

Characteristics of Mothers with Chronically Ill Children in Jeddah, Saudi Arabia

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Abstract

Children are their parents' pride and joy. Parents have hopes, dreams and expectations for their children to grow and develop in a holistic healthy manner physically, emotionally, and socially. It is an extremely vulnerable situation when the life and health of children are threatened; hence, when a child is diagnosed with a chronic condition, parents grieve for the loss of their child's health, their expectations and dreams can be challenged, and their sense of protection, feeling of invulnerability are severely shaken. **Objectives:** This study focuses on Saudi parents and in particular the mothers who have children with chronic illnesses. It aimed to describe and explore the coping patterns of Saudi mothers who have chronically ill children. **Method:** A survey questionnaire was administered to 122 Saudi parents with chronically ill children in paediatric wards at three public hospitals in the Jeddah region in Saudi Arabia. Demographic data, Quality of Life Scale (QOL), The General Self-efficacy scale (GSE) and Social Support Questionnaire (SSQ) were distributed to the Saudi parents with identified chronically ill children. **Results:** The results of the descriptive statistical analyses provided significant correlations between QOL score and GSE, between QOL and SSQ, between QOL and stress and adversity, between GSE and SSQ, between stress and adversity and duration of child's illness, and between stress and adversity and family time spent in caring activities. In addition, a nearly significant result was found between GSE and stress and adversity. **Conclusion:** The results of the study emphasise the importance of a thorough and holistic assessment of families, their social environments and the level of support they require to assist them to cope with the chronic illness of their children.

Keywords: chronic illness, stress, quality of life, coping, children, Saudi Arabia

1. Introduction

Children are their parents' pride and joy. Parents have an expectation that their children will grow and develop in a holistic, healthy manner physically, emotionally and socially. When the life and health of a child is threatened by accident or illness, parents find themselves in extremely vulnerable situations. Hence, when a child is diagnosed with a chronic condition, the parents' expectations are challenged and they grieve for the loss of their child's health (Lowe, Lyne & Gregory, 2004; Marshall, Fleming, Gillibrand & Carter, 2002). Taking care of a chronically ill child is arguably one of the most draining and difficult tasks a parent can face. A child's chronic illness increases the risk of developing a range of difficulties, including physical, emotional, cognitive and psychosocial dysfunctions within the family (Lowe et al., 2004; Tsamparli & Kounenou, 2004). Children with a chronic illness change the family's established patterns of functioning. This disrupts the normal routines of everyday life. In turn, this leads to changes in relationships among family members (Anderson, Loughlin, Goldberg & Laffel, 2001; Barlow & Ellard, 2006; Charron-Prochownik, 2002; McCubbin & McCubbin, 2001; Patterson, 2002).

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These changes can add to the range of challenges a family has to cope with due to the child's illness, and can lead to increased stress levels within the family. The family's ability to cope with this stress is important, as stress has been found to have a negative impact on health (Amato, 2005; Mackay, 2005). Worldwide, 10 to 15 per cent of children under 16 years of age are affected by chronic long term conditions. The prevalence of children with chronic illnesses varies widely, with an overall rate of 10 to 20% (Janse, Uiterwaal, Gemke, Kimpen & Sinnema, 2005). This rate is expected to increase further (Omran, Elimam & Yin, 2013). In the past two decades, there has been an alarming increase in the prevalence of chronic diseases among children in Saudi Arabia, such as diabetes, hypertension and heart disease, cancer, genetic blood disorders and childhood obesity (Al-Qurashi, El-Mouzan, Al-Herbish, Al-Salloum & Al-Omar, 2009; Al-Turki, 2000; World Health Organization (WHO), 2010). Disease patterns in Saudi Arabia have changed over time from communicable to non-communicable and chronic diseases affected by lifestyle changes. The Saudi Council of Health Services (MOH, 2009) stated that approximately 10% of Saudi families in the Jeddah region have a child with a chronic illness, and 121,000 children aged 5–14 years in the same region are diagnosed with a chronic illness such as cancer, diabetes, cystic fibrosis, epilepsy and asthma. This rate is expected to increase further (Omran et al., 2013). In 2009 and 2011, the Saudi MOH conducted two consecutive studies to identify chronic illnesses among children in the Jeddah region. The studies showed that the five most common diseases in children with long term effects were respiratory diseases (such as pulmonary infections and bronchial asthma), leukaemia, diabetes mellitus, anaemia and brain tumours (see Table 1). These studies also illustrate that the incidence of many of these diseases increased over that period of time.

