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Bedouin fathers of children with developmental disabilities—Stress, stigma and collaboration with professionals

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A R T I C L E I N F O

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A B S T R A C T

Background: Research has not fully elucidated the challenges experienced by the caregivers of children with developmental disabilities (DDs) in different sociocultural contexts. Studies on parents, especially fathers, of children with DDs in the Middle East are especially rare. Similarly, the subject of collaboration between Bedouin fathers and professionals has seen little research. This study fills these gaps by highlighting the experiences of Bedouin fathers raising children with DDs.

Aims: This study answered the following questions: A) Do stigma and stress affect the collaboration between Bedouin fathers and professionals? B) Do relationships exist between stigma, stress and collaboration?

Methods: Eighty-eight Bedouin fathers of children with DDs completed questionnaires on sociodemographic details, stigma, stress and collaboration between parents and professionals. Data were analysed using Pearson correlations, a correlation matrix and hierarchical linear regression.

Results: The findings revealed a significant positive relationship between stigma and stress, a significant negative relationship between stigma and collaboration and a significant negative relationship between stress and collaboration. Three demographic characteristics were associated with greater influence on fathers' collaboration with professionals: 1) comorbidity in s child's diagnosis, 2) age of DD diagnosis and 3) father's age.

Conclusions and implications: The findings emphasise the need to develop tailored intervention programmes to assist fathers in reducing their sense of stigma and stress and in increasing their competence in collaborating with professionals.

1. Introduction

Although previous studies have provided important insights into the families of children with disabilities, the perspectives and experiences of fathers living in different sociocultural contexts remain poorly understood. Furthermore, studies focusing on developmental disabilities (DDs) in the Middle East from the last decade are rare. The extant research has focused on several areas: the prevalence of children with DDs in the Middle East (Almahmoud & Abushaikha, 2023); the history of pregnancy, birth and perinatal complications (Masri et al., 2011) and children's gender (Soleimani et al., 2018);family history; and consanguinity, which was reported as being significantly associated with DD-related complications (Masri et al., 2011). Historically, most of the research on parents of children with DDs in the Middle East has focused on mothers. For example, Nazzal and Al-Rawajfah (2018) focused on the

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lived experiences of Jordanian mothers caring for children with disabilities; Abu-Ras et al. (2018) focused on the challenges and determination of Palestinian mothers of children with disabilities; and Bahkali (2021) focused on the experiences of Saudi Arabian mothers of children with disabilities. Some of the research has focused on parental units (fathers and mothers). For example, Abu-Ras et al. (2018) researched Palestinian parents of children with disabilities. Azar and Badr (2010) researched the Lebanese context and predictors of coping. Bwalsa (2016) conducted research in Jordan on psychological stress and coping strategies. Alnahdi (2024) conducted research in the Saudi Arabian context on well-being among parents.

However, studies focused exclusively on fathers are scarce in non-Western contexts, such as the Middle East. Available studies have mainly been limited to the coping of Bedouin fathers of children with DDs with stigma and somatisation (Kabiyea & Manor-Binyamini, 2019) and the experiences of Bedouin fathers of children with DDs (Manor-Binyamini, 2019). Therefore, the current study focuses on the fathers of children with DDs in the Bedouin community.

1.1. Fathers of children with DDs in the Bedouin community

Historically, the Bedouin migrants were nomads who migrated through the deserts of the Middle East", with nomadic shepherd tribes in many deserts. The majority of Bedouins are part of a Sunni Islamic population that adheres to pre-Islamic tribal customs and traditions (Yahel & Galilee, 2023). Israel's Bedouin population includes nearly 250,000 people (Central Bureau of Statistics [CBS], 2019). The Bedouin community of the Negev is similar to other Bedouin Arab communities in the Middle East with regard to some of its sociodemographic and cultural characteristics (e.g. marriage between relatives, polygamy and the extended family/hamula as the most basic social unit) but is distinct in other respects (Al-Krenawi & Slonim, 2009). As an ethnic minority group, the Bedouin population in Israel faces numerous social, cultural, political and financial difficulties (RHA Center for Bedouin Studies and Development, 2010). Some members of the Bedouin community in the Negev live in unrecognised settlements, inhabiting structures such as shacks and tents without access to basic services, including electricity, paved roads and convenient public transportation, health or education services (Manor-Binyamini, 2019). The Bedouins have maintained a non-Western traditional collective lifestyle and a patriarchal society in which the status of men is considered to be higher than that of women (Dwairy, 2015). As the head of the family, the Bedouin man makes most of his family's decisions concerning outside community systems, and the women make most of the decisions concerning daily life (Manor-Binyamini, 2019). Additionally, the father is the family's link to the outside community, including the education system. A recognised gap in the literature has led researchers to the conclusion that we need a deeper understanding of fathers' experiences in general (Mohamed et al., 2024), particularly within non-Western and non-English-speaking societies. This recognition motivated the present study, which explores the stigma and stress experienced by fathers raising children with DDs in a Bedouin community and their collaboration with professionals.

