

Original Paper

Understanding Family-centered Care and Related Factors From the Perspective of Mothers of Children With Autism Spectrum Disorder



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ABSTRACT

Introduction: Autism spectrum disorder (ASD) presents numerous challenges for families with affected children due to communication and social interaction difficulties. Adopting a family-centered care approach can enhance the quality of care and increase the satisfaction of families seeking medical services for children with ASD.

Objective: This study aims to assess the status of family-centered care and its related factors among mothers of children with ASD in Rasht City, Iran.

Materials and Methods: A cross-sectional analytical study was conducted on 183 mothers of children with ASD in Rasht, utilizing a census approach at Guilan Welfare Centres in September 2020. Data collection tools involved questionnaires on individual-family characteristics and the measure of processes of care, a 20-item questionnaire, which was validated and reliable. Descriptive and inferential statistics, including the Pearson test, independent t-test, analyses of variance, and multiple linear regression, were used for data analysis.

Results: Out of 183 participants (69.31%), met the study criteria most mothers held a diploma (41%) and were housewives (74.3%). The scores for "empowerment and partnership" and "general information" aspects were below mean score, while "specific information", "comprehensiveness and coordination" of services, and "respect and support" aspects received scores above mean score. The aspect of "specific information" received the highest score (55.4±16.2), while the "general information" aspect received the lowest (45.3±88.1). The regression model revealed that the child's gender (B=-0.58, 95% CI, -1.07% to 0.001%, P=0.001), sufficiency of health insurance (B=-1.19, 95% CI, -2.17% to -0.21%, P=0.017), and severity of ASD (B=-1.25, 95% CI, -2.46% to -0.04%, P=0.042) significantly influenced empowerment and participation, general information, and specific information aspects. The family residence also impacted the aspect of respect and support (B=-1.24, 95% CI, 0.57% to 1.17%, P=0.001).

Conclusion: The study findings revealed that mothers' understanding of family-centered care in empowerment/participation and general information was below mean score. This finding highlights the importance of focusing on family-oriented approaches while providing services and care to families with children with ASD.

Keywords:

Autistic spectrum disorder,
Family nursing, Mothers, Child

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Highlights

- Autism spectrum disorder is a well-known childhood developmental disorder characterized by stereotyped behavior and social communication problems.
- Family-centered care effectively improves medical services and enhances family satisfaction for children with autism spectrum disorder.
- Various factors can influence mothers' understanding of family-centered care.
- Enhancing mothers' understanding of family-centered care can lead to more accurate care planning, referrals, and follow-up for children with autism spectrum disorder

Plain Language Summary

Autism spectrum disorder (ASD) is a developmental disorder in childhood marked by stereotyped behavior and difficulties in social communication. Adopting a family-centered care approach can improve medical services and increase satisfaction for families with ASD children. Since mothers play a crucial role in caring for their children, their understanding of family-centered care can impact their received services and reduce maternal anxiety, ultimately benefiting their children's health. Therefore, this study aims to explore the status of family-centered care and related factors from the perspective of mothers with ASD children. The research revealed that most mothers scored below average in empowerment/participation and general information concerning family-centered care. Identifying factors related to family-centered care can help improve the quality of services for children with ASD in care centers.

Introduction

Autism spectrum disorder (ASD) is a developmental disorder that typically manifests in childhood and is characterized by stereotyped behaviors, excitability, destructive behaviors, and challenges in social communication, often occurring before age 3 [1, 2]. This disorder affects brain function, and the severity of symptoms may vary across 3 areas: Social interaction, communication, and repetitive behaviors [3]. Approximately 6 out of every 1000 children are affected by some form of autism spectrum disorder [4]. In Iran, the prevalence was reported as 2.95 per 10000 children in 2014 [5].

The challenges of an ASD child's growth and development significantly impact the family system [6, 7]. Thus, besides focusing on the child with special needs, attention should be directed toward families with such needs. The family-centered approach emerges as promising to improve medical services and enhance satisfaction among families with children with autism spectrum disorder. This approach emphasizes mutual respect, acceptance of family choices, service exclusivity, and flexibility, family participation in decision-making, provision of necessary information and knowledge, and efforts to empower family cooperation and communication between the family and therapists [8].