Table 1: Most Common Chronic Illnesses among Children Aged 5–14 years in Jeddah, Saudi Arabia in 2009 & 2011

Chronic Illness	Jeddah	
	2009	2011
Respiratory Diseases	48%	50%
Leukaemia	40%	38%
Diabetes Mellitus	27%	34%
Anaemia	21%	28%
Brain Tumour	13%	20%
Tuberculosis	Incident rate 807/100,000 cases 49 children	Incident rate 792/100,000 cases 28 children

2. The Structure of Saudi Families

Similar to many legal systems around the world, the Saudis base their laws on the stereotypical image of the ideal family that consists of a father, mother and children (Alkhadhari, 2009). The family is the primary basis of identity and status for the individual, whose loyalty is first and foremost to the family (Alsaleh, 2012). Families in the Middle East including Saudi Arabia tend to be patriarchal, with the male being the household head (Alsaleh, 2012). Throughout history, women took the role of caring for ill family members (Johansson, Anderzen-Carlsson, Ahlin & Andershed, 2012). Saudi women are viewed as the primary caregivers in a Saudi family, beside their household responsibilities (Brown, 2005). Furthermore, women in a traditional Saudi family are not expected to work outside the house (Sullivan, 2012).

In Saudi Arabia, women face several restrictions based entirely on gender. Regardless of age or marital status, a woman is required to have a male guardian who may be her father, husband, brother, uncle, or even her own son (Alkhadhari, 2009; Al-Mohamed, 2008; Pellegrini & Scandura, 2008). A woman cannot travel, attend university, work or marry without her guardian's permission. Thus, the Saudi woman's quality of life depends entirely on her family, namely the male members. If a woman is lucky enough to come from a modern open Saudi family, she will be educated, encouraged to work if she chooses, and may have a say in who she marries. If she comes from a more traditional conservative family, she may not be allowed to do any of these things (Alsaleh, 2012). However modern Saudi women have a desire to contribute to the nation's drive for progress and Saudi women are increasingly willing to assume new social roles (Alsaleh, 2012). Thus, there are Saudi women who currently hold professional positions in media and correspondence, Saudi television, schools, financial institutions and hospitals (Alsaleh, 2012). An understanding of the structure and role of the members of a Saudi family is valuable to health professionals caring for a chronically ill child and his/her family.

This study surveyed mothers as they are the main caregivers. In addition, the survey was conducted during the child's hospital stay. Fathers could only visit whereas mothers stayed for longer periods by the bedside of their child. Therefore, the role of Saudi women only was described here.

3. The Effect of Chronic Illness on the Family

Mothers of a chronically ill child may struggle to meet the demands of parenting. The nature of the child's disease, the need to manage symptoms, and the complexity of treatment all cause emotional strain (Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2004). One study reported that parents of chronically ill children often become emotionally strained, not knowing what they should do for their child and not being able to take care of the hospitalised child (Hopia et al., 2004). Additionally, responses may include feeling guilty and a decline in self-worthiness (Erdogan & Kahraman, 2008; Wise, 2007). Parents of chronically ill children may become overprotective and overly concerned about their ill child's health (Britton & Moore, 2002; Katz, 2002). Some parents may also experience periods of anxiety or depression.

4. Influence of Culture on Coping Mechanisms

Understanding culture provides guidelines for standards of behaviour in the presence of disease (Doumit, Huijjer & Nassar, 2010). Culture refers to a set of contexts, structures, values, traditions and ways of engaging members within a society and is transmitted across generations through social learning (Richerson & Boyd, 2005). In Arab countries, chronic illness is viewed as a long term disorder that causes havoc in the victim's life (Doumit et al., 2010). It is therefore increasingly important to understand the issues surrounding families of children with serious illnesses in the Arab countries, and in particular, the effect on parents and other family members (Graungaard & Skov, 2007). In Saudi societies, shared concepts, rules and regulations are underlined, and are expressed in the way people live. Understanding the interplay among themes, such as coping strategies, faith, body image and identity can highlight innovative ways of addressing and approaching illness. It is important to understand the coping mechanisms of Saudi families to assist health care professionals establish appropriate ways to support families with chronically ill children. There is a paucity of research on coping mechanisms of Saudi families which this study aimed to address.

5. Study Aims and Objectives

This study aims to describe and explore the coping patterns of Saudi parents and in particular the mothers as primary caregivers of chronically ill children.