1.2. Stigma and DDs in the Bedouin community

Stigma is a major problem faced by individuals with DDs and their families. According to the World Health Organization (2019), the severity of stigma associated with DD differs based on cultural context. Researchers are increasingly acknowledging the importance of culture and context in the experience of stigma (Jansen-van Vuuren & Aldersey, 2020). An additional concern is that, though disability stigma is universal, its specific manifestations may vary according to culture (Abdul-Chani et al., 2021). Disability stigma may have a particularly significant effect on individuals with DDs and their families in traditionally collectivistic cultures, which value family reputation as well as community perception and inclusion (Abdul-Chani et al., 2021). Previous research has found that collectivist cultures place high value on the family unit, with the family being the source of social, economic and personal support (Black et al., 2003). However, previous research has also found that collectivist cultures are more likely to stigmatise those who deviate from social norms compared to individualist cultures (Mitter et al., 2019). The role of culture in stigma could therefore be especially pertinent in collectivist cultures, where having a child with DDs is in itself stigmatising (Chiu et al., 2013). Because individualistic beliefs dominate Western cultures, other variables, such as child behaviours that run counter to social norms or the type of DD, may have a more significant influence on stigmatisation (Ilgaz et al., 2022).

Additionally, studies have shown that attitudes towards people with disabilities are more negative in collectivist societies, such as Bedouin societies, than in individualistic societies (Fakhr El-Islam, 2008), as collectivist societies promote the needs of the group over the needs of the individual (Al-Krenawi & Slonim, 2009). In a study that examined attitudes towards people with disabilities and the barriers they face in four different communities in Jordan, the respondents generally reported negative attitudes towards people with disabilities (Nagata, 2014). The Bedouin population in Israel, similar to the rest of the Arab world, generally presents negative attitudes towards people with DDs, and people with DDs experience internal social exclusion within this community (Manor-Binyamini, 2019). Furthermore, Bedouin parents of children with DDs fear that they may be stigmatised due to their children's disabilities.

The current study attempts to expand this narrow body of knowledge by examining affiliate stigma among fathers of children with DDs in the Bedouin community.

1.3. Stress experienced by fathers of children with DDs

Stress has been identified as a public health problem and a contributor to adverse health outcomes and health disparities (Klemmer, 2019). Amireh (2019) demonstrated that parents of children with DDs experience considerable stress. The literature has pointed to several reasons for this. Fathers experience higher levels of stress because of their children's social skills and acceptability delays (Ridding & Williams, 2019). Additionally, parental stress results from the discrepancy between parents' expectations for their child

(ren)'s situations and their children's conditions and skills (Daulay, 2018; Enea & Rusu, 2020). Parenting children with DDs is generally considered to be more challenging than parenting children with typical development due to the wide range of impairments, inappropriate or unpredictable behaviours or emotional problems exhibited by children with DDs (Estes et al., 2013); the severity of DD symptoms (Rivard et al., 2014); or financial difficulties and the need to divert financial resources to treatment, interventions and education (Zablotsky et al., 2013). Children's behavioural problems and the caregiving burden significantly contribute to parenting stress (Park et al., 2018; Porter & Loveland, 2019). Therefore, fathers of children with DDs frequently report higher levels of parenting stress (Hayes & Watson, 2013), depression (Hayes & Watson, 2013; Stein et al., 2011), anxiety (Stein et al., 2011) and health-related problems (Stein et al., 2011) compared to parents of children without disabilities. Furthermore, parenting stress negatively impacts parental mental health-related quality of life (Enea & Rusu, 2020).

