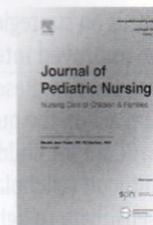




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## Mothers' satisfaction with emergency care when their child has an autism spectrum disorder

Merav Ben Natan, RN, PhD \*, Heba Igbarin, RN, BA, Arwa Watted, RN, BA

Pat Matthews Academic School of Nursing, Hillel Yaffe Medical Center, Hadera, Israel



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### ABSTRACT

**Purpose:** This study aimed to examine factors identified by mothers as affecting their satisfaction with the care provided to their children in the Emergency Department (ED), among mothers of children with autistic spectrum disorder (ASD) in comparison to mothers of children without ASD.

**Design and methods:** In this correlational quantitative study, 128 Israeli mothers – 59 (46%) mothers of children with ASD and 69 (54%) of children without ASD - completed an online survey based on a Ministry of Health national survey of patient experience.

**Results:** Mothers of children with ASD expressed lower satisfaction with the care provided. The difference was particularly evident concerning waiting times for examination of the child by nurses and physicians in the ED, whether the nurses were attentive and responsive to the mother's questions and concerns, whether the ED staff demonstrated coordination and cooperation with regard to medical care of the child, and whether work in the ED was conducted in an orderly and organized manner. The presence of communication difficulties in children predicted mothers' satisfaction with care.

**Conclusions:** These findings suggest that certain needs of mothers and/or their children with ASD do not receive an appropriate response in the ED.

**Practice implications:** It is important to raise the awareness of healthcare providers in EDs regarding the needs of children with ASD and their parents, especially children with communication difficulties. Strategies should be implemented to improve the experience of children with ASD and their parents in the ED.

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### Introduction

Autism spectrum disorders (ASD) are a range of neurodevelopmental disorders characterized by a combination of difficulties with social communication and interactions, in addition to a tendency to repetitive and restrictive behavior (Hodges et al., 2020). The prevalence of ASD has risen worldwide as well as in Israel. Thus, it is estimated that the global prevalence of ASD in children has increased from 0.6% to 1% in the last decade (Zeidan et al., 2022). Similarly, according to Israeli National Insurance Institute data, the prevalence of ASD in Israeli children has risen from 0.5% to 0.96% (Dinstein et al., 2023; Kerub et al., 2018). This rise has been attributed to growing awareness and the development of diagnostic tools (Zeidan et al., 2022).

Children with ASD are a vulnerable group, who in addition to their primary developmental, social, and communication problems may experience acute and chronic health problems (epilepsy, sleep disorders/

disturbance, gastrointestinal disorders, obesity, anxiety, depression, bipolar disorder, feeding/eating challenges) (Bennett, 2017; Bishop-Fitzpatrick & Kind, 2017) requiring healthcare services (Dizitzer et al., 2020). There is evidence that ED usage is more common for children with ASD than for children without ASD (Lytle et al., 2018).

EDs are chaotic environments. Uncertainty about the child's health, overcrowding in the ED, and the medical staff's failure to provide parents with comprehensive information, may cause anxiety in parents and their children (Rochat et al., 2018).

Parental loss of control and anxiety can arise due to inadequate communication with healthcare professionals (HCPs) and the care provided to children in the ED (Gripko et al., 2023). It is crucial to recognize that a child's anxiety is closely linked to the family's emotional state, which can significantly impact the course of treatment (Williamson et al., 2016). Furthermore, the sensory overload experienced by a child in the ER can lead to aberrant behaviors, further increasing anxiety in the mother or caregiver (Rabbani Javadi, 2022). This heightened anxiety can hinder the mother's ability to effectively engage with healthcare practitioners, ultimately affecting satisfaction with the care provided (Gripko et al., 2023). To address these challenges, it is essential to

\* Corresponding author at: Pat Matthews Academic School of Nursing, Hillel Yaffe Medical Center, P.O.B. 169, Hadera 38100, Israel.