6. Methods

The inclusion criteria for the sample were Saudi mothers aged 18 years and over with identified chronically ill children aged between 6 months to 16 years with over 3 months hospitalisation periods/year. Mothers were recruited from paediatric wards at three main public hospitals in Jeddah region in Saudi Arabia. Non-Saudi parents and parents whose children had been recently diagnosed with an acute or chronic illness (less than one month) were excluded. Recruiting began after ethical approval was obtained from the Human Research Ethics Committee at RMIT University (BSEHAPP 33 – 11 KATOOA) and the Saudi Health and Medical Research Committee and the High Authority of the Nursing Department in the Saudi MOH. The researcher contacted the director of nursing of each hospital to seek permission to access the paediatric ward. The researcher then met with the paediatric ward head nurse and managers of each hospital and explained the purpose of the study, the data collection tool, and the time required for parents to complete the questionnaire. Subsequently, the paediatric ward head nurse and managers facilitated the recruitment and screening of the eligible chronically ill children within their ward. The study was advertised through posters placed on notice boards of the paediatric wards in the three hospitals. Mothers who met the inclusion criteria were provided with an envelope through the researcher which included a plain language statement explaining the importance of the study, the questionnaire, a card with the researcher's contact details, and consent form. Participants were asked to return the questionnaire to the researcher through a box that were labelled 'Saudi Family Resilience' and placed in the nursing station of each paediatric ward in the three hospitals. All the documents provided in the envelopes were in both Arabic and English. A total of 358 envelopes were distributed, of which 122 were returned giving a response rate of 34%.

To assess the parents' self-efficacy, social support and quality of life, three reliable and valid instruments were used. These instruments were the 'General Self-Efficacy Scale' (GSE) (Schwarzer & Jerusalem, 1995), the 'Social Support Questionnaire' (SSQ) (Sarason, Levine, Basham & Sarason, 1983), and the 'Quality of Life Scale' (QOL) (Flanagan, 1982), in addition to the demographic data. These instruments had Likert-type response scales that were used to enable the researcher to quantify the variables being measured for data analysis. The scales and questionnaires have established reliability and validity in Middle Eastern research studies (Abdel Hai, Taher & Abdel Fattah, 2010; Al Khatib, 2012; Duvdevany & Abboud, 2003; Elsheshtawy & Abo Elez, 2011; Hoffman, Ushpiz & Levy-Shiff, 1988), as they have been translated into many languages including Arabic. These questionnaires and scales identify stress and coping levels, as well as the QOL of individuals living with a chronically ill child. All participants were informed that they were able to choose to respond to either the Arabic or English version of the questionnaire. The data was analysed using SPSS Version 20.00 software. The descriptive statistics analyses and data were presented in the form of frequencies, percentages, means (M) and standard deviations (SD). Correlations were used based on scores on stress and adversity and QOL.

7. Results

7.1 Demographic and Group Characteristics

The demographic characteristics of the 122 participants are summarised in Table 3. The sample was dominated by females with 92% being mothers of chronically ill children. Forty three per cent of the participants were aged 22 to 32 years. Eighty-eight per cent were married, 5% were widowed and 7% were divorced. More than half (56%) of the participants were employed. Participants' family annual income ranged between 24,000 SR and 55,000 SR and above. The majority of participants had at least a secondary or technical level of education (39% had a technical certificate, 26% had a secondary school education, 27% had a tertiary degree)(see Table 2).

Table 2: Demographic and Group Characteristics of the Study (N=122)

Participants of the study	N	Per Cent
<u>Gender:</u>		
Male	8	7
Female	114	93
<u>Relationship to the chronically ill child:</u>		
Mother	112	92
Father	8	7
Grand Parent	2	1
<u>Age groups:</u>		
Less than 21	16	13
22–32	53	43
33–42	37	30
43–52	14	12
Above 53	2	2
<u>Marital status:</u>		
Married	108	88
Widowed	6	5
Divorced	8	7
<u>Occupation:</u>		
Employed	68	56
Unemployed	54	44
<u>Family annual income:</u>		
SR (24,000–35,000)	26	21
SR (36,000–45,000)	34	28
SR (46,000–55,000)	19	16
SR (55,000 and above)	43	35
<u>Highest level of education:</u>		
Primary	9	8
Secondary	32	26
Technical	48	39
Tertiary	33	27