Hsu et al. (2023) presented interesting findings regarding the connection between fathers' stress in collectivist cultures. They found a significant negative correlation between parental age and stress in parents of children with DDs. Their explanation for this finding is that parents from collectivist cultures tend to be protective and are actively involved in their children's lives; consequently, parents' stress levels do not diminish as their children with DDs grow older. Another study reported that low-income parents show higher levels of stress (Lisak et al., 2018). Dukmak and Alkhatib (2021) found that stress is significantly related to fathers' level of education, with university-educated fathers being associated with greater parental stress than fathers who only completed primary school education. Kabiyea and Manor-Binyamini (2019) researched the Bedouin community in Israel and found significant negative relationships between general stress and parental self-efficacy. Therefore, research on parental stress is crucial to improving parent support programmes because parental stress negatively impacts the effectiveness of treatments (Osborne et al., 2008).

A recent systematic review of the literature synthesising the current state of knowledge revealed that parental stress has been extensively studied as an independent, outcome and mediator variable in the management of children with DDs (Enea & Rusu, 2020). Fathers of children with DDs were the subject of several studies featured in this review. Furthermore, some approaches have challenged the medical model of disability and pushed a social model of disability. However, they have failed to adequately explore the sociocultural elements that lead to stress (Riser, 2021). Amireh (2019) highlighted the importance of focusing on fathers' stress and reported a lack of knowledge regarding this important parental group.

1.4. Collaboration between professionals and fathers of children with DDs

A rich body of literature on the collaboration between professionals and families of children with DDs has identified the advantages of and key barriers to collaboration. With the expanded view on how we describe health and disability, parents of children with DDs and professionals in paediatric health care have been given a powerful framework for guiding discussions, identifying a family's and child's strengths, facilitating the setting of goals and identifying people who require support (Novak-Pavlic et al., 2023). Furthermore, collaboration between professionals and parents allows the synthesis of various forms of knowledge; professionals bring their professional knowledge, and parents bring both their parenting knowledge and their knowledge of their environment and culture (Manor Binyamini, 2015). Parents' participation in the educational process leads to an improvement in the quality of family life, reducing stress and improving relationships within the family. By implementing parent involvement practices, particularly with families of different cultures, professionals may be able to enhance parents' knowledge and skills, leading to effective parenting and the achievement of personal goals, as well as catalysing the social and cognitive development of children with DDs (Bierman et al., 2018).

However, there are barriers impeding family–professional collaboration. Notable ones include the deficit-based perceptions of families and children with disabilities, narrow definitions of 'family' that limit the participation of some members (e.g. fathers) and historical biases that constrain the participation of culturally and linguistically diverse families (Rao et al., 2020). Family-centred services have acknowledged the importance of family engagement in therapeutic processes and focusing on the needs of all family members. This way of thinking and such practices are becoming increasingly recognised as an optimal care delivery model for families of children with DDs. However, in most places, disability services are often 'child-centric', wherein family members are seen only as partners in therapy or care delivery while their needs are not addressed (Rao et al., 2020). An additional barrier of importance is that research on parental involvement in the care of children with DDs with a focus on intercultural diversity remains limited (Acar et al., 2021).

However, in recent years, several studies have been published on the subject of collaboration between experts and parents of children with DDs in the Middle East. These studies investigated the phenomenon of collaboration from a variety of perspectives and in several countries in the Middle East. For example, some studies focused on parents' perspectives (e.g. Khalifa et al., 2017). Working in the Qatari context, Khalifa et al. (2017) interviewed parents of children with DDs to unveil the components of true collaboration practices in different educational institutions. Other studies focused on the point of view of experts in Lebanon; Aouad and Bento (2019) used a narrative approach to grasp the temporal dimension of teachers' experiences interacting with parents. Another study explored the influential factors impacting the provision of family-centred care for children with cerebral palsy in Saudi Arabia (Alharbi & Albalwi, 2023). A similar study focused on the reality of and barriers to collaboration in relation to early interventions in Saudi Arabia (Bukhary, 2021). Specifically analyzing the Bedouin community Referring specifically to the Bedouin community, Morad et al. (2004) examined the attitudes of Bedouin and Jewish physicians towards providing medical care for persons with intellectual disabilities in the Bedouin Negev community.

The extant evidence suggests that culture shapes parental collaboration, especially in non-Western societies (Mitter et al., 2019). Understanding the impact of culture on child development and family collaboration may help practitioners better provide culturally responsive services (Acar et al., 2021).

Therefore, this study focuses on culture and the collaboration between professionals and Bedouin fathers of children with DDs

while concentrating on the relationships between stress, stigma and collaboration.

