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24-Nov-2021

NOP-2021-Aug-1354: "Care burden, Coping styles and Involvement in care in Mothers of Autistic Children in pandemic of COVID-19"

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MANUSCRIPT DETAILS

TITLE: Care burden, Coping styles and Involvement in care in Mothers of Autistic Children in pandemic of COVID-19

ABSTRACT: Aim: The aim of the present study was to investigate the burden of care, coping styles and involvement in the care of mothers of autistic children in pandemic of COVID-19 in Iranian society.

Design: A cross-sectional study

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Conclusions: Mothers of autistic children reported high caring burden and low coping in pandemic of COVID-19, but despite the high burden of care, they have continued to be actively involved in caring for autistic children.

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Care burden, Coping styles and Involvement in care in Mothers of Autistic Children in pandemic of COVID-19

Reviewer Affiliation

Universitas Islam Negeri Sumatera Utara, counseling

Manuscript ID:

NOP-2021-Aug-1354

Wiley - Manuscript type

Research Article

Search Terms

Caregiver Burden, Coping, Child

Date Assigned:

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req Are the following stated?

Research question



Design



Methods



Limitations



Yes No N/A

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The focus of the manuscript on coping styles is certainly an issue of interest in the current context. There are several parts that must be revised and clarified so that readers can better understand this paper.

Comments to the Author

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Care burden, Coping styles and Involvement in care in Mothers of Autistic Children in pandemic of COVID-19

Journal:	<i>Nursing Open</i>
Manuscript ID	NOP-2021-Aug-1354
Wiley - Manuscript type:	Research Article
Search Terms:	Caregiver Burden, Coping, Child
Abstract:	<p>Aim: The aim of the present study was to investigate the burden of care, coping styles and involvement in the care of mothers of autistic children in pandemic of COVID-19 in Iranian society.</p> <p>Design: A cross-sectional study</p> <p>Methods: 134 mothers completed questionnaires online. Data were analyzed by SPSS software version 22.</p> <p>Result: Findings showed that burden of care has a strong and direct correlation with involvement in care ($p < 0.001$, $r = 0.78$) and strongly and indirectly correlated with coping styles ($p < 0.001$, $r = -0.82$). Variables of coping styles, involvement in care, mothers' occupation, and number of children, age and functional level of autism can predict 81.27% of the variance in care burden in these mothers.</p> <p>Conclusions: Mothers of autistic children reported high caring burden and low coping in pandemic of COVID-19, but despite the high burden of care, they have continued to be actively involved in caring for autistic children.</p>

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Key words: care burden, coping styles, involvement in care, mothers, autistic Children COVID-19

1. Introduction

Autism is one of the most important developmental-behavioral disorders of the last decade that with its growth more than 6% in the world, has been caused a large number of families in the population of any society confronting to the challenges of caring for these children (Feldman & Werner, 2002; Sarabi, 2011). This issue will face organizations providing health care services to many challenges in the near future (McGuire, 2016). Because children with autism have many problems in the fields of cognition, movement and interaction (Greenspan & Wieder, 2006) that affect the behavioral development, verbal development and social interactions of these children in different situations (Ingersoll & Hambrick, 2011; Suzuki et al., 2015). Inability to self-care and dependence on the caregiver has been suggested as one of the most important problems for children with autism (Bal, Kim, Cheong, & Lord, 2015; Jasmin et al., 2009). It is clear that parents, and especially mothers, are the primary caregivers of children with autism (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016; Jenaro et al., 2020), who are in a difficult situation due to the many problems of these children and bear a heavy care burden that affects various aspects of their life (Greenspan & Wieder, 2006).

