

Coping Strategies of Mothers having Children with Special Needs

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Abstract

Families with a child who has special health care needs experience life differently than other families. Mothers appear to carry the larger burden of care and may feel a need to be with their child at all times and experience stress related to coping with the heavy load of care giving. The current descriptive research design is aimed to identify existing coping strategies of mothers who have children with special needs and determine whether there is a relationship between the coping strategies and the mothers' demographic variables. Mother's coping strategies were assessed using the Family Crisis Oriented Personal Evaluation Scale (F-COPES). The study concluded that there is significance relationship between age and both reframing and passive appraisal, as well as between birth order and mobilizing family to acquire and accept help. The study recommended that future research should be done on larger populations and additional research might address the coping strategies of other family members, such as siblings and the extended family.

Key Words : Coping strategies, mothers, children, special needs, Family Crisis Oriented Personal Evaluation Scale (F-COPES).

1. Introduction

For most parents, the birth of their child is a joyous time. However, nearly 4% of parents receive distressing news about their child's health. In fact, about every 3.5 minutes a parent is told that their child has a serious chronic medical illness, health defect, disability, sensory impairment, or mental retardation . For these parents, the time of their child's birth may become mixed with stress and despair (Barnett & et al , 2003). Parenting is a highly stressful job, and becoming a parent of a child with disability is one of the most stressful life events that can occur. Families with a child who has special health care needs experience life differently than other families. Mothers are usually the primary caregivers of these children because most of them remain in the family environment during their treatment and they appear to carry the larger burden of care and they may feel a need to be with their child at all times so they experience stress related to coping with the heavy load of care giving (Thompson, 2000 & James & Ashwill, 2007 & Peters & Jackson, 2009).

Child with special needs is difficult to define, because there is no single definition or classification system that is used .For many years a number of terms have been used to classify and describe children with special health care needs. These terms include chronic illness, congenital disability, developmental delay, developmental disability, disability, handicap, impairment, and technology-dependent child(Stein, Shenkman & Wegener, 2003). More recently there has been impetus to develop a definition of children with special health care needs to be used .To date, children with special health care needs, as defined by the federal Maternal and Child Health Bureau are "children who have or are at increased risk for a chronic physical, behavioral, developmental, or emotional condition and who also require health related services of a type or beyond that required by children in general. The terms "child with special needs" and "disability" are utilized interchangeably"(Hockenberry & Wilson, 2007 & Miller, Recky & Armstrong, 2004 & Msall, Avery & Tremont, 2003 & Beers, Kemeny & Sherritt, 2003) .

Disability is described as any restriction or lack of ability to perform an activity in a manner or within a range considered normal for human beings. There is a large and growing number of persons with physical, mental, or sensory disabilities in the world today. However, the incidence and causes of disabilities vary throughout the world according to age ,level of economic developmental, access to health care, educational, environmental, and other factors(Harwood, Sayer & Hirschfeld, 2004).The estimated ratio of disabled persons ranges between 5.2-18.2% in the world populations. In developing countries, up to 5% of the children are born disabled or became disabled during their childhood .Disability is related to the population's health quality as well as the individual's health problem. The type and causes of disabilities should be determined to detect the precautions which prevent disability and planning approaches for rehabilitation for the disabled . Many factors are responsible for the rising numbers of disabled children .Lack of oxygen in the fetus during birth due to torsion of the umbilical and dystocia, various diseases in the postnatal period, heredity and genetic defects are the most common factors of disabilities (Donbak & et al, 2006 & Cooke , 2005).

Mothers can never fully prepare themselves for the news that their child is different. Whether the diagnosis of a disability is shortly after birth or later on in life, family dreams and expectations suddenly change. Mothers may have to face immediate decisions about their child's medical care and treatment (Case-Smith, 2004). More ever, mothers of children with disabilities cope with the same responsibilities and pressures that other mothers face; however, these mothers reported higher amounts of stress and they experience greater demands made by

caring for a child with special needs. This sense of stress may be associated with a child's characteristics, greater financial and care-giving demands, feelings of being unprepared for the tasks of parenting, and a sense of loneliness and isolation (Sullivan-Bolyai, Sadler & Knafel, 2003 & Oruche & et al, 2012).