Family-centered care comprises services tailored to children with special needs and their families. This approach underscores family involvement in decision-making, cooperation, and communication between the family and therapists, as well as mutual respect, acceptance of family choices, family support, service flexibility, and efforts to empower families. It has become a cornerstone of many early intervention and rehabilitation programs [9]. Family-centered care reduces anxiety and tension associated with treatment, shortens recovery time, and improves patient cooperation in care implementation. Moreover, it enhances the ability to address clients' problems and issues, reduces situational anxiety in mothers, and leads to better clinical decision-making and follow-up in child nursing. Family-centered care fosters family cooperation with therapists, recognizes the family's capacity and capability, and enhances communication among care team members [10-13].

The perception of family-centered care can be influenced by factors such as an individual's experiences, beliefs, convictions, and care standards [10]. Mothers' individual and social factors are also linked to their perception of family-centered care [2, 10, 14, 15]. Variables like age, parents' education, economic status, insurance adequacy, understanding of the disease and its severity in the family, the health status of family members, pres-

ence of healthy or chronically-ill siblings alongside the child with ASD, government financial support for care services, and government policies related to receiving family-centered care can all impact the quality of care received [12, 16].

Given their scope of work, community health nurses can improve the receipt of family-centered care by playing diverse roles within families with special needs, including those with ASD children. However, this effort requires a thorough understanding of the existing situation and surrounding factors. Therefore, due to the scarcity of research conducted in Iran, particularly in Guilan Province, we aimed to explore the understanding of family-centered care and its related factors among the mothers of children with ASD in Rasht City, Iran.

Materials and Methods

This research is a cross-sectional analytical study conducted in educational and rehabilitation centers covered by the Welfare Organization in Rasht during 2020. The research population comprised all mothers with children under 18 years diagnosed with ASD in Rasht, receiving care at the centers under the Rasht Welfare Organization. The inclusion criteria for the study included having a child under 18 with ASD, caring for the child at home, living with a husband, and providing consent to participate. The exclusion criteria comprised incomplete questionnaire responses or confusion in completing the questionnaire. The sampling method employed was a census, and out of the total research population of 264 people, 183 individuals (69.31%) willingly participated in the study.

The study data were collected using a two-part questionnaire. The first part assessed individual-family characteristics and factors related to understanding family-centered care. They included the age of the mother and father, the age of the child with ASD, the number of children in the family, the age at which ASD was diagnosed, the family's monthly income and its sufficiency, the mother's and father's occupations and education levels, sex and rank of the child with ASD, the severity of ASD, type of health insurance and its sufficiency, family residence, and supplementary insurance for the child with ASD. The second part included the 20-item questionnaire of measure of processes of care, which was used to investigate the understanding of family-centered care from the perspective of mothers of children with ASD.

The questionnaire consists of 20 questions in 5 aspects: Empowerment and participation, providing general information, providing specific information about the child, comprehensiveness and coordination of services for the child and family, and respectful and supportive care. This tool has been translated and validated in several countries to assess the understanding of family-centered care by parents of children with chronic diseases and various care team members (e.g. doctors, nurses, psychologists, therapists, and social workers) [17, 18]. Given that this tool effectively covers the concepts of family-oriented care, it has been used in numerous similar studies [2, 19, 20].

The questionnaire is rated on a 7-point Likert scale, ranging from "never" with a score of 1 to "very much" with a score of 7. The Persian version of this instrument was used in the present study [9]. Due to the COVID-19 pandemic, data collection was conducted either in person by adhering to health protocols or via telephone with the research participants, following coordination with the [Guilan Welfare Province](#) and identifying the care centers covered by the Welfare Organization. The inclusion criteria were completed within 3 months. Of the participants, 30(16.39%) completed the questionnaire in person, and 153(83.61%) completed it by telephone due to the pandemic. Each questionnaire took approximately 15 to 20 minutes to complete.

The collected data were analyzed using SPSS software, version 24 at a significance level of 0.05. Quantitative variables were presented as Mean±SD, while qualitative variables were expressed as percentage frequency. To determine the correlation of study variables, the Pearson correlation, independent t-test, and analyses of variance were employed. Additionally, the multiple linear regression model was utilized to identify factors related to the perception score of family-centered care while controlling for individual-family factors.

Result

The research findings indicate that 183 participants (69.31%) met the study criteria, with an Mean±SD age of 58.42±14.5 years. Most mothers (41%) had a high school diploma. Many participants (54.6%) had children diagnosed with severe ASD, a male gender predominance (82%), and an Mean±SD age of 11.99±3.06. Additional personal and social information can be found in [Table 1](#).

