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Psychosocial problems among the families of children with physical special needs: A cross-sectional survey in Saudi Arabia

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Abstract

Background: The disability of any child affects not only the child themselves but also impacts their families. The extent of this impact can affect the family's ability to function well and may delay the speed with which they can reach their expected outcome goals. In Saudi Arabia, very limited research has been done on the psychological aspects of being the parent of a child with a disability. Hence, this study aims to assess the psychosocial problems faced by parents of a child with a disability.

Methods: The study design of this research was a cross-sectional as well as an exploratory correlational study. The study was conducted in the Prince Sultan bin Abdulaziz Humanitarian City and the Disabled Children's Association in Riyadh city. The subjects of the study were the families of 153 Saudi children.

Results: The results of the study revealed that "anxiety" was the most common psychological problem, with the highest mean (1.503). "Feeling stress as a result of carrying hardship of care" had the highest mean (1.96) among the family's social problems. "The child's integration in social life" had the highest mean (3.013) among perceptions on how to best care for the child, followed by "dealing with the situation in a realistic way" (2.922).

Conclusion: The study indicated the presence of anxiety and psycho-physiological symptoms for the among families of physically disabled children. Feeling stressed as a result of the increased hardship of childcare as well as the extra expenses and the absence from work were common social problems for the families. Hence, we recommend sharing both verbal and physical affection within the family, along with economic aids, support groups and educational resources.

Keywords: Disabilities; Child; Parents; Psychological; Social; Emotional; Saudi Arabia.

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1. Introduction

The disability of a child poses a lot of difficulty to said child as well as their family, creating obstacles that limit their ability to function well, and slowing down the tare with which they can reach expected outcome goals[1]. From a sociological perspective, a family is a social system which represents one of the bases of society that is formed through mutual agreements between two adults. The aim is commonly to further establish a healthy happy family with maximum wellbeing and enjoyment [1, 2].

The family's assumed primary duty is to train, develop, look after children, establish good communication between family members, and help children in the process of gaining their independence as they grow older [3, 4]. A child who is mentally or physically disabled deserves to have an equal chance of training and developing in the direction of physical health and mental growth [4, 5].

Among many families, the initial diagnosis of a child's disability represents a crisis that is likely to be a difficult and shocking experience to the parents [6]. In most cases, initial family reactions are likely to be negative and, like those related to bereavement [7]. The family may experience the different stages of grief upon receiving this news starting with disbelief and denial and ending with acceptance [7]. After the shock and disbelief phase, families could adapt flexibly and mobilize into effective action, or freeze in various degrees of rigid and ineffective reactions, whereas others tend to resist or even deny the diagnosis itself [7, 8].

It should also be noted that the families of children with disabilities face both the normal pressures and tensions throughout their life as well as those as a result of the child's disability. The family's inability to adjust to the presence of child with a disability is another dilemma to the whole family that usually requires assistance in order to reorganize their lives while maintaining positive adaptation [9-11].

Disability places a set of extra demands or challenges on the family system; most of these demands last for a long time. Many of these challenges cut across disability type, age of the person with the disability, and type of the family which the person has [12, 13]. Parents of children with disabilities play an essential role in the successful rehabilitation of their children. However, the high level of care required may affect the mental health of the parents. It may exacerbate parents' complains and consequently contribute to unfavorable rehabilitation outcomes that may reciprocally be reflected on the child [13, 14].

Parents experience a wide variety of negative emotions, which range from mild anger to tiredness and frustration. Psychological problems such as depression may limit the role of parents in the management of the child's illness [13-15].

The emotional distress of a parent may contribute to the emotional and psychiatric distress of the child and may affect the family's ability to cope with the disability, thus making the disability have a greater impact on the family [16]. There are some studies that suggest that poor psychological health in the caregiver is associated with more severe disability in the child. A child's disability is a potential stressor, and diminished functional independence in the child typically translates into increased care-giving demands on the parents [17, 18].

Several published articles have found increased symptoms of depression and incidence of major depressive disorder among parents of children with medical conditions [13-15, 17]. Therefore, early identification of parents who are at risk of poor mental health is important because interventions directed at caregivers are likely to be more successful if they target modifiable determinants of parenting burdens and address specific parental needs. In Saudi Arabia, research on the psychological aspects of parents of children with disabilities has been very limited. Therefore, this study aims to assess the psychosocial problems faced by parents of child with physical disabilities.

2. Subjects and Methods

2.1 Study design

The study design of this research is a cross sectional study, and an exploratory correlational study

2.2 Study setting:

The study was conducted in the Prince Sultan bin Abdulaziz Humanitarian City and in the Disabled Children's Association in Riyadh. The Prince Sultan bin Abdulaziz Humanitarian City is part of the Prince Sultan bin Abdulaziz charity association and is a non-profit organization.

