

Stress, Coping Strategies, and Quality of Life among Jordanian Parents of Children with Autistic Disorder

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Abstract

Background: Parents in different cultures show different psychological functioning when caring for a child with chronic disability such as Autistic Disorder. Arabs are united in a shared culture that is considered substantially different from their western counterparts. Nevertheless, no investigations regarding the experience of parenting a child with Autistic Disorder have been made in the Arab world yet. Therefore, the purpose of this study was to investigate the psychosocial impacts of raising children with Autistic Disorder in a sample from the Arab world. The study examined the levels of parenting stress, the coping strategies, and the levels of quality of life reported by Arab parents.

Methods: Using a descriptive cross-sectional design, the convenience sample of the study consisted of 184 parents of children with Autistic Disorder. Data were collected using self-administered questionnaires on parenting stress, coping strategies, and quality of life.

Results: The results revealed that parents of children with Autistic Disorder experience significant high levels of parenting stress. Positive reappraisal was the most frequently used coping strategy among those parents. Meanwhile, confrontive coping was the least frequently used strategy. In regard to parents' quality of life, parents reported poor physical, psychological, social, and environmental health scores, with mothers reporting relatively lower scores. The lowest scores for parents were reported on the environmental health domain.

Conclusion: The findings from this study indicate that Jordanian parents of children with Autistic Disorder suffer significant impairments in their psychosocial health. Thus, those parents are in need for a wide range of support and educational programs that offer broad information about Autistic Disorder alongside with therapeutic and effective strategies to address their stressors and improve their quality of life.

Keywords: Autistic disorder; Parents; Quality of life; Parenting stress; Arabs

Introduction

Autistic Disorder has been recently recognized as a major epidemic problem found in all racial and ethnic groups and across the socioeconomic continuum [1]. It is considered one of the most complex childhood developmental disabilities that can devastatingly affect children's communication and social abilities [American Psychiatric Association (APA), 2000]. A substantial body of research has uniformly found that parenting a child with Autistic Disorder can disturb the whole family life and result in several economic, social, physical and psychological problems [2-4]. Therefore, the quality of those parents' lives is placed in serious jeopardy. In fact, parents of children with Autistic Disorder have been found to experience significantly higher levels of parenting stress and psychological distress compared with parents of typical children and parents of children with other developmental disabilities [5,6].

Parenting a child with chronic pervasive disability is considered a unique experience that varies significantly according to its socio-cultural contexts. Thus, in order to conduct valid and reliable support programs for affected parents; recognition of diversities among cultures is necessary. To date, all the studies that have targeted parents of children with Autistic Disorder were conducted in western or developed eastern countries. No studies have investigated the experiences of parents providing care to children with Autistic Disorder in the Arab world. Arabs have their unique culture that is considered substantially different from westerners [7]. Further, in low- and middle-income countries (as in most of the Arab countries), parents who have a child with Autistic Disorder face a pile up of several

stressors due to their low socio-economic status and poor household conditions. Indeed, according to United Nations (UN), 85% of people with disabilities live in developing countries, and therefore are doubly disadvantaged by poverty and disability [8]. The UN has also reported that interventions targeting Autistic Disorder in developing countries face many challenges, most notably the poor treatment of the cases due to the presence of many co-morbidities and the lack of adequate number of centers and trained staff to deal with this disorder.

According to the World Health Organization's world report of disability (WHO, 2011), one of the main obstacles that hinder the establishment of efficient support programs for parents of children with Autistic Disorder in the developing countries is the lack of research studies that can inform about the psychosocial impacts of raising children with Autistic Disorder on their parents. Therefore, the purpose of this study was to investigate the psychosocial impacts of raising children with Autistic Disorder in a sample from the Arab world. The study examined the levels of parenting stress, the coping strategies, and the levels of quality of life reported by Arab parents.

