

Relationship of autistic children's self-care performance with coping and quality of life in mothers of autistic children

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Abstract

Introduction: Inability in self-care in children with autism can severely affect different aspects of mothers' lives, especially coping and quality of life. The aim of this study was to evaluate the relationship between autistic children's self-care performance and mothers' coping and quality of life.

Material and methods: This was a cross-sectional study. 110 mothers and their autistic children were selected via convenience sampling. Three questionnaires were completed by participants. Data were analyzed by SPSS software version 16.

Results: There was a strong and direct correlation between self-care performance and coping of mothers and mothers' quality of life ($p < 0.001$). The variables of coping, quality of life, autistic child's age and gender, number of siblings, level of function, mothers' education and job predicted approximately 70.65% of self-care performance variation.

Conclusions: Children with autism had fairly good self-care performance, which had a positive effect on adaptation and consequently quality of life of their mothers. Self-care performance promotes the coping and quality of life in mothers of children with autism. Therefore, health officials and policymakers are recommended to use the findings of this study to increase coping and quality of life in these mothers, improve their self-care performance, and pay attention to this point in clinical practice.

Key words: autism, self-care performance, quality of life, coping, mother.

Introduction

Autism is one of the most important developmental-behavioral diseases in recent decades (Greenspan and Wieder 2009). One of the most important problems of children suffering from autism is their inability in self-care (Ismail *et al.* 2022). Epidemiological studies regarding the prevalence of autism show that this is a growing disorder (Haque *et al.* 2021). Further, the available statistics show that we are witnessing more than 6% growth in cases of autism worldwide (Rong *et al.* 2021). On the other

hand, in Iran, 6.25 children suffer from autism per every 10,000 five-year-old children (Samadi and McConkey 2015). Since the prevalence of this disorder in recent years has reached about 0.5-1% in the population of any society, this may seriously challenge healthcare providing organizations in near future (McAuliffe *et al.* 2022). The mentioned limitations in establishing communication and social interactions among this group of children in turn cause limitations in physical activities and weakness in their complex motor activities. Although weakness in the mo-

tor function in this group of children is not a specific skill for diagnosis of autism (Hudry *et al.* 2020), studies have shown that proper motor functioning in these children leads to improvements in performing their daily activities and self-care (Ozboke *et al.* 2021).

Self-care is a fundamental concept and central factor in survival and sense of well-being, which plays a key role in advancing social and independent life (James *et al.* 2015; O'Brien and Kuhaneck 2019). Meanwhile, learning self-care skills usually begins in preschool age, and develops throughout the developmental period of the child with development of fine and gross movements as well as improvement of cognitive-psychological-social skills of children (Mounzer and Stenhoff 2022; O'Brien and Kuhaneck 2019). Most of the self-care performances are shaped within the first 10 years of life of any child including independence in nutrition, bathing, taking care of personal hygiene, etc., which in turn causes greater development and growth as well as survival of children (Baker *et al.* 2021; Case-Smith and O'Brien 2014). However, autistic children have many problems with self-care because of their motor and cognitive disorders. In this regard, studies show that (Baker *et al.* 2021; Malucelli *et al.* 2021) about 50% of autistic children are fully dependent on their family and care providers for performing self-care, as well as doing social and academic activities, and they require full-time care. Liss *et al.* (2001) stated that although high-performance autistic children have a better level of performance compared to those with low performance, they still require assistance for performing their self-care activities. Also, other studies have stated that the process and speed of learning the self-care skills in children with autism reaches a plateau over time and with aging beyond 13 years (Bal *et al.* 2015; Gray *et al.* 2014; Tomaszewski *et al.* 2020). Accordingly, training self-care skills from school age is essential for autistic children (Chi and Lin 2022). This is because it not only leads to promotion of adaptive behaviors in these children, but also contributes to greater approval of autistic children by the family and in turn the society (Shishefar *et al.* 2018).

Meanwhile, it is clear that families and especially mothers of children with autism play a significant role in providing care and training for these children (Ramezani *et al.* 2014), and the major burden and responsibility of taking care of these children are on the shoulders of their families and mothers (Koolae *et al.* 2014). On the other hand, taking care of these children is

very difficult and burdensome because of their limited and superficial interests as well as their cognitive and behavioral disabilities. All these make their mothers experience severe psychological pressure because of anxiety, depression, confusion in social conditions, and loss of personal freedom and leisure time (Bravo-Benítez *et al.* 2019). These factors severely affect coping of parents and their attempts for coping with the child's disease. This becomes so intense that some mothers either quit taking care and training their child over the long run (Antonopoulou *et al.* 2020), or they continue training their child with severe psychological and physical fatigue plagued by frustration, which again affects the quality of life of mothers in the long run (Bravo-Benítez *et al.* 2019).