E-mail address: [meraav@hy.health.gov.il](mailto:meraav@hy.health.gov.il) (M. Ben Natan).

focus on strategies for lowering mothers' anxiety levels, as this can lead to improved interaction with HCPs and, consequently, higher overall satisfaction. Research indicates that this approach can have a positive impact on the quality of patient care (Efe et al., 2022).

Care for children with ASD in the ED is increasingly recognized as difficult (Nicholas et al., 2016). ASD-specific concerns may arise from sensitivity to lights, sounds, or odors common in medical settings, discomfort at being touched by staff or instruments, and distress due to the lack of predictability (Muskat et al., 2015). All this in addition to being in an unfamiliar environment while ill, in pain, or experiencing distress (Garrick et al., 2022). The traditional hospital environment may not be equipped to suitably address the needs of children with ASD (Garrick et al., 2022; Muskat et al., 2015), compounded by ED staff unawareness of ASD-related issues (Garrick et al., 2022; Lucarelli et al., 2018; Muskat et al., 2015; Pratt et al., 2012). Lack of experience and knowledge of autism has been found to be a major cause of parent dissatisfaction (Kirsch et al., 2018; Nicholas et al., 2016). Not recognizing the child's individual needs can result in escalation of disruptive behavior and lead to negative interactions between parents and staff (Garrick et al., 2022; Muskat et al., 2015).

These circumstances may lead to negative experiences of the ED stay (Kirsch et al., 2018; Muskat et al., 2015; Nicholas et al., 2016). Thus, parents of children with ASD identified issues that negatively affected their care experiences in the ED, including treatment processes, communication issues, insufficient staff knowledge about ASD, and inadequate partnership with parents (Nicholas et al., 2016). Similarly, Kirsch et al. (2018) found that healthcare staff's interpersonal and communication styles, wait times, and whether the child showed disruptive behavior, were major areas predicting parental satisfaction with care.

Since to the best of our knowledge no comparisons have been made between the experiences of parents of children with ASD and parents of children without ASD, it is not clear whether the difficulties experienced by the former when visiting the ED are typical specifically of these children or stem from the difficulties of children in the ED in general. Parental satisfaction with care, comprised of different aspects such as kindness and concern, psychosocial support, service speed, and service provider competency, is an indicator of the quality of care provided by healthcare providers (Byczkowski et al., 2013; Janhunen et al., 2019). A comparison of satisfaction with care among parents of children with and without ASD may provide insights regarding the experiences of parents of children with ASD in the ED and gather information that may improve satisfaction for mothers of children with ASD during ED visits.

## Methods

### Aims

The aim was to examine factors that mothers identify as affecting their satisfaction with the care provided to their children in the ED, among mothers of children with ASD in comparison to mothers of children without ASD.

### Study design and sample

This is a correlational quantitative study. The participants in this study were 128 mothers of children, including 46.1% mothers of children with ASD ( $n = 59$ ) and 53.9% mothers of children without ASD ( $n = 69$ ). The research population was sampled using convenience sampling. The participants were reached via WhatsApp groups for parents of children with ASD and WhatsApp groups for parents. Inclusion criterion: Mothers of children under 18 with and without ASD who had visited the ED in the last year with their children. The ASD diagnosis, and thus also the definition of the communication difficulty and degree of impairment, was determined by self-report of the mothers.

### Data collection

The data were collected using a digital questionnaire based on the Ministry of Health national survey of patient experience in general hospitals – EDs, comprising two parts and 32 questions (Binder-Bachrach et al., 2017).

Part 1: This part collects sociodemographic data of mothers and children who visited the ED, including the child's reason for presenting at the ED, health condition, and the presence of communication difficulties (14 questions).

Part 2: This part explores the mother's satisfaction with the care provided to her child in the ED. Sample statement: "I felt that my child and I are in good hands during the visit to the ED". The mothers were requested to note their degree of agreement with the statements on a Likert scale of 1 to 5, where 1 represents strongly disagree and 5 strongly agree. The reliability of the questionnaire in the current study was  $\alpha = 0.895$ .

