

Factors associated with the unmet needs of parents of children with autism in Qatar

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Abstract

Objective: The current study examined whether the unmet needs of parents of children with autism in Qatar predicted parent well-being and whether sociodemographic factors and child characteristics were associated with parental unmet needs.

Background: Parents of children with autism have unmet needs that may negatively impact family members. There is little research examining unmet needs outside Europe or North America.

Method: Participants of this cross-sectional, correlational study were 41 parents of a child with autism residing in Qatar. Parents completed surveys in Arabic about their sociodemographic characteristics, their unmet needs, their well-being, social support, and their child's behavior.

Results: Regression analyses were performed to test the research questions. Greater unmet needs were a significant predictor of life satisfaction. Child behavior problems were a significant predictor of unmet needs, namely the need for family support and help explaining their child's diagnosis to others.

Conclusions: The findings suggest that the unmet needs of parents of children with autism are negatively associated with life satisfaction and are heightened in families where children have more behavior problems.

Implications: The Qatar government developed a national plan for autism and our results underscore the need to

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implement programs to support families of children with autism. An important first step is to ensure that developmentally appropriate information is provided to families and to facilitate connections between families and other stakeholders (e.g., other parents and service providers) in their community.

KEYWORDS

Arab countries, autism, parents, Qatar, unmet needs, well-being

Autism is a neurodevelopmental disorder characterized by difficulties in social communication (e.g., expressive language, eye contact, social interaction difficulties, etc.) and engagement in restricted and repetitive behaviors (e.g., repetitive hand and body movements, interest in unusual objects, etc.; American Psychiatric Association, 2013). Autism affects approximately 78 million people around the world (Lord et al., 2022). The prevalence rate in many low- and middle-income countries is unknown and within Arabic countries there are limited studies examining prevalence rates. To date, a single study of the prevalence of autism among school-aged children in Qatar reported a rate of 1.14%, which is comparable with other regions of the world (Alshaban et al., 2019). This suggests that a growing number of parents in Qatar find themselves raising a child with autism. Unfortunately, there is a paucity of research that examines the well-being of parents of children with autism in Qatar. The current study fills this gap by examining the factors associated with the unmet needs of this understudied group.

Parenting children with autism

Parents in Western countries report a variety of challenges associated with parenting a child with autism. From the first concerns about their child's development, parents report difficulties navigating the health care system, receiving services for their child, and problems with the education system (e.g., Brown et al., 2012). As a result, parents may experience poorer well-being, which can include emotional health, life satisfaction, and relationship quality. Studies consistently demonstrate that mothers of children with autism report elevated levels of parental stress compared to mothers of neurotypical children and mothers of children with other developmental disabilities (e.g., Enea & Rusu, 2020). Life satisfaction is another component of well-being, and parents of children with autism have reported being slightly dissatisfied with their lives (Landon et al., 2018). The challenges associated with raising a child with autism may negatively impact the quality of parents' romantic relationships. For example, parents with a child with autism report less satisfaction (Sim et al., 2016) and more frequent and unresolved conflict (Hartley et al., 2017) compared to parents with a neurotypical child. Some of the factors associated with poor well-being include the severity of the child's autism symptoms and behavior problems (Ekas & Whitman, 2010; Rodriguez et al., 2019), and a lack of social support and feelings of social isolation (Drogomyretska et al., 2020; Landon et al., 2018). Taken together, these studies suggest that the well-being of parents of children with autism is negatively impacted.

Research conducted in Arab countries is generally consistent with that found in Western nations. For example, Lebanese mothers of children with autism reported significantly worse well-being and less social support compared to mothers of neurotypical (NT) children (Obeid & Daou, 2015). In Saudi Arabia, parents of children with autism reported significantly higher symptoms of depression and anxiety compared to parents of NT children (Almansour et al., 2013). In Qatar specifically, Kheir et al. (2012) found that parents of children with autism had similar mental health scores as parents of NT children, but their health-related quality of

life scores were significantly lower. Although we were unable to find research examining the impact on parents' relationship satisfaction, a study of parents of children with autism in Saudi Arabia found that greater relationship satisfaction promoted better well-being, which suggests this is an important aspect of well-being to explore further (Khusaifan & El Keshky, 2022). For parents in Arab countries a variety of factors were associated with decreased well-being including child behavior problems (Obeid & Daou, 2015), child age (Khusaifan & El Keshky, 2021), parent age and income (Dardas & Ahmad, 2014), and discrimination and stigma (Dababnah & Parish, 2013). Taken together, these studies suggest that parent well-being may be negatively impacted after their child's diagnosis of autism, and it is imperative that studies seek to identify factors contributing to poorer well-being as this could inform policies and program development aimed at improving parent well-being.