2.3 Subjects:

The total number of the study participants was **153** Saudi children's families. **83** children's families participated from the Prince Sultan bin Abdulaziz Humanitarian City**,** while the families of **70** children were sampled from the Disabled Children's Association. The response rate was (100%) all questionnaires distributed were returned.

2.4 Study tools:

A structured self-administered questionnaire was developed by a researcher after reviewing the literature to understand the subject to collect data and information about the study. The questionnaire consisted of four parts. The first part was about the demographic information. The second and third parts were about the family’s psychological problems and social problems, respectively. The fourth part was about the parents’ perception about how to best care their child. A four-point Likert scale were utilized to score these tools range from continuously (4), to rarely (1).

2.5 Statistical technique:

All information in the questionnaire were coded and entered into the computer through statistical package for social sciences (SPSS) version 22. Variables were described using frequency distribution for categorical variables and means with standard deviations for continuous variables according to the objectives of the study. Pearson's correlation coefficient was used to reveal the validity of the internal consistency of the study instrument. For the measurement of the reliability of the study instrument Cronbach's alpha was used.

2.6 Ethical considerations:

Ethical approval was obtained from the Prince Sultan Bin Abdulaziz Humanitarian City and Disabled Children’s association in Riyadh Saudi Arabia. Subjects were assured that their confidentiality would be maintained and were made aware of all research ethical rights, i.e. that inclusion is voluntary in the study and that they could refrain at any time from continuing the study.

2.7 Validity and reliability of the questionnaire:

The validity of internal consistency of the questioners was tested using person correlation coefficient between the score of each item in the questionnaire and the total score of all items in each scale. The Pearson’s correlation coefficients show that all the statements are significantly correlated with the total score of each scale. The reliability of scales was tested using Cronbach's Alpha coefficient. Table 1 show the overall reliability of 0.828, which is high and excellent.

Table (1) **Reliability of the factors**

Scale	Cronbach's Alpha value
The family psychological problems	0.825
The social problems	0.753
Understanding parent’s perception about how to care their child	0.864
All items	0.828

3. Results

3.1. Socio-demographic characteristics for the family and the child:

Most of the respondent family members were between the ages of 30 and 45 years (64%). The majority of the primary caregivers were mothers (80.4%). 55% of the children were males and 45% were females. 35.3% of the children were younger than 4 years of age, 41.1% were younger than 8 years of age and 23.5% were older than 8 years. The disabilities of 32% of the children were diagnosed immediately after birth, whereas 68% of the children were diagnosed later in different circumstances. Regarding the education level, most of the parents had completed their secondary & university level of education and no one among them was illiterate. Near two thirds of them had no job, while the family income of the majority (55%) of them ranged between 5000 and 10000 SAR. Moreover, over half of the subjects had less than five of family members.

The majority (60.7%) of the children's disabilities were mobility type. Quadriplegia-polio accounted for 11.8%, while paraplegia polio constituted 7.8% and 15.7% of the sample mentioned other disabilities. Most of these disabilities were caused by a lack of oxygen (52.3%), an injury of the central nervous system (7.8%), an injury of spinal cord (5.9%), or other factors (34.1%).

3.2. Psychological problems of parents with children physical special needs.

Table 2 shows the analysis of the family psychological problems scale items. The overall mean was 1.27, which indicates that psychological problems within the family are rare to happen as the overall mean fall in the category "rarely".

Table (2) Family psychological problems scale items

Statement	**Rarely**	**Sometimes**	**To a large extent**	**Continuously**	**Mean**	**Standard Deviation**
	%	**%**	**%**	**%**		
Psycho somatic symptoms without mentioned organic reasons	77.80%	14.40%	5.90%	2.00%	1.32	0.675
Psycho-Physiological Symptoms (diabetes, high blood pressure, skin disease...)	75.20%	11.10%	3.30%	10.50%	1.49	0.974
Hypochondria and compelling fears	83.70%	11.10%	3.30%	2.00%	1.235	0.604

High sensitivity in interaction with others	75.20%	15.70%	6.50%	2.60%	1.366	0.723
Depression	82.40%	12.40%	3.90%	1.30%	1.242	0.585
Anxiety	65.40%	23.50%	6.50%	4.60%	1.503	0.812
Agoraphobia	78.40%	13.10%	7.20%	1.30%	1.314	0.664
Aggression	98.70%	1.30%	0.00%	0.00%	1.013	0.114
be arrogant	95.40%	3.30%	1.30%	0.00%	1.059	0.286
Unrealistic Thinking	87.50%	9.20%	2.60%	0.70%	1.164	0.481
Social Withdrawal	82.40%	13.10%	3.30%	0.70%	1.281	0.949
Emotions Disruption	77.10%	17.60%	4.60%	0.70%	1.288	0.581
Attention deficit	79.10%	11.80%	7.20%	2.00%	1.32	0.694
Inability of decision making	79.70%	8.50%	5.20%	0.70%	1.209	0.558
Negative thinking	81.00%	14.40%	4.60%	1.30%	1.275	0.61
Overall					1.271	1.268