1.5. The purpose of the study

The present study has three main objectives: 1) to investigate whether stigma and stress affect fathers' collaboration with professionals; 2) to examine the relationship between stigma, stress and collaboration; and 3) to examine which variables, including sociodemographic variables, impact collaboration and stress as mediators.

2. Methods

This study focused on Bedouin fathers of children with DDs to examine the relationship between collaboration (dependent variable), stigma and stress (independent variables). Statistical tests, such as Pearson's correlation and multiple regression, were carried out to aid in the analyses of data.

2.1. Participants

The study included 88 Bedouin fathers of children diagnosed with DDs. Table 1 presents the demographic background data on the fathers, which show that most of the fathers were aged 23–40 (87.7 %), most only had a high school education (65.9 %), most worked as employees (72.2 %), most were married (97.7 %) and most had a below-average economic status (50 %). Most of the fathers had 7 children on average.

Table 2 shows that most of the children were boys (53.4 %) aged 8–10 years (56.8 %), and most families had two children with disabilities (63.6 %). Most children were diagnosed at 3 years of age and above (46.6 %). The most common diagnosis among the children was autism (33 %). It is important to note that this study made a distinction between children with one disability (autism) and children with a combination of disabilities (autism and DD). The children diagnosed with a combination of disabilities (autism and DD) made up about 15 % of the sample.

2.2. Procedure

After acquiring ethical approval from the Ministry of Education Ethics Committee (reference number 156/24), a meeting was held with three principals of three special education schools in the Bedouin community. Consent was obtained from the principals and the teachers for their cooperation, and only fathers able to read and write were identified as possible participants. The fathers who agreed to participate in the study received from the researcher a document explaining the nature of the study, its purpose and its course,

Table 1
Characteristics of the study participants ($N = 88$).

Variable	Value	Number	%	Mean	Standard deviation	Range
Fathers' age	28–40	40	45.5			
	41–50	27	30.7			
	51–70	21	23.9			
Education						
	Didn't study	8	9.1			
	Primary	2	2.3			
	Tertiary	14	15.9			
	High	58	65.9			
	Academic	6	6.8			
Employment						
	Employees	64	72.7			
	Self-employment	6	6.8			
	Unemployed	18	20.5			
Family status						
	Married	86	97.7			
	Widower	2	2.3			
Economic status						
	Below average	36	40.9			
	Average	44	50			
	Above average	8	9.1			
Health condition	Poor	36	40.9			
	Moderate	38	43.2			
	Good	14	15.9			
Number of persons living in home				8.63	3.03	3–17
Number of children				6.94	4.39	1–28
Religion						
	Secular			53.4	47	
	Traditional			46.6	41	

Table 2
Characteristics of the children with DD ($N = 88$).

Variable	Value	Number	%
Gender	Male	47	53.4
	Female	41	46.6
Age			
	5–7	25	28.4
	8–10	50	56.8
	11–13	13	14.8
Number of children with disability			
	1	21	23.9
	2	56	63.6
	3–5	11	12.5
Primary disability	Autism	29	33
	Down syndrome	18	20.5
	Other chromosomal condition	14	19.9
	Intellectual disability	14	15.19
	Intellectual disability and autism	13	14.8
Diagnosed	Up to two years	19	21.6
	2–3 years	28	31.8
	3 +	41	46.6

emphasising that their participation would be voluntary and that all information collected during the study would be kept anonymous. Participants who expressed a desire to participate were asked to sign a form providing their informed consent prior to their participation in the study. Afterwards, the researcher distributed the questionnaires to the participants. After the fathers filled out the questionnaires, they sealed the envelopes and returned them to. Fathers received no incentive to participate.

2.3. Measures

The research questions were examined using five self-report questionnaires. All questionnaires were translated into Arabic by two bilingual translators from the Arab community who worked separately. The two versions were then evaluated by a Bedouin PhD student studying the Arabic language who chose the most culturally appropriate translation. The goal of this procedure 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 cross-cultural and conceptual equivalence rather than creating a linguistic/literal equal. The criteria used to determine a culturally appropriate translation were as follows: (a) formal Arabic instead of spoken Arabic, which differs between villages; (b) relevance: translating the conceptual equivalent of a word or phrase (not a word-for-word translation); (c) simplicity, clarity and conciseness; and (d) consideration of gender and age issues and avoidance of terms that would be considered offensive to the target population.