Coping involves psychological resources and coping strategies that help to eliminate, modify, or manage a stressful event or crisis situation. Having a child with special needs creates a crisis event, how mothers respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event, the family's sources of support, community resources, and family structure. The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family's ability to cope. Strong marital relationship and social support also help determine mother adjustment (Emerson, 2003 & Fazil, Wallace & Singh, 2004). The goal of coping strategies is to strengthen or maintain family resources, reduce the source of stress or negative emotions, and achieve a balance in family functioning. Strategies directly aimed at coping with the source of stress, such as problem solving and seeking information are more adaptive strategies than those efforts to deny or minimize the situation (Bailey & Smith, 2000).

Moreover, the literature on the adaptation of families of children with special needs repeatedly indicates that it is important for service providers to understand family belief systems, both in a general sense and entity. Researchers document the importance of understanding families' worldviews, values and spiritual beliefs and day-to-day priorities and concerns (King & et al, 2009).

Because each family system is unique, each family may have different coping strategies. So, professionals need to know that what coping strategies are helping each family. One should not assume that any one specific strategy works well for all families. Professionals should identify family sources of support and promote the utilization of both formal and informal support systems. Furthermore, nurses who work with mothers who have children with special needs must understand how to assist the mothers in coping with their stressors. In order to accomplish this, nurses can help mothers realize their abilities and strengths, identify problems, develop problem-solving strategies, and identify new coping strategies (Hockenberry & Wilson, 2007 & Woodgate, Aleah & Seccol, 2008). The professional-parent relationship is also very important. While professionals may suggest ways to help a child with disabilities and offer information regarding the child's disability, mothers are the real experts on their child's like/dislikes and how they communicate. Mothers and professionals need to work together concerning their child's level of care, as well as individual and family needs. Professionals should also direct their attention towards what is helping the mothers cope with the added stressors of raising a child with special needs (Sivberg, 2002 & King, et al, 2009).

2. Significance of the problem

The statistical reports of Ministry of Health in Kingdom of Saudi Arabia (2011) stated that, the total number of handicap was 720000 and this number account for 4% of total population of Saudi Arabia. In relation to children it was reported that, birth rate is 400000 - 500000 per year, about 400 - 500 of them is handicap and they account about 6.3% of all children in Saudi Arabia.

3. Aim of the Study

The aims of this descriptive study were to identify the coping strategies of mothers who have children with special needs and determine whether there is a relationship between the coping strategies and the mothers' demographic variables.

4. Methodology

4.1 Research design:

The current research design was a descriptive design aimed to identify the coping strategies of mothers who have children with special needs and determine whether there is a relationship between the coping strategies and the mothers' demographic variables.

4.2 Setting:

The study was conducted at Out-Patient Clinics in Asser Central Hospital, Abha, Kingdom of Saudi Arabia.

4.3 Subjects:

The study involved 146 mothers having children with different types of disabilities or special needs. The data collected during three months started from February to April 2012. The mothers with their children was attending out-patient clinics in two days only per week (Monday – Tuesday) for follow up.

4.4 Instrument

The data was collected using the following tools:-

(A) -The structured questionnaire sheet was developed by the researcher. It was written in simple Arabic language. The questionnaire was concerned with gathering data related to:

- 1- Mothers' demographic characteristics that include age, marital status, educational level, number of children, sex and birth order of the child with special needs, family monthly income, and the nature of the child's disability.

- 2- An additional open-ended question was added to ask the mothers to further state what was most helpful in coping with their child's disability (i.e., seeking spiritual support, maintaining a positive attitude, seeking help from family members, seeking help from friends, community resources, acquiring additional information, professionals support and others things).

(B) - Mother's coping strategies were assessed using the Family Crisis Oriented Personal Evaluation Scale (F-COPES) developed by (McCubbin, Olson, and Larsen ,1981). This 5-point likert, self-report scale was designed to indicate the point at which a person agrees or disagrees with each statement (1= strongly disagree and 5= strongly agree). The F-COPES contains 30-items that been divided into five coping pattern subscales: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal (McCubbin et al., 1991). Researchers have used the F-COPES in a variety of circumstances, some of which include: parents coping with children who have learning disabilities, mental retardation, or physical disabilities. F-COPES has been shown to have high construct validity and reliability.

4.5 Definition of variables:-

Acquiring social support is the family's ability to actively engage in acquiring support from relatives, friends, neighbors, and extended family (e.g., sharing our difficulties with relative).

Reframing assesses the family's capability to redefine stressful events in order to make them more manageable (e.g., knowing that we have the strength within our family to solve our problems).

Seeking spiritual support is finding comfort in a higher belief system (e.g., participating in religious or spiritual activities).