Unmet needs of parents of children with autism

Parents of children with autism have a variety of needs related to raising their child and researchers have sought to identify which needs parents identify as important and whether these needs are met. Needs can be thought of as resources the parent identifies as important to help cope with the stressor they are experiencing. This is important research as parents often report feelings of frustration because they know that the needs of the family are not being met (Montes et al., 2009). Researchers have identified several areas of unmet needs commonly reported by parents of children with autism. For example, in the United States, parents had unmet needs related to their child's development, planning for the future, and the impact on the family (Hartley & Shultz, 2015). The need for financial support was a common unmet need reported in the United States (Kiami & Goodgold, 2017) and parents also expressed a need for respite care (Hodgetts et al., 2015; Kiami & Goodgold, 2017). Parents also cited the need for information about their child's diagnosis and about available services and which services would be best for their child (e.g., Brown et al., 2012).

Research examining the challenges faced by parents of children with autism in Arab countries is limited in comparison to Western countries; however, there are some studies that provide evidence in Arab countries. For example, Jordanian parents of children with autism reported issues with having to rely on multiple providers for their child's care, the financial burden of services, the availability of services, and the degree of collaboration between parents and providers (Al Jabery et al., 2014). In the Sultanate of Oman, 60% of families reported they were unhappy with the services their child received (Al-Farsi et al., 2013). Notably, in the only study of parents of children with autism in Qatar, parents reported dissatisfaction with the length of time to receive services (Kheir et al., 2012). Although there are no studies formally assessing unmet needs in Arab countries, the available research suggests that parents' unhappiness and dissatisfaction with services might translate into a high level of unmet needs. It is vital to examine unmet needs within the context of Arab countries as the research conducted in other cultures may not translate. Lord et al. (2022) highlighted the cultural heterogeneity of autism and the need for research in countries around the world to help better inform the development of intervention programs for children with autism and their families. This may be important in the context of Arab countries as qualitative research in Saudi Arabia (Alqahtani, 2012) suggests that providing services to families may be difficult due to a lack of knowledge and culture-specific beliefs about the causes of developmental disabilities (i.e., evil eye, black magic).

Factors associated with unmet needs

The unmet needs of parents of children with autism may negatively impact their quality of life and their psychological well-being. For example, Kiami and Goodgold (2017) found that

greater unmet needs were associated with increased parenting stress among mothers of children with autism. In another study of mothers of adolescents with autism, a higher number of hopeful connections to service providers (i.e., a desire to be connected to services) was associated with greater perceived burden (Kuhn et al., 2018). Several qualitative studies report that parents of children with autism expressed feelings of hopelessness, fatigue, frustration, and stress as a result of their family's unmet needs (e.g., Carbone et al., 2010). Studies examining unmet needs and parent well-being in Arab countries are limited; however, some research examines variables that could serve as a proxy for unmet needs, such as financial stress. One qualitative study of expat parents in the United Arab Emirates reported mothers of children with autism felt frustrated when searching for services for their child (Lamba et al., 2022). Another study of Palestinian parents of children with autism found parents struggled with the financial needs associated with their child's diagnosis and reported being worried about finding resources for their child (Dababnah & Parish, 2013). A recently published quantitative study in Saudi Arabia found that higher levels of unmet needs were associated with greater anxiety symptoms for parents of children with autism (Khusaifan & El Keshky, 2022). Based on previous research examining well-being in parents of children with autism, the current study examined the extent to which levels of unmet needs were associated with several aspects of parent well-being, including parent stress, life satisfaction, and relationship satisfaction.

Identifying factors that predict the amount (and type) of unmet needs is vital for the development of interventions to improve well-being for parents of children with autism. Although this is a relatively understudied research question, several family- and child-level predictors have been identified. For example, Hartley and Schultz (2015) found that parents with lower levels of education and parents of children with greater behavior problems reported a greater proportion of unmet support needs (i.e., unmet support needs/total support needs). Hodgetts et al. (2015) also identified factors associated with less unmet needs; mothers who were employed reported less unmet needs. A study of parents of autistic adults transitioning out of high school found that lower income households were less likely to report their adult child was receiving services (Shattuck et al., 2011). The lack of services may suggest that the family is experiencing unmet needs. Unfortunately, all these studies were conducted in North America, and we do not know whether these same factors would predict levels of unmet needs in families residing in other regions of the world. It is critical to identify factors that may be unique to a given region so that appropriate policies and programs can be developed.