2.3.1. Demographic information questionnaire

This questionnaire was used to acquire information about the fathers (i.e. age, marital status, years of education, employment, religious affiliation and number of children). Information on children's age, gender, diagnosis, current therapeutic or educational framework and number of years under the current framework was also gathered. With reference to the demographic variable of a child's diagnosis, a distinction was made between children diagnosed with a single disability (autism) and children diagnosed with a combination of disabilities (autism and DDs). This distinction was made to discover variations in the research variables (pressure/stigma and collaboration) based on whether the fathers were raising a child or children with one disability (autism) or a child or children with a combination of disabilities (autism and DDs).

2.3.2. Dimensions of collaboration between parents of children with DDs and educational team questionnaire

The questionnaire was developed by Manor Binyamini et al. (2011). A self-report questionnaire for assessing the degree of collaboration between parents and the educational team at their children's schools was used to determine dimensions of collaboration between parents of children with DDs and the interprofessional team involved in the children's education. The complete questionnaire includes 40 items ranked on a Likert scale from 1 ('strongly disagree') to 5 ('strongly agree'). The items are divided into six categories: initiative (e.g. 'I am active and proactive in front of the school'), communication (e.g. 'The team listens to my opinion and needs as a parent'), interpersonal skills of the team (e.g. 'The team is supportive and encouraging'), professional skills of the team (e.g. 'The staff members have the ability to receive criticism related to working with the child'), means of communication (e.g. 'There are meetings with the team') and means of communication between the staff and the parents (e.g. meetings or a contact book with the parents). In this study, for the purposes of the analyses, the first five categories were defined as Variable 1, and the relationship means were defined as Variable 2.

The more items that scored high on the Likert scale, the higher the parents' collaboration with the school team was considered to be. The highest score possible, meaning that the participants indicated that they strongly agreed for every item, was 200 points. The internal consistency (Cronbach's alpha) of the questionnaire used in the current study was $\alpha = 0.83$.

2.3.3. Affiliate stigma scale (ASS)

The ASS was developed by Mak and Cheung (2008) as a self-report questionnaire for assessing the internal stigma among the family members of people with DDs. The complete questionnaire includes 22 items across three domains (cognitive with 7 items, affective with 7 items and behavioural with 8 items). Sample items include 'I try to leave the house as little as possible with my disabled child' and 'I'm afraid that other people will know that I have a child with a disability'. Three items were omitted to reduce the number of negatively worded items that were difficult to answer. The three items omitted were 'Having a child with disability makes me lose face', 'Given that I have a family member with disability, I've cut down the contact with my neighbours' and 'I feel inferior because one of my children is a child with disability'. Participants were asked to rank the items adapted to the DD context on a Likert scale from 1 ('strongly agree') to 4 ('strongly disagree'). Higher scores on the ASS indicated greater caregiver self-stigma. The internal consistency (Cronbach's alpha) of the questionnaire in the current study was $\alpha = 0.90$.

2.3.4. Parental stress questionnaire

This questionnaire was developed by Pearlin and Schooler (1978) as a self-report questionnaire for examining parents' sense of stress in three areas of functioning: marital, parental and economic. The questionnaire consists of 24 items ranked on a Likert scale ranging from 1 ('not at all') to 4 ('to a large extent'). The questionnaire was weighted using the average of each field; that is, the higher the score, the higher the level of stress reported. Sample items include 'When you think about your financial situation, how do you feel'? and 'When you think about your experience as a parent, how do you feel'? The structural validity of this research tool was tested using factor analysis. The analysis of the relationship between parental stress and stress in other roles, as well as between these types of stress and coping measures, was also conducted. The current study found the scale to be reliable (Cronbach's alpha = 0.89).

2.4. Data analysis

Data analysis was executed in four phases using IBM SPSS Statistics 28.0. First, descriptive statistics were performed to compute the means, standard deviations and ranges of the variables. Second, Pearson correlations between the study variables were examined. Then, the correlation matrix (Pearson) between sociodemographic variables and collaboration was examined. Lastly, hierarchical linear regression was carried out to test stress as a mediator between stigma and collaboration.

3. Findings

First, Pearson correlations between the study variables were examined (see Table 3).

Table 3 shows the positive and significant relationships between all levels of stress (marital, parental, economic and overall) and stigma and the negative and significant relationships between stigma and collaboration (communication, interpersonal skills of the team and means of communication as Collaboration Variable 2). In addition, negative and significant relationships were found between collaboration (interpersonal skills of the team and means of communication) and stress (besides economic stress and means of communication as Collaboration Variable 2). Second, a correlation matrix (Pearson) was performed between sociodemographic variables and Collaboration Variable 1 (Table 4).