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Autistic disorder Jordan

Jordan is a low-income country which is located in the Arab region. The population of Jordan is about 6.5 million [Jordanian Department of Statistics (DOS), 2012]. The country is a relatively homogeneous society with 98% of the total population extending from Arabic origins. The health sector in Jordan provides primary, secondary and tertiary health care to the general population via a network of hospitals and health care centers, which are distributed across the country [9,10]. The health care system in Jordan is one of the most efficient in the region in delivering high standards of care to people with disabilities. In a national effort to support the children with Autistic Disorder and their families, the Jordanian Ministry of Social Development (JMOSD) [11] developed a comprehensive plan to provide reliable diagnosis and early detection methods for the disorder. Further, the plan worked on conducting training courses for staff assigned to provide care for the diagnosed children and expanding service coverage for individuals with Autistic Disorder (JMOSD, 2012). On the other hand, there are notable efforts to raise the public awareness about Autistic Disorder and its lifelong impacts.

A non-official statistics have recently released showing that the registered number of children diagnosed with Autistic Disorder in Jordan reached around eight thousands (Petra, 2011). As there is no register of people with Autistic Disorder in Jordan, accurate incidence rates are not available. However, estimates based on the international screening studies can be done. The most recent report provided by the CDC revealed that autism spectrum disorder has an average of 1 in 110 children in the United States, while the percentage is higher in Asia, Europe, and North America [12]. Regardless debatable statistics, Autistic Disorder is perceived by many countries as a disorder that can result in a strain on the service system in terms of the cost, provision, and organization of supports for children with Autistic Disorder.

Methods

Procedure

Using convenience sampling, a total of 426 questionnaires were distributed to parents of children with Autistic Disorder. Of them, 184 clean questionnaires were returned. Almost all the available eligible centers in the country were reached yielding a relatively representative sample. The Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (fourth edition, text revision) was used to diagnose the children by certified licensed professionals (APA, 2000). Those professionals worked collaboratively to accurately validate the diagnosis of children as Autistic Disorder. The criteria of the DSM-IV were used across the regions from which children were recruited as it is considered a standardized diagnostic procedure for Autistic Disorder in the country. Parents were contacted through public and private Jordanian centers and associations that offer services for children with Autistic Disorder. Participants who agreed to participate in the study were offered a detailed description for the study purpose, procedures, benefits, risks, duration, confidentiality and participants' rights. Participants were then provided with a package that contained three questionnaires on parenting stress, coping strategies, and QoL, and a fourth questionnaire on the parent's and their children's characteristics. Furthermore, the author met the participants individually and in group and provided them with the needed instructions on how to fill the questionnaires. Participants were also provided with explanation sheet to ensure their understanding.

Ethical considerations

The ethical guidelines for nursing research were adequately applied and followed. The rights of the participants were carefully protected. The study was reviewed by the Academic Research Committee at the Faculty of Nursing and the Academic Research Committee at the Deanship of the Academic Research and gained the University of Jordan approval. The participants were fully aware about the study purpose, expectations, significance and contact information to access the investigators and to express interest in participation. In addition, participants were aware about the study procedures, benefits, risks, and duration. Confidentiality of the information obtained was assured by assigning an identification number to the participants. Each participant received small incentives for participation.

Measures

The Parenting Stress Index-Short Form (PSI-SF): The PSI-SF is a 36-item self-reported questionnaire designed to measure stress associated with parenting [13]. The measure has three subscales, each consisting of 12 items: Parental Distress (PD); Parent-Child Dysfunctional Interaction (PCDI); and Difficult Child (DC) [14]. The items of the scale range from 1 (strongly disagree) to 5 (strongly agree) and has a 5th grade reading level. The expected time to complete the questionnaire was between 10 and 15 minutes. In the present sample, Cronbach's alpha coefficient ranged from .82 to .91 for the participants across the total stress scale and the three subscales. Based on guidelines in the PSI-SF scoring manual, the PSI-SF yields scores for each subscale as well as a total score. The total scores can range from 36 to 180 with high scores starting at or above a score of 90. Raw scores above 33 on the PD and DC subscales and above 27 on the PCDI subscale are considered clinically elevated [14].

The Ways of Coping Checklist-Revised (WCC-R): The Revised Ways of Coping Checklist is an empirically derived inventory composed of 66-item coping strategies that people use to deal with the internal and/or external demands of specific stressful encounters [15]. Fifty of the items are grouped into eight scales: Confrontive coping, Distancing, Self-controlling, Seeking social support, Accepting responsibility, Escape-avoidance, Planful problem-solving, and Positive reappraisal [15]. Participants were required to respond to a specific stressor (raising a child with Autistic Disorder) and subsequently respond to each statement in the scale by expressing the extent to which they used the strategy in coping with that stressful situation on a 4-point scale from 0 (not used) to 3 (used a great deal). In this sample, Cronbach's alphas for the eight subscales ranged from moderate to high.