The current study

The goal of the current study was to examine the unmet needs of parents of children with autism in Qatar. Examining these processes in Qatar provides a unique opportunity to expand on the limited research conducted in Arab countries and meet the call for increased research in cultures that are not traditionally represented. The first aim sought to determine whether the level of unmet needs was associated with parent well-being. We hypothesized that greater needs would be associated with higher levels of parenting stress and lower levels of life and relationship satisfaction. The second aim was to identify sociodemographic and child factors associated with parents' levels of unmet needs. We expected that parents with greater resources (e.g., social support, household income, education) would report lower unmet needs and parents whose children were more severely affected (e.g., required greater support, higher behavior problems) would report higher unmet needs.

METHOD

Participants

Participants consisted of 41 parents (34 mothers, 7 fathers) of a child with autism. On average, parents were 42 years of age ($SD = 8.50$, range: 28–63 years) and the majority were married (87.80%). Around half of the parents were working either part-time (24.40%) or full-time (26.80%); however, 56.10% of all parents reported they reduced or stopped working because of their child's diagnosis. More than half of the sample (53.70%) reported a household income greater than 20,000 Riyals per month (equivalent to US\$5,714) and 65.90% had a college or professional degree. The majority of parents had one child diagnosed with autism (82.90%), but seven parents (17.10%) had two children with autism. Parents with more than one child were instructed to answer questions about their youngest child to ensure that parents were not systematically choosing to report on their child with the most challenging behaviors. Most of the children were boys (61.00%) and ranged in age from 3 to 22 years ($M = 11.99$, $SD = 5.17$). Finally, 61.00% of parents reported their child required very substantial support, 26.80% required substantial support, and 7.30% required support. All participants were Qatari nationals. Detailed demographic information is provided in Table 1.

TABLE 1 Demographic characteristics of study sample

	Percent	Mean (<i>SD</i>)	Range
Marital status			
Married	87.80	—	—
Single	4.90	—	—
Separated	4.90	—	—
# of children in home	—	3.32 (1.84)	1–8
Child age (years)	—	11.99 (5.17)	3–22
Support needs of child			
Requires very substantial support	61.00	—	—
Requires substantial support	26.80	—	—
Requires support	7.30	—	—
Parent employment status			
Not working	43.90	—	—
Working part time	24.40	—	—
Working full time	26.80	—	—
Monthly household income			
Less than 5,000 Riyals	4.90	—	—
5,001–10,000 Riyals	22.00	—	—
10,001–20,000 Riyals	4.90	—	—
20,001–30,000 Riyals	39.00	—	—
30,001–40,000 Riyals	0	—	—
40,001–50,000 Riyals	9.80	—	—
More than 50,001 Riyals	4.90	—	—
Parent education level			
Less than college	31.70	—	—
College/professional degree	65.90	—	—

Procedure

The current study was part of a larger project examining the well-being of parents of children with autism. The study was a cross-sectional, correlational design. Participants were recruited with the assistance of nationally recognized service providers in Qatar and through a parent support group. Parents who expressed interest in the study were provided with paper copies of the consent form and questionnaires to complete. All study materials were in Arabic. Although we sought to find validated measures with Arabic translations, this was not always possible. In these cases (identified below) a native English speaker who was fluent in Arabic translated the measure. The measure was then back-translated by a native Arabic speaker who was fluent in English. Any disagreements in the translations were resolved by the two translators (Maneesriwongul & Dixon, 2004). As part of this process, questions were identified that were not relevant or appropriate for individuals residing in Qatar. For example, questions related to alcohol would not be culturally sensitive and some questions referred to resources or activities that are not present in Qatar. Although this limits the ability to make direct comparisons to research conducted in Western countries, this was not the primary focus of the study and presenting parents with a culturally sensitive survey was a priority. These questions were then removed. The removal of questions understandably raises concerns about the reliability and validity of the altered measures. We present reliability data in the form of internal consistency below. With respect to validity, we were able to determine face validity by having study authors review the measures, having employees of a service provider that work with families of autistic children review the measures, and participants who completed the survey were able to provide feedback on the study. None of these sources expressed concerns about the measures and the expert reviewers felt they adequately captured the constructs of interest. The survey took approximately 30 minutes to complete, and participants were not compensated. The study was completed prior to the COVID-19 pandemic. Institutional review board approval was received prior to the start of the study (Qatar University QU-IRB 821-E/17), and the work was carried out in accordance with the ethical standards of the institutional review board and with the Declaration of Helsinki.

