stress level and those with a child diagnosed with lymphoma had the lowest. In the other group, parents of children with cerebral palsy had the highest mean stress score and parents of children with asthma had the lowest.

Table 3 Parental mean stress scores of different diagnoses

Child's diagnosis	*N*	*Mean score of parental stress level (SD)*
Cancer diagnosis:		
Liver	19	28.53 (7.13)
Bone	24	26.50 (9.62)
CNS	71	25.04 (7.81)
Leukaemia	118	23.97 (9.63)
Kidney	26	23.04 (9.64)
Testis	12	19.58 (6.29)
Lymphoma	35	14.40 (5.82)
Non-cancer chronic illness:		
Cerebral palsy	20	22.40 (7.31)
Congenital heart disease	60	21.17 (7.83)
Diabetes mellitus	150	21.07 (7.38)
Disability	45	20.07 (9.40)
Asthma	20	18.30 (6.97)

Discussion

This study showed that the mean number of children in the family in the two groups was around three children. This is similar to the Jordanian national data, which shows that about 90% of the families have less than six children, and most have between three and four children (Jordanian Department of Statistics, 2007).

The results showed that the proportion of parents who work is around 50% of all participants for the two groups. This is a lower percentage than the wider Jordanian population, where 26% of mothers of school aged children were in paid employment (Rami; Masa'deh, Jacqueline; Collier, & Carol Hall, 2012). In the current study, this is not a surprising result as half of the participants were mothers and the vast majority of them were the primary caregivers for their ill child, therefore if they were working previously they had to quit their job upon assuming the primary caregiver role.

In the current study, parents of a child with cancer reported significantly higher stress scores than parents of a child with non-cancer chronic illness. A suggested explanation of why cancer parents reported higher stress scores than non-cancer parents may be due to the seriousness of the cancer as a disease, the child's health status, the meaning of cancer to them and the treatment side effects. Also, this may be explained by Stress and Coping model identified by Lazarus and Folkman, which explains the differences of stress levels through the lines of difference in exposure and/or difference in resources (Lazarus & Folkman, 1984).This finding is in agreement with previous studies investigating stress in parents of children with cancer, which found that those parents reported high stress scores (Bayat, Erdem, & Gul Kuzucu, 2008; Norberg, Lindblad, & Boman, 2005, 2006; Patino-Fernandez, et al., 2008; Pöder, Ljungman, & Essen, 2008; Pöder, Ljungman, & von Essen, 2010; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006; Yeh, 2002).

Klassen et al. (2007) concluded that the stress and coping model by Lazarus and Folkman was the most frequently used in literature investigating stress in parents of children with chronic disease. Moreover, Han (2003) conducted a study about Korean mothers parenting a child with cancer and suggested that this stress and coping framework is appropriate in explaining parental stress in parents of children with chronic disease across cultures. This model has been adopted in a study exploring stress in parents of children of cancer in Jordan (Masa'Deh, et al., 2013).

The findings in the current study showed that the overall mean stress score of all participants of the two groups combined was significantly higher than parents in the general population in Jordan (Rami; Masa'deh, et al., 2012). This is not a surprising result, as parenting is a demanding responsibility that becomes even harder when caring for a seriously ill child.

Conclusion

Consistent with previous studies, the results showed that parenting a child with a chronic illness is stressful and becomes more stressful when the diagnosis is cancer. There was an effect of the type of diagnosis on the parental stress levels for both groups. However, the overall total stress score for all parents combined was significantly higher than those parenting children in the normal Jordanian population. These findings provide evidence about the need for provision of psychological support for families caring for a child diagnosed with a chronic disease in Jordan. As Middle Eastern countries have many similarities in their culture and religion, the findings of this research may also benefit parents of children diagnosed with a chronic disease in other surrounding countries.

Acknowledgement:

The author is grateful to the Applied Science Private University, Amman, Jordan, for the partial financial support granted to this research project (Grant number DRGS 2015-2016-14).

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