7.2 Family Structural Information and Illness Characteristics

Mothers were asked detailed information about their family structure, the number of sick children in the family, the types of illnesses their children have and the duration of their children's illnesses. They were also requested to identify how much time they were spending with their immediate family, and whether they received respite help, and to identify the source of this respite help. Table 3 below shows the responses of Saudi parents with chronically ill children. The majority of mothers (71%) reported having between one and six children. The majority of the participants in this study (77%) indicated that they had only one child suffering from a chronic illness, whereas 23% reported having two to five children suffering from a chronic illness. Mothers provided detailed information on their children's illnesses or conditions. The most common illnesses reported included: respiratory diseases (32%) and diabetes (26%), with reports of cancer (leukaemia, brain tumour) (16%), blood disorders (anaemia, thalassemia) and cardiovascular diseases (14%), bone and joint conditions (12%), neurological conditions (11%), and kidney and urologic conditions (9%). Furthermore, mothers provided information about the age of the child at the onset of illness, amount of time spent on caring for the child, and the daily activities of the children with chronic illnesses. All illnesses were long term and required significant care. Nearly half of the children (48%) had an age of onset of one to two years, and 22% of the children had chronic illnesses from birth. Almost half of the children (43%) required continuous care, yet the majority of the parents (75%) indicated that they spent time daily with their immediate family. Mothers were also asked to provide information on the sources of respite help they received. Nearly 60% of the participants stated that they received respite help from family and or friends, 25% reported receiving help from multiple sources (including not only family and friends, but also government associations and the hospital). Eighteen per cent of the participants indicated that they were not receiving any respite help (see Table 3).

Table 3: Family Structural Information and Illness Characteristics of the Study (N=122)

Participants of the study	N	Per Cent
<u>Number of children:</u>		
1	35	29
2	30	24
3	22	18
4	21	17
5	7	6
6	7	6
<u>Child's Chronic Condition:</u>		
Neurological condition	13	11
Blood diseases (Anaemia, Thalassemia)	17	14
Cancer (Leukaemia, Brain Tumour)	20	16
Respiratory diseases	39	32
Cardiovascular diseases	17	14
Diabetes diseases	32	26
Bone and Joint conditions	15	12
Kidney and Urologic conditions	11	9
<u>Duration of child's chronic illness:</u>		
From birth	27	22
1-2 years	59	48
3-4 years	23	19
Above 5 years	13	11
<u>Time spent each day in caring activities:</u>		
Less than 1 hour	1	1
2-3 hours	13	11
4-5 hours	29	24
More than 6 hours	26	21
Continuous care	53	43
<u>Immediate family spent time together:</u>		
None	1	1
1-2 hours/day	1	1
3-4 hours/day	4	3
5 and more hours/day	14	11
Daily	92	75
Once a week	0	0
2-3 times a week	8	7
Monthly	2	2
<u>Respite help:</u>		
Family	21	17
Friends	1	1
Hospital	1	1
Government association	2	6
Family and friends	50	42
All	31	15
No help	18	18
<u>Number of sick children in each family:</u>		
1	94	77
2	22	18
3	5	4
5	1	1

7.3 The General Self-Efficacy Scale

The individual item responses for the GSE are presented in Table 4 below. Dividing the value of the mean responses into the four categories (1=not at all true, 2=hardly true, 3=moderately true, 4=exactly true) using the mean score differentiations, three items demonstrated an 'exactly true' mean score, which included 'I can solve most problems if I invest the necessary effort', 'I can remain calm when facing difficulties' and 'I can usually handle whatever comes my way'. However, most subjects demonstrated a 'moderately true' score. Also, it was found that the overall combined mean was 3.25, which reflects a 'moderately true' mean response. In addition, the total GSE scale scores demonstrated a mean (*M*) of 32.52 for the group of 122 subjects, with a standard deviation (*SD*) of 4.05.

Table 4: The General Self-Efficacy Scale Results

	Not at all true		Hardly true		Moderately true		Exactly true		Mean	Std. Deviation	Ranking	Mode
	Per cent	N	Per cent	N	Per cent	N	Per cent	N				
I can always manage to solve difficult problems if I try hard enough.	1.6	2	3.3	4	69.7	85	25.4	31	3.19	.565	6	Moderately true
If someone opposes me, I can find the means and ways to get what I want.	1.6	2	2.5	3	70.5	86	25.4	31	3.20	.555	5	Moderately true
It is easy for me to stick to my aims and accomplish my goals.	1.6	2	4.9	6	72.1	88	21.3	26	3.13	.560	9	Moderately true
I am confident that I could deal efficiently with unexpected events.	-	-	4.9	6	73.8	90	21.3	26	3.16	.487	8	Moderately true
Thanks to my resourcefulness, I know how to handle unforeseen situations.	-	-	4.9	6	69.7	85	25.4	31	3.20	.513	5	Moderately true
I can solve most problems if I invest the necessary effort.	.8	1	3.3	4	27.9	34	68.0	83	3.63	.592	1	Exactly true
I can remain calm when facing difficulties because I can rely on my coping abilities.	4.1	5	6.6	8	46.7	57	42.6	52	3.28	.763	3	Exactly true
When I am confronted with a problem, I can usually find several solutions.	-	-	8.2	10	69.7	85	22.1	27	3.14	.535	7	Moderately true
If I am in trouble, I can usually think of a solution.	.8	1	5.7	7	60.7	74	32.8	40	3.25	.597	4	Moderately true
I can usually handle whatever comes my way.	1.6	2	6.6	8	49.2	60	42.6	52	3.33	.673	2	Exactly true
Combined Mean (3.25 = Moderately true)												