Measures

Unmet needs

The Family Needs Survey (FNS; Bailey et al., 1992) measures a family's need for information and support related to their child with autism. Several areas of needs are included: information, family support, financial assistance, explaining to others, child care, professional support, and community services. We removed three questions and added four questions for a total of 37 questions. The four additional questions included paying for special food for my child, finding films and TV materials to educate others, locating an evening day care program for my child, and locating a lab or x-ray center who will see my child. These were selected based on conversations with parents of autistic children in Qatar (see Community Involvement Statement section below). All items were translated into Arabic (see Procedure section for details on translation process). For each item, parents indicated whether they had no need at all, little need, or a lot of need. A total score was created by averaging the items. Thus, a higher score reflects greater unmet needs. The internal consistency was good, $\alpha = .91$, and face validity was established (see Procedure for details). Depending on the research question, this variable was specified as both an outcome and a predictor variable.

Parenting stress

The Arabic version of the Parenting Stress Index–Short Form (PSI-SF; Reitman et al., 2002) was used to assess parents' level of stress related to their child's behavior. The Arabic version has been previously used in the Arab world and is reliable and valid (e.g., Dardas & Ahmad, 2014). The original version contains 36 items scored on a 5-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*), however, two items from this Arabic version were removed in the current study (Items 6 and 22). A total score was calculated by summing the items, and a higher score indicates greater parenting stress. Internal consistency in the current study was excellent, $\alpha = .95$, and face validity of this altered version was established (see Procedure for details). This variable was specified as an outcome variable.

Child behavior problems

The 25-item Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) Arabic translation was completed by parents to assess children's positive and negative behaviors. For each item, parents indicated if the behavior was not true, somewhat true, or certainly true for their child during the past 6 months. For this study, the total difficulties score (possible range = 0–40) was calculated by summing scores from all scales except the prosocial scale and a higher score reflects higher behavior problems. The measure was previously found to be reliable and valid in an Arabic-speaking sample (Alyahri & Goodman, 2006). Internal consistency in the current study was good, $\alpha = .82$. This variable was specified as a predictor variable.

Social support

The Arabic translation of the Multidimensional Scale of Perceived Social Support (MSPSS; Merhi & Kazarian, 2012) was used in the current study. The original version contains 12 items; however, in the current study six items were removed (Items 3, 6, 7, 10, 11, 12). Participants responded to each question using a 5-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). The scale was reliable and valid in an Arabic speaking population (Merhi & Kazarian, 2012). Items were averaged to create a score representing overall social support, with a higher score indicating greater social support. Internal consistency in the current study was good, $\alpha = .76$, and face validity of this altered version was found (see Procedure for details). This variable was specified as an outcome variable.

Life satisfaction

The Satisfaction With Life Scale (SWL; Diener et al., 1985), Arabic translation (Abdallah, 1998) was used. The scale contains five items answered on a 7-point Likert scale (1 = *strongly disagree* to 7 = *strongly agree*). A total score was calculated with higher scores indicating greater life satisfaction. Abdallah (1998) found the Arabic translation to be reliable and valid in an Arabic speaking population. Internal consistency in the current study was good, $\alpha = .84$, and this variable was treated as an outcome variable.

Relationship satisfaction

The Couples Satisfaction Index (CSI; Funk & Rogge, 2007) measures parents' satisfaction in their romantic relationship. In the current study we retained 11 items (Items 1–4, 7, 11, 12, 14–

17) and translated them to Arabic (see Procedure for translation process). We retained the original Likert-scale response formats for each question. The items were summed to create a total satisfaction score, with higher scores indicating greater relationship satisfaction. Internal consistency in this study was good, $\alpha = .80$, and face validity of this altered version was established (see Procedure for details). Relationship satisfaction was specified as an outcome variable.

Community involvement statement

The larger study was designed in collaboration with members of a nongovernmental organization (NGO) that works to advance knowledge on Arab families. Prior to the selection of study measures, the authors met with several mothers and one father of a child with autism to learn about their parenting experiences in Qatar. The authors also met with service providers in the region. Members of the NGO provided feedback on survey questions prior to data collection and one service provider also provided feedback on the final survey sent to families.

RESULTS

Examination of skewness and kurtosis values suggested that the variables of interest were normally distributed. A series of *t* tests determined that mothers and fathers did not significantly differ on any study variables. Therefore, all analyses were conducted without controlling for parent gender. Table 2 presents descriptive statistics for all study variables and Table 3 presents correlations between study variables. In general, unmet needs was positively associated with parenting stress and child behavior problems and negatively associated with life satisfaction.