Quality of life is the most important reflection of the all-around sense of well-being (Adams *et al.* 2020). The World Health Organization (1995) describes quality of life as mental perception of wellness of life regarding positive and negative dimensions of personal performance in cultural and belief contexts (Group 1995). Quality of life is a general term in physical and psychological health dimensions including good physical performance, suitable attractions and behaviors, desirable performance, and sense of well-being (Özgür *et al.* 2018).

Meanwhile, it seems that the parents of autistic children experience lower quality of life compared to those who grow as normal children in terms of development (Özgür *et al.* 2018; Wang *et al.* 2022).

Since in Iran the challenges of taking care of children with autism have been examined at a very limited level, such that the parents, especially mothers, have received insufficient support by health care provision systems (Mohammadi *et al.* 2018), one of the most important duties of the healthcare team and especially pediatric nurses is helping the mothers of autistic children in coping with this disease.

In this way, the mothers could well understand the behavioral and developmental conditions and characteristics of their autistic children and adopt realistic expectations and behaviors about their children. Further, the healthcare team and nurses that provide care for autistic children should provide the ground for enhancing the quality of life of mother and their autistic children through extensive support and education (Özgür *et al.* 2018; Rodriguez *et al.* 2019). Thus, the family and especially mothers eventually acquire suitable coping strategies in the adaptation stage (Wang

et al. 2022), which is considered the transition period from the crisis in the reconstruction path of the family structure (Ismail *et al.* 2022). The mothers of these children should revisit their current status for recognizing sense of integrity and playing their parental role, whereby they could control their emotions so that with financial support, they could interpret new norms and rules in favor of their children (Ismail *et al.* 2022). Thus, because of the close and mutual relationship between the psychological and physical status plus the self-care status of children with autism and the coping as well as quality of life of mother, this study seems to be essential.

Accordingly, we intended to conduct a study for exploring the relationship between self-care performance and coping as well as quality of life of mothers with autistic children.

Material and methods

Study design and setting

This was a descriptive-analytical study with a cross-sectional approach performed in three autism centers affiliated with medical sciences universities in the west of Iran from June 2021 to November 2021. Two aims of this study were to determine the extent of self-care performance of 7-12-year-old children with autism who had high and moderate performance, and to evaluate the relationship between self-care performance of 7-12-year-old autistic children with high as well as moderate performance and coping plus quality of life of their mothers.

Participants and sampling

The sample size in this study consisted of all 7-12-year-old children with high and moderate performance who were under training and care in the autism center affiliated with medical sciences universities. According to the statistics of the Association of Autism affiliated with the University of Medical Sciences, about 120 autistic children with high and moderate performance who received training and care in this association were present. This same number of children alongside their mothers was chosen through available sampling method and invited to the study.

The inclusion criteria were children with autism 7-12 years of age who were autistic children with high and moderate performance according to the Diagnostic and Statistical Manual of Psychological Disorders (DSM-IV) and based on the opinion of a pediatric and adolescent psychiatrist.

Also, based on the questionnaire of measuring the spectrum of autism in the medical file of children, they needed to have acquired a score of 22 from the trainer or 19 from the mother. Further, the children with autism participating in this study should have not had mental retardation or any other physical, developmental-cognitive disorders. Meanwhile, the mothers of these children should have had the ability to participate in this study and the literacy (reading and writing) to complete the questionnaires.

The inclusion criterion was not returning back the relevant questionnaires, and not responding to more than 20% of the questionnaire items was the exclusion criterion.

After receiving the ethics code, research ID, and introduction letter, the researcher referred to the autism centers affiliated with medical sciences universities of West of Iran, and after receiving informed consent from the mothers, they were requested to complete the data collection instruments including the demographic characteristics form, adaptation questionnaire, and the Parent Quality of Life Questionnaire (P-QoL). Further, the questionnaire for assessing the self-care performance and process was completed by a trainer who was very frequently close to the child after observing the behavior of the child at least two times, and eventually all questionnaires were completed in November by the researcher. Ten participants did not return the questionnaires. Accordingly, statistical analysis was performed based on participation of 110 mothers of children with autism. This means that the response rate of questionnaires was 91.66%. The reason for not responding to questionnaires was spread of coronavirus and irregular presence of mothers in centers.

Data collection instruments

Demographic information

This questionnaire includes age, gender, economic status, number of children, number of diseased children, number of children with autism as well as their severity of autism, age of mother and father, parental education, the child's head of family (living with father and mother, father or mother). The face and content validity of this questionnaire in this study have been confirmed by 10 faculty members of the research center of autism as well as the psychiatric nursing and pediatric nursing group. Also, in the present study, the reliability of the questionnaire was estimated 97% based on the Cronbach α method of 5%.