Mobilizing family to acquire and accept help is the family's ability to seek out community resources and accept help from others (e.g., seeking assistance from community agencies and programs designed to help families in situation).

Passive appraisal is the family's ability to accept problematic issues that minimizes reactivity (e.g., believing if we wait long enough, the problem will go away).

4.6 Methods:

Official permission to conduct the study was taken from the hospitals responsible authorities after explanation of the aims of the study. Self-administered structured questionnaire sheet was developed and Family Crisis Oriented Personal Evaluation Scale (F-COPES), was translated into Arabic by researcher.

A jury of 5 experts in the field of nursing was done to ascertain the content validity of the tool, necessary modifications were carried out accordingly. A pilot study was carried out on 10 mothers having children with special needs to ensure the clarity and applicability of the tools. Family Crisis Oriented Personal Evaluation Scale (F-COPES), was tested for its reliability. Test and retest reliability was computed using a small sample of mothers having children with special needs (10) and it was satisfactory for research purposes ($r = 0.90$).

Data was collected during actual visits to the previously mentioned setting. A self-report questionnaire takes 15-20 minute to be completed. The researcher take verbal consent from the participants after explanation of the purpose of the study. The data was revised, coded, tabulated, and presented using descriptive statistics in the form of frequencies and percentage for qualitative variables, and means and standard deviations for quantitative variables. Qualitative variables were compared using 2-tailed test. Correlation is significant at the 0.05 and 0.01 level. Statistical analyses were performed using the SPSS (Version 17.0) software.

5. Results

Frequencies and percentages of the demographic variables will be presented. Descriptive statistics will be reported on each of the five subscales, as well as the results of the open-ended question. In addition, this section will also discuss any significance found between demographic variables and coping strategies .

Table 1 shows that, more than one third (31.5%) of studied mothers ,their age were more than forty years and the highest percent (47.9%) of them had middle level of education. In relation to marital status, the majority(91.15%) of studied mothers were married. Concerning number of children , more than two thirds (68.5%) of mothers had four or more children and (5.5%) of them had one child. In relation to birth order of the child with special needs, the ranking of (40.4%) of them were the fourth or more . As regards the sex of the child with special needs, more than half of them (51.4%) were male. Regarding monthly income, more than half (52.7%) of studied mothers , their income were sufficient while the income of (47.3%) were not sufficient.

Table 2 indicates that , 40.4% of studied mothers, the nature of their children disability were cognitive disability (mainly Down's syndrome) while (2.1%) of them had psychological disability. In addition, (32.2%) of them had physical disability and the rest (25.3%) of them had both physical and cognitive disability.

Table 3, it is observed from this table that, the most subscale coping strategies used by mothers was acquiring social support followed by reframing.

Table 4 shows that, the most of mothers (43.2%) reported using more than one way in coping with the child's disability is the most beneficial way in coping with the child's disability followed by seeking spiritual support (14.4%) and the least way was seeking help and support from their friends (0.7%).

Table 5 clarifies that, there is significance relationship between age and reframing and passive appraisal, as well as between birth order and mobilizing family to acquire and accept help. Moreover, there is significance relationship between income and reframing and mobilizing family to acquire and accept help. Meanwhile, there is no significance relationship between marital status, level of education, number of children, sex of the child and five subscales of coping strategies.

6. Discussion

When one becomes a parent it is always necessary to adjust to a new way of life and all parents wish for a healthy baby, but some parents though not by their choice are gifted with child with special needs. Some are able to cope up with such a situation and some experience psychological stress. Parenting those child is not an easy task. Having a child with special needs places strain on the whole family (Nissel & et al , 2003). Parents having a child with special needs experience a variety of 'psychological stress' related to the child's disability. Parents especially mothers need every help and encouragement possible in their difficult task, which is, indeed, easier for them while the child is still a baby. An anxious love, on the part of the mother, may do much to exacerbate the defective's disability (Kumar,2008). Following the diagnosis of a chronic health condition in a child, changes occur in the family's day to day routines, plans for the future, feelings and meaning about self (Kuster & et al , 2004). The child with special needs and his or her family are both affected by the child's condition and way of living. Each member of the family experiences effects related to the child's special needs. Family members' experiences and their responses to the child's illness influence each other directly (Kyle, 2008). Mothers who have children with special needs report higher amounts of stress compared to mothers who do not have children with special needs. A mother's ability to adapt to stressful situations depends upon a number of variables, including an individual's psychological strengths, individual and family resources, and the type of coping strategies utilized (Ahmann, 2006).The aims of this study were to identify the coping strategies of mothers who have children with special needs and determine whether there is a relationship between the coping strategies and the mothers' demographic variables.