The World Health Organization Quality of Life Assessment-Brief WHOQOL-BREF self-administered instrument: The WHOQOL-BREF has been developed by the WHOQOL Group to provide a short form QoL assessment that looks at domain level profiles, using data from the WHOQOL-100. It is based on a four domain structure [16]. Each domain covers several aspects of individual's life. The WHOQOL-BREF contains a total of 26 items. The range of score in each item is between 1 and 5, with higher scores denoting higher QoL levels. A validated Arabic version for the WHOQOL-BREF was used after gaining the permission from the WHO permissions and licensing center [17]. The Cronbach's alphas for the QoL scale and subscales as resulted in this study have ranged between .67 (for the 3 items of social relations) and .93 (for the 24 items total scale).

Translation procedures: Validated Arabic version for the WHOQOL-BREF was used in this study. The measure was validated

by Ohaeri and Awadalla (2009) and was used in this study after gaining the official permission from the WHO measurement and health information systems. No validated Arabic versions were available for the PSI-SF and WCC-R. However, a translated Arabic version for the PSI-SF was obtained from the PAR publisher of psychological assessment materials. A translated Arabic version for the WCC-R was obtained from one of the authors of the scale. The translated versions went through several procedures to determine its reliability and validity including face validity, content validity, and internal consistency reliability tests. Pilot testing was conducted to confirm the appropriateness of the translation. The piloting yielded reliable and valid results for subsequent work.

Pilot testing: We never test the depth of a river with both feet. A pilot study was conducted prior data collection to guide the planning of the large-scale investigation. The goal was to assess recruitment potential; to assess the feasibility of collaboration and coordination with the proposed recruitment settings; to increase clinical experience with the study protocol; to refine or modify the research methodology for a study, and identify any potential obstacles and challenges in a reasonable period of time so it could be possible to avoid potentially disastrous consequences of embarking on a large study. A total of twenty one participants were included in the pilot study. Of them, 11 participants were mothers. The mean age for the sample was 33 years (SD=4.5). All were married and had diploma or baccalaureate degree. Only one of the participants had a female child with autistic disorder. The mean age for the children was 3.8 years (SD=1.29). Reliability analyses for the translated scales were checked and revealed that all the translated Arabic versions of the scales had Cronbach's Alpha Coefficients ranging from 0.61 to 0.92, indicating moderate to high internal consistency. Overall evidence of feasibility of the study was identified and the goals of piloting were successfully achieved.

Results

Sample's characteristics

One hundred and eighty four participants were included in this study. The mean age for the sample was 37 years (SD=7.6) ranging from 21 to 69 years. The vast majority (96.7%, n=178) were married (the rest was divorced), and about half of the participants (53%, n=99) had diploma or baccalaureate degree. Approximately, half of the participants (51.1%, n=94) had no medical insurance. Of the remaining participants who had an insurance, only 9.8% (n=18) had their insurance covering the health services for their child's Autistic Disorder. Almost 80 % of the participants were living under the poverty line. Regarding the parents' monthly payment for Autistic Disorder-related care, the mean score was 193 JD (SD= 234; 1 JD=1.4 US Dollar) ranging from 0 to 1000 JD. About half of the participants (53.5%, n=98) had two to three children including their child with Autistic Disorder. The majority of the participants reported that mothers were the primary caregivers for their children with Autistic Disorder (83.7%, n=154). The rest reported that both fathers and mothers shared the caring responsibilities. Only one female participant reported that the father was the primary caregiver for the child with Autistic Disorder.

In regard to the children's with Autistic Disorder characteristics, 84.2% (n=155) of them were males. The mean age for the children was 6.3 year (SD=3) ranging from 2 to 12 years. The mean age for the children at which symptoms firstly appeared was 2 year (SD=1). Table 1 shows the demographic characteristics of the parents (Table1).