### Analysis

Statistical data analysis was conducted using SPSS software for Windows, version 27 (SPSS, Chicago, IL, USA). Descriptive analysis was performed, including frequencies, means, standard deviations, and percentages. *t*-tests and chi-square tests were conducted to examine differences between the two groups of mothers. In addition, a Pearson correlation analysis was conducted to explore associations between the research variables. Finally, linear regression analysis was conducted to examine predictors of mothers' satisfaction with care provided to their children in the ED. Statistical significance was set at  $p < 0.05$ .

### Ethical consideration

The study received Helsinki Committee approval, ID number 0002–23-HYMC. The digital questionnaire was sent by e-mail and WhatsApp to mothers in the WhatsApp groups who agreed to participate in the study, accompanied by an explanation. The purpose of the study was explained to the participants, and the voluntary nature of participation was emphasized. In addition, the participants were assured that their anonymity would be maintained and that the data would be used for research purposes only. Completion of the questionnaire was considered consent to participate in the study. Questionnaire completion time was approximately 10 min. Data collection was performed from January to April 2023. One-hundred-and-fifty questionnaires were distributed while 128 were completed, for a response rate of 85.3%.

## Results

The participants in this study were 128 mothers of children, including 46.1% mothers of children with ASD ( $n = 59$ ) and 53.9% mothers of children without ASD ( $n = 69$ ). Several differences were found in the characteristics of the mothers in the two groups. Tables 1 and 2 present a comparison between the groups. Thus, the mean age of mothers of children with ASD was found to be higher ( $39.6 \pm 9.1$ , range 23–58) than that of mothers of children without ASD ( $35 \pm 6.8$ , range 22–52). Also, a higher proportion of mothers of children with ASD were Jewish (86.4% versus 60.9%). In addition, a lower percentage of mothers of children with ASD had a higher education (76.3% versus 92.8%). In contrast, no difference was found between the two groups of mothers in country of birth, where most of the mothers were born in Israel, and no difference was found in religiosity – most of the mothers defined themselves as secular or traditional. Furthermore, no difference was found in marital status – most of the mothers were married.

It was also found that, among mothers of children with ASD, the mean age of the child with whom they presented at the ED was higher.

**Table 1**

Sample characteristics: Mothers of children with ASD versus mothers of children without ASD – Chi-square test.

Variable	Categories	Mothers of children with ASD (n = 59)		Mothers of children without ASD (n = 69)		$\chi^2$	df	p-value
		n	%	n	%			
Education	Elementary	2	3.4%	1	1.4%	6.906	2	0.032
	Secondary	12	20.3%	4	5.8%			
	Higher education	45	76.3%	64	92.8%			
Ethnicity	Jewish	51	86.4%	42	60.9%	10.468	1	0.001
	Arab	8	13.6%	27	39.1%			
	Single	2	3.4%	1	1.4%			
	Second	17	28.8%	20	29.0%			
	Third	14	23.7%	14	20.3%			
Child has communication difficulties	Other	4	6.8%	3	4.3%	22.135	1	<0.001
	No	22	37.3%	54	78.3%			
	Yes	37	62.7%	15	21.7%			

**Table 2**

Sample characteristics: Mothers of children with ASD versus mothers of children without ASD – t-test for independent samples.

	Mothers of children with ASD (n = 59)		Mothers of children without ASD (n = 69)		t	df	p-value
	M	SD	M	SD			
Mother's age	39.6	9.1	35.0	6.8	-3.27	126	0.001**
Number of children	3.0	1.5	2.5	1.1	-1.79	126	0.076
Age of child presenting at ED	8.6	4.7	4.7	5.1	-4.46	126	0.001**
Reported number of diseases of child presenting at ED	0.6	0.9	0.4	0.7	-1.74	110.7	0.084

Also, a higher proportion of mothers of children with ASD noted that the child with whom they presented at the ED has language difficulties (62.7% versus 21.7%). Then again, no difference was found between the two groups in the child's gender – most were male, and no difference was found in the child's number in the family – most of the children were first- or second-born. Also, no difference was found in the number of children in the family and in the child's reported number of diseases.