Assessment of Motor and Process Skills (AMPS)

This scale is a precise instrument for evaluating the functional problems of children two years of age and above based on observation of their daily activities. This questionnaire consists of 36 items in motor skills (status of the limbs, grabbing and holding objects, moving oneself and objects, as well as stable performance: 16 items) and processing skills (constructive performances, use of knowledge, time organization, space and object organization, functional organization: 20 items). This questionnaire is completed by a trainer who had contact with the child for at least two sessions. The trainer scores each item based on a 4-point Likert scale from 1 to 4 based on the extent of the child's attempts as well as the manner of advancing activities, precise assessment of the position the child has towards objects, the extent of observing safety issues, and need for help in doing the activity. A score of 4 represents absence of a problem and adequacy in self-care, a score of 3 denotes probability of performance dissociation (lack of performance stability), a score of 2 shows ineffective performance or clear functional dissociation, and a score of 1 refers to fatigue, inadequacy, lack of safety in doing activity, and the need for verbal or physical support in advancing the daily routine skills. Higher scores indicate a high level of adequacy in child self-care. The face and content validity as well as reliability of this scale were explored and established in 2011 by Merritt *et al.*; the reliability based on the Cronbach α method for motor skills and process skills was 0.92 and 0.91, respectively, showing suitable reliability according to the coefficients calculated by the test (Merritt 2011). In this study, the content validity and reliability of this questionnaire were 0.97 and 0.96 for motor and process skills, respectively, based on the Cronbach α method, which are very acceptable.

Coping Health Inventory for Parents

The Coping Health Inventory for Parents developed by McCubbin *et al.* for measuring parental adaptation to chronic disorders of children. This questionnaire has 45 items in three subscales of adaptive behaviors group 1 with 19 statements (integrity of the family and making the situation desirable), adaptive behaviors group 2 with 18 statements (social support, self-esteem, and psychological stability), and eight statements for adaptive behaviors group 3 (communication and medical advice). This scale is scored based on a four-point Likert scale

(1 – useless, 2 – minimum utility, 3 – relatively useful, 4 – very useful). If any behaviors are not done by children, the parent should specify whether that behavior is not performed selectively or it is not possible to do it. Higher scores represent greater adaptation. McCubbin *et al.* obtained the reliability of this instrument in two different studies as 0.79 and 0.71 with Cronbach's α (McCubbin and Patterson 1983). In this study, the reliability of this instrument *via* the Cronbach α method was 0.93, which is very acceptable.

Parent Quality of Life Inventory (P-QoL)

The Parent Quality of Life Inventory, prepared and developed in 1998 by the World Health Organization, includes 26 items. The first two items deal with general questions, while the other 24 items capture four areas of psychological health, physical health, social health, and environmental health based on a 5-point Likert scale (1-5). Items 3, 4, and 26 are reverse scored. The score has a range 0-100. The range of scores in each area is 4-20, with higher scores representing greater quality of life. The reliability and validity of this questionnaire in Iran were established by Nejati *et al.* in 2006; its reliability using the test-retest method has been reported as 0.77 for physical health, 0.77 for psychological health, 0.75 for social relations, and 0.84 for environmental health (Group 1998). Note that the content validity and reliability of this questionnaire in the present study was 0.94 based on the Cronbach α method, which is very acceptable.

Statistical methods

Once collected, the data were analyzed by SPSS 16. For this purpose, descriptive statistics (mean, percentage, and standard deviation) and various tests of inferential statistics (Pearson correlation coefficient, chi-square test) used to investigate the relationship between self-care performances of autistic children coping as well as quality of life of their mothers. In all of the mentioned tests, the significance level was defined as $p < 0.05$. Next, the variables of coping, quality of life, age and gender of the child with autism, number of children, autism functioning level, education and occupation of mother which had $p < 0.25$ were inputted into multiple linear backward stepwise regression model.

Ethics approval and consent to participate

The study was approved by the ethics committee of the University of Medical Sciences with

the code of 1399-965. At the beginning of the project, the researcher introduced himself and explained the objectives to the research units, and assured them about their free participation and possibility of refusal to continue their participation. Written informed consent was taken for participants in the study.

Results

Demographic information

The age range of the participating mothers was 18-45 years with a mean of 32.57 ± 2.42 . Most mothers had a diploma ($n = 80, 72.72\%$), and a limited number of them had academic degrees. Most of these mothers ($n = 85, 77.27\%$) were homemakers. The mean age of the fathers was 45.67 ± 2.54 years; most of them had a diploma and freelancing jobs. The parents of children with autism in this study had 2-3 children, and one child had autism. The children with autism in this study had a mean age of 10.24 ± 1.71 years, and the mean duration of living with the disease was 9.97 ± 1.53 years, with most of the autistic children living with both parents. The economic status of most families was average. Boys constituted a majority in this study (69.10%). Children with autism with moderate performance had the highest percentage in comparison to high-performance autistic children (Tables 1-3).