Demographics	Fathers (n=70)	Mothers (n=114)
Age: Mean (SD)	39.9 (7.6)	35.4 (7.03)
Income: Median (SD)	420 (650)	412 (630)
	N (%)	N (%)
Education		
11 th grade or less	13 (18.6)	17 (14.9)
Tawjihi (high school)	19 (27.1)	36 (31.6)
Diploma	16 (22.9)	28 (24.6)
BSc and higher	22 (31.4)	33 (28.9)
Employment		
Employed	59 (84.3)	22 (19.3)
Not employed	11 (15.7)	92 (80.7)
Marital status		
Married	69 (98.6)	109 (95.6)
Divorced, widowed, separated	1 (1.4)	5 (4.4)

Table 1: Demographic characteristics of the participants.

Scale+	Fathers (N=70)		Mothers (N=114)		All sample (N=184)	
	Mean	SD	Mean	SD	Mean	SD
PD	39.06	10.34	41.05	10.51	40.29	10.47
PCDI	38.51	8.61	37.20	8.80	37.70	8.73
DC	39.31	7.77	40.34	7.91	39.95	7.86
Total Score	116.89	22.53	118.60	22.60	117.95	22.53

+ PD (Parental Distress); PCDI (Parent-Child Dysfunctional Interaction); DC (Difficult Child)

Table 2: Means and standard deviations (SDs) for the Parenting Stress Index Scales.

Stress

The PSI-SF that was used in this study to measure parenting stress has a reliability scale (Defensive Responding) consisting of seven items from the parental distress subscale. Respondents scoring less than a raw score of 10 is thought to signify either that parents are minimizing parenting stress, that they are more competent than the average parent and unusually sanguine, or that they do not care enough about the child to feel stressed by the difficult behavior [14]. In this study, the mean score for the defensive responding reliability scale was 23 (SD=5.7) indicating valid results for subsequent analyses.

The analysis showed that the mean score for the fathers' stress was 117 (SD=23) ranging from 43 to 167. The mean scores for the PD, PCDI, and DC subscales were (39, SD=10); (39, SD=9); and (39, SD=8) respectively. For mothers, the reported mean stress score was 119 (SD=23) ranging from 47 to 168. Table 2 shows the mean scores for the total stress and three subscales for fathers, mothers, and the entire sample. To have a closer view for the profiles of parenting stress, the percentages of parents who were in the clinically significant range was identified. The results revealed that approximately 89% of the parents reported stress scores higher than 90.

Coping strategies

The results revealed that positive reappraisal was the most commonly used coping strategy among both the father and mothers of children with Autistic Disorder. Meanwhile, confrontive coping was the least frequently used coping strategy. Table 3 presents the eight coping strategies as reported by the parents.

Quality of life

The WHOQOL-BREF scale produces a profile with four subscales scores and two individually scored items about an individual's overall perception of QoL and health (Q1 and Q2). With regard to the first

Scale+	Fathers (N=70)		Mothers (N=114)		All sample (N=184)	
	Mean	SD	Mean	SD	Mean	SD
Positive reappraisal	72.90	12.33	75.19	13.34	74.30	12.97
Seeking social support	68.39	17.09	71.98	17.07	70.57	17.12
Planful problem-solving	66.84	14.87	66.78	14.44	66.80	14.57
Self-controlling	63.72	12.45	64.97	12.32	64.48	12.35
Accepting responsibility	57.76	16.36	62.50	14.78	60.64	15.54
Distancing	55.77	13.50	56.91	14.92	56.47	14.36
Escape-Avoidance	55.49	14.97	55.70	15.01	55.62	14.95
Confrontive coping	54.70	13.64	55.50	13.57	55.19	13.56

+ A standardized total scores (percentages) were used to facilitate comparisons between the scales.

Table 3: Means+ and standard deviations (SDs) for the eight coping subscales.

Scale+	Fathers (N=70)		Mothers (N=114)		All sample (N=184)	
	Mean	SD	Mean	SD	Mean	SD
Physical health	67.67	14.37	64.91	13.84	65.96	14.07
Psychological health	63.47	14.27	59.67	16.00	61.12	15.43
Social health	69.04	15.76	64.26	17.33	66.08	16.87
Environmental health	55.92	13.92	55.78	14.21	55.84	14.06
Total Score	82.38	15.42	79.23	16.81	80.43	16.33

+A standardized total scores (percentages) were used to facilitate comparisons between the scales.