Mothers of children with ASD reported lower satisfaction with care (3.4 ± 0.96) than did mothers of children without ASD (3.8 ± 0.8) [t = 1.7(df = 126), p = 0.04]. Table 3 presents differences between the two groups of mothers in specific statements regarding satisfaction with care. The percentages in the table combine responses of “strongly disagree” and “disagree” and “strongly agree” and “agree”. Thus, a higher proportion of mothers of children with ASD agreed and strongly agreed that there had been a long waiting time for a nurse to examine their child (49.2% versus 24.7%, respectively). Furthermore, a smaller proportion of mothers of children with ASD agreed and strongly agreed that the nurses in the ED had been attentive to them and had responded to their questions and concerns (50.8% versus 62.3%, respectively). Also, a smaller proportion of mothers of children with ASD agreed that work in the ED had proceeded in an orderly and organized manner (39% versus 62.3%, respectively).

*Factors associated with mothers' satisfaction with care provided to their children in the ED*

Several factors were found associated with mothers' satisfaction with care provided to their children in the ED. Thus, mothers who noted that the child has communication difficulties reported lower satisfaction with care (3.4 ± 0.8) than mothers who did not note that the child they brought to the ED has communication difficulties (3.8 ± 0.9) [t = 2.8(df = 126), p < 0.01]. This was found for both mothers of children with ASD and without ASD. A negative association was also found between the child's age and the mother's satisfaction with the child's care in the ED (r = -0.22, p < 0.05). In addition, a negative association was found between the child's reported number of diseases and the mother's satisfaction with the child's care in the ED (r = -0.26, p < 0.01). Namely, the older the child and the more reported diseases the child has, the lower the mother's satisfaction with care. In contrast, no association was found between the mother's age, the number of children in the family, and the mother's satisfaction with care. Moreover, as indicated by t-tests for independent samples, no association was found between the mother's ethnicity, the child's gender, and the mother's satisfaction with care.

Variables found associated with mothers' satisfaction with care provided to their children in the ED in a univariate analysis were entered

**Table 3**

Differences between mothers of children with and without ASD in statements regarding satisfaction with care.

Statement	Mothers of children with ASD (n = 59)		Mothers of children without ASD (n = 69)		$\chi^2$	df	p-value
	n	%	n	%			
In my opinion, there was a long waiting time for the nurse to check my child	20	33.9%	38	55.0%	12.169	3	0.016*
The nurses in the ED were attentive to me and responded to my questions and concerns	18	30.5%	6	8.7%	11.667	3	0.020*
There was a long waiting time of the ED physician to check my child	12	20.4%	25	36.2%	10.972	3	0.027*
In my opinion, the ED staff demonstrated coordination and cooperation concerning my child's care	13	22.1%	9	13%	9.595	3	0.048*
In my opinion, work in the ED proceeded in an orderly and organized manner	16	27.1%	14	20.3%	10.394	3	0.034*

\* p < 0.05, % agreement was quantified as the % of mothers of children with and without ASD who responded “agree” or “strongly agree” to each statement on a 5-point Likert scale.

**Table 4**  
Predictors of mothers' satisfaction with care provided to their children in the ED.

Variable	B value	Standard error	$\beta$ value	t value	P-value
Child diagnosed with ASD	0.027	0.179	0.015	0.151	0.880
Child having communication difficulties	-0.350	0.174	-0.192	-2.008	0.047*
Child's age	-0.029	0.016	-0.170	-1.818	0.072
Child's number of reported diseases	-0.177	0.096	-0.166	-1.845	0.067

\* $P < 0.05$ ,  $R^2 = 12.5\%$ ;  $F = 13.641$ ;  $P < 0.002$ .

into a linear regression. When entering all these variables, it is evident that only the presence of communication difficulties in a child predicted his/her mother's lower satisfaction with care, as shown in Table 4. This was found for both mothers of children with ASD and without ASD. In contrast, diagnosis of ASD in a child was not found to explain satisfaction with care. Of note, the child's age and his/her reported number of diseases were of borderline statistical significance. This model explained 12.5% of the variance in the mothers' satisfaction ( $p = 0.002$ ).