One-way analysis of variance (ANOVA) showed that there was a significant relationship between self-care performance of children with autism and occupation plus education of their mothers ($p < 0.05$) (Table 1). This test also showed a significant relationship between the self-care performance of autistic children and the number of children in each household ($p < 0.05$) (Table 2). Meanwhile, the independent *t*-test indicated a significant relationship between self-care performance of children with autism and gender as well as their autism functioning level ($p < 0.05$). Also, ANOVA again showed that there was a significant relationship between self-care performance of children with autism and their age ($p < 0.05$) (Table 3).

Self-care performance of children with autism, coping of mothers, quality of life of mothers

The obtained results showed that the mean self-care performance of children with autism in motor and process areas was 115.2 ± 10.34 . Also, the motor performance area had a higher mean compared to its process counterpart. The mean coping value in the mothers of children with autism was 129.2 ± 77.64 . On the other hand, the area of family integrity and making the situation desirable claimed the largest mean in comparison to the other two areas. The mean

Table 1. Frequency distribution of demographic information of mothers and its association with the self-care performance of children with autism

Variable	n (%)	Self-care performance Mean (SD)	Test statistic	P-value
Mother's age (years)				
18-24	16 (14.55)	111.37 (2.28)	2.79	0.83
25-31	71 (64.54)	113.89 (2.45)		
32-38	18 (16.36)	111.32 (2.25)		
39-45	5 (4.55)	114.26 (2.34)		
Total	110 (100)			
Mother's education				
Primary	11 (10.00)	119.58 (2.21)	2.48	0.034
Diploma	80 (72.72)	125.19 (2.55)		
Bachelor's	10 (9.10)	129.75 (2.31)		
Master's and above	9 (8.18)	131.04 (2.37)		
Total	110 (100)			
Mother's occupation				
Housewife	85 (77.27)	115.77 (2.42)	2.53	0.039
Freelancing job	15 (13.63)	119.09 (2.61)		
Employee	10 (9.10)	126.32 (2.21)		
Total	110 (100)			

Table 2. Frequency distribution of demographic information of mothers in terms of household characteristics and its association with the self-care performance of children with autism

Variable	n (%)	Self-care performance Mean (SD)	Test statistic	P-value
No. of children				
One child	43 (39.09)	113.47 (3.68)	2.76 ¹	0.021
2-3 children	58 (52.72)	129.32 (2.57)		
4 children and more	9 (8.18)	134.62 (2.23)		
Total	110 (100)			
No. of children with autism				
One child	100 (90.90)	111.37 (2.43)	3.14 ²	0.81
2-3 children	10 (9.10)	114.42 (2.26)		
Total	110 (100)			
Head of household				
Mother	10 (9.10)	110.37 (2.28)	2.31 ¹	0.82
Father	13 (11.80)	112.27 (2.11)		
Mother and father (both)	87 (79.10)	111.42 (2.62)		
Total	110 (100)			
Economic status				
Poor	11 (10.00)	111.87 (2.18)	2.42 ¹	0.83
Average	81 (73.63)	114.19 (2.23)		
Good	18 (16.36)	113.02 (2.43)		
Total	110 (100)			

¹ANOVA test, ²Independent t-test

Table 3. Frequency distribution of demographic information of mothers in terms of child's characteristics and its association with the self-care performance of children with autism

Variable	n (%)	Self-care performance Mean (SD)	Test statistic	P-value
Child's gender				
Boy	76 (69.10)	112.32 (2.27)	2.53 ¹	0.025
Girl	34 (30.90)	131.29 (2.34)		
Total	110 (100)			
Child's age (years)				
7	16 (14.55)	109.12 (2.13)	2.38 ²	0.019
8	17 (15.45)	114.87 (2.36)		
9	21 (19.10)	121.37 (2.28)		
10	18 (16.36)	125.53 (2.16)		
11	20 (18.18)	129.61 (2.54)		
12	18 (16.36)	131.92 (2.46)		
Total	110 (100)			
Autism functioning level				
Moderate performance	67 (60.90)	117.51 (2.37)	2.62 ¹	0.027
High performance	43 (39.10)	132.37 (2.48)		
Total	110 (100)			
Duration of having autism (years)				
3-5	28 (25.45)	117.47 (2.54)	2.57 ²	0.78
6-8	65 (59.10)	119.56 (2.38)		
9-11	17 (15.45)	121.96 (3.32)		
Total	110 (100)			

¹Independent t-test, ²ANOVA test

Table 4. Mean and standard deviation of variables of self-care performance, adaptation, and quality of life of mothers having autistic children participating in the study

Variable	Areas	Mean \pm SD in each dimension	Mean \pm SD of total measure
Self-care performance	Motor	116.2 \pm 63.27	115.2 \pm 10.34
	Process	113.2 \pm 58.41	
Adaptation	Household integrity and making the situation desirable	136.2 \pm 21.47	129.2 \pm 77.64
	Social support, stability, and self-esteem	121.2 \pm 74.83	
	Medical advice and communication	131.2 \pm 36.74	
Quality of life	Physical	91.2 \pm 36.46	85.2 \pm 25.34
	Psychological	86.2 \pm 94.32	
	Social	83.2 \pm 26.27	
	Environmental	79.2 \pm 54.31	

quality of life of mothers with autistic children was 85.25 ± 2.34 , with the environmental area showing the lowest percentage (Table 4).