To examine the first research question, whether unmet needs was associated with parent well-being, a single multivariate regression analysis was performed. The family needs total score was entered as a predictor of parent stress, life satisfaction, and relationship satisfaction. Due to listwise deletion, the sample size for this analysis was $n = 30$. Results showed that levels of unmet needs were only a significant predictor of life satisfaction ($B = -7.68$, $SE = 3.57$, $p < .05$, 95% confidence interval [CI] $[-14.99, -.37]$, $\eta^2 = .14$). This represents a large effect ($\eta^2 > .14$). The results for the outcomes of relationship satisfaction ($B = -5.51$, $SE = 5.13$,

TABLE 2 Descriptive statistics for study variables

Variable	<i>n</i>	<i>M</i> (<i>SD</i>)	Range
Family needs Total	41	2.17 (.34)	1.38–2.70
Family needs: Information	40	2.49 (.50)	1.14–3.00
Family needs: Family support	41	1.97 (.38)	1.13–2.75
Family needs: Explaining to others	41	1.99 (.63)	1.00–3.00
Family needs: Child care	41	1.99 (.46)	1.00–3.00
Family needs: Professional support	41	2.38 (.56)	1.50–3.00
Family needs: Community services	41	2.41 (.51)	1.00–3.00
Parent stress	40	107.03 (22.78)	62.00–154.00
Child behavior	40	19.80 (6.54)	8.00–36.00
Social support	40	3.91 (.84)	1.83–5.00
Life satisfaction	37	21.57 (7.06)	5.00–33.00
Relationship satisfaction	33	44.82 (9.40)	21.00–58.00

TABLE 3 Correlations between study variables

	1	2	3	4	5	6
1. Family needs	—					
2. Parent stress	.40*	—				
3. Child behavior	.40*	.57***	—			
4. Social support	-.12	-.04	-.11	—		
5. Life satisfaction	-.39*	-.41*	-.46**	.45**	—	
6. Relationship satisfaction	-.19	.03	.09	.20	.36*	—

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

TABLE 4 Multiple regression analysis of child, family, and contextual factors predicting level of family needs

Variable	<i>B</i> (<i>SE</i>)	β	<i>t</i>	<i>p</i>
Child behavior	.02 (.01)	.43	2.80	.01
Parent age	.00 (.01)	.02	0.07	.94
Child age	-.02 (.02)	-.36	-1.49	.15
Child support required	-.13 (.08)	-.25	-1.63	.12
Parent stopped working	-.11 (.10)	-.17	-1.08	.29

$p = .29$, CI [-16.01, 4.99], $\eta^2 = .04$) and parent stress ($B = 17.26$, $SE = 10.16$, $p = .10$, CI [-3.55, 38.07], $\eta^2 = .09$) were nonsignificant. To explore the significant finding further, we examined correlations between the different types of unmet needs and life satisfaction. The unmet need for family support was negatively associated with life satisfaction, $r(37) = -.56$, $p < .001$. This represents a large effect size.

To determine factors that predict the level of unmet needs, our second research question, a multiple regression analysis was performed. However, to reduce the number of predictors, preliminary analyses were first conducted to identify variables of interest that were significantly associated with the outcome variable. Correlations showed that parent age ($r = -.48$, $p < .01$), child age ($r = -.45$, $p < .01$), and children's support needs ($r = -.47$, $p < .01$) were significantly associated with unmet needs, whereas the number of children living in the home was not ($r = .21$, $p = .21$). As shown in Table 3, child behavior problems were significantly associated with unmet needs. For categorical variables, a series of analyses of variance (ANOVAs) were conducted. Level of unmet needs differed as a function of whether the parent stopped working because of their child's diagnosis, $F(1,37) = 6.36$, $p < .05$. Analyses containing household income, parent education, marital status, number of children with autism, and child gender were nonsignificant ($ps > .05$). The results of the multiple regression analysis are shown in Table 4. After controlling for other predictors in the model, only child behavior problems were a significant predictor of unmet needs ($B = .02$, $SE = .01$, $p = .01$). To assess the magnitude of this effect, we calculated f^2 for the effect of child behavior problems, which was .18 and represents a medium effect. To explore the significant finding further, we examined correlations between the different types of unmet needs and child behavior problems. The unmet needs for family support, $r(40) = .51$, $p = .001$, and explaining to others, $r(40) = .45$, $p < .01$, were associated with greater child behavior problems. The magnitude of these associations represents a large and medium effect size, respectively.