Table 1. Distribution of individual-family factors (n=183)

Variables		No. (%)
Mother's education level	Sub-diploma	64(35)
	Diploma	75(41)
	University graduated	44(24)
Mother's occupation	Employed	47(25.7)
	Housewife	136(74.3)
Father's education level	Sub-diploma	92(50.3)
	Diploma	45(24.6)
	University graduated	46(25.1)
Father's occupation	Unemployed	0(0)
	Employee	37(20.2)
	Freelance job	119(65)
	Retired	27(14.8)
Monthly income of the family	<\$ 100	43(23.5)
	100-\$ 150	104 (56.8)
	>\$ 150	36(19.7)
Sufficiency of the family's monthly income	Less than meeting the needs of life	119(65)
	To meet the needs of life	64(35)
	More than meeting the needs of life	0(0)
Gender of the child with ASD	Male	150(82)
	Female	33(18)
The birth rank of the child with ASD	Single child	39(21.3)
	1 st child	45(24.6)
	2 nd child	98(53.6)
	3 rd child or more	1(0.5)
Severity of ASD	Mild	28(15.3)
	Medium	55(30.1)
	Severe	100(54.6)
Health insurance for the child with ASD	Medical service insurance	36(19.7)
	Social security insurance	100(54.6)
	Rural insurance	18(9.8)
	No insurance	29(15.9)

Variables	No. (%)
Supplementary insurance for the child with ASD	Yes 19(10.4)
	No 164(89.6)
Sufficiency of Health insurance for the child with ASD	Yes 9(4.9)
	No 174(95.1)
Family residence	Urban 162(88.5)
	Rural 21(11.5)

Variables	Max	Min	Mean±SD
Mother's age (y)	58	34	42.58±5.14
Father's age (y)	58	37	47.71±6.68
Number of children in the family	3	1	1.80±0.60
Age of child with ASD (y)	17	6	11.99±3.06
Child's age at diagnosis of ASD (y)	7	3	3.30±1.58

ASD: Autism spectrum disorder.

The Mean±SD of the scores obtained in the family-centered care aspects, from the highest to lowest, were as follows: "Specific information", 4.55±2.06; "respect and support", 4.08±1.82; "comprehensiveness and coordination" of services, 4.03±1.99; "empowerment and participation", 3.77±1.87; and "general information", 3.45±1.88. Among the quantitative variables, the number of children in the family showed significant correlations with empowerment and participation (P=0.002, r=0.226), general information (P=0.001, r=0.322), specific information (P=0.001, r=0.327), comprehensiveness and coordination (P=0.001, r=0.370), and respect and support (P=0.001, r=0.200). Additionally, the age of the child at the time of ASD diagnosis exhibited significant correlations with empowerment and participation (P=0.001, r=-0.214), general information (P=0.001, r=0.441), specific information (P=0.001, r=0.462), comprehensiveness and coordination (P=0.001, r=-0.404), and respect and support (P=0.001, r=-0.378). Moreover, the father's age showed statistically significant correlations with general information (P=0.001, r=-0.201), specific information (P=0.028, r=-0.162), comprehensiveness and coordination (P=0.001, r=-0.233), and respect and support (P=0.01, r=-0.191).

The independent t-test and chi-square test revealed significant differences in scores obtained across all 5 aspects according to certain studied variables. Notably, the score of empowerment and participation differed sig-

nificantly based on the mother's occupation (P=0.001) and the gender of the child with ASD (P<0.05). The score of general information significantly differed based on the rank of the child with ASD (P=0.009) and the family's place of residence (P=0.001). Additionally, the score of comprehensiveness and coordination significantly differed based on insurance sufficiency (P=0.001) and supplementary insurance (P=0.001), and the score of respect and support aspect significantly differed based on the family's place of residence (P=0.001).

One-way analysis of the variance indicated significant differences in scores obtained across all 5 aspects according to certain studied variables. For instance, the score of empowerment and participation differed based on the father's education level (sub-diploma and diploma, P=0.001; university graduate and diploma, P=0.001) and occupation (retired and freelance, P=0.01). The score of general information significantly differed based on the mother's education level (undergraduate and university education, P=0.01) and the father's occupation (retired and freelance, P=0.01). Additionally, the score of specific information aspects significantly differed based on the severity of ASD (mild and moderate, P=0.01; mild and severe, P=0.01). The score of comprehensiveness and coordination significantly differed based on the severity of ASD (mild and moderate, P=0.001; mild and severe, P=0.001) and the type of child's health insurance (medical service insurance and

Table 2. Factors related to the aspects of understanding of family-centered care using the multiple linear regression test with the stepwise method (n=183)