## Discussion

The aim of this study was to examine factors that mothers identify as affecting their satisfaction with the care provided to their children in the ED, among mothers of children with ASD in comparison to mothers of children without ASD. The study found that mothers of children with ASD reported lower satisfaction with care. The difference between the two groups was particularly evident concerning issues of wait times for examination of the child by nurses and physicians in the ED, nurses' attentiveness and responsiveness to the mother's questions and concerns, demonstration of coordination and cooperation by the ED staff with regard to medical care of the child, and whether work in the ED proceeded in an orderly and organized manner.

Thus, mothers of children with ASD were more inclined to report that there had been a long wait time for a nurse or physician in the ED, and that nurses in the ED were not attentive to them and did not respond to their questions and concerns. In addition, mothers of children with ASD were more inclined to agree that the ED staff did not demonstrate coordination and cooperation with regard to medical care of their child and that work in the ED did not proceed in an orderly and organized manner. Notably, satisfaction surveys reflect subjective experiences that do not necessarily reflect reality. Interestingly, a previous study found no significant difference in length of ED stay for children with and without ASD (Casey et al., 2015).

Several significant differences were indicated between the groups of mothers in their sociodemographic characteristics. A higher proportion of mothers of children with ASD were Jewish. This finding is consistent with the literature that identified gaps between Jews and Arabs in the rate of ASD diagnosis. These gaps can be attributed to lack of awareness, undiagnosed cases, stigmatization of neurological disorders in the Arab population, as well as impaired access to care (Kerub et al., 2018).

Furthermore, the research findings show that in the group of mothers of children with ASD the mean age of the child presenting at the ED was higher than in the group of mothers of children without ASD. Similarly, in a systematic review by Lytle et al. (2018), children with ASD who visited the ED were older than children without ASD. Therefore, caution should be taken when applying the current research results, as they refer to relatively older children with ASD.

These differences may affect the manifestation of different needs when visiting the ED, in addition to the fact of being a parent of a child with ASD. Then again, it has been previously acknowledged in the literature that children with ASD have unique needs such as addressing sensory sensitivities, using alternative communication methods, providing predictability and routine, offering visual supports, tailoring care plans, exercising patience and flexibility, creating sensory-

friendly environments, and recognizing the vital role of parents or caregiver, necessitating additional accommodations when accessing healthcare (Nicholas et al., 2016). Mothers of children with ASD may have unique expectations of visits to the ED with their child (Washington-Nortey et al., 2023). Washington-Nortey et al. (2023) also found that communication issues, insufficient staff knowledge about ASD, and inadequate partnership with parents negatively affect the parental ED care experience. The current findings are compatible with the literature, which identified the staff's lack of experience and knowledge of autism as a major cause of parent dissatisfaction (Kirsch et al., 2018; Nicholas et al., 2016).

Although mothers of children with ASD expressed lower satisfaction with care provided to their children in the ED, diagnosis of ASD in a child was not found to predict mothers' satisfaction with care. These findings indicate that it is not necessarily a diagnosis of ASD that affects mothers' satisfaction with care, but rather this may perhaps reflect the existence of unmet needs. This is compatible with previous evidence whereby parental satisfaction with care varies by parents' expectations of the healthcare services and by their needs (Uysal & Cirlak, 2014).

In the current study, a higher proportion of mothers of children with ASD noted that the child has communication difficulties. This finding is not surprising, as communication difficulties are a primary feature of ASD (Hodges et al., 2020). More importantly, in the present study, the presence of communication difficulties in both non-ASD and ASD children predicted lower mothers' satisfaction with care. Communication barriers can interfere with assessment and treatment. This may be especially relevant in acute care settings where frequent physical exams and invasive medical procedures are required (Zwaigenbaum et al., 2016). Care practices in EDs may not take into account the individual needs of children with ASD. Not recognizing the child's individual needs can result in escalation of disruptive behavior and lead to negative interactions between parents and staff (Garrick et al., 2022; Muskat et al., 2015).

Of note, ASD can range from very mild to severe, depending on the degree of impairment in the domains of social communication and restricted and repetitive behaviors (Waizbard-Bartov et al., 2023). This may explain why, in the present study, the presence of communication difficulties in a child, rather than the diagnosis of ASD, predicted the mother's lower satisfaction with care. Our findings suggest that the presence of communication difficulties in a child with ASD is a significant feature affecting mother's satisfaction with care.