DISCUSSION

The purpose of the current study was to examine factors associated with unmet needs among parents of children with autism in Qatar. Qatar recently developed a national autism plan, launched in 2017, that focuses on improving the lives of individuals with autism (Qatar Ministry of Public Health, 2017). One notable feature of the plan is the emphasis on providing support for parents of children with autism and increasing access to information and resources. The current study was conducted early in the implementation of the plan (2017–2018) and provides critical information for researchers, policymakers, and stakeholders not only in Qatar, but in other Arab countries in the region. Our findings suggest that the unmet needs of parents of children with autism are negatively associated with life satisfaction and are heightened in families where children have more behavior problems.

Identifying unmet needs in Qatar

Parents of children with autism in Qatar reported their greatest unmet need was for more information about their child's diagnosis. This was followed by a need for community services and professional support. The need for information included information about their child's development, how to parent their child with autism, and services that are available. This finding is consistent with research in the United States (Hartley & Schultz, 2015); however, to our knowledge, this study is the first to demonstrate this in an Arab country, specifically Qatar. Needing information about available services for their child is a common stressor reported by families in Arab countries, such as Jordan (e.g., Al Jabery et al., 2014), and this is reflected as an unmet need in parents residing in Qatar. Parents in this study also reported needing to meet with professionals (e.g., counselor, child's teacher, or therapist), having difficulty finding other professionals in the community to meet their child's needs (e.g., doctor, dentist), and connecting with other parents of children with autism. Although parents in this study are receiving diagnostic services, it appears that information on how to best meet their child's unique needs in several domains is lacking. When this information does exist, a challenge for providers and government agencies is determining how to disseminate the information to the appropriate stakeholders. Research shows that parents of children with autism are seeking different kinds of information based on the age of their child (Gibson et al., 2017), which creates additional challenges for information dissemination. Parents of children with autism in the United States report that they rely on other parents and local sources for information, as opposed to the internet (Gibson et al., 2017). Although it is unclear whether these findings would translate to a different culture, parents living in Qatar might benefit from better facilitation of contact with other parents in their local community and a more interconnected system of providers in the community.

Predictors and outcomes of unmet needs

As a parent of an individual with autism, it can be frustrating not knowing where to get help for your child or identifying the kind of assistance that your child needs. This can lead to feelings of hopelessness and stress (e.g., Carbone et al., 2010), which could negatively impact parents' well-being. In the present study, higher levels of unmet needs were associated with lower life satisfaction. Previous research found reciprocal associations between life satisfaction and mental health disorders, such that higher life satisfaction predicted fewer mental health problems (e.g., depression, anxiety, suicidality, substance use) and increased mental health problems predicted lower life satisfaction (Fergusson et al., 2015). Thus, addressing the unmet needs of parents could be critical in preventing the development of more serious mental health problems.

In the multivariate model, levels of unmet needs were not a significant predictor of relationship satisfaction. Relationship satisfaction generally encompasses feelings of happiness and connectedness with a romantic partner (Funk & Rogge, 2007). Thus, it is possible parents' unmet needs are not associated with these feelings because they are both experiencing frustration at not being able to help their child. As a couple, they may continue to feel connected to one another, or feel as if they are a team, as they try to search for resources to help their child. It would be interesting for future research to include couples and examine the extent to which couples agree or disagree about unmet needs. In addition, unmet needs were not a significant predictor of parent stress in the larger, multivariate model; however, unmet needs and parent stress were significantly associated when examined independently. This may simply be due to the sample size of the current study and research with larger samples is needed to ascertain whether the univariate association between unmet needs and parent stress would hold in a larger model.

We further examined which unmet need was most salient in predicting life satisfaction and found evidence for the need for family and social support. This includes needs such as having people inside and outside the family to talk to, helping spouse accept their child's condition, helping the family communicate and support one another better, and helping the family coordinate family tasks and recreational activities. It is possible that the levels of life satisfaction reflect a sense of isolation or loneliness, which is common among parents of children with autism (Ekas et al., 2016). Indeed, studies in other Arab countries found higher levels of stigma toward autism (Obeid et al., 2015) and significant misconceptions about autism (Alqahtani, 2012), which may contribute to these feelings. It is critical to raise awareness about autism to reduce the stigma that individuals in the family's community might have. Moreover, the importance of the unmet need for family support highlights the importance of incorporating a family systems approach to treating autism. The importance of family in collectivist cultures, such as Qatar, may explain why this unmet need, compared to the other unmet needs, was associated with life satisfaction. If parents are experiencing feelings of social isolation, or that their immediate and extended family are not supportive or understanding, this could translate into a negative evaluation of their life.