Family-centered Care Area	Model	B	SE	P	95% CI	
					Lower	Upper
Empowerment and participation R ² =40.4	Constant value	11.36	1.14	0.0001	9.11	13.6
	Supplementary insurance for the child with ASD (not having insurance vs having insurance)	-2.89	0.40	0.001	-3.68	-2.10
	Severity of ASD (Mild vs moderate and severe)	0.86	0.14	0.001	0.58	1.14
	Monthly income of the family (<\$100 vs \$100-\$150 and >\$150)	-1.07	0.19	0.001	-1.45	-0.69
	Family residence (rural vs urban)	-1.44	0.34	0.001	-2.11	-0.76
	Rural insurance (vs health services insurance)	2.64	0.41	0.001	1.83	3.46
	Social security insurance (vs medical services insurance)	1.62	0.27	0.001	1.09	2.15
	Sufficiency of health insurance for the child with ASD (yes vs no)	-0.72	0.55	0.006	-1.23	-0.21
	Gender of the child with ASD (female vs male)	-0.53	0.27	0.048	-1.07	0.001
General information R ² =50.7	Constant value	8.49	1.60	0.0001	5.32	11.67
	Severity of ASD (mild vs moderate and severe)	1.38	0.13	0.001	1.11	1.66
	Supplementary insurance for the child with ASD (not having insurance vs having insurance)	-2.59	0.39	0.001	-3.38	-1.81
	Rural insurance (vs medical services insurance)	2.31	0.39	0.001	1.54	3.09
	Monthly income of the family (<\$100 vs \$100-\$150 and >\$150)	-1.02	0.19	0.001	-1.04	-0.64
	Social security insurance (vs medical services insurance)	1.05	0.23	0.001	0.58	1.52
	The rank of the child with ASD in the family being the 2 nd child vs being the only child or the 1 st child)	0.63	0.21	0.0001	0.21	1.05
	Sufficiency of Health insurance for the child with ASD (yes vs no)	-1.19	0.49	0.017	-2.17	-0.21
Family residence (rural vs urban)	-0.79	0.34	0.022	-1.47	-0.11	
Specific information R ² =40.7	Constant value	10.28	1.81	0.0001	6.70	13.86
	Severity of ASD (mild vs moderate and severe)	1.19	0.17	0.001	0.85	1.53
	Supplementary insurance for the child with ASD (not having insurance vs having insurance)	-3.00	0.49	0.001	-3.97	-2.02
	Monthly income of the family (<\$30 vs \$30-\$60 and >\$60)	-0.81	0.23	0.001	-1.26	-0.35
	The rank of the child with ASD in the family (being the 2 nd child vs more than being the only child or the 1 st child)	0.72	0.26	0.007	0.20	1.24
	Sufficiency of health insurance for the child with ASD (yes vs no)	-1.25	0.61	0.042	-2.46	-0.04

Family-centered Care Area	Model	B	SE	P	95% CI	
					Lower	Upper
Comprehensiveness and coordination of services R ² =50.0	Constant value	9.16	1.24	0.0001	6.71	11.62
	Supplementary insurance for the child with ASD (not having insurance vs having insurance)	-3.23	0.42	0.001	-4.08	-2.39
	Severity of ASD (mild vs moderate and severe)	0.87	0.15	0.0001	0.57	1.17
	The rank of the child with ASD in the family (being the 2 nd child vs more than being an only child or the 1 st child)	0.90	0.23	0.0001	0.45	1.45
	Social security insurance (vs medical services insurance)	1.40	0.25	0.0001	0.90	1.91
	Monthly income of the family (<\$100 vs \$100-\$150 and >\$150)	-1.10	0.20	0.0001	-1.51	-0.69
	Rural insurance (vs medical services insurance)	1.88	0.42	0.0001	1.04	2.73
	Family residence (rural vs urban)	-1.14	0.36	0.0001	-1.87	-0.41
Respect and support R ² =42.7	Constant value	11.98	1.17	0.0001	9.67	14.29
	Supplementary insurance for the child with ASD (not having insurance vs having insurance)	-3.44	0.41	0.0001	-4.26	-2.62
	Severity of ASD (mild vs moderate and severe)	0.77	0.14	0.001	0.48	1.05
	Monthly income of the family (<\$100 vs \$100-\$150 and >\$150)	-1.22	0.20	0.001	-1.61	-0.82
	Family residence (rural vs urban)	-1.24	0.35	0.001	-1.94	-0.54
	Rural insurance (vs medical services insurance)	1.72	0.41	0.001	0.91	2.53
	Social security insurance (vs medical services insurance)	0.75	0.24	0.002	0.27	1.24

ASD: Autism spectrum disorder.

social security insurance, P=0.001). Finally, the mean score in the aspect of respect and support significantly differed based on the severity of ASD (mild and moderate, P=0.001; mild and severe, P=0.001) and the type of health insurance (medical service insurance and social security insurance, P=0.001; medical services insurance and no insurance, P=0.02).

