



Ways of coping and mental burnout of Bedouin mothers compared to Bedouin fathers of children with ASD

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ABSTRACT

Objective

The present study compares the ways of coping, and mental burnout of Bedouin mothers with those of Bedouin fathers of children with autism spectrum disorder (ASD), and examines whether there are any relations between these variables.

Method

A comparison was made between the 74 Bedouin mothers and 74 Bedouin fathers of children with ASD, on ways of coping, and mental burnout. Questionnaires were used: a demographic questionnaire; a Ways of Coping Questionnaire, developed by Folkman and Lazarus and Mental Burnout Questionnaire developed by Pines.

Results

In the comparison between Bedouin mothers and Bedouin fathers of children with ASD on the measures of ways of coping differences between mothers and fathers were found only for escape-avoidance coping. On the measures of mental burnout, a significant difference was found thus, the mothers showed significantly higher mental burnout than the fathers. In examining the relations between the variables: significant relations were found between ways of coping strategies and mental burnout for both Bedouin mothers and fathers of children with ASD.

Conclusions

The findings of the current study highlight the need for subsequent research, particularly on the escape-avoidance coping, as well as on culturally-tailored interventions, which are focused on social support for both parents.

Keywords

Ways of coping, Mental burnout, Bedouin parents, ASD

Introduction

Autism spectrum disorder (ASD) is a debilitating, life-long neuro-developmental disorder characterized by social deficits, restricted interests and repetitive behaviors [1]. Children

with ASD have more challenging behaviors [2], sleep disorders [3] and psychopathologies [4,5] than typically developing children. Every culture in the world has children with ASD and the diagnosis of ASD for children continues to rise.

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Although cross-cultural similarities exist related to stress in caring for a child with disabilities [6,7], individual and cultural differences play a critical role in how parents respond and cope with the challenges related to their child [8]. Relatively little is known about the coping behaviors of Middle Eastern mothers, and there is only one published study on fathers [9]. Till now, no research has been conducted on fathers in the Bedouin community.

The Bedouin community

The Bedouin community has unique characteristics. It is estimated that the population of Bedouins living in the Negev numbers about 190,000 people [10]. This is a traditional, tribal and patriarchal society that lives in familial clans. The permanent Bedouin townships are ranked in the lowest national economic standard-of-living percentiles. Yet only half of the Bedouin population lives in these recognized townships; the other half lives in unrecognized settlements, where there are no basic municipal services.

Women in the Bedouin community do not have a role in the public sphere. Their responsibilities are limited to their household: the family tent, procreation and raising their children are their only duties. Bearing many children, especially boys, reinforces the social status of women in the Bedouin community. In addition, there is a barrier between them and the outside world, due to a variety of reasons, such as for instance: the distance from the city, the insufficient means of transportation and road infrastructure, cultural restrictions on women's independence and movement, a lack of child care, and being responsible for a large number of children. In fact, some live without basic conditions, such as water and electricity.

With regard to men and their role in the community: the man is the breadwinner, and family protector. Characteristic of traditional and collective societies around the world, here as well, gender determines division of labor. This maintains the existing social structure and places the man as the highest authority in management of the family and the tribe [11]. This study is, therefore, significant in its unprecedented assessment of ways of coping and burnout in Bedouin parents, taking particular note of fathers of children with ASD. The conclusions found here provide a unique contribution to the literature on gender differences in parental coping.

Ways of coping, mental burnout

Families of a child with ASD face unique challenges and stressors due often to an ambiguous diagnosis, the severity and duration of the disorder, and problems with the child's lack of adherence to social norms. Parents of children with ASD confront daunting challenges and multiple demands in their daily life. Compared to parents of children with other disabilities or to those of typically developing children, parents of children with ASD exhibit higher levels of stress, anxiety and depression. Therefore, a family whose child has ASD must make significant adjustments in order to cope and function adequately [12].

Also, the family system is an important part of the environment and plays a central role in the developmental outcome of children [13]. Studies of families with a child with ASD have traditionally examined this interaction by focusing on the effect parents have on the child, rather than the child's effect on the parents. More recently, research has focused on the difficulties that parents face related to caring for a child with ASD, and the strategies employed to cope with the stress associated with raising these children [14]. However, the majority of studies on ASD focuses on the mother-child relationship and typically do not include an analysis of the fathers.