To effectively disseminate information to parents and alleviate their unmet needs, it is critical to identify which parents have unmet needs. Previous research found sociodemographic factors, such as parent education and income, and child behavior problems were associated with unmet needs (Hartley & Schultz, 2015; Hodgetts et al., 2015). In the present study, the bivariate analyses, without controlling for other variables, found significant associations with sociodemographic variables, such that older parents and parents of older children with less support needs were reporting lower unmet needs. It may be that older parents have greater cognitive maturity and better coping skills to seek out resources. In addition, when children require less support the parents may need less access to resources for their child. After controlling for child behavior problems, we did not find evidence for any sociodemographic factors predicting parents' levels of unmet needs; however, child behavior problems were a significant predictor such that parents of children with greater behavior problems also reported higher unmet needs. Behavior problems, such as aggression, noncompliance, emotional dysregulation, and irritability, are a concern for parents of children with autism and the prevalence rate of comorbid behavior problems may be as high as 25% (Hill et al., 2014). This is particularly concerning because comorbid behavior problems are often found to negatively impact parent well-being, above and beyond the child's core autism symptoms (Ekas & Whitman, 2010). With respect to parents' unmet needs, their child's co-occurring behavior problems may create additional difficulties in identifying service providers that can address both their child's core autism behaviors and comorbid behaviors. Parents whose children exhibit aggressive behaviors or have trouble managing emotions may find it difficult accessing child care or being able to take their child out in public, thus exacerbating the needs that these parents have.

Further exploration of the data found that child behavior problems were significantly associated with the unmet needs of family and social support and explaining to others. The demands of caring for a child with high levels of behavior problems may interfere with the ability of parents to receive social support, which may lead to increased mental health problems. Indeed, in a review of the literature, Boyd (2002) found that mothers of children with more behavior problems were more likely to seek out social support and low levels of social support were associated with depression and anxiety. Mothers of children with autism in the United Arab Emirates found support groups to be helpful, but they also reported that they struggled to get support from their family members (Lamba et al., 2022). In the context of Arab culture, where the needs of one's family is more important than the individual's needs (Nydell, 2002), the unmet need for support may be especially important to address as this could represent a fundamental human need that is not being met.

In this study, parents of children with greater behavior problems also expressed a need for help explaining their child's diagnosis to individuals inside and outside the family. Autism is often referred to as an *invisible disability* because there are no outward physical signs of the disorder (e.g., Hatfield et al., 2017). When a child with autism engages in disruptive behaviors, people in society, including family members, may blame parents for the child's behavior and call them "bad parents" (Neely-Barnes et al., 2011). These misperceptions could be corrected through increased awareness of autism-related behaviors in the community. Fortunately, Qatar's National Autism Plan lists increasing awareness as one of their top priorities and parents may soon have less difficulty explaining their child's diagnosis to others.

Children's behavior problems were not significantly associated with the remaining unmet needs (information, financial assistance, child care, professional support, and community services). It is possible that children's core autism symptoms are more strongly associated with these unmet needs. Although behavior problems are challenging to manage, they are behaviors that also occur in nonautistic youth and there may be more services and professional support available to help parents with these behaviors. On the other hand, services specific to core symptoms of autism (i.e., social communication and restricted and repetitive behaviors) may have longer wait-lists, cost more money, and generally have less availability. Future research is needed to disentangle the relative influence of children's autism symptoms versus co-occurring conditions on the levels of family's unmet needs.

Limitations and future directions

Although the current study makes important contributions to our understanding of parents' unmet needs in Qatar, there are limitations related to the study design that merit discussion. The sample size in this study was small, but consistent with previous research of this population in Qatar (e.g., Kheir et al., 2012). This may be particularly relevant for the multivariate regression analysis that was used to investigate the outcomes of unmet family needs. This technique allowed us to reduce the number of statistical tests performed and the effect sizes were generally consistent with medium to large effects. Nonetheless, we interpret the results of those analyses with caution and highlight the need for research with large sample sizes in this population. There were also several measures that lacked Arabic translations and were historically used in non-Arab cultures. Thus, the research team, in collaboration with community partners in Qatar, removed items that were deemed culturally insensitive or inappropriate. Although each of the altered measures were reliable, we were only able to examine face validity. Further research is needed to develop measures related to family functioning that are culturally sensitive. The sample was primarily mothers and consisted of parents who were receiving services or part of a support group. Although this limits the generalizability of the findings, this is noteworthy as these parents were still reporting they had unmet needs while they were currently