In relation to characteristics of the studied mothers, the findings of the present study showed that, more than two thirds (63.7%) of studied mothers ,their age were more than thirty years and more than two thirds (68.5%) of mothers had four or more children, the ranking of (40.4 %) of the child with special needs were the fourth or more. In addition, (40.4%) of studied mothers, the nature of their children disability were cognitive disability (mainly Down's syndrome).These results supported by Niazi &et al,(1995) who conducted a study in Riyadh to determine the incidence and distribution of Down's syndrome births during a 9-year period from July 1982 to June 1991, found that an incidence of Down's syndrome was 1 in 554 live births (1.8 per 1,000). A trend towards an increased incidence of Down's syndrome with advanced maternal age or increased maternal parity was found. Similarly, this result is in agreement with Faud,(2006) who stated that, Down syndrome (DS) is a common disorder that occurs in approximately 1:600 newborns; however, this incidence greatly increases among children born to mothers over 35 years of age. Affected children almost always have mental retardation . Moreover, Riper, (2007) who reported that Down syndrome is the most common chromosomal cause of intellectual disabilities and the incidence of it remains steady, occurring once in every 800– 1,000 live births.

As regarding level of education, the results of the present study revealed that, the majority of the mother (71.2%) were educated .No significance was found regarding mother's coping strategies and their level of education. These results are contradicted with Kumar, (2008) who stated that, mothers with higher educational status had low psychological stress and high coping strategy scores. Most of the mothers who are educated seek professional help for coping. Educated mothers are also able to provide appropriate and timely treatment for various problems of the child. The mothers were aware of attending seminars and workshops to enhance their coping strategies and to deal with the problems of the child successfully. Further, the educated mothers are more exposed to the prevailing facilities that will improve their child's condition and enhance the strategies that they can adopt to cope effectively with the psychological stress and they have frequent contacts with the experts and professionals.

Furthermore, more than half of mothers(52.7%%) who had sufficient income. However, a significant relationship was found between family income and reframing as well as family income and seeking spiritual support and mobilizing family to acquire and accept help . Mothers who had a higher income utilized reframing and seeking spiritual support coping strategies to a greater extent than those who had insufficient income. One possible reason for this may be that mothers who have a higher income may also have more resources available to them, which helps make the situation less stressful.

In the open-ended question, mothers had listed a variety of helpful coping strategies. The results found that the majority of mothers (43.2%) listed that using more than one coping methods is more beneficial in dealing with their children's disability. This result supported by Barentt,et al,(2003) who stated that having a wide variety of strategies is more helpful than having only one or two. The results of the current study revealed that, the most coping strategies used by mothers was acquiring social support followed by reframing. This

finding is congruent with Totiska & et al , (2011) who reported that when caregivers are supported, they are better able to cope with the challenges of providing care for a child with special needs. In addition, this result is agreement with Pritzlaff,(2001) who conducted a study to examine the coping strategies of the parents who have children with disabilities, found that, the two most frequently utilized coping strategies were acquiring social support and reframing. Seeking spiritual support was the least utilized. This result is not correspondent with Ayrault, (2001) who stated that some mothers avoid their relatives and friends, fearing that they may not understand their children's needs and spend much of their time caring for their children, taking them for assessment, therapy or medical treatment . As a result, their social life is interrupted and their quality of life in this domain decreases. Similarly, this is confirmed by Li-Tsang & Leung ,(2003) who reported that while it takes time for mothers to accept their children, as the children grow, mothers might feel pressure from society, especially on the occasions when their children exhibit unpredictable misbehavior in public, such as screaming. In order to avoid these embarrassments, mothers sometimes refrain from social activities. Thus, they limit their social networks. Moreover, this result was supported with Churchill & et al,(2010) who conducted a study on 129 parents of children with special health care needs (CSHCN) to describe and quantify coping skills and prevalence of depressive symptoms in those parents and describe the association of coping skills with parental depressive symptoms, severity of child's condition and family demographic characteristics, they found that ,the most coping strategy used by parents was reframing followed by acquiring social support and the least one was seeking spiritual support.

In general, parents of children with disabilities are more withdrawn from society. However, previous reports have observed that some parents actively participate in parental self-help support groups. These parents tend to be educated, with higher intellectual function, stable family backgrounds, no financial difficulties, outgoing, confident, efficient, and motivated. Parents' attitudes, rather than their children's level of disabilities, seem to be the main determinant for active social participation (Atkin, 2000; Li-Tsang, Yau & Yuen, 2001).