7.4 The Social Support Questionnaire

Results from the SSQ were also provided by individual item scores and by total SSQ score. The individual item scores were divided into six categories (1= strongly disagree, 2= disagree, 3= slightly disagree, 4= slightly agree, 5= agree, 6= strongly agree). From Table 5 below, the results show eight items that demonstrated a mean response score in the 'strongly agree' range and four terms that demonstrated a mean response score in the 'agree' range. The overall combined mean was 5.31, which means that the subjects 'strongly agreed', representing a high social support result. In addition, descriptive statistics for the SSQ score demonstrated ($M=63.66$, $SD =11.665$) for the group of 122 participants, with a minimum score of 12 and a maximum score of 73.

Table 5: The Social Support Questionnaire Results

	Strongly disagree		Disagree		Slightly disagree		Slightly agree		Agree		Strongly agree		Mean	SD	Std.	Ranking
	Percent	N	Percent	N	Percent	N	Percent	N	Percent	N	Percent	N				
There is a special person who is around when you are in need.	1.6	2	-	-	.8	1	10.7	13	13.1	16	73.8	90	5.55	.919	Strongly agree	5
There is a special person with whom you can share joys and sorrows.	.8	1	1.6	2	1.6	2	7.4	9	12.3	15	76.2	93	5.57	.926	Strongly agree	2
Your family really tries to help you.	.8	1	.8	1	4.1	5	4.9	6	11.5	14	77.9	95	5.59	.925	Strongly agree	1
You get the emotional help and support you need from your family.	1.6	2	2.5	3	.8	1	5.7	7	12.3	15	77.0	94	5.56	1.021	Strongly agree	4
You have a special person who is a real source of comfort to you.	.8	1	.8	1	3.3	4	9.0	11	13.1	16	73.0	89	5.52	.947	Strongly agree	6
Your friends really try to help you.	5.7	7	4.9	6	.8	1	19.7	24	19.7	24	49.2	60	4.90	1.445	Agree	11
You can count on your friends when things go wrong.	5.7	7	5.7	7	5.7	7	16.4	20	19.7	24	46.7	57	4.79	1.506	Agree	12
You can really talk about your problems with your family.	3.3	4	2.5	3	3.3	4	7.4	9	15.6	19	68.0	83	5.34	1.237	Strongly agree	8
You have friends with whom you can share your joys and sorrows.	5.7	7	5.7	7	3.3	4	11.5	14	20.5	25	53.3	65	4.95	1.493	Agree	9
There is a special person in your life who cares about your feelings.	.8	1	1.6	2	1.6	2	8.2	10	11.5	14	76.2	93	5.57	.936	Strongly agree	3
Your family is willing to help you make decisions.	2.5	3	1.6	2	3.3	4	8.2	10	13.1	16	71.3	87	5.42	1.142	Strongly agree	7
You can talk about your problems with your friends.	6.6	8	4.9	6	4.1	5	13.9	17	18.0	22	52.4	64	4.91	1.543	Agree	10
Combined Mean (5.31 = Strongly agree)																

7.5 The Quality of Life Scale

For evaluating the scale results, the QOL scale scores were divided by value into seven categories (1=terrible, 2=unhappy, 3=mostly dissatisfied, 4=mixed, 5=mostly satisfied, 6=pleased, 7=delighted). The terms were ranked according to their means, which indicated: (a) that marital comforts, such as home, food, conveniences, and financial security were ranked as first; (b) socialising, such as meeting other people, doing things, going to parties, was ranked second; (c) health, such as being physically fit and vigorous was ranked third; (d) health, such as being physically fit and vigorous was ranked fourth; and (e) the lowest rank was associated with the item of 'participating in organisations and public affairs' (see Table 6). In addition, the overall QOL scores were calculated by summing the results of each item. The overall combined mean score for the group of study participants was 95.49 ($SD=12.07$).