Ways of coping - One of the main challenges for parents is to effectively cope with the child's condition while juggling the requirements of everyday living. Coping may be a valuable and much utilized tool for positive family functioning in families that have a member with a disability [15].

Over the last two decades, researchers have studied the ways of parental coping with children with disabilities [16]. Despite the abundance of research on coping styles of families of children with disabilities, the research on coping among parents of children with ASD, in particular, remains scarce [17]. Therefore, one of the aims of this study was to examine the ways of coping among Bedouin parents and to examine whether there is a connection between coping and family functioning.

Burnout - A recent meta-analysis suggested that parenting stress is higher in parents of children with ASD than in parents of typically development children. Other studies have shown that the stress levels of mothers of children with ASD are higher than those of mothers of non-

disabled children [18]. Quantitative cohort studies and quasi-experiments in Latin America found that the sensation of tiredness and high demand on the parents caused by taking care of the child with ASD did not change in the time of the follow-up. Another important finding was the higher prevalence of exhaustion in mothers than in fathers [19,20]. The findings of a study published in 2015 showed that life stress, burnout and depression are closely associated and could share some underlying mechanisms [21]. The depression and the emotional exhaustion are correlated with the number of life stress events [21]. According to the description made by Procaccini and Kiefaber [22], parental burnout is a condition resulting from untreated chronic exhaustion due to the persisting demands of family needs and the cessation of non-parental activities, which deplete the energy and motivation of the parents [22].

Raising a child with ASD can be enervating. These children experience a complex range of social, emotional and behavioral difficulties that present significant and ongoing concerns for parents [23]. However, there have not yet been studies that examine this dimension in parents of children with ASD in the Bedouin community. This study will examine the mental burnout among mothers compared to that of the fathers, as well as the potential connections between coping, and mental burnout of mothers as compared with fathers.

The purpose of the study

The assumption of this study which is based on the characteristics/different roles of fathers and mothers in the Bedouin community are that the roles of the each parent are fundamentally different, and so substantial differences will be found in the nature of the coping, and mental burnout of each of these groups. Therefore, the purpose of this research is to reveal whether there are differences between Bedouin mothers and fathers of adolescent children with ASD on these measures. The key three questions of this study are as follows:

- 1) Are the ways of coping, and mental burnout of Bedouin mothers of children with ASD different from those of the fathers?
- 2) Will there be differences in the character of the correlations between Bedouin fathers and mothers of children with ASD in the variables of ways of coping and mental burnout?

Method

■ Participants

Participants in the study were 148 Bedouin parents, (74 mothers and 74 fathers) of children with ASD, all between the ages of 10-18, 81% boys and the rest, 19%, girls. All attend a special education school for students with ASD in the Negev. In order to be included in the study, the parents had to have at least one child that had been diagnosed with ASD, by a specialist physician, according to the criteria of the DSM-IV-TR (2000). They also needed to receive approval from a placement committee, which then referred them to a special education school for students with ASD, as is customary in Israel according to the Special Education Law (1988). The criteria for participants in the study were parents who: can read and write, agree to sign an informed consent form, live in a non-polygamous family, are married, and have at least one child with ASD. The parents' demographic characteristics are presented in **Table 1**.

The number of children of the parents is distributed in the following way: 3% 5-10 years old, 79% 11-16 years old, and 18% 17-21 years old. With regard to income sources, none of the mothers reported that they work; 49% of the fathers reported that they had work; and the remaining 51% reported that they receive an allowance.

■ Procedure

After the study was approved by the ethics committee of the Chief Scientist of the Ministry of Education of the State of Israel, a pool of parents who had children attending the school for students with ASD was selected. The teachers presented the study and its objectives to the parents, as well as the intended use of the data to be gathered throughout the research. Each parent needed to sign a consent form, and to parents who live together (families who have polygamous marriage were not selected). The data were stored protecting the anonymity of the participants. The data collection process took place from April, 2015 to August, 2015.

■ Assessment tools

Demographic questionnaire and family profile

Questions were asked regarding the age, gender, number of children in the family, level of education, family's source of income, and the gender and age of the child with ASD.