The care burden is referred to a set of psychological, emotional, social, and economic challenges experienced by the caregiver of physical and mental diseases that leads to psychological problems, poor quality of life, low energy level, fatigue as well as physical disorders (Akram, Batool, & Bibi, 2019). However, caring for children with autism is difficult and tedious, and requires a structured program and a lot of energy and time (Mohammadi, Rakhshan, Molazem, Zareh, & Gillespie, 2020). Therefore, caring for and educating these children imposes a lot of care burden on mothers (Mohammadi, Rakhshan, Molazem, & Zareh, 2018). The care burden imposed on the mothers of children with autism has led them to find strategies to cope with

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existing conditions in order to control caring stresses and cope with existing conditions (Brown, Whiting, Kahumoku-Fessler, Witting, & Jensen, 2020; Dobre & Topalá, 2020). There are two general types of problem-based coping in these mothers (strategies aimed at solving a problem or doing something to change stress) and emotions-based coping (strategies aimed at reducing or managing the anxiety caused by stressors) (Bozkurt, Uysal, & Düzkaya, 2019). These strategies have been identified as important mechanisms in controlling stress, fatigue, care burden, and improving health level of these mothers (Furrukh & Anjum, 2020), which causes to promote the mothers' involvement in the care of these children. Parental involvement is one of the key elements in providing quality care (Ygge & Arnetz, 2004), ranging from the passive presence of parents to full involvement in care (Abdelkader, Arabiat, Holmes, & Hamdan-Mansour, 2016). However, parental involvement in child care is considered as one of the major challenges for health care providers, who seek to enhance parental competence, self-confidence, and improve mother-child interactions (Aein, Alhani, Mohammadi, & Kazemnejad, 2009). Regarding to this matter that children with autism need the basic cares of parents, especially mothers, it is important to examine the factors affecting parental involvement in caring of these children (Wang et al., 2020). However, fathers are often less involved in caring for their children due to work commitments (Rankin, Paisley, Tomeny, & Eldred, 2019), so research shows that fathers of children with autism spend less time to care their children (Wang et al., 2020). While the studies have shown that there is a significant negative relation between fathers' involvement and mothers stress in families having children with autism (DeMontigny, Gervais, Pierce, & Lavigne, 2020; Hu et al., 2017). However, the emerging disease of COVID 19 can affect the care burden and coping styles methods of these parents.

The emerging coronavirus disease has been started in China in 2019 and changed in to a pandemic in many countries, including Iran. And it has caused illness and death of many people around the world(jamaicaobserver, 2020). Accordingly, more than 143 million people worldwide have currently infected with this disease, and more than 3 million of them have eventually died(jamaicaobserver, 2020; Wu & McGoogan, 2020). However, in Iran, the spread of COVID-2019 is complicate. Iran is currently facing with fourth wave of pandemic(Nemati, Ebrahimi, & Nemati, 2020; Wu & McGoogan, 2020). About 2 million people in Iran have been infected with COVID-2019 and more than 67,000 of them have lost their lives(Colizzi et al., 2020; Harapan et al., 2020), this is while the governments have performed unprecedented measures due to the rapid spread of this virus, including imposing quarantine on citizens.

The experience of being quarantine provides a wide range of psychological problems in a significant number of people. It seems that having a psychiatric background during quarantine leads to worse and more unpleasant results, and these people need more support during quarantine(Alhuzimi, 2021). Meanwhile, it seems that COVID19 pandemic severely affect people with special needs, including children with autism and their families, so that parents of children with autism during the COVID19 crisis are likely to bear high care burden due to ambiguous economic situation, limited access to treatment and medical procedures, as well as long delays in accessing care programs and experience more stress and decrease their capacity to care for their children(Lin, Iao, Lee, & Wu, 2020). However, one of the most important tasks of the treatment team, especially pediatric nurses, is helping the mothers of autistic children in coping with the disease of autistic child, controlling stress and parenting tensions, and helping them to provide care for these children and reduce care burden. So that these mothers can better understand the behavioral

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and developmental conditions and characteristics of their autistic children and control and manage their parenting stress(Alhuzimi, 2021; Furrugh & Anjum, 2020).

Therefore, due to the close and reciprocal relationship of the care burden with coping strategies and involvement in caring mothers of children with autism, we decided to design and implement a study with the general purpose of investigating the relationship of parenting stress with care burden and coping strategies in mothers of children with autism.

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2. Methods

2.1. Study design and setting

This study is a cross-sectional research. The conducted investigation is based on the strengthening the reporting of observational studies in epidemiology statement (STROBE), that is checklist for observational research, from April to June 2021. The two following aims were examined in study “evaluation of care burden, coping styles and involvement in the care in mothers of autistic children” and “investigating the relationship between care burden, coping styles, involvement in the care and demographic characteristics in in mothers of autistic children”.