Table 6: The Quality of Life Scale Results

	Strongly disagree		Disagree		Slightly disagree		Slightly agree		Agree		Strongly agree		Mean	SD	Std.	Ranking
	Percent	N	Percent	N	Percent	N	Percent	N	Percent	N	Percent	N				
There is a special person who is around when you are in need.	1.6	2	-	-	.8	1	10.7	13	13.1	16	73.8	90	5.55	.919	Strongly agree	5
There is a special person with whom you can share joys and sorrows.	.8	1	1.6	2	1.6	2	7.4	9	12.3	15	76.2	93	5.57	.926	Strongly agree	2
Your family really tries to help you.	.8	1	.8	1	4.1	5	4.9	6	11.5	14	77.9	95	5.59	.925	Strongly agree	1
You get the emotional help and support you need from your family.	1.6	2	2.5	3	.8	1	5.7	7	12.3	15	77.0	94	5.56	1.021	Strongly agree	4
You have a special person who is a real source of comfort to you.	.8	1	.8	1	3.3	4	9.0	11	13.1	16	73.0	89	5.52	.947	Strongly agree	6
Your friends really try to help you.	5.7	7	4.9	6	.8	1	19.7	24	19.7	24	49.2	60	4.90	1.445	Agree	11
You can count on your friends when things go wrong.	5.7	7	5.7	7	5.7	7	16.4	20	19.7	24	46.7	57	4.79	1.506	Agree	12
You can really talk about your problems with your family.	3.3	4	2.5	3	3.3	4	7.4	9	15.6	19	68.0	83	5.34	1.237	Strongly agree	8
You have friends with whom you can share your joys and sorrows.	5.7	7	5.7	7	3.3	4	11.5	14	20.5	25	53.3	65	4.95	1.493	Agree	9
There is a special person in your life who cares about your feelings.	.8	1	1.6	2	1.6	2	8.2	10	11.5	14	76.2	93	5.57	.936	Strongly agree	3
Your family is willing to help you make decisions.	2.5	3	1.6	2	3.3	4	8.2	10	13.1	16	71.3	87	5.42	1.142	Strongly agree	7
You can talk about your problems with your friends.	6.6	8	4.9	6	4.1	5	13.9	17	18.0	22	52.4	64	4.91	1.543	Agree	10
Combined Mean (5.31 = Strongly agree)																

7.6 Stress and Adversity

While the research instruments used in this study did not directly measure stress and adversity, specific individual items to identify stress and coping were selected from the questionnaires, based on findings of previous studies (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006). These identified that the financial burdens of illness, and the difficulties associated with raising a child with a chronic illness have negative effects on families and cause a high level of stress, not only for the parents, but for all family members (Freedman & Boyer, 2000; Parish & Cloud, 2006). Block and colleagues (2002) reported that families with chronically ill children may be likely to face high levels of stress associated with life adversities. Families with low income, higher unemployment rates and lower levels of education are even more prone to stress-related adversity. Caring for chronically ill children at home can be emotionally, physically, psychologically and financially exhausting for the caregiver. Caregivers require temporary relief from the burden of day-to-day care of these children (O'Connor, Vander Plaats & Betz, 1992). Thus, eight individual questions from the demographic questionnaire supported by evidence relate to: occupation, income, education, number of sick children with a chronic illness in each family, type of child's chronic illness, duration of child's chronic illness, the time parents spent in caring activities for their sick child, and whether the family received respite help. These were selected as measures of stress and adversity. The scores for each demographic item were calculated and added together to obtain a final total single score that inferred the level of stress and adversity of the Saudi parents in this sample (see Table 7).

Table 7: The Total Level of Stress and Adversity

Demographic Variable	Scores
Occupation	0= Unemployed 1= Employed
Income	0= 24,000–45,000 SR 1= 46,000 SR and above
Education	0= Primary or Secondary 1= Technical or Tertiary
Income	0= 24,000–45,000 SR 1= 46,000 SR and above
Number of Sick Children	1= 1 child 2= 2 children 3= 3 children 4= 4 children 5= 5 children
Duration of Illness	1=1–2 years 2=3–4 years 3= Above 5 years 4= From birth
Time Spent in Caring Activity	1=less than 1 hour 2= 2–3 hours 3= 4–5 hours 4= More than 6 hours 5= Continues care
Respite Help	1= Yes 2= No

7.7 Correlations

Correlation statistics were calculated to reveal correlations among social support, QOL, and general self-efficacy. Table 8 below shows the correlations among QOL, GSE, SSQ and stress and adversity, duration of child's chronic illness, family time spent in caring activity, and immediate family time spent together. There was found to be a significant correlation between QOL score and GSE ($p < .001$), between QOL and SSQ ($p < .001$), between QOL and stress and adversity ($p = .02$), between GSE and SSQ ($p < .001$), and between stress and adversity and family time in caring activities ($p < .001$). There is only one significant correlation related to duration of child's chronic illness, which was with stress and adversity. This was not related to QOL, GSE or SSQ. SSQ and immediate family time spent together did not correlate with any of the variables. In addition, a nearly significant result or trend was found between GSE and stress and adversity ($p = .06$) (see Table 8).