Table 4 shows that among the sociodemographic variables, the type of disability of the child, the age of the child's diagnosis and the age of the father were negative and significant with collaboration.

Finally, hierarchical linear regression was performed to examine the mediating power between stress, stigma, and collaboration. Only the variables that were found to be significant in the correlation analyses (see Tables 3 and 4) were included in the mediation test.

Table 5 shows that the first model was found to be significant [$F(4,83) = 5.701$, $p < .001$, $R = .464$, $R^2 = .216$, $R^2_{adj} = .178$]. A significant contribution was found for most of the variables (except father's age), and the explained variance was 21.6 %. A combination of disabilities (autism and DD) compared to one single disability increased fathers' collaboration. Fathers' collaboration with professionals also increased with increases in the age at which children were diagnosed with DDs. At the same time, the higher the

Table 3
Pearson correlation between all variables and collaboration with professional staff ($N = 88$).

Variable	Stigma	Initiative	Communication	Interpersonal skills of the team	Professional skills of the team	Means of communication	Collaboration variable 1	Collaboration variable 2
Marital stress	.544***	.094	− .201	− .238*	− .137	− .217	− .104	− .279**
Parental stress	.462***	− .072	− .164	− .322**	− .227*	− .045	− .149	− .241*
Economic stress	.490***	.005	− .063	− .221*	.001	− .036	− .043	− .110
Overall stress	.600***	.012	− .174	− .313**	− .148	− .122	− .120	− .255*
Stigma	–	.057	− .220*	− .247*	− .201	− .139	− .134	− .259*

* $p < .05$.
** $p < .01$.
*** $p < .001$.

Table 4
Correlation matrix (Pearson) between sociodemographic variables and collaboration 1 ($N = 88$).

	Child gender	Intellectual disability	Autism	Other chromosomal conditions	Down syndrome	Intellectual disability and autism	Child age	Number of children with DDs	Disability percentage according to the National Insurance Institute	Child age	The degree of independence of the child
Collaboration Variable 1	− .061	− .051	− .012	− .048	− .117	.250*	.126	.088	− .026	.214*	− .118
	Father age	Education	Father employment	Economic status	Health condition	Number of persons living in home Number of children	Religious affiliation	Number of children			
Collaboration Variable 1	.241*	.133	0.004	.043	.036	.14	.09	.07			

Table 5
Hierarchical linear regression to test the mediation of stress between stigma and collaboration.

	First model: Collaboration			Second model: Stress			Third model: Collaboration			Fourth model: Collaboration		
Independent variable	B	SE B	B	B	SE B	B	B	SE B	B	B	SE B	B
Type of disability	0.286	0.111	0.259*	0.12	0.142	0.073	0.312	0.108	0.282**	0.307	0.109	0.278**
Age at diagnosis	0.003	0.001	0.267**	− 0.001	0.001	− 0.046	0.003	0.001	0.25*	0.003	0.001	0.256*
Father's age	0.005	0.004	0.136	0.013	0.005	0.225*	0.008	0.004	0.211*	0.008	0.004	0.194
Stigma	− 0.137	0.058	− 0.234*	0.569	0.075	0.653***				− 0.039	0.075	− 0.066
Stress							− 0.201	0.064	− 0.298**	− 0.173	0.084	− 0.257*
R^2		0.216			0.42			0.251			0.254	
F		5.701***			15.021***			6.964***			5.576***	

* $p < .05$.
** $p < .01$.
*** $p < .001$.

feeling of stigma, the lower the fathers' collaboration level.

The second model was found to be significant [$F(4,83) = 15.021$, $p < .001$, $R = .648$, $R^2 = .42$, $R^2_{adj} = .392$]. A significant contribution was found for fathers' age and sense of stigma, and the explained variance was 42 %. As fathers' age increased, stress levels increased.

The third model was found to be significant [$F(4,83) = 6.964$, $p < .001$, $R = .501$, $R^2 = .251$, $R^2_{adj} = .215$]. The demographics and stress variables explained 25.1 % of the variance. A combination of disabilities (autism and DD) compared to one single disability increased fathers' collaboration. Furthermore, fathers' collaboration with professionals increased with increases in the age at which children were diagnosed with DDs. At the same time, the higher the fathers' age, the greater their collaboration with professionals. However, the higher the fathers' stress, the lower the level of collaboration with professionals.