7. Conclusion and Recommendations

The present study concluded that, the most of mothers reported that , using more than one coping methods is more beneficial in dealing with their children with special needs. The most used coping strategies was acquiring social support followed by reframing. Furthermore, there is significance relationship between age and both reframing and passive appraisal, as well as between birth order and mobilizing family to acquire and accept help. Moreover, there is significance relationship between income and both reframing and mobilizing family to acquire and accept help. Meanwhile, there is no significance relationship between marital status, level of education, number of children, sex of the child and five subscales of coping strategies. This study recommended that, future research should be done on larger populations , additional research might address the coping strategies of other family members, such as siblings and the extended family. Examining parental coping strategies at different stages of development, further research should focus on comparative study between coping strategies used by mothers versus those used by fathers and personal interviews could be conducted to avoid subjectivity.

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Tables

Table 1: Percentage distribution of mothers according to their characteristics.

<i>Demographic variables</i>	<i>Frequency</i>	<i>Percent</i>
Age		
Less than 20 years	23	15.8
From 20 years to 24 years	11	7.5
From 25 years to 29 years	19	13.0
From 30 years to 34 years	24	16.4
From 35 years to 39 years	23	15.8
More than 40 years	46	31.5
$X \pm SD$	4.03 ± 1.81	
Marital status		
Married	133	91.1
Divorced	6	4.1
Widow	7	4.8
Level of education		
Illiterate	42	28.8
Middle level of education	70	47.9
High level of education	34	23.3
Number of children		
One	8	5.5
Two	20	13.7
Three	18	12.3
Four or more	100	68.5
Birth order of the child with special needs		
First	34	23.3
Second	34	23.3
Third	19	13.0
Fourth or more	59	40.4
Sex of the child with special needs		
Male	71	48.6
Female	75	51.4
Income		
Extremely not sufficient	29	19.9
Not sufficient	40	27.4
Sufficient	66	45.2
Extremely sufficient	11	7.5
Total	146	100.0

Table 2: Percentage distribution of type of special needs.

<i>Type of disability</i>	<i>Frequency</i>	<i>Percent</i>
- Physical	47	32.2
- Cognitive	59	40.4
- Psychological or emotional	3	2.1
- Combination	37	25.3
Total	146	100.0

Table 3 : Descriptive statistics of five subscales of coping strategies.

<i>Five subscales of coping strategies</i>	<i>Mean</i>	<i>Std. Deviation</i>	<i>Maximum</i>	<i>Minimum</i>
Acquiring social support	33.0	9.4	85.00	15.00
Reframing	30.5	6.1	40.00	12.00
Seeking spiritual support	16.9	3.0	20.00	5.00
Mobilizing family to acquire and accept help	15.8	3.6	20.00	7.00
Passive appraisal	12.3	3.2	20.00	4.00

Table 4: Percentage distribution of the most beneficial way in coping with the child's disability (open end question).

<i>Items</i>	<i>Frequency</i>	<i>Percent</i>
- Seeking spiritual support	21	14.4
- Maintaining a positive attitude	9	6.2
- Seeking help and support from family	16	11.0
- Seeking help and support from friends	1	0.7
- Professionals support	17	11.6
- Acquiring additional information	5	3.4
- Community resources	14	9.6
- Others (more than one way)	63	43.2
Total	146	100.0

Table (5) Relationship between demographic characteristics and five subscales of coping strategies

<i>Characteristics</i>	<i>Acquiring social support</i>		<i>Reframing</i>		<i>Seeking spiritual support</i>		<i>Mobilizing family to acquire and accept help</i>		<i>Passive appraisal</i>	
Age	-.053	.522	.164*	.048	.155	.062	-.055	.510	.182*	.028
Marital status	.146	-.135	.146	-.155	.038	.647	-.052	.535	.010	.905
Level of education	-.028	.737	.155	.061	.077	.353	-.017	.840	-.037	.661
Number of children	-.017	.834	.044	.599	-.050	.552	-.118	.156	-.018	.825
Birth order	-.089	.284	.044	.599	-.050	.552	-.188*	.023	-.018	.825
Sex of the child	-.069	.405	.087	.295	.045	.587	-.107	.197	-.110	.185
Income	.114	.170	.190*	.022	.046	.579	.286**	.000	-.025	.76

** Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).