Table 8: Correlations QOL, GSE, SSQ, Stress & Adversity, Duration of Child's Illness, Family Time Spent in Caring Activity, and Immediate Family Spent Time Together

	Total QOL	Total GSE	Total SSQ	Total Stress & Adversity	Duration of child's chronic illness	Family time spent in caring activities for the sick child	Immediate family spent time together
Quality of Life Scale (QOL)	1	.46**	.71**	.21*	<.01	-.06	-.01
		< .001	< .001	.02	.95	.50	.95
Total General Self-Efficacy Scale (GSE)		1	.41**	.17	.11	-.11	.01
			< .001	.06	.25	.24	.89
Total Social Support Questionnaire (SSQ)			1	.03	-.01	-.03	.11
				.76	.91	.76	.24
Total Stress & Adversity				1	.56**	.46**	-.04
					< .001	< .001	.67
Duration of child's chronic illness					1	-.029	.10
						.75	.40
Family time spent in caring activities for the sick child						1	.01
							.95
Immediate family spent time together							1

Note: N= 122

** . Correlation is significant at the .01 level

* . Correlation is significant at the .05 level

8. Discussion

In the analysis, parents provided information on the age of onset of illness, amount of time spent in caring for the child, and the daily activities of the children with chronic illnesses. All children in this study had illnesses that were long term, requiring significant care, and could not be permanently cured by current medical treatment. Nearly half of the children (48%) had an age of onset of one to two years, and an additional 22% of the children suffered a chronic illness from birth. Almost half of the children (43%) required continuous care, yet the majority of the parents (75%) indicated that they spent time daily with their immediate family. Mothers were not only caring for their ill children; they were also taking care of their other family members, as well as fulfilling other responsibilities (as a housewife or as an employee). According to these mothers, another important aspect found to significantly affect Saudi parents coping patterns were related to caregiving. More specifically, these factors that negatively affected their coping was the severity of the illness of the sick child. The results revealed significant correlations between QOL score and GSE ($p < .001$); between QOL and the SSQ scores ($p < .001$); between QOL and stress and adversity ($p = .02$); between GSE and SSQ ($p < .001$); between stress and adversity and duration of illness ($p < .001$); and between stress and adversity and family time in caring activities ($p < .001$). In addition, a nearly significant result was found between GSE and stress and adversity ($p = .06$). It can be interpreted from these correlations that the chronic illness (as well as its aspects, such as the severity or length of illness) produces great stress in these families.

Moreover, the variable of the number of sick children in family demonstrated a nearly significant result ($p = .06$), suggesting a particular effect on stress and adversity. Twenty-three per cent of respondents reported having more than one child suffering from a chronic illness (2–5 children). Aside from their ill child (or children), the respondents also had their other children to care for. These participants reported having between one and six children, with the majority of parents having more than one child (71%). Studies from the literature review investigated families with only one child affected by a chronic illness: these empirical studies cited the severity of the condition as a major factor that affected their coping (Gerhardt et al., 2003; Haimour & Abu-Hawwash, 2012; Kilmer, Cook, Taylor, Kane & Clark, 2008; Motamedi, Seyednour, Noorikhajavi & Afghah, 2007; Seltzer, Greenberg, Floyd, Pettee & Hong, 2011).

The study of Seltzer et al. (2011) in particular, found that parents whose children suffered from developmental disabilities were observed to have lower rates of employment, larger size families, and lower levels of social participation. These negative effects were comparatively less grave than those observed in the parents of children suffering from more severe conditions, such as mental health disorders. These parents were more likely to suffer from health conditions and depression (Seltzer et al., 2011). Similarly, Haimour and Abu-Hawwash (2012) observed the same findings in their study, as the QOL scores of respondent families varied according to the type of condition the child suffered from. In contrast, this study found that families of children with learning disabilities had the highest QOL scores (followed by those who suffered from physical disabilities) than those with intellectual disability, with families of children with autism garnering the lowest QOL scores (with most having negative scores). Mothers also provided detailed information on their children's illnesses or conditions. The most common illness reported included: respiratory diseases (32%) and diabetes (26%), with reports of cancer (leukaemia, brain tumour) (16%), blood disorders (anaemia, thalassaemia) and cardiovascular diseases (14%), bone and joint conditions (12%), neurological conditions (11%), and kidney and urologic conditions (9%). This compares favorably with the MOH studies from the literature identified the chronic illnesses among children in the Jeddah region. The five most common diseases in children with long term effects in 2009 and 2011 were respiratory diseases (such as pulmonary infections and bronchial asthma) (48% and 50%), leukaemia (40% and 38%), diabetes mellitus (27% and 34%), anaemia (21% and 28%) and brain tumours (13% and 20%).