Table 1: The demographic characteristics of the parents.

Demographic variables	Mothers	Fathers
	(N=74)	(N=74)
Age (%)		
30-39	18	3
40-49	52	28
50-59	23	62
60 and older	7	7
Education (%)		
Below high school	82	4
High school	61	89
Higher education	2	7

The two questionnaires were translated from English to Arabic by two bilingual translators working separately from the Bedouin community. The two versions were then evaluated by a PhD student of the Arabic language who chose the most culturally appropriate translation. The goal of this procedure, as recommended by the World Health Organization, was to obtain a language version conceptually equivalent to the English instrument but appropriate for the target culture. In other words, the focus was on achieving a cross-cultural and conceptual equivalence rather than on a linguistic/literal one. The culturally appropriate translation criteria in this study were as follows: (a) Formal Arabic was used instead of spoken Arabic which differs between villages. (b) Relevancy: translating the conceptual equivalent of a word or phrase (not a word-for-word translation). (c) Simplicity, clarity and conciseness. (d) Consideration of gender and age issues and avoidance of using terms that would be considered offensive to the target population.

Ways of Coping Questionnaire (WOC)

The Ways of Coping Questionnaire- WOC was developed by Folkman and Lazarus [24]. grouped into eight scales: Confrontive coping (six items; refers to making active effort to contain a situation, sometimes associated with aggression, hostility and risk taking), Distancing (six items; undertaking cognitive efforts to detach oneself from a stressful situation and minimize its significance), Self-controlling (seven items; an individual’s active effort to regulate their feelings and actions), Seeking social support (six items; refers to effort aimed at obtaining informational, tangible and emotional support), Accepting responsibility (four items; refers to the recognition of one’s contribution to the problem and undertaking efforts to overcome it), Escape-avoidance (eight items; includes wishful thinking and behavioral efforts to escape the problem), Planful problem-solving (six items; focusing

on solving the problem in order to contain the situation, includes careful problem analysis and generation of possible solutions), and Positive reappraisal (seven items; covers efforts aimed at creating a positive meaning for a situation by focusing on personal growth). There are 66 self-report items. Each item is scored on a 4- point Likert-type scale based on the frequency with which the individual has utilized that particular coping strategy [24]. The internal consistency reliability coefficients ranged from .68 to .79 for these subscales [24]. Participants are asked to recall a recent stressful parenting situation (one that occurred over the past 2 weeks), and then to estimate the frequency with which they used the coping strategies described by individual items. The ratings are 0 (does not apply or not used), 1 (used somewhat), 2 (used quite a bit) and 3 (used a great deal).

Mental burnout questionnaire

The questionnaire was developed by Pines [25] and its purpose is to measure the physical exhaustion that occurs as a result intensive mental involvement (with a challenging situation over an extended period of time). The questionnaire includes 21 items. The 21 items correspond to the three components of the burnout definition physical exhaustion (e g, feeling weak, tired, rundown), emotional exhaustion (e g, feeling depressed, trapped, hopeless) and mental exhaustion (e g, feeling worthless, disillusioned, and rejected), Four of the 21 items are positive (eg, feeling happy, optimistic). Parents were asked to mark their answer on a 5-scale Likert scale (1 = very rarely, to 5 = very often) as to the frequency with which they experience the statements that are described in the questionnaire. The mothers and the fathers filled out the questionnaire separately. The reliability of the questionnaire ranges from 0.66 - 0.89 (Pines & Aronson, 1981). In this study, an internal reliability of 0.92 was found. The burnout score is the average of the responses to all the individual items. The higher the score, the higher the level of burnout.

■ **Data analysis**

First, t tests for dependent samples were carried out, in order to see if there are any differences between mothers and fathers in: A) the ways of coping (confrontive, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, positive reappraisal) with their child’s disability; B) The measure of emotional burnout. Second,

in order to examine the relations between the ways of coping and the level of parental mental burnout, correlation analysis was conducted for each group between the variables of ways of coping and the mental burnout.

Results

Differences between Bedouin mothers and fathers of children with ASD in ways of coping, and mental burnout

To compare coping strategies used by mothers and fathers of children with ASD (parent's gender) analysis of variance was carried out for each of the coping strategies scales (Table 2).