Table 4: Means+ and standard deviations (SDs) for the QoL subscales.

question in the QoL scale (how would you rate your quality of life?), the results revealed that 41.8% (n=33) of the fathers described their QoL as either good or very good. For mothers, about 48% rated their QoL as good or very good. Regarding the second question in the QoL scale (how satisfied are you with your health?), almost half of the fathers and mothers were satisfied with their health.

On the QoL subscales, both fathers and mothers showed similar pattern of physical, psychological, social, and environmental health scores, with mothers reporting relatively lower scores across the four subscales. The lowest scores were reported for the environmental health domain (Table 4).

Discussion

Autistic Disorder represents one of the most complex childhood developmental disorders that can dramatically affect parents' psychological functioning. Therefore, it is important to have the research work directed toward the goal of reducing the negative psychological impacts of such unique parenting experience. Assessing the nature of these impacts would be an appropriate beginning to meet this goal. This study was conducted in an attempt to highlight the pathways between parenting stress, coping strategies and QoL among Jordanian parents of children with Autistic Disorder, a scope that has not been covered adequately in Jordan.

Parenting stress

Parenting stress is an aversive psychological reaction to the demands of being a parent that stems from a complex combination related to the child, the parent, and the child-parent interactions [14]. Caring for a child with chronic and complex disability like Autistic Disorder is considered a significant source of stress for parents. This stress involves psychological and physical strain over long periods of time, has the capacity to spill over into various areas of parents' life, and it is frequently accompanied by low levels of QoL.

Consistent with previous relevant studies [18,19], the results of

this study revealed significantly high levels of stress among parents across the three PSI-SF subscales as well as the total level of stress. According to Abidin, total stress score reflects the stresses the parents are experiencing specifically due to their role as parents. Thus, it can be inferred from this study that Jordanian parents of children with Autistic Disorder need to be referred to mental health professionals who can help them adapt with their chronic stressors [14].

With regard to the PD subscale, the significant high results reported by the parents reflect that their stress is negatively affecting their sense of parenting competence and may lead to many restrictions on their lives. Therefore, according to Abidin [14], interventions aimed at raising parents' self-esteem and sense of parental competency may be helpful. The high scores for the parents on the PCDI scale indicate a sense of dissatisfaction and disappointment with their children interactions. Abidin [14] maintained that parents who report high score on this scale should be given information to enhance their confidence and competence in their ability to bond and build intimate relationship with their child. This study also revealed high scores on the DC scale. High scores on the DC scale reflect how difficult the parents perceive their children. Those parents are expected to benefit greatly from strategies aimed at handling challenging behaviors [14].

Parental coping

The results showed that positive reappraisal was the most commonly used coping strategy among the parents. According to Folkman and Lazarus [15], positive reappraisal can be defined as efforts to create positive meaning by focusing on aspects like personal growth, finding new faith, rediscovering the important things in life, and being inspired to be creative. The high reporting of the use of positive reappraisal as a coping strategy may be partially explained by the Jordanian culture where one need to believe in God's will and pray to bring comfort and calm. This can be supported by the finding that "I pray" was one of the items among the 'positive reappraisal' strategy which showed high scores among the parents. On the other hand, the irreversibility of the chronic illness of their children might be positively associated with parents' religious activities in an attempt to find new faith and strengthen personal growth.

'Seeking social support' was also found to be the next highest strategy in use among parents of children with Autistic Disorder. This result is consistent with previous findings that viewed seeking social support as one of the most important for parents of children with chronic disability [20,21]. Moreover, as the sample of this study is part from the Arab world, social support is considered a valued Arabic tradition that plays a prophylactic role in the development of mental health problems. The extended family system in the traditional Arab cultures was found to significantly help individuals deal with their life stressors [22,23]. The sample demographic characteristics also supported this finding as the vast majority (97%) of the parents was married.