As mentioned earlier, in Saudi Arabia, chronic illness is the most diagnosed type of illness among Saudi children annually (Al-Qurashi et al., 2009; Ng, Zaghoul, Ali, Harrison & Popkin, 2011). In this current study, 92% of mothers of chronically ill children were aged between 22 and 42 years. The majority of the mothers participating in this study had the responsibility of caring for their children, because of the nature of the female role in Saudi Arabia (Ali, Mahmood, Moel, Hudson & Leathers, 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish, Zumla, Al-Hakeem, Al-Rabeeah & Stephens, 2013). Women are generally viewed as the primary caregivers for their sick children (Baghdadi, 2011; Elamin & Omair, 2010; Flynn, 2011). The level of support mothers received, whether it was emotional or social, from a variety of individuals: their spouses, children, extended family members, nurses, neighbours, friends and even support groups has also been stated. Sixty per cent of the Saudi mothers stated that they received respite help from family and or friends, 25% reported receiving help from multiple sources (including not only family and friends, but also government associations and the hospital), and finally, 18% of the participants indicated that they were not receiving help.

A commonly recurring observation among the mothers in this study was that the lack of support from the people around them led to lower levels of coping. Saudi mothers most commonly relied on their own family and friends for support, although some of the respondents reported receiving no form of support whatsoever. Previous research has often found parents to be socially isolated when they have a child with a chronic illness, and this adds significantly to their stress and anxiety (Brown et al., 2008; Chiou & Hsieh, 2008; Kratz, Uding, Trahms, Villareale & Kieckhefer, 2009). In addition, Arab women have learned to hide their feelings and pretend that they are healthy, especially when they have any disease that might affect their social life. According to studies by Goldblatt, Cohen, Azaiza and Manassa (2013) as well as Azaiza and Cohen (2008), the way Arab women think is very common because these women who are also mothers are expected to be strong for their families. The women's ascribed role is that of the primary caregiver (Ali et al., 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish et al., 2013). Any weakness, whether perceived or actual, must be hidden for the sake of the family. These women learn to cope with their problems, projecting an image of selfless fortitude by being at the service of their family (Ali et al., 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish et al., 2013).

9. Limitations

A main weakness of the study regarded the sample group used to represent the total population. This related to the relatively small sample size obtained from the selected hospitals, and that this was only in one city in Saudi. Another limitation was that the data were limited to the perspective of the mothers. The number of fathers of chronically ill children who responded was minimal.

10. Recommendations

It is recommended that further studies consider a longitudinal research design to investigate coping mechanisms among Saudi families with a chronically ill child. Observing family coping including mothers, fathers and the siblings of the chronically ill child in a relatively lengthy period of time is particularly important to identify how this develops and changes throughout the duration of the child's chronic illness.

11. Conclusion

It is extremely difficult having a child suffering from a chronic illness. Aside from the financial burdens that accompany with caring for chronically ill children (Lubkin & Larsen, 2006; Lukemeyer, Meyers & Smeeding, 2000); families experience, physical, mental and emotional burdens that add to their challenges (Sharpe & Rossiter, 2002; Hummelinck & Pollock, 2006). This study aimed to explore the topic of how Saudi families cope with all these challenges. This study presented the statistical descriptive results of a study concerning the coping patterns of Saudi mothers with chronically ill children in three main public hospitals in the Jeddah region, in Saudi Arabia. The results of the descriptive statistical analyses provided significant correlations between QOL score and GSE, between QOL and SSQ, between QOL and stress and adversity, between GES and SSQ, between stress and adversity and duration of child's illness, and between stress and adversity and family time spent in caring activities. In addition, a nearly significant result was found between GES and stress and adversity. This research suggests that mothers strive to normalise their lives as much as they possibly can. In order to assist, it is important that these mothers turn to helpful forms of support to cope with the stress and adversity connected to having a chronically ill child. These strategies assist family members to cope and can help foster resilience in each individual in the family to deal with their problems in a healthy and productive manner. More studies are recommended in the KSA to corroborate the findings of this study and to integrate the effect on other family members.

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