However, in a comparison of the Bedouin mothers and fathers of children with ASD on mental burnout (Table 3), a significant difference was found thus, the mothers showed significantly higher mental burnout than the fathers.

Correlations between variables-ways of coping and mental burnout in Bedouin mothers compared to fathers of children with ASD

In examining the relations between the ways of coping and mental burnout of the fathers compared to the mothers (Table 4), Pearson r correlation coefficient was calculated between the overall mental burnout and its eight coping strategies for each parent group separately (Tables 4).

The findings in Table 4 reveal that in examining the relations between the ways of coping and the mental burnout of the fathers compared with those of the mothers, in the group of mothers, the highest mental burnout correlation coefficients were obtained for accepting responsibility and distancing. Accepting responsibility was found to be negatively correlated with mental burnout. The use of distancing strategy was positively correlated with mental burnout. Mental burnout was also positively correlated with self-controlling and seeking social support. In the group of fathers, the strongest positive correlations were found between mental burnout and self-controlling and seeking social support.

Discussion

This study examined the ways of coping and mental burnout, and the interactions among these variables in Bedouin mothers compared to Bedouin fathers of children with ASD.

Table 2: A comparison of means and standard deviations of the coping strategy of Bedouin mothers and fathers of children with ASD.

Coping Strategy Mothers of children with ASD (N=74) M SD	Fathers of children with ASD (N=74)	
	M	SD
Confrontive 14.33 2.14	14.46	2.66
Distancing 10.20 1.74	9.18	1.18
Self-controlling 16.64 2.12	5.84	2.32
Seeking social support 11.60 2.90	13.73	2.72
Accepting responsibility 10.25 1.80	9.42	1.50
Escape-avoidance 24.00 3.60	21.50	3.24
Planful problem-solving 12.79 2.41	11.81	2.15
Positive reappraisal 15.00 2.77	15.94	2.97

Differences between mothers of children with ASD and fathers were found only for escape-avoidance coping Mothers of children with ASD (mean for the whole group=24.00) used this strategy more often than fathers (mean for the whole group=21.50).

Table 3: A comparison of means of the mental burnout of mothers compared to fathers of children with ASD.

Variables	Mothers of children with ASD (N=74) M SD	Fathers of children with ASD (N=74) M SD	F(7,89)
	Mental burnout	4.92 .76	

***P<.001

Table 4: Correlations between ways of coping of fathers compared to mothers and the level of burnout for each group.

Coping Strategy	Mental burnout	
	Mothers	Fathers
Confrontive	-.074	-.120
Distancing	.321*	.080
Self-controlling	.263*	.441**
Seeking social support	.266*	.412**
Accepting responsibility	-.452**	-.004
Escape-avoidance	.120	0.201
Planful problem-solving	-.211	-.118
Positive reappraisal	-.211	-.250

*p<0.5, **p<0.1

The comparison in terms of parental coping strategies revealed only one difference between fathers and mothers of children with ASD. The only difference was found in escape-avoidance coping, which was employed more frequently by mothers of children with ASD. Other investigators have reported similar results [26].

Withdrawal from a stressful situation may be associated with increased level of stress, parental depression and decreased level of positive mood [27-29]. It follows from the results of the present study that mothers of children with ASD should be supported in developing those coping methods that will protect them from stress and reduce its negative consequences. It should be noted, however, that the difference between the study

groups in terms of this strategy was minor, with membership in a particular group accounting for only a small percentage of variance.

Regarding the measure of mental burnout, the mothers scored significantly higher than did the fathers. This is not surprising, considering that the Bedouin mother is primarily responsible for the raising and care of children. Furthermore, she is the one who manages the challenges and needs of the child with ASD, and often with neither professional support, nor a sufficient understanding of the nature of her child's difficulties. Several studies have investigated the frequency and severity of emotional exhaustion among parents of children with disabilities [30,31]. Those studies showed an association between the parent's gender and the emotional exhaustion level. Few of these studies done outside North America and have examined levels of caregiver burden across different ethnic groups. White American caregivers report more negative consequences and burden than black American caregivers [32], even though the former were less likely to reside with their ill son or daughter [33]. No previous studies have directly examined differences in burden among parents in the Bedouin community in Israel.