Relationship between self-care performance of autistic children and coping plus quality of life of mothers

The findings indicated that there was a strong correlation between the self-care performance of children with autism and the coping of their mothers ($p < 0.001$, $r = 0.92$) as well as between self-care performance of these children and their

mother's quality of life ($p < 0.001$, $r = 0.95$). Meanwhile, a direct and a strong correlation was found between coping and quality of life of these mothers ($p < 0.001$, $r = 0.89$).

Predictor factors in the self-care performance of children with autism

The variables of adaptation, quality of life, age and gender of children with autism, number of children, autism functioning level, education and occupation of the mother, for which $p < 0.25$, were introduced into the multiple lin-

Table 5. Predictor factors of self-care performance of autistic children of participants in the study

Factors	Nonstandard coefficients		Standard coefficients	T	P-value	
	B	SE	β			
Adaptation	2.76	1.23	0.34	2.24	0.001	
Quality of life	2.68	1.17	0.27	2.29	0.001	
Child's age (years)	2.47	1.54	0.65	1.60	0.015	
No. of children	2.31	1.38	0.48	1.67	0.021	
Autism functioning level	2.18	1.32	0.42	1.65	0.026	
Child's gender						
	Boy	Reference	–	–	–	
	Girl	3.05	1.43	0.54	2.13	0.025
Mother's education						
	Primary	Reference	–	–	–	
	Diploma	1.96	1.23	0.34	1.59	0.033
	Bachelor's	2.18	1.13	0.37	1.92	0.034
	Master's and above	2.23	1.18	0.41	1.88	0.032
Mother's occupation						
	Housewife	Reference	–	–	–	
	Freelancing job	1.95	1.24	0.41	1.57	0.036
	Employee	2.03	1.16	0.43	1.75	0.039

Adjusted $R^2 = 70.65\%$

ear backward stepwise regression model. These variables remained in the model and explained about 70.65% of the variance of the self-care performance in children with autism (Table 5).

Discussion

Based on the findings obtained from this study, the mean of the self-care performance scores of autistic children was 115.2 ± 10.34 . In this regard, Chi and Lin (2020) reported that children with autism have a lower share of visual perception and less ability in doing self-care skills compared to normal children. They found that the self-care performance of normal children was high, but that of autistic children was low. Thus, the level of visual perception and motor skill of children with autism directly affected their ability to do their daily self-care skills (Chi and Lin 2020). The findings of this study, not in line with the present research, showed lower mean scores of self-care performance among autistic children, which may be due to the younger age of children participating in that study. Further, based on the findings of Sheza Ahmed *et al.* (2021), children with autism had low self-care performance because of some sensorimotor defects; they were dependent on their mothers in doing the most rudimentary daily life skills (Ahmed *et al.* 2021a). The lower mean scores of self-care performance in children with autism in this study may be due to applying a different instrument called the Barthel scale. It deals with investigating the independence level of the child in doing their daily activity skills for assessing a sensory and motor disability. The studies of Günel *et al.* (2019) showed that self-care skills of autistic children were very poor because of cognitive and motor defects in comparison to normal children, emphasizing the necessity for healthcare providers to implement educational programs. Based on other studies by Chi and Lin (2022), 53.3% of children with autism had motor and process problems at preschool ages; half of the children with autism required training in doing their daily activities in their preschool ages (Chi and Lin 2022). The difference in the age range of participants in the study, functioning level of autism, and use of different instruments can explain these different results.

Also, the mean of the coping scores of autistic children mothers in this study was 129.2 ± 77.64 . Meanwhile, based on the results obtained from this study, a strong and direct correlation was reported between self-care performance and coping of mothers ($p < 0.001$).

These findings suggested that the ability of the autistic child to do the self-care tasks has a direct relationship with the coping behaviors of mothers at three levels of family integrity, social support, and medical advice, potentially affecting adaptation of mothers for accepting behavioral, motor, and process disorders of autistic children. In line with the present study, Selvakumar and Panicker (2020) reported that the mothers of autistic children because of the performance and cognitive defects of their children had to provide greater and more specific care compared to mothers with normally developed children. Thus, performing care affairs constantly resulted in fatigue and apathy in the long run, thereby reducing the coping ability of mothers. Indeed, the mothers of autistic children showed less coping compared to the parents of children with normal development (Selvakumar and Panicker 2020). Furthermore, based on the results of Antonopoulou *et al.* (2020), the developmental-behavioral conditions of autistic children and their inability to do daily activities result in worries and chronophobia, thereby affecting their parents coping with the disorder of their children. Accordingly, there is a direct relationship between self-care performance of autistic children and parental coping, which is in line with the present study (Antonopoulou *et al.* 2020). Nevertheless, the lower mean scores of coping of these parents compared to the present research may be due to usage of different instruments and fewer mothers participating in this study. Meanwhile, the study by Sabra Ahmed *et al.* (2021) showed that the parents of autistic children have low coping levels, and usually employ inefficient and negative coping strategies, where training coping strategies were effective in enhancing the coping of mothers raising children with autism (Ahmed *et al.* 2021b). The coping scores of mothers of autistic children in this study were lower than in the present research. It did not show a relationship between this factor and the ability of the autistic child in doing self-care performance, thus being incongruent with the present study.