Distancing coping was found to be amongst the least frequently used coping strategies. Distancing was defined by Folkman and Lazarus [15] as undertaking cognitive efforts to detach oneself from a stressful situation and minimize its significance. Convictions like 'went on as if nothing had happened'; 'refused to think too much about it'; and 'tried to forget the whole thing' are examples of distancing responses measured through the distancing subscale. Distancing coping can work as a moderator in the relationship between stressors and mental health [24,25]. Therefore, parents with chronic stressors may benefit from being encouraged to distance themselves appropriately from

their situation [26]. On the other hand, almost half of the parents were using 'escape avoidance' as a coping strategy. It should be noted that although avoidance strategy may be helpful in the short term, it can adversely affect the mental health of the parents when used on the long run when dealing with chronic stressors such as raising a child with a lifelong disability [27].

Overall, the results revealed that Jordanian parents of children with Autistic Disorder employ several coping styles to deal with their children-related stressors. The findings revealed that all coping strategies were used by the parents with percentages reached almost 50%-70%. The ability of parents to adopt variety of coping responses is considered by itself a positive indicator that can lead to positive mental health outcomes [28].

Parental QoL

Quality of life is believed to be comprehensive and multidimensional outcome measure which can be used to explore subjective variables such as subjective wellbeing and life satisfaction [29]. This study examined the QoL concept among parents of children with Autistic Disorder. The results revealed poor physical, psychological, social, and environmental health scores. The lowest QoL scores were reported on the environmental health domain, while the highest scores were found in the social health domain.

The low scores in the environmental health domain can be explained by referring to the parents' socioeconomic status. Almost 79.3% (n=146) of the participants were living under the poverty line defined by the directorate of economic statistics at the Jordanian department of statistics (2010). As such, the housing and living conditions are expected to be unsatisfactory for the parents. The highest scores in the social field can be partially explained by the Jordanian culture. An extended family system dominates the Jordanian culture. In this type of family structure, households can be a beneficial living arrangement to all those who partake in it. Children in extended families learn to share and get love and safe, convenient and free childcare from grandparents [30,31]. Therefore, working parents can have no worries of their children's day care. Extended family systems in the Arab world provide more resources to help member in times of tragedy through creating a support system emotionally, financially and culturally.

Limitations

There are some methodological issues that should be considered when interpreting the results of this study. First, this study used cross-sectional data to explore parents' of children with Autistic Disorder perceived stress, coping, and QoL which are considered dynamic processes that change over time. Second, the study did not assess the influence of the characteristics of children with Autistic Disorder on their parents' psychological adjustment. However, several studies have suggested that a major source of stress for parents arises from social acceptance of the child's disability rather than from the child's disability itself. In other words, the presence of a child with disability in the family might be stressful regardless of the severity of the disability and it may be more directly associated with factors such as social support which has been already measured in this study using the QoL-social health domain.

Conclusion, Implications and Recommendations

As can be gleaned from this study, having a child with Autistic Disorder in a family poses unique and long-term challenges for the

parents who become at risk for negative psychological outcomes including high levels of stress and impaired QoL.

Empowering parents of children with Autistic Disorder by helping them make use of available sources of social support, providing assistance with coping strategies, and enhancing feelings of self-control are particularly worthwhile for those parents. A better understanding of the parenting experiences and their effects on health is needed. The parents need to be integrated into the planning and delivery of health care services provided to their children. Parents of children with Autistic Disorder need the collaborative partnerships with professionals which is often associated with positive outcomes for both the child and the family QoL. The provision of support services would be especially beneficial in developing countries like Jordan where formal support is almost nonexistent and the stigma of a child with disability is there hindering the informal support as well.

Another important area that needs a special attention in practice is related to the diagnostic procedures for Autistic Disorder. Although the DSM-IV diagnoses of Autistic Disorder is adopted in most of the diagnostic clinics and centers in Jordan, a standard diagnostic instrument should also be used to further validate the clinical diagnosis. On the other hand, the breadth of research needs to be expanded by moving beyond description and focusing more efforts on identifying interventions that could enhance family functioning. It is also recommended to conduct research that investigate the long-term outcomes of different coping strategies and stress responses for diverse groups of families with children with Autistic Disorder.

Additional research is also needed to provide a deeper understanding of the influence of the relationship within the family subsystems (e.g., marital subsystem, siblings' subsystem). Studying these subsystems may illuminate the bidirectional influences that those systems have on each other which in turn can provide a clearer picture for the dynamics of families that have children with Autistic Disorder.

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