The study also examined correlations among the variables: ways of coping and mental burnout and of the Bedouin mothers compared to that of the fathers of children with ASD. The findings of this study reveal that in examining the relations between the ways of coping and the mental burnout of the fathers compared with those of the mothers, in the group of mothers, the highest mental burnout correlation coefficients were obtained for accepting responsibility and distancing. Accepting responsibility was found to be negatively correlated with mental burnout. The use of distancing strategy was positively correlated with mental burnout. Mental burnout was also positively correlated with self-controlling and seeking social support.

In the group of fathers, the strongest positive correlations were found between mental burnout and self-controlling and seeking social support.

Mental burnout is a dynamic disposition which encourages adaptive coping. In this study, mental burnout, were positively associated with seeking social support and self-controlling in Bedouin parents of children with ASD. As we know, coping by seeking support is associated with level of daily positive mood [29] and parents' subjective well-being [34]. Our results add

to this picture by showing that the higher the level of mental burnout, the more likely parents are to use coping by seeking support and make efforts to regulate their feelings and actions (self-controlling coping). A particularly interesting result is the relationship between mental burnout and accepting responsibility in Bedouin parents of children with ASD. Mental burnout was negatively correlated with this coping strategy. Accepting responsibility, similar to distancing, self-controlling and escape avoidance is characterized as way of managing a stressful situation through cognitive and emotional efforts without modifying the situation itself. It is described as mainly emotion-focused coping [24]. People who use this coping strategy blame themselves for the problem [35]. This strategy may be associated with negative outcomes of stress [24] and depression [36]. Glidden [34] showed that accepting responsibility is negatively correlated with subjective well-being in parents of children with developmental disabilities. It is particularly important to investigate the determinants of this strategy due to its negative effects. Our findings may suggest that one of the negative consequences of low mental burnout may be a tendency to blame oneself for the occurrence of stressful situations related to parenting the child. It should be emphasized that this relationship was only found in the group of mothers. This information adds to our knowledge on the underlying mechanisms of self-blame and could be an important factor to take into account in mothers support programmers. In the group of fathers, statistical analysis revealed positive correlations between distancing and mental burnout. So far we have not established what determines the use of this coping strategy by fathers. In some circumstances, especially those associated with a sense of helplessness in fathers, it could potentially play an important role in coping with stress. This issue requires further analysis, especially in the context of other empirical data suggesting that distancing is negatively related to family strengths [37].

Based on these findings, it is critical for support service experts to develop formal and informal social support tailored to the Bedouin culture and its values, for the families of children with ASD.

Limitations

It is important to bear several limitations in mind when considering the findings and

implications of this study. The first is that this research was the first to examine the way(s) of coping, and mental burnout of Bedouin parents of children with ASD, in general and of the fathers' perceptions in particular. Therefore, no cause-effect inferences can be made. Moreover, using self-report as the exclusive method of data collection is inherently limiting. It is also important to note that the findings of this study are correct within the specific cultural context of the Bedouin community in Israel, and should be applied judiciously to cases of parents who have children with ASD in non-Arabic speaking western communities in the world. By the same token, further research in other non-Western/non-English speaking communities is needed in order to deepen our understanding of the challenges and needs of parents of children with ASD.

Conclusion

Significant differences were found between Bedouin mothers and fathers of children with ASD on ways of coping as well as mental

burnout. In an examination of the relations between the variables: significant relations (positive and negative) were found between ways of coping and mental burnout, in both Bedouin mothers and fathers of children with ASD. These findings underscore the need for further research, in particular, on the dimension of and in light of the argument of Higgins [38] that little work has been conducted in particular on (the impact of mental burnout on) family functioning.

All of the above points to the need for developing more culturally tailored interventions, which focus on social support for mothers and fathers in the Bedouin community. There are two reasons for this: the first is based on qualitative findings demonstrating that social support is an integral piece of the coping milieu in families with a child with ASD [14]. The second reason is that the Middle Eastern culture relies on a strong family support system based on the extended family lifestyle [9]. It is possible that effective social support could lead to better ways of coping, which in turn would help reduce mental burnout and lead to improved functioning, for both mothers and fathers [39-43].

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