Furthermore, based on the findings obtained from the present study, the mean of the scores of quality of life of mothers with autistic children was 85.2 ± 25.34 . There was a strong and direct correlation between the self-care performance and quality of life of mothers with autistic children ($p < 0.001$). These findings suggest that independence in performing personal and daily affairs among high and moderate performance children with autism in motor and process

dimensions could enhance the quality of life of mothers of these children in four areas: physical, psychological, social, and environmental. In line with these findings, the study by Beheshti *et al.* (2022) showed quality of life of mothers of children with autism with the mean of 95%. A direct correlation was also found between the quality of life of mothers of autistic children and the self-care performance of these children (Beheshti *et al.* 2022). This similarity may be due to conducting the study in the same cultural context. Also, studies of Adams *et al.* (2020) showed that the quality of life of mothers of autistic children had a direct relationship with the physical and emotional problems of these children; the mean score of quality of life in the four areas of physical, psychological, social, and environmental was 93.6% in total (Adams *et al.* 2020). Also, Cappe *et al.* (2018) reported that there was a direct relationship between the performance level of autistic children as well as their ability to do daily activities and the quality of life of parents of these children. The results of this study are in line with the present study findings. Discordant with the present study, Klein *et al.* (2021) found that the mean (SD) of the quality of life of mothers of autistic children was 169 ± 94 . On the other hand, the mean scores of quality of life of mothers in the study by Klein *et al.* were higher than in the present research. This difference may be due to employing a different instrument for measuring the quality of life and conducting the study across different cultural contexts. Indeed, various factors such as culture, attitude of individuals, and socioeconomic factors affect the quality of life.

The findings of this study also showed that the variables of adaptation, quality of life, age, and gender of children with autism, number of children, autism functioning levels, as well as mothers' occupation and education explained about 70.65% of the variance of the self-care performance in children with autism. In this regard, there was no research available to the researcher that had interpreted the predictor variables of self-care performance in high and moderate performance children with autism. Thus, the researcher used other studies that have examined the self-care performance and its related factors. In this study, the effect of each of the predictor variables was discussed and investigated separately. According to Table 6, the factor of coping followed by quality of life of mothers were the most important predictor factors for that self-care performance in autistic children. In this regard, Sabra Ahmed (2021)

showed that increased adaptation of mothers in the family enhances not only the ability of the mother, but also that of the other family members involved in providing care issues and training daily skills for fulfilling the child's needs (Ahmed *et al.* 2021b). Also, the study by Selvakumar and Panicker (2020) showed that coping of parents was effective for their participation in training the child and thus improving the self-care performance of the child. Also, in the present study, the quality of life of mothers was another important factor that could explain and predict the self-care performance of autistic children. In this regard, Kabasakal found that the problems of autistic children in doing motor and process activities have a direct effect on the quality of parents, especially mothers (Kabasakal *et al.* 2021). Meanwhile, age and gender of autistic children were other important predictor factors for self-care performance of autistic children. On the other hand, Bal *et al.* (2015) also stated that as the age of children increases, self-care skills would be higher in them, though it is not in proportion with the developmental age of these children. In line with the present study, Klein showed that presence of another child in the family who does not have autism is effective in enhancing the self-care performance of the autistic child in the family. This is because it decreases the responsibility of parents for taking care of the child with autism. The presence of a healthy child also causes higher speed of learning of self-care skills and social interactions in autistic children (Klein *et al.* 2021). The autism functioning level was another factor that explained and predicted the self-care performance of autistic children. According to studies by Ozboke, increase in the severity of autism affects the functioning level of autistic children; reduction of autism functioning level leads to decreased ability of these children to do their daily activities and self-care performance (Ozboke *et al.* 2021). In addition, the education and occupation of mothers in this study affected the self-care performance of children. In this regard, Kabasakal stated that higher levels of maternal education and being a housewife contributed to their greater participation in taking care of the autistic child and enhancing their self-care performance (Kabasakal *et al.* 2021).