3.3. Are parents of children physical special needs at a higher risk of social problems than other families?

Table 3 shows the analysis of the family social problems scale items. The overall mean was 1.44, which indicates that family social problems were rare to happen as the overall mean falls in the category “rarely”.

Table (3) Family social problems scale items

Statement	**Rarely**	**Sometimes**	**to a large extent**	**Continuously**	**Mean**	**Standard Deviation**
	%	**%**	**%**	**%**		
Impressment with Psychological Problems	86.90%	9.80%	2.60%	0.70%	1.17	0.484
Quarrelling with children	73.20%	19.00%	5.90%	2.00%	1.366	0.686
Quarrelling with family members	73.90%	20.90%	3.90%	1.30%	1.327	0.616
Social withdrawal and isolation	78.40%	15.00%	5.20%	1.30%	1.294	0.627
Affected by the opinions of others about your child	69.90%	20.90%	4.60%	4.60%	1.438	0.785

Drop-out the participation in social activities	73.90%	17.60%	6.50%	2.00%	1.366	0.695
Feeling stress as a result of carrying hardship of care	41.80%	28.80%	20.90%	8.50%	1.961	0.986
Shame because the others asking why is the disability	83.00%	11.10%	4.60%	1.30%	1.242	0.596
The child extra expenses considered a materialistic pressure	59.50%	15.70%	17.60%	7.20%	1.725	0.995
Absence form work	63.40%	20.30%	11.10%	5.20%	1.582	0.886
Marital problems	69.90%	19.00%	5.20%	5.90%	1.471	0.843
Overall					1.443	0.745

3.4. Parents' perceptions about how to care for their child:

Table 4 shows the analysis of the parents' perception of how to best care for their child scale items. Statement "The child integration in social life" had the highest mean (3.013), which indicate that this item is the most common to show in the parent's perception about how to care for their child scale, as they fall in the second category to a large extent. Then comes in second the statement "Dealing with realism" with mean (2.922). Then comes in third statements "Awarding the child with an opportunity to express himself and express about his opinion" with mean (2.837). The least impact statements in this scale are "Requesting support from Friends" with mean (1.739) and "Participating in the special needs Clubs" with mean (1.24).

Table (4) Parents' perceptions of how to care for their child scale items

Statement	Rarely	Sometimes	To a large extent	Continuously	Mean	Standard Deviation
	%	%	%	%		
Dealing with the situation in a realistic way	19.00%	6.50%	38.60%	35.30%	2.922	1.097
No- isolation in the home	40.50%	13.10%	17.00%	28.80%	2.359	1.291
The child toward the only concern	35.90%	19.60%	24.20%	19.60%	2.294	1.169
The child integrating in social life	15.00%	11.80%	30.70%	41.80%	3.013	1.082

Requesting assistance from specialists	23.50%	20.30%	24.80%	30.70%	2.647	1.167
Requesting support from Friends	55.60%	24.80%	9.80%	9.80%	1.739	0.992
Supporting the other family members	27.50%	25.50%	23.50%	22.90%	2.438	1.14
Giving the siblings the responsibility of caring for their disabled sibling	42.50%	26.80%	20.30%	9.80%	1.993	1.042
Motivating the child on Independence	30.70%	19.60%	28.80%	20.30%	2.405	1.144
Participating in the special need's clubs	55.60%	18.30%	13.70%	12.40%	1.83	1.081
Awarding the child with an opportunity to express himself and express about his opinion	21.60%	11.80%	28.80%	37.30%	2.837	1.167
Not talking with the child about the disability	54.90%	17.00%	16.30%	11.10%	1.856	1.097
Entering the child to a school which appropriate to his needs	45.80%	3.30%	19.60%	31.40%	2.366	1.336
Educating the Child that the world is a way crossing to the other Permanent world	44.40%	11.10%	15.00%	29.40%	2.294	1.302
Provide his with patience	30.70%	9.20%	20.30%	39.20%	2.699	1.288
Informing him that Allah will reward you on that pain	34.20%	5.30%	17.80%	42.10%	2.697	1.337
Overall					2.39	1.17

4. Discussion

The psychosocial problems of disabled children can contribute to a variety of training difficulties and may hinder mental health, well-being and life enjoyment. Parents may suffer if they do not learn of new trends on coping as well as strategies for managing the situation. The family plays a vital role in guiding the child to be a member of the society. In order to meet the expectations [16, 19]. Having physically disabled child may exert pressure on the parents' psychologically, physically and in their social functioning. It is necessary to look at the issues related to parents of physical disabled children psychosocial aspects[20, 21].