The fourth model was found to be significant [$F(5,82) = 5.576$, $p < .001$, $R = .504$, $R^2 = .254$, $R^2_{adj} = .208$]. The demographics and stress variables explained 25.4 % of the variance. A combination of disabilities (autism and DD) compared to one single disability increased fathers' collaboration. Additionally, fathers' collaboration with professionals increased with increases in the age at which children were diagnosed with DDs. Finally, the higher the pressure they felt, the lower their level of collaboration.

4. Discussion

The main objective of the current study was to examine the effects of stigma and stress on Bedouin fathers of children with DDs in terms of their collaboration with their children's professional teams.

4.1. Relationship between stigma and stress

The findings revealed a significant positive relationship between stigma and stress (marital, parental and economic) among fathers. A possible explanation for the findings is that the parents of children with DDs wanted to avoid exposing their children to their social environments so that the children and the entire family would not become stigmatised (Kabiyea & Manor-Binyamini, 2019). Such avoidance may reduce the stress fathers feel. Additionally, the parents reported that they tended to avoid looking for support (e.g. treatments offered by speech therapists, social workers or psychologists) outside of the family that might help them care for their children because of the stigma that might be attached to them (Al-Krenawi & Slonim, 2009). A straightforward explanation may be that family members of people with disabilities feel greater shame, embarrassment and distress and even feel marginalised by society (Ali et al., 2012). Therefore, it could be hypothesised that fathers felt increased stress as a result of stigmatisation. Their way to cope with this situation was to keep their children from being exposed to their social environments, which meant they avoided seeking help outside the family.

Additionally, children with DDs exhibit socially inappropriate behaviours (e.g. throwing tantrums, engaging in self-destructive acts, flapping and mouthing objects). The exhibition of these behaviours in public and people's reactions make parents of children with DDs feel judged, ashamed, isolated and humiliated (Broady et al., 2017). Additionally, Bedouin fathers may feel a lot of stress as a result of repeated exposure to stigma, resulting in the internalisation of this stigma (Chiu et al., 2013).

Aligned with these research findings, a recent systematic review of the literature synthesising the state of knowledge revealed that parental stress has been extensively studied as an independent, outcome and mediator variable in DD research (Enea & Rusu, 2020). Mazhar et al. (2020) found that stress predicts stigma, thus also supporting this relationship.

4.2. Relationship between stigma and collaboration

A negative and significant relationship was found specifically between affiliate stigma and collaboration.The term 'affiliate stigma' refers to the negative feelings that relatives of stigmatised individuals develop towards themselves because they perceive the associative stigma that prevails in society. Previous research has shown that parents of children with DDs experience a severe level of affiliate stigma (Zhou et al., 2018) and that this severe stigma has meaningful interpersonal and intrapersonal consequences (Chan & Lam, 2018). It can be assumed, then, that the more stigma the fathers who participated in the study felt, the less inclined they were to collaborate with professionals. An alternative hypothesis is supported by Neely-Barnes and Dia (2008), who found that cultural context may produce different levels of social stigma associated with disability. Along with the sense of stigma, these researchers found that families with a child with DD tended to experience discrimination, limited educational opportunities and low social support. These experiences may result in low coping resources. It is possible that the more stress the Bedouin fathers felt, the more they felt that they had fewer resources or that they did not have the resources to collaborate with professionals.

At the same time, it seems that there is room to add caveats to the explanations presented above in examining the contributions and effects of the fathers' demographic variables on their collaboration with professionals. To determine which factors were most strongly related to collaboration with professionals, a regression analysis was conducted. The regression analyses of the three models showed clear and interesting findings. Specifically, three demographic variables were found to increase the fathers' collaboration with professionals: a lack of comorbidity in a child's diagnosis (one disability increased the fathers' collaboration), a later age of initial DD diagnosis in children and higher father age.

A possible explanation for the findings is that the fathers who had children with DDs looked for ways to help their children cope and to work in collaboration with professionals to meet the complex needs of their children, but when the children had comorbidities, the burden involved with caregiving was so extreme that the fathers did not have the time or emotional bandwidth to research collaboration with professionals. The feeling of stigma was found to be higher among families with a child born with two disabilities

compared to one (Mak & Cheung, 2008).