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2.2. Participants and sampling

In this study 134 of mother autistic children, that had the inclusion criteria were invited and selected via convenience sampling to participate in the study from 3 center of autism center affiliated with University of Medical Sciences in the west of Iran. Inclusion criteria were as follows: age between 6 and 16 years old; high or moderate performance based on the psychiatrist's report and the Diagnostic and Statistical Manual of Mental Disorders (DSM V) Guideline; 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 on their questionnaires or did not return their questionnaires were excluded. The participants were asked to complete and submit the questionnaires—a personal (demographic) characteristics questionnaire, a care burden, coping styles and involvement in the care scales—online. The researchers sent emails and reminder messages to the participants; so that the majority of the questionnaires (90%) were completely gathered in June.

2.3. Questionnaire

2.3.1 Demographic information questionnaire

Included age, sex, economic status, number of children, number of sick children, number of children with autism and their severity of autism, parents' age, parents' educational level, parents' occupation, and living with parents.

2.3.2 Burden Assessment Scale (BAS)

The *Burden Assessment Scale* (1994) has been designed by *Reinhard & Horowitz*. This questionnaire (scale) assesses the care burden and physical and psychological challenges imposed on caregivers of patients with neuropsychiatric disorders. This tool consists of 19 questions and is ranked on a 4-point *Likert* scale (score 1: not at all to score 4: high). Higher scores indicate more care burden. Face and content validity as well as the reliability of this scale were examined in the study of *Reinhard* (1994), so that the face and content validity was appropriate and the reliability of this scale was estimated 0.89 % by *Cronbach's alpha* method. In this study, the reliability of the tool was estimated 0.91(Reinhard, Gubman, Horwitz, & Minsky, 1994).

2.3.3 Parental Bonding Instrument (PBI)

The *Parental Bonding Instrument* was developed in 1979 by *Parker et.al* and is used to assess parental involvement in caring for their child. It includes 25 items and 2 subscales of care (12 questions) and extreme support (13 questions). It is scored on a 4-point Likert scale (very high: 0 to very low: 3). It should be noted that 1, 5, 6, 8-13, 17, 19 and 20 items are scored conversely. Higher scores indicate a positive bonding of the child with the parent. Face and content validity as well as the reliability of this scale were examined in the study of *Shayeghian et.al* (2011), so that it has a very good internal homogeneity with a reliability coefficient of 0.88 for the care subscale and 0.74 for the extreme support subscale by split-half method(Shokri, Khanjani, Hashemi, & Esmailpuor, 2017).

2.3.4. Coping Strategies Questionnaire (CSQ)

The *Coping Strategies Questionnaire* (1980) was designed by *Lazarus & Folkman*. It is a tool to study how people cope with tensions. This questionnaire consists of 66 questions and has 8 components (direct coping, avoidance, self-control, seeking social support, responsibility, escape and avoidance, managerial problem-solving and positive re-evaluation). Questions are scored on a 4-point Likert scale (from score 0: I have not used at all to score 3: I use a lot). In this questionnaire, if the calculated score is between 0 and 66, it is a sign of using low level of coping style in the person, if the calculated score is between 66 and 110, it is a sign of using moderate level of coping style in the person, and finally, if the calculated score is 110 or higher, it is a sign of using high level of coping style in the person. Face and content validity as well as the reliability of this scale were examined in *Attaran* study in 2012, so that face and content validity is appropriate and the reliability of this questionnaire has been in scales from 0.61 to 0.79 by Cronbach's alpha method(Fadaei, Dehghani, Tahmasian, & Farhadei, 2011).

2.4. Statistical Methods

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In this study, the collected data will be analyzed with SPSS software version 22. 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 caring burden, and demographic information. The significance level was considered $P < 0.05$. Then the coping strategies and parental bonding and demographic characteristics ($p < 0.25$) were entered into the multiple linear regression model with a backward strategy. 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

The study design was approved by the Ethics Committee of the ██████ University of Medical Sciences ██████. Also at the beginning of study 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. Finally, the written informed consent was obtained from all the participants after providing them with sufficient information on the study.