In the present study, mostly mothers participated and gave answer to the questionnaire. Similar studies in the same field revealed that mothers were the main caregivers for the disabled child. Similarly, the care-giving mothers were within the same age group of the families as present in this study [22, 23].

The analysis of the families' psychological problems reveals that psychological problems are rare to happen among families of children with disabilities, as reflected by the overall mean. Furthermore, result showed that "anxiety" had the highest mean and was therefore the most common psychological problem for families, followed by psycho-physiological symptoms (diabetes, high blood pressure, skin disease). A different study on the effects of providing a high level of care for a child with a disability concluded that the functional limitations may affect the psychological health of the parents [8, 13]. Psychological problems such as depression have been ranked by other studies as the most common problems among parents and were said to limit the role of parents in the management of the child's illness[12].

Analysis of the family social problems in the present study indicate the presence of family social problems in spite that many answered that it rarely happened. "Feeling stress as a result of carrying hardship of care" had the highest mean an was therefore the most common form of social problems for families. The research has evaluated the types, degrees and determinants of the stress faced by the families in caring for their disabled members. It has been evident and well documented that the parents of children with disabilities experience chronic stress [24, 25]. The difficulties encountered by parents coping a disabled child and their familial relationships have been cited as a source of anxiety, overprotection, rigidity, as well as an explanation for lower levels of coherence, less emphasis on the personal growth of other family members, and a greater emphasis on control within the family [26, 27].

However, for some parents, not having enough money, marital conflict, recent bereavement or simply having two or more very young children were greater sources of stress than the child's disability. In addition, a lack of emotional support was found to be of a greater effect on quality family performance [28]. The intervening effect of mediators like social support will enable parents to cope better with the situation thus minimizing the effect of problems they face in the family and in society [15, 29, 30]

Analysis of the parents' perception of how to care for their child reflect that the overall mean is (2.39) which indicate that statements within the parent's perception about how to care for their child are to a large extent happen as the overall mean. The major perceptive problems were of "the child's integration in social life". Studies report that parental expectations from their disabled child were mostly negative and unrealistic. Studies reveal that this negative attitude adversely affects the parents. Family members of children with disabilities are often perceived to experience harmful psychological effects. These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction. Parents are found with unstable emotionality, constant grief, psychological ill health, and unsatisfactory social health. It is also found that the parents of children with disabilities perceive more problems in themselves and their families [31, 32].

Most of the literature has highlighted the stress and the subsequent negative consequences whenn caring for a child with a disability. The primary focus in this literature seems to be on stress, strain, grieving, and other negative issues. In fact, researchers have even proposed that when a child is diagnosed as having a severe disability, the parents may experience similar cognitive processes to those individuals who have experienced a traumatic event [33].

Although many researchers have found that the families of children with disabilities report more stress than other families, other research shows that there is no clear evidence that they also report fewer positive feelings or perceptions[34]. In fact, data is suggestive of no differences or even reports of more positive perceptions in families of children with disabilities [35].

In a review of published research on positive perceptions of families with children with development disabilities, Hastings and Taunt (2002) compared themes, items and factors in various research studies and found some key themes about the nature and structure of parents' positive perceptions and experiences of their child with a disability and the caregiving experience [36].

There are quite a few methodological issues which ought to be discussed here. As it was a Cross-sectional study, we cannot preclude inferences of causality. Secondly, the questionnaire was self-administered and there was a possibility of over reporting. Despite these limitations, our questionnaire shows high reliability and 100% response rate.

5. Conclusion

Results of this study showed the presence of psychosocial problems among families of physically disabled children, reflected by the presence of anxiety and psycho-physiological symptoms. In regard to social problems, it manifested in the form of stress as a result of increased hardship of childcare, the extra expenses causing a materialistic pressure. Also, absence form work was among the social problems. Although each family's situation is unique, there are some recommended aspects that can help parents of children with disabilities and may be useful to share both verbal and physical affection within the family.

There are areas of need (medical services, childcare) which should be available as an economic aid, as well as aid in socialization through joining a support group for parents. Educational resources are also helpful in providing clear information about the disability and the educational and behavioral implications.

6. Declarations

6.1 Conflict of Interest Statement

The authors have no conflict of interests to declare.

6.2 Funding Disclosure

None.

7. References

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