Limitations

One of the major limitations of the present study was the relatively low return rate of the questionnaires via e-mail, which could have been

due to the hectic work schedules of nurses in the crisis. Moreover, the variables addressed in the present study were measured over a 6-month period – it is suggested that future studies assess self-care performance with coping and quality of life in mothers of autistic children in other societies and larger samples. Health administrators and policymakers can use these findings to develop comprehensive plans for the current and future crises.

Clinical application

The healthcare authorities and policymakers investigating and benefiting from the findings of this research could establish educational programs for enhancing the self-care performance of these children and take effective steps for improving the daily skills of autistic children for increasing their independence and greater presence in the society.

Conclusions

The findings indicated that the self-care performance of high and moderate performance autistic children had a direct relationship with the level of coping as well as quality of life of mothers of these children. The more competent the child is in their self-care issues and doing daily activities, the higher will be the coping and quality of life of mothers. This study also showed that the variables of gender and the child functioning level plus coping, quality of life, age, level of education and occupation of mothers explained 70.65% of changes in the self-care performance of children with autism.

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Ethics approval and consent to participate

The institutional review board of the Hamedan University of Medical Science located in the west of Iran provided ethics approval (approval number: 1399.965) with research project number 9912128919. Also at the beginning of each interview, the researcher introduced herself and explained the goals of the study

and assured that all information would remain confidential and that they could withdraw from the study at any time. The researchers provided the opportunity for participants to inform the researcher about their withdrawal from the study at any stage of the research. Finally, written consent was obtained from study participants.

Disclosure

The authors declare no conflict of interest.

References

- Adams D, Clark M, Simpson K. The relationship between child anxiety and the quality of life of children, and parents of children, on the autism spectrum. *J Autism Dev Disord* 2020; 50: 1756-1769.
- Ahmed S, Waseem H, Sadaf A, et al. Daily living tasks affected by sensory and motor problems in children with autism aged 5-12 years. *Am J Occup Ther* 2021a; 59: 100-123.
- Ahmed SM, El-Ghadban FES, Atea STH, et al. Effect of parent training regarding coping strategies on reducing stress among parent of children with autism spectrum disorder. *Egypt J Health Care* 2021b; 12: 47-60.
- Antonopoulou K, Manta N, Maridaki-Kassotaki K, et al. Parenting and coping strategies among parents of children with and without autism: The role of anxiety and emotional expressiveness in the family. *Austin J Autism Relat Dis* 2020; 6: 1054.
- Baker E, Stavropoulos KK, Baker BL, Blacher J. Daily living skills in adolescents with autism spectrum disorder: Implications for intervention and independence. *Res Autism Spectr Disord* 2021; 83: 101761.
- Bal VH, Kim SH, Cheong D, Lord C. Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age. *Autism* 2015; 19: 774-784.
- Beheshti SZ, Hosseini SS, Maroufizadeh S, Almasi-Hashiani A. Occupational performance of children with autism spectrum disorder and quality of life of their mothers. *BMC Res Notes* 2022; 15: 1-6.
- Bravo-Benitez J, Pérez-Marfil MN, Román-Alegre B, Cruz-Quintana F. Grief experiences in family caregivers of children with autism spectrum disorder (ASD). *Int J Environ Res Public Health* 2019; 16: 4821.
- Cappe É, Poirier N, Sankey C, et al. Quality of life of French Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors. *Qual Life Res* 2018; 27: 955-967.
- Case-Smith J, O'Brien JC. Occupational therapy for children and adolescents-e-book. Elsevier Health Sciences 2014.
- Chi IJ, Lin LY. Using the assessment of motor and process skills and the pediatric evaluation of disability inventory to assess self-care performance among preschool children with autism spectrum disorder. *Am J Occup Ther* 2022; 76: 58-72.
- Chi IJ, Lin LY. Relationship between the performance of self-care and visual perception among young children with autism spectrum disorder and typical developing children. *Autism Res* 2020; 14: 315-323.