The current study found that the older the child presenting at the ED, the lower the mother's satisfaction with care. Moreover, the more reported number of diseases the child has, the lower the mother's satisfaction. However, these two factors were not found to be statistically significant predictors of the mother's satisfaction with care. When entering all the variables, it was evident that only the presence of communication difficulties in a child predicted his/her mother's lower satisfaction with care. This suggests that age and number of reported diseases possibly reflect other factors that affect mothers' satisfaction with care. A previous study by Efe et al. (2022) suggested that a more severe clinical status of the child increases the anxiety of his/her parents, which in turn leads to lower satisfaction with care provided in the ED. It is recommended to conduct a subsequent study with a larger sample size, aiming to compare the experiences of older and younger children presenting at the ED.

It should be noted that in the present study the factors explored, and particularly the presence of communication difficulties in a child, explained only a small part of the variance in the mothers' satisfaction with care, suggesting that other important factors may play a role as well.

## Limitations

There are several limitations. Thus, the relatively small sample recruited using a convenience sampling method may limit generalization

of the results. In addition, the research findings could have been influenced by social desirability and recall biases. Moreover, due to the research design, a cause-and-effect relationship could not be established.

In addition, the ASD diagnosis was determined by self-report of the mothers, possibly affecting the accuracy/reliability of the diagnosis and how the communication difficulty and degree of impairment were determined. Also provided by self-report was the number of reported diseases. Other limitations are that this study did not gather information about previous ED admissions or what brought the mother and child to the ED for the specific visit, which could potentially impact how a parent may view their ED visit. In addition, it did not check whether the mother had any other caregiver present with them at the visit (for instance, the father or another relative such as a grandmother, aunt, etc.). Additionally, the study lacked information regarding the recency of ED admissions, beyond the broad timeframe of within the last month. This lack of data could potentially impact participants' ability to recall their experiences accurately. Furthermore, the study did not consider the frequency of ED visits or the specific medical conditions from which the patients were suffering; it focused solely on the number of conditions without specifying the nature of these illnesses. Other data that may have been beneficial is the general location of the hospital (rural vs. major urban medical center).

#### Recommendations for further research

Following the limitations listed above, further research should address cultural differences. As stated in the article, being from an Arab culture may have impacted the likelihood of a child's diagnosis, which could have affected the results. In addition, previous ED history, reason for visit, and severity of injury/illness prompting visit should also be investigated. Also worthy of research attention is the number of caregivers at the visit, as additional support could affect satisfaction. Further research should be based on medical records rather than self-report to obtain more accurate information.

#### Implications for practice

Lower satisfaction with care among mothers of children with ASD suggests that certain needs of mothers and/or their children do not receive an appropriate response in the ED. Also, the presence of communication difficulties in a child predicted mothers' satisfaction with care. This study suggests that it is important to raise the awareness of healthcare providers in EDs regarding the needs of children with ASD and their parents, especially in the case of children with communication difficulties. Strategies should be implemented to improve the experience of children with ASD and their parents in the ED.

#### Conclusion

In summary, children with ASD present a distinctive set of challenges and needs in the ED, encompassing complex medical conditions, communication and behavioral challenges, sensory sensitivities, and a lack of awareness among healthcare providers. Nonetheless, this study emphasizes the potential for improvement in the ED experience for these children and their mothers. By fostering a deeper understanding of ASD and implementing strategies to address these challenges, healthcare providers can make a positive difference in the care provided to children with ASD, ultimately enhancing their quality of life and ensuring more satisfactory emergency care experiences for their families.

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#### CRediT authorship contribution statement

**Merav Ben Natan:** Methodology, Formal analysis, Supervision, Writing – review & editing. **Heba Igarin:** Conceptualization, Data curation, Writing – original draft. **Arwa Watted:** Data curation, Writing – original draft, Writing – review & editing.

#### Declaration of Competing Interest

The authors declare no financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work.

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