3. Results

110 of the subjects completed and returned the questionnaires via e-mail or a social network. Thus, the response rate was 82.089%, the mothers' reasons for not being participated in this study were high prevalence of COVID2019 in Iran, heavy workload, also infected with COVID2019.

3.1. Demographic Information

Of the 110 mothers who participated in the study. The range of the participants' ages was between 24 and 55 years with the mean of 34.74 ± 3.16 years. The majority of the participants

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88.18% were married, 40.90% of whom had two children. Also, most of the participants had a diploma 59.10%, were housewife 50. %, had boy child 70.90%. The findings of the study showed that there was a statistically significant relationship between *caring burden with* mother's job, number of children, children's age and level of autism in children .So that, employee mothers with 3 or more children that had children with low-functioning autism and autistic children age 12-14 years reported more care burden.

3.2. Caring burden, coping strategies and parental bonding in the participants

The *caring burden* means score of the mothers who participated in the present study was 64.74 ± 2.57 , the coping strategies means score was 68.81 ± 2.76 . Also, the parental bonding means score was found to be 45.51 ± 1.88 during the COVID-19 crisis (Table 2).

3.3. The relationship between caring burden, coping strategies and parental bonding in the participants

The findings of the study show that there is a strong and direct correlation between caring burdens with parental bonding in mothers of children with autism in pandemic of COVID-19 ($p < 0.001$, $r = 0.78$). Also, a more strong and indirect correlation was found to exist between caring burden with coping strategies ($p < 0.001$, $r = -0.82$).

3.4. The predictor variables of caring burden in mothers of children with autism in pandemic of COVID-19

The variable of coping strategies, parental bonding, mother's job, number of children, children's age and level of autism in children which had a p-value of smaller than 0.25 were entered into multiple linear regressions with the backward technique. These variables remained in the model

and accounted for about 81.27% of the caring burden variance in the mothers of autistic children in pandemic of COVID2019 (Table 3).

4. **Pembahasan**

This study showed nurses have reported high levels of caring burden, low levels coping strategies and high levels bonding in mothers of children with autism. There is a strong and indirect correlation between caring burden with coping strategies but strong and direct correlation between caring burden with parental bonding. Although a few studies have addressed the work stress, knowledge, and awareness in these mothers during COVID 2019, there are not any studies of caring burden, coping strategies and parental bonding to gather during COVID 2019 in this group. Therefore, the researchers had to use articles which measure caring burden, coping strategies and parental bonding in these mothers separately before incidence COVID 2019.

The care burden score reported by mothers of children with autism as the primary caregiver of these children in this study was 2.57 ± 64.74 , which indicates the high care burden that mothers bear in caring for these children. However, the care burden is one of the most challenging issues in the care and maintenance of these children. The findings of this study show that the number of children, maternal occupation, age and performance level of children with autism strongly affect the care burden imposed on these mothers. In line with the findings of this study, other studies have shown that parents, especially mothers of children with autism, have reported a high care burden for these children (Bozkurt et al., 2019; Marsack-Topolewski & Maragakis, 2021; Marsack-Topolewski, Samuel, & Tarraf, 2021). *Topolewski et.al* (2020) also stated that mothers of children with autism have reported a high care burden for these children. They also stated that the severity of autism disorder and subsequently, behaviors and care needs of these children

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significantly affect the care burden imposed on these parents, which is consistent with the present study (Marsack-Topolewski & Maragakis, 2021). Although *Bozkurt et.al* (2019) also stated in their study that parents of children with autism experienced a high care burden that is consistent with the present study, they reported that care burden has been more on parents with one child compared to several children and having a girl compared to a boy, which is contrary to the above study (Bozkurt et al., 2019). This difference may be due to diversity in the cultural and supportive context governing the two societies. Because in Iran, due to unfavorable economic conditions, it is not possible to provide wide and comprehensive support from these parents, who may affect the severity of the care burden imposed on these parents. Consistent with the findings of this study, *Topolewski et.al* (2021) reported a higher care burden for children with autism and stated that care burden for these children depends on their ability to perform daily activities and self-care. So that, whatever developmental disorders in children are more, their dependent on parents and subsequently care burden reported by the parents of these children will be higher.