13. Gray KM, Keating CM, Taffe JR, et al. Adult outcomes in autism: Community inclusion and living skills. *J Autism Dev Disord* 2014; 44: 3006-3015.
14. Greenspan SI, Wieder S. *Engaging autism: using the floortime approach to help children relate, communicate, and think*. Da Capo Lifelong Book, Colorado, Philadelphia, Pa. 2009.
15. Group TW. The World Health Organization quality of life assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med* 1998; 46: 1569-1585.
16. Group W. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995; 41: 1403-1409.
17. Günel A, Bumin G, Huri M. The effects of motor and cognitive impairments on daily living activities and quality of life in children with autism. *J Occup Ther Sch Early Interv* 2019; 12: 444-454.
18. Haque MM, Rabbani M, Dipal DD, et al. 2021. Informing developmental milestone achievement for children with autism: Machine learning approach. *JMIR Med Inform* 2021; 9: e29242.
19. Hudry K, Chetcuti L, Hocking DR. Motor functioning in developmental psychopathology: A review of autism as an example context. *Res Dev Disabil* 2020; 105: 103739.
20. Ismail MF, Safii R, Saimon R, Rahman M. Quality of life among Malaysian parents with autism spectrum disorder child: the double ABCX model approach. *J Autism Dev Disord* 2022; 52: 113-123.
21. James S, Ziviani J, Ware RS, Boyd RN. Relationships between activities of daily living, upper limb function, and visual perception in children and adolescents with unilateral cerebral palsy. *Dev Med Child Neurol* 2015; 57: 852-857.
22. Kabasakal E, Özpulat F, Bakır E. Analysis of the nutrition, self-care skills, and health professional support in schools of children with autism spectrum disorder. *Florence Nightingale J Nurs* 2021; 29: 239-249.
23. Klein L, Azim SI, Masi A, et al. Behavioural concerns of children on the autism spectrum and the impact on parental quality of life. *Res Square* 2021; 4: 47-60.
24. Koolae AK, Khazan S, Tagvae D. Mother-child relationship and burden in families of children with mental retardation. *Middle East J Psychiatry Alzheimers* 2014; 84: 1-5.
25. Liss M, Harel B, Fein D, et al. Predictors and correlates of adaptive functioning in children with developmental disorders. *J Autism Dev Disord* 2001; 31: 219-230.
26. Malucelli ER, Antoniuk SA, Carvalho NO. The effectiveness of early parental coaching in the autism spectrum disorder. *J Pediatr (Rio J)* 2021; 97: 453-458.
27. McAuliffe T, Cordier R, Chen YW, et al. In-the-moment experiences of mothers of children with autism spectrum disorder: a comparison by household status and region of residence. *Disabil Rehabil* 2022; 44: 558-572.
28. McCubbin HI, Patterson JM. The family stress process: The Double ABCX Model of adjustment and adaptation. *Marriage & family review*. *Autism* 1983; 6: 7-37.
29. Merritt BK. Validity of using the assessment of motor and process skills to determine the need for assistance. *Am J Occup Ther* 2011; 65: 643-650.
30. Mohammadi F, Rakhshan M, Molazem Z, Zareh N. Parental empowerment of the parents of children with autism: a qualitative study. *Sadra Med J* 2018; 6: 261-274.
31. Mounzer W, Stenhoff DM. Early intensive behavioral intervention program for children with autism in Syria. *Focus Autism Other Dev Disabil* 2022; 45: 83-112.
32. Nejati V, Zabihzadeh A, Maleki G. Comparing quality of life of severely mental retarded in home and residential center. *Iranian J Excep Child* 2012; 11: 353-361.
33. O'Brien J, Kuhaneck H. *Using occupational therapy models and frames of reference with children and youth*. Case-Smith's occupational therapy for children and adolescents. E-book, 2019; 18.
34. Ozboke C, Yanardag M, Yilmaz I. Exploring the relationships between motor proficiency, independence and quality of life in adolescents with autism spectrum disorder. *Int J Dev Disabil* 2021; 68: 850-857.
35. Özgür BG, Aksu H, Eser E. Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. *Indian J Psychiatry* 2018; 60: 278-285.
36. Ramezani T, Shirazi ZH, Sarvestani RS, Moattari M. Family-centered care in neonatal intensive care unit: a concept analysis. *Int J Community Based Nurs Midwifery* 2014; 2: 268-278.
37. Rodriguez G, Hartley SL, Bolt D. Transactional relations between parenting stress and child autism symptoms and behavior problems. *J Autism Dev Disord* 2019; 49: 1887-1898.
38. Rong Y, Yang CJ, Jin Y, Wang Y. Prevalence of attention-deficit/hyperactivity disorder in individuals with autism spectrum disorder: a meta-analysis. *Res Autism Spectrum Dis* 2021; 83: 101759.
39. Samadi SA, McConkey R. Screening for autism in Iranian preschoolers: Contrasting M-CHAT and a scale developed in Iran. *J Autism Dev Disord* 2015; 45: 2908-2916.
40. Selvakumar N, Panicker AS. Stress and coping styles in mothers of children with autism spectrum disorder. *Indian J Psychol Med* 2020; 42: 225-232.
41. Shishefar S, Kargarbarzi H, Darvish NS, Mohammadlo H. Comparison of the effectiveness of teaching social cognitive skills and cognitive behavioral play therapy on the social skills and social acceptance of children with disruptive behavior disorders. *JOEC* 2018; 17: 87-100.
42. Tomaszewski B, Hepburn S, Blakeley-Smith A, Rogers SJ. Developmental trajectories of adaptive behavior from toddlerhood to middle childhood in autism spectrum disorder. *Am J Intellect Dev Disabil* 2020; 125: 155-169.
43. Wang R, Liu Q, Zhang W. Coping, social support, and family quality of life for caregivers of individuals with autism: Meta-analytic structural equation modeling. *Pers Individ Dif* 2022; 186: 111351.

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