receiving services or connected with other parents. Although this study included several fathers, future research is needed that systematically examines the experiences of fathers. Fathers are generally understudied, but research from Western countries suggests they may be impacted differently in their experiences raising a child with autism (Pisula & Porębowicz-Dörsmann, 2017). Studying fathers may also help to better understand how raising a child with autism impacts the family system. Historically, the role of fathers in Arab countries is to provide for their family. As a result, they spend more of their time in employment and away from their family (Barakat, 2005). The financial costs associated with raising a child with autism are substantial (Rogge & Janssen, 2019) and Arab fathers may experience heightened stress associated with the cultural expectation to provide for the family, which may spillover and impact other family members. Given that autism disproportionately affects males, and Arab countries are generally patriarchal cultures, fathers may have unmet needs that differ from those of mothers.

Parents in the current study varied with respect to the age of their child and the level of support their child needed. It would be particularly informative to examine whether unmet needs systematically differed as a function of the child's age and autism symptom severity. Moreover, it may be helpful to also determine whether children have other co-occurring diagnoses. As previously discussed, Gibson et al. (2017) found that the type of information that parents searched for differed throughout their child's life span. For example, parents of toddlers sought information about language and physical development, whereas parents of school-aged children focused on school-related concerns and parents of adolescents searched for information related to sexuality and transitioning out of school. A recent study of parents of autistic adults in Qatar reported that respite care was a particularly important need for families (Habayeb et al., 2022). Thus, large-scale studies are needed that would allow for more sophisticated modeling of subgroups of family needs. This would help providers in Qatar to disseminate critically needed information that meets a family's unique needs.

Conclusion

The findings of the current study highlight the importance of unmet needs for parents raising children with autism in Qatar. Parents in Qatar reported a variety of unmet needs related to their experiences raising a child with autism, including a need for information about their child's diagnosis and a need for support and services for their child. These unmet needs were elevated among those parents whose children had co-occurring behavior problems and were associated with lower levels of parental life satisfaction. The unmet need for family and social support emerged as a particularly salient need for parents and highlights the isolation that some parents raising a child with autism can experience. Future studies should assess unmet needs of parents of children with autism in other Arab countries, include more fathers in research, and include larger, more representative samples.

Implications

The recent development of the National Autism Plan demonstrates Qatar's investment in improving the lives of individuals with autism and their families. Parents in this study were eager to participate and share their experiences and the largest service provider in the country was committed to assisting with recruitment. Continued investment by the government and stakeholders is critical to ensure that the needs of all families of individuals with autism in Qatar are met. Because parents reported that information about their child's development was an unmet need, an important first step is to ensure that developmentally appropriate information is provided to families and to facilitate connections between families and other stakeholders

(e.g., other parents and service providers) in their community. One way this could be accomplished is through ensuring that autism education is implemented in physician residency programs. For example, the Autism Case Training Curriculum (ACT) not only trains physicians to identify and diagnose autism, but also how to communicate with families and provide recommendations for intervention and education (Major, 2015). In addition to training physicians, parents of children with autism would also benefit from intervention programs that are tailored to their unique needs. The Stepping Stones Triple P Group Parenting Program was found to be effective at reducing parenting stress and increasing parenting self-efficacy (Schrott et al., 2019). This particular program involves group sessions where parents have the opportunity to learn from trained clinicians and from other parents of children with autism. This group format may be particularly helpful as the results of the current study demonstrated that parents have an unmet need for social support. Thus, this type of program not only targets the unmet need for information about their child's development, but also provides informal social support. Another program that could also meet both unmet needs (information and social support) is the Parents Taking Action (PTA) program (Magaña et al., 2021). This is a parent-mediated program where parents of children with autism are trained to deliver the intervention to other parents. Although the program was initially designed for Latino parents in the United States, it has since been adapted for parents of differing cultural backgrounds and also implemented outside the United States. Thus, it may be possible to adapt this program to be culturally sensitive to the experiences of parents in Qatar.

Further investment in research is also needed, particularly related to ways to help parents support their children and help families flourish. A recent review of studies focused on autistic individuals and their families found significant gaps in the research, that most research was conducted in a limited number of countries (Jordan, Saudi Arabia, and Lebanon), and the research was deemed to be weak quality (Alallawi et al., 2020). Qatar is well poised to contribute to expanding this body of research with large-scale, high-quality research. This will not only improve the lives of families in Qatar, but also those of families living throughout the Arab world. This is critical as the Lancet Commission recently highlighted the need for the development of culturally sensitive research and clinical practices for autistic people and their families (Lord et al., 2022).

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