On the other hand, in this study, care burden score was reported high and coping strategies score was reported low, and there was a strong and inverse relationship between care burden and coping strategies in mothers of children with autism. Consistent with the findings of this study, *Bozkurt et.al* (2019) stated that there is a strong and inverse relationship between care burden and coping strategies in the parents of children with autism, so that, whatever the care burden was high, the coping strategy was weaker and coping strategies were explained and described 42 % variance of care burden imposed on the parents of autistic children (Bozkurt et al., 2019). The reason for this similarity could be the use of the same tools to assess coping strategies in mothers of autistic children. *Ang et.al* (2019) also stated in their study that parents' coping of autistic children was strongly and inversely related to the rate of behavioral problems and the severity of

autism in their children. So that, whatever children's behavioral problems has been more, the parents have had more stress and depression and less coping; and stress and coping strategies have explained 51% of mental disorders and depression in these parents. The low level of coping with the increase of autism and behavioral problems in this study is consistent with the present study(Ang & Loh, 2019). On the other hand, *Samadi et.al* (2020) also reported low coping and good-feeling in parents of autistic children and stated that low coping due to behavioral problems, conditions of autistic children and poor formal and informal support from these parents in Iranian society has caused that good-feeling has been extremely low in these parents, which is in line with the present study(Samadi, 2020).

However, in the present study, the coping score in parents of autistic children has been reported lower than similar studies. This difference could be due to the occurrence of the Covid-2019 pandemic and imposing the traffic restrictions and quarantine. Because all educational centers for autistic children in Iran are closed and there are work restrictions, sometimes parents even prefer to keep their children at home because of Covid-19, but these restrictions have caused the mothers to involve with autistic children all day and night and impose higher care burden for parents, and they have less time for their other tasks and unconsciously their coping becomes less.

In the present study, the score of mothers' involvement in the care of autistic children has been reported high and there was a strong and direct relationship between care burden and mothers' involvement in the care of autistic children. Consistent with the present study, several studies have expressed that the involvement of mothers with autistic children in the care of these children is high(Flippin & Crais, 2011; Mello, Rivard, Terroux, & Mercier, 2019; Mo et al., 2020). In this regard, *Wang et.al* (2020) stated that mothers of autistic children have a wide role

and involvement in the care of these children. So that , whatever the life skills and self-care in these children is lower, actually the care burden imposed on parents is more and they have had more active involvement in the care of autistic children(Mo et al., 2020). Also, *flippin et.al* (2011) stated that mothers of autistic children are primarily responsible for the care of these children in the family who have a high care load and active participation in child care and there is a strong relationship between the burden of caring for autistic children and the participation of their mothers in care, which is in line with the findings of the present study(Flippin & Crais, 2011).

Coinciding with this study, *Mello et.al* (2019) also reported that mothers of children with autism are most involved in caring for these children, and that whatever the care burden for these children is more, their involvement in care is the wider(Mello et al., 2019).

Finally, it can be stated that according to the findings of this study, mothers of children with autism, although carrying a high burden in caring for their children, and do not adapt well to existing conditions but are still actively involved in caring of their autistic children. Therefore, it is necessary basic planning and extensive support to reduce caring burden and subsequently improve coping strategies in these mothers.

Limitations

One of the most important limitations of the present study was the non-return of questionnaires. This is probably due to the busy mothers in the Corona crisis. On the other hand, the studied variables have been measured during 12 months involving with Coronavirus. Accordingly, it is suggested to evaluate the care burden, coping strategies during Corona in different societies and with larger sample size to achieve more accurately estimation about the care burden of autistic

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children' mothers in Corona crisis, and subsequently, based on these findings ,managers and policymakers can make more comprehensive measurements and planning for this crisis or similar crises.

Conclusions

The care burden for mothers of autistic children during Covid-2019 pandemic was reported high in this study. However, coping strategies, involvement in care, mother's job, the number of children, age and functional level of autistic child affected the care burden imposed on these mothers, so that, the variance of 81