The stepwise multiple linear regression test results demonstrate that in the final model, most of the demographic variables significantly influenced the scores obtained in all 5 aspects. Specifically, the gender of the child with ASD (B=-0.58, 95% CI, -1.07% to 0.001%, P=0.001), general information (B=-1.19, 95% CI, -2.17% to -0.21%, P=0.017), specific information (B=-1.25, 95% CI, -2.46% to -0.04%, P=0.042), the sufficiency of health insurance, comprehensiveness and coordination of services (B=0.87, 95% CI, 1.17% to 0.57%, P=0.001), and family residence in the aspects of respect and support (B=-1.24, 95% CI,

-1.94% to 0.54%, P=0.001) are significantly related to the perception of family-centered care from the perspective of mothers. More details can be found in [Table 2](#).

Discussion

The findings of this research, aimed at determining family-centered care from the perspective of mothers with children having ASD in Rasht City, Iran, revealed that the scores obtained in the aspects of “empowerment/participation” and “general information” were lower than the average, while the aspects of “specific information”, “comprehensiveness and coordination” of care, and “respect and support” scored higher than the mean. These results differ from a study by Russell et al. using the same tool, where research samples scored medium to high in all aspects except for “general information” [21]. The difference might be attributed to societal differences and distinct care policies.

In this study, the aspect of “specific information” had the highest mean score, while “general information” had the lowest, consistent with Fontil’s study on Canadian and immigrant families of children with ASD in elementary school [22], Russell’s study in New York [21], Myrhaug’s study on parents of preschool children with brain paralysis [23], Wang’s study [24], and Stefánsdóttir’s study on parents of children under 5 needing rehabilitation services [25]. Care providers may prioritize providing “specific information” to families with children with ASD, potentially neglecting the importance of providing general information.

Regression test analysis demonstrated a significant relationship between understanding family-centered care and certain studied variables. Myrhaug’s study also found a positive correlation between greater financial support and higher scores in comprehensiveness and coordination of medical services [23]. Although direct financial support was not mentioned in the current study, the relationship between having supplementary insurance and family-centered care areas might be due to the high cost of rehabilitation care for children with ASD and limiting access to welfare centers only. Consequently, the quality of care provided may not fully meet family-centered care requirements. Stefánsdóttir’s study on parents’ and therapists’ understanding of family-centered care found age, performance, and type of disability of the sick child to be relevant factors. Younger children received more family-centered care, and parents of children with ASD scored lower in general information than other disabilities [25].

In this study, mothers with male children, except for the aspects of general information and specific information, scored higher in understanding family-centered care. Additionally, higher severity of the disease was associated with lower scores in family-centered care areas. Molinaro’s study similarly revealed that single and unemployed parents and families with lower socioeconomic status scored lower in family-oriented care aspects [26]. The findings suggest that employment status, father’s education, and father’s occupation, apart from general information, influenced higher scores in family-centered care aspects. However, having medical service insurance obtained a lower family-centered care understanding score compared to other insurance types, potentially due to less coverage of medical service insurance compared to social security insurance and rural insurance.

Overall, the mothers’ understanding of family-centered care for children with ASD was mean in three as-

pects and below mean in two aspects, indicating a need for improvement in the quality-of-care services. This research has limitations, such as using a questionnaire to assess mothers’ understanding, excluding 30% of research samples due to non-inclusion criteria, and conducting a large part of the questionnaire via telephone during the COVID-19 pandemic, potentially affecting respondents’ psychological state.

Ethical Considerations

Compliance with ethical guidelines

The study was approved by the Ethics Committee of [Guilan University of Medical Sciences](#) (Code: IR.GUMS.REC.1399.238). Ethical principles were fully observed in this study. Informed consent was obtained from all study participants, who were aware of the research process. They were also assured that their information would be kept confidential.

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Authors' contributions

Data collection: Neda Feizi Mangoodehi; Statistical analysis of data: Neda Feizi Mangoodehi and Ehsan Kazemnejad Lieli; Writing the original draft: Leila Mirhadyan and Neda Feizi Mangoodehi; Conceptualization and final approval: All authors.

Conflict of interest

The authors declared no conflict of interest.

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