In addition, based on the findings of the regression analysis, the level of collaboration between Bedouin fathers of children with DDs and professionals and specialists varied or increased in relation to the age of the children's initial diagnoses. A later age of initial diagnosis increased the likelihood of fathers' collaboration with professionals. This finding can be explained by research that examined the relationship between specific parental concerns and age of diagnosis in children with DDs. Prior research has found that parents are concerned about language, communication delays and child behavioural problems (Zablotsky et al., 2017). It is possible that fathers whose children were diagnosed at a later age and who were aware of or feared certain issues related to their children's difficulties looked for support services for them, as professionals are the ones who have knowledge and provide support services in relation to DDs. Therefore, these fathers could be hypothesised to be more likely to collaborate with professions.

The results also revealed that higher father age correlated with greater collaboration with professionals. This finding can be explained by a study conducted in Scotland (Hwang et al., 2020). This study confirmed that age is associated with parenting style; older parents with children with DDs engage more in authoritative parenting than younger parents with children with DDs, and authoritative parenting contributes to higher levels of parental collaboration with professionals.

4.3. Relationship between stress and collaboration

The research findings revealed a significant and negative relationship between all kinds of stress (marital, parental, financial and general) and collaboration. The higher the feeling of stress, the lower the fathers' level of collaboration with professionals. It is possible that these fathers, who bear the responsibility and obligation to search for financial and educational resources for their children, must continuously search for therapeutic information. As a result, it is possible that this continuous search for information and resources leads to frustration and even mental fatigue due to the lack of support services that exist in the Bedouin community for children with DDs. Consequently, a high level of frustration and mental fatigue may cause fathers to avoid collaboration with professionals.

5. Conclusions

5.1. Limitations

Notably, this study had several limitations. First, the findings were from fathers' self-reports, with no additional perspectives offered by people who come into contact with children with DDs, such as other family members and professionals.

Second, the focus of this study on certain research variables (stigma, stress and collaboration) resulted in the ignoring of other key measures that may shed light on the coping of fathers with children with DDs, such as their self-esteem, faith, optimism and hope.

Lastly, the findings of this study may not be generalisable to other communities and countries, as the Bedouin community is a specific community.

Despite the limitations of this study, the findings indicate the importance of the subject and the need for further studies. Specifically, the results and limitations of this study suggest that longitudinal studies with heterogeneous samples are required. Specifically, these samples should include fathers of younger and older children, mothers and professionals who work with the DD population. Because of the use of self-report questionnaires, it is also important that future studies deepen our understanding of the relationships between the variables through interviews and observations to further elucidate fathers' perspectives on the concept of collaboration with professionals.

5.2. Implications and recommendations for future research

This study offers practical implications. Given the impact of the experiences of stigma (e.g. cultural variations) and stress (e.g. economics) on fathers' collaboration (e.g. the ways in which educational systems provide services to children with DDs), it is important to develop tailored intervention programmes. The purpose of these programmes would be to assist fathers of children with DDs in the Bedouin community in reducing their sense of stigma and stress and in increasing their competence in collaborating with professionals. For diagnoses to be helpful in supporting fathers, it is important to refer to the time of a child's diagnosis and to examine whether children who are diagnosed later in their lives may have lower support needs than those diagnosed earlier. Additionally, it is important to determine whether time of diagnosis may play a role in fathers' involvement in collaboration.

Such programmes should include ways to increase fathers' awareness and knowledge of DDs, an issue highlighted by Buobaid (2021) who examined the perceptions of parents and experts on collaboration with professionals in Saudi Arabia. Buobaid's (2021) main recommendation was that professionals must prioritise increasing parents' awareness of their children's conditions. Woodgate et al. (2008) discovered that teaching others is a way for parents of children with DDs to cope with stigma, as experts have a lot of knowledge about disabilities and their characteristics. It is important that experts expand fathers' professional knowledge or teach them how to explain their children's disability to members of the community. Professionals who occupy positions where they regularly interact with fathers should be trained on and supported in being a good resource for fathers and addressing some of the fathers' needs within the scope of their practice (Novak-Pavlic et al., 2023).

What This Paper Adds

This article provides a deeper understanding of fathers' experiences in non-Western and non-English-speaking societies.

Specifically, it offers new perspectives on the involvement of fathers in the raising of children with DDs in the Bedouin community. This research brings to light the fact that stigma and stress are important variables that correlate with and impact collaboration with professionals. It provides insight into ways to develop tailored intervention programmes to assist fathers in reducing their sense of stigma and stress while increasing their collaboration with professionals.

CRediT authorship contribution statement

Iris Manor-Binyamini: Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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Data availability

The data that has been used is confidential.

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