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Parental stress, care burden, and coping styles in mothers of autistic children during the pandemic of COVID-19†

Original article

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Abstract: **Objectives:** To investigate the parenting stress, care burden, and coping styles in mothers of autistic children during the pandemic of COVID-19. The outbreak of COVID-19 and the closure of education and care centers for these children may affect stress, care burden, and adaptation of these mothers.

Methods: This study was a cross-sectional research. A total of 110 mothers completed questionnaires. Data were analyzed by descriptive statistics (frequency, percentage, mean, and standard deviation), independent t-test, ANOVA, and multiple linear regressions.

Results: Findings showed that parenting stress has a strong and direct correlation with caring burden ($P < 0.001$, $r = 0.95$), and a strong and indirect correlation with coping styles ($P < 0.001$, $r = -0.91$). Variables of caring burden, coping strategies, mother's age, mother's job, mother's education, number of autistic children, economic status, children's age, and functional level of autism in children can predict 72.21% of the variance in parenting stress in these mothers.

Conclusions: In the present study, parenting stress of mothers of autistic children was reported to be high during the COVID-19 pandemic. Based on the findings of this study, it can be concluded that pediatric nurses and health policymakers should provide a suitable educational and supportive environment for mothers of autistic children to enhance the coping level of these mothers and consequently reduce their parenting stress and care burden.

Keywords: *autistic children COVID-19 • care burden • coping styles • mothers • parental stress*

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1. Introduction

Autism is one of the most important neurodevelopmental disorders of the last decade with a global increase of >6%, placing a lot of stress and psychological and physical pressure on a large number of families in every society.[1,2] This will cause many problems for healthcare providers in the near future,[3] because autistic children have various disorders in the cognitive, motor, and interactive domains that affect their verbal, behavioral, and social interactions in different situations.[4,5]

Incapability of self-care and dependence on the caregiver are recognized as one of the most important problems of children with autism.[6] So, caring for children with autism requires a lot of time and energy and, in the long run, it imposes high physical and psychological pressures on caregivers.[7] It should be noted that parents, especially mothers, are the main caregivers of children with autism, who often face many challenges due to the various problems of these children and are affected by various aspects of their lives.[2,8,9] In a family with a child with autism, family life revolves around the affected child, and the child's needs lead to chronic stress and neglect of other aspects of family life.[10] Although stress is an unavoidable aspect of parenting and is considered a normal experience commensurate with childcare responsibilities, excessive parenting stress in those with autistic children leads to negative effects on physical–mental health of these parents.[11]

Parenting stress is an adverse psychological response to an imbalance between parents' expectations of themselves and their ability to meet those expectations.[12] Parenting stress in those with autistic children is related to the main features of this disease, including social communication disorders, limited interests, and stereotyped behaviors of these children.[13] Behavioral problems of a child with autism include the severity of the disease, limited access to educational-caring services, worries about the future of the child, and the care burden of autistic children, which are the most important factors that cause parenting stress.[14,15]

Care burden refers to a set of psychological, emotional, social, and economic challenges experienced by caregivers of the physically/mentally ill that lead to psychological problems, poor quality of life, low energy levels, fatigue, and physical disorders in these caregivers.[16] Clearly, caring for children with autism is difficult and requires careful planning, energy, and time.[7] Therefore, caring for and educating these children impose a lot of pressure on parents.[7] On the contrary, there is a close and two-way relationship between parenting stress and care burden in autistic children, so stress makes caring for and educating autistic children difficult and increases the care burden. More problems and a higher care burden lead to higher parenting stress.[17] Parenting stress and the care burden imposed on mothers of children with autism have led them to search for appropriate coping strategies to control the situation.[18] Coping practices in these mothers include two general types of problem-based coping strategies (those aimed at solving a problem or doing something to change stress) and emotion-based coping (those aimed at reducing or managing anxiety from stressors).[17] Problem-based coping strategies reduce the stress levels experienced by parents of children with ASD, while emotion-based coping strategies do the opposite and are associated with more stress and depressive symptoms.[19]

In the meantime, the COVID-19 pandemic has been suggested as one of the factors affecting parenting stress, care burden, and coping methods in mothers of autistic children. The quarantine experience during this pandemic causes many psychological problems for a significant number of people. Having a psychiatry-related history during quarantine seemingly leads to more unpleasant results, and these people need more support during quarantine.[20] The COVID-19 pandemic also appears to severely affect people with disabilities, including children with autism, and their families. During the COVID-19 pandemic, due to economic uncertainties, parents of children with autism had limited access to treatment and medical procedures and faced long delays before accessing caring plans. This likely results in a greater care burden, higher parenting stress, and reduced capacity to care for their children.[21]

One of the most important responsibilities of a child caregiver is to educate and support children and their families. In the meantime, autistic children and their parents are among the neediest groups in terms of nursing services.[22] Parents of these children usually refer to child caregivers for counseling, management of parenting stress, greater coping with the child's illness, education of children, reducing the care burden, and stabilizing the family environment so that mothers can understand their child's behavioral and developmental conditions and characteristics so that they could control their parenting stress.[20,23]

Therefore, due to the close and reciprocal relationship between parenting stress and the care burden and to investigate the coping methods in mothers of children with autism, we decided to conduct a general study to investigate the relationship between parenting stress, care burden, and coping methods in mothers of children with autism.

2. Methods

2.1. Study design and setting

This study employed a cross-sectional research design. The investigation is based on the strengthening the reporting of observational studies in epidemiology statement (STROBE), a checklist for observational research, from September 2021 to January 2022. The following aims were examined in this study: evaluation of parenting stress, care burden, and coping styles in mothers of autistic children and investigation of the relationship between parenting stress, care burden, coping styles, and demographic characteristics in mothers of autistic children.

2.2. Participants and sampling

For sampling, the researcher referred to three autism centers affiliated to Hamadan University of Medical Sciences. After receiving moral approval, the researcher received the contact number of mothers of children with autism who met the inclusion criteria. The researcher then contacted and invited them to participate in the study, in case they wished. Questionnaires were given to mothers in person at autism centers. Thus, 120 mothers of autistic children were invited to participate in the study by convenience sampling method.

Inclusion criteria were as follows: age between 6 years and 12 years; high or moderate performance based on the psychiatrist's report and the Diagnostic and Statistical Manual (DSM V) guidelines of mental disorders ; no other physical, cognitive developmental or mental disorder, and the desire and consent of their parents to participate in this study. The participants who failed to answer more than half of the items in their questionnaires or did not return their questionnaires were excluded. The majority of the questionnaires (90%) were completely gathered in January. Notably, 110 mothers completed and returned the questionnaires. Thus, the response rate was 91.66%, and the mothers' reasons for not participating in this study were not having time to fill out the questionnaires and being busy.

2.3. Questionnaire

2.3.1. Demographic information questionnaire

Demographic information includes age, sex, economic status, number of children, number of sick children, number of children with autism and their autism level, parents' age, parents' education, parents' occupation, and child caregiver (living with parent or parent).

2.3.2. Parenting Stress Inventory – Short Form

Parenting Stress inventory – Short Form (PSI-SF) (1995) was designed by Abidin. It provides a comprehensive assessment of overall parental stress through subscales of parental disorder (items 1–12), dysfunctional parent–child interaction (items 13–24), and characteristics of the problematic child (items 25–36). The questionnaire has 36 items that are scored on a five-point Likert scale (1: strongly disagree to 5: strongly agree). Higher scores indicate more parenting stress. Face and content validity as well as the reliability of this scale were examined in the study of Fadaei et al.,[24] so that the face validity and content were appropriate and the reliability of this questionnaire was found to be 0.9 for mothers of boys and 0.91 for mothers of girls by Cronbach's alpha method.

2.3.3. Burden Assessment Scale

Burden Assessment Scale (BAS) (1994) was designed by Reinhard and Horowitz. This questionnaire assesses the care burden and physical–psychological challenges imposed on caregivers of patients with neuropsychiatric disorders. The tool consists of 19 items that are scored on a four-point Likert scale (1: not at all to 4: very much). Higher scores indicate a greater care burden. Face and content validity as well as the reliability of this scale were examined by Reinhard et al.[25] so the face and content validity were appropriate and the reliability of this scale was determined as 0.89 by Cronbach's alpha method.

2.3.4. Coping Strategies Questionnaire

Coping Strategies Questionnaire (CSQ) (1980) was developed by Lazarus and Folkman as a tool for assessing how people cope with stress. This questionnaire consists of 66 items and 8 components (direct confrontation, avoidance, self-control, seeking social support, responsibility, elusion, managerial problem solving, and positive reassessment). Items are scored on a four-point Likert scale (0: not used at all to 3: used a lot). In this questionnaire, the low rate of application of coping methods scores 0–66, moderate rate 66–110, and high rate 110 and more. Face and content validity as well as the reliability of this scale were examined in Attaran's study.[26] Thus, the face and content validity of this questionnaire is appropriate and the reliability was obtained from 0.61 to 0.79 by Cronbach's alpha method.[26]

2.4. Statistical methods

In this study, the collected data were analyzed with the SPSS software version 22 (IBM Corporation, Armonk, New York, United States). For this purpose, descriptive statistics (frequency, percentage, mean, and standard deviation) were used. Independent *t*-test and ANOVA were also used to investigate the relationship between parenting stress and demographic information. The significance level was considered $P < 0.05$. Then, demographic information, care burden, and coping strategies ($P < 0.25$) were entered into the multiple linear regression model with a backward strategy. In addition, comparing the results of simple and multiple linear regressions, we investigated the effect of moderator variables on the relationships between parenting stress with demographic information, care burden, and coping strategies. The researcher evaluated, before performing multiple linear regression, hypotheses including normality of data, homogeneity of variance, and independence of the residual.

2.5. Ethics approval and consent to participate

This study was approved by the ethics committee of Hamadan University of Medical Sciences (IRB approval number: 1400.227). Also, at the beginning of the study, the researcher introduced herself, 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. Finally, written informed consent was obtained from all the participants after providing them with sufficient information on the study.

3. Results

3.1. Demographic information

A total of 110 mothers participated in the study. The range of the participants' ages was between 18 years and 45 years with a mean of 31.97 ± 2.42 years. The majority of the participants 79.1% were married, 58% of whom had two or three children. Also, most of the

Demographic variables	Number, n (%)	Parenting stress, mean ± SD	*P*-value
Mother's age (years)			0.021**
18–24	16 (14.55)	143.37 ± 3.38	
25–31	71 (64.54)	139.89 ± 3.55	
32–38	18 (16.36)	121.32 ± 3.13	
39–45	5 (4.55)	114.26 ± 3.57	
Mother's education level			0.025**
Primary	11 (10)	112.58 ± 3.21	
Diploma	80 (72.72)	126.19 ± 3.49	
Bachelor	10 (9.10)	131.75 ± 3.28	
Master's degree and higher	9 (8.18)	140.04 ± 3.17	
Mother's job			0.023**
Self-employed	15 (13.63)	126.09 ± 3.61	
Employed	10 (9.10)	142.32 ± 3.03	
Housewife	85 (77.27)	115.27 ± 3.42	
Financial status			0.015**
Weak	11 (10.00)	162.37 ± 3.18	
Moderate	81 (73.63)	139.89 ± 3.23	
Good	18 (16.36)	124.02 ± 3.43	
Number of children			0.75**
1	43 (39.09)	124.17 ± 3.68	
2–3	58 (52.72)	126.09 ± 3.57	
4 and more	9 (8.18)	121.02 ± 3.23	
Number of children with autism			0.013*
1	100 (90.90)	127.37 ± 3.43	
2	10 (9.10)	168.42 ± 3.26	
Sex of child			0.81*
Boy	76 (69.10)	127.32 ± 3.41	

(*Continued*)

Table 1. Continued

Demographic variables	Number, n (%)	Parenting stress, mean ± SD	*P*-value
Girl	34 (30.90)	128.29 ± 3.47	
Child's age (years)			0.011**
6–8	37 (33.64)	124.79 ± 3.77	
9–11	47 (42.73)	126.24 ± 3.12	
12–14	26 (23.63)	128.29 ± 3.47	
Autism performance level			0.019*
High performance	43 (39.10)	129.37 ± 3.48	
Moderate performance	67 (60.90)	168.51 ± 3.37	

Note: *Independent t-test; **ANOVA test.

Table 1. Participants' demographic characteristics and parenting stress scores.

participants 72.72% had a diploma, 77.27% were housewives, and 69.1% had a boy child (Table 1).

3.2. Relationship between parenting stress and demographic information

The findings of the study showed that there was a statistically significant relationship between parenting stress with mother's age, mother's job, and mother's education and number of autistic children, children's age, economic status, and level of autism in children. Mothers with Master and PhD's degree education, employed mothers who had three or more children, mothers who had children with low-functioning autism, and mothers who had autistic children of age 12–14 years reported more care burden.

3.3. Parenting stress, caring burden, and coping strategies in the participants

The parenting stress mean score of the mothers who participated in the present study was 142.19 ± 3.35, and the caring burden mean score was 65.55 ± 2.38. Also, the coping strategies mean score was found to be 95.45 ± 1.64 during the COVID-19 pandemic (Table 2).

3.4. Relationship between parenting stress, caring burden, and coping strategies in the participants

The findings of the study show that there is a strong and direct correlation between parenting stress and caring burden in mothers of children with autism during the COVID-19 pandemic ($P < 0.001$, $r = 0.95$). Also, a strong and indirect correlation was found to exist between parenting stress and coping strategies ($P < 0.001$, $r = –0.91$).

Variable and dimension	Per dimension	Total
Parenting stress		142.19 ± 3.35
Parental distress	140.37 ± 3.31	
Parent–child dysfunctional interaction	142.58 ± 3.47	
Difficult child characteristics	143.62 ± 3.27	
Caring burden		65.55 ± 2.38
Physical	63.71 ± 2.46	
Mental	67.39 ± 2.31	
Coping strategies		95.45 ± 2.64
Confrontive coping	89.21 ± 2.47	
Self-controlling	98.36 ± 2.74	
Seeking social support	110.29 ± 2.59	
Escape – avoidance	104.57 ± 2.43	
Accepting responsibility	96.34 ± 2.61	
Distancing	114.11 ± 2.83	
Plan full problem-solving	78.43 ± 2.73	
Positive reappraisal	72.36 ± 2.78	

Table 2. Mean and standard deviation (M ± SD) of the participants' parenting stress, caring burden, and coping strategies.

3.5. Predictor variables of parenting stress in mothers of children with autism during the pandemic of COVID-19

The variables such as caring burden, coping strategies, mother's age, mother's job, mother's education, number of autistic children, economic status, children's age, and level of autism in children which had a *P*-value <0.25 were entered into multiple linear regressions with the backward technique. These variables remained in the model and accounted for about 72.21% of the parenting stress variance in the mothers of autistic children during the pandemic of COVID-19 (Table 3).

Variable	Unstandardized coefficients		Standardized coefficients β	*t*	*P*-value
	B	Standard deviation			
Caring burden	2.98	1.18	0.5	2.52	0.001
Coping strategies	−2.76	1.07	0.65	2.57	0.001
Child's age	2.78	1.43	0.61	1.94	0.013
Number of children with autism	2.63	1.27	0.58	2.07	0.014
Financial status	−2.58	1.12	0.54	2.3	0.015
Autism performance level	−2.43	1.32	0.47	1.84	0.02
Mother's age	−2.26	1.1	0.43	2.05	0.021
Mother's education level					
Elementary	Reference	–	–	–	–
Diploma	1.87	1.11	0.36	1.68	0.028
Bachelor	1.99	1.13	0.39	1.76	0.029
Master and PhD's degree	2.04	1.16	0.42	1.75	0.026
Mother's job					
Housewife	Reference	–	–	–	–
Self-employed	1.82	1.09	0.31	1.66	0.022
Employed	2.04	1.11	0.37	1.75	0.023

Note: Adjusted R2: 72.21%.

Table 3. Predictor variables of parenting stress in mothers of children with autism during the pandemic of COVID-19.

4. Discussion

This study showed that mothers of children with autism reported high parenting stress, high care burden, and moderate level of coping strategies. There was also a strong and direct correlation between parenting stress and care burden and a strong and inverse correlation between parenting stress and coping styles. In addition, the results showed that the variables of care burden, coping methods, number of children with autism, child age, autism performance level, economic status, maternal age, mother's job, and mother's education were predictors of parenting stress in mothers of autistic children, and these variables revealed 72.21% of the variance of parenting stress of these mothers. Although a number of studies have analyzed parenting stress, care burden, and coping patterns in mothers of children with autism during the COVID-19 pandemic, no study has focused on the relationship between parenting stress, care burden, coping patterns, and demographic information of these mothers.

Although a few studies have examined the work stress, knowledge, and awareness of mothers with autistic children during the COVID-19 pandemic, no article has investigated the relationship between parental stress, care burden, and coping styles in mothers of autistic children during the pandemic of COVID-19. Therefore, the researchers used other articles that measured the parental stress, caring burden, and coping strategies in mothers with autistic children separately before the pandemic of COVID-19.

The parenting stress score reported by mothers of children with autism in the present study was 142.19 ± 3.35, which indicates the high parenting stress in these mothers caring for their children. Parenting stress seems to be one of the most challenging issues in the care of children with autism. The findings of this study also showed that parenting stress had a statistically significant relationship with the number of children with autism, child age, autism performance level, economic status, maternal age, maternal occupation, and maternal education. Consistent with the findings of the present study, other studies have shown that parents, especially mothers of children with autism, report high parenting stress.[11,27] In this regard, Ishtiaq et al.[27] stated that the level of parenting stress was high in parents of autistic children. They also stated that with the increase in the number of sick children, parental stress has also increased.[27] Also, in line with the present study, Lin et al.[11] reported high parenting stress in parents of children with autism. They also stated that this stress was directly related to the child's behavioral problems, so the more the child's behavioral problems, the more the parents' parenting stress.[11] On the contrary, Alhuzimi[21] reported that parents of children with autism had low parenting stress, and this result is inconsistent with the present study. He also stated that there was a direct relationship

between the age of the child and the severity of autism symptoms with parenting stress. With the increasing age of the child and the severity of the symptoms of autism, parenting stress also increases, which is consistent with the present study.[21] Differences in the age range of children, the number of samples, as well as involving fathers in the above study can be the factors for inconsistent results.

This study showed that the score of care burden among mothers of autistic children was high, and there was a direct and strong correlation between parenting stress and care burden in these mothers. Consistent with the findings of this study, Patel et al.[28] and Jain et al.[29] also stated that the care burden was high in parents of children with autism. Mumtaz et al.[30] also stated that the care burden of mothers of autistic children was high and there was a direct and strong correlation between parenting stress and care burden in these mothers. Thus, when the stress of parenting has increased, the care burden has also increased.

In the present study, the score of coping strategies in mothers of children with moderate autism was reported and there was a strong and inverse correlation between parenting stress and coping strategies in these mothers. Consistent with the findings of the present study, Miranda et al.[31] and Amireh[32] stated that there was a strong and inverse correlation between parenting stress and coping styles in parents of autistic children; hence an increase in employing the coping methods decreases the parental stress. On the contrary, Samadi[33] stated that coping was low in parents of children with autism. Although this study was conducted in a cultural context similar to the present study, the parents who participated in the Samadi's study had a lower income than those who participated in the present study, so the low income of the families may have led to lower coping.

The findings of this study showed that the variables of care burden, coping methods, age of autistic child, number of children with autism, economic status, level of autism performance, mother age, mother's education, and mother's job explained and predicted about 72.21% of the variance of parenting stress in mothers with autistic children. In this regard, no study was found that could explain the high and moderate level of performance of predictor variables of parenting stress in mothers of children with autism. Therefore, the researcher used other studies that examined parenting stress and related factors. In this study, the effect of each predictor variable was discussed separately. It is noteworthy that the authors found no study that examines the care burden and maternal occupation as a predictor of parenting stress. In this regard, in line with the present study, Miranda et al.[31] proposed the use of coping methods as one of the predictors of parenting stress. Alhuzimi[21] and Lee and Chiang[34] also showed that the age of the child was a predictor of parenting stress. On the contrary, Amireh[32] rejected the effect of child age on parenting stress. These mixed results may be due to differences in the age range of children with autism under study. In addition, in an inconsistent study, Alhuzimi[21] rejected the effect of the number of children with autism on parenting stress. Differences in the age range of children, the number of samples, and involving fathers in the study can be the factors of mixed results. In line with the present study, Anuar et al.[35] concluded that economic status has an effect on parenting stress. On the contrary, Amireh[32] concluded that economic status has no effect on parenting stress. These mixed results may be due to the different age range of children and involving fathers in this study. In line with the present study, Giannttti et al.[36] and Miranda et al.[31] also emphasized the positive effect of autism performance level on parenting stress. According to Anuar et al.[35] in a coherent study, since the experiences of parents increase with age, their parenting stress is gradually reduced. In line with the present study, Di Renzo et al.[37] and Yan et al.[38] suggested maternal education as a predictor of parenting stress. On the contrary, Anuar et al.[35] stated that although parental education was a predictor of parenting stress, parents with higher education had less parenting stress. Differences in the age range of children, number of samples, and tools for measuring parenting stress are the factors of mixed results.

5. Conclusions

In the present study, parenting stress of mothers of children with autism was reported to be high during the COVID-19 pandemic. Also, the variables of caring burden, coping strategies, number of children with autism, age of the child, level of autism, economic status, mother's age, mother's job, and mother's education strongly affected the parenting stress of these mothers. Relying on the findings of this study, it can be concluded that pediatric nurses and community health policymakers should provide a suitable educational and supportive environment for mothers of autistic children to enhance their coping performance and consequently reduce their parenting stress and care burden.

Limitations

One of the most important limitations of the present study was the concurrence of data collection with the fourth and fifth waves of the COVID-19 pandemic, following the increase in the incidence of the pandemic and the closure of unnecessary occupations, autism centers, and data

collection hubs. This led to a prolonged sampling period. The lack of participation of some mothers due to their busy schedules was another limitation of the present study. It is thus suggested that in future studies, during the pandemic, online questionnaires are provided to parents and the variables are studied in different communities with a larger sample size to more accurately estimate parenting stress, care burden, and coping in mothers of autistic children.

Authors' contributions

FM, NS, SKH, THT and SB were involved in the conception of the study and designed the study. They were responsible for data collection. SKH analyzed data. FM and NS drafted the primary manuscript.

Ethics approval

This study was approved by the ethics committee of Hamadan University of Medical Sciences (IRB approval number: 1400.227) with research project number (140005123994).

Conflicts of interest

All authors declare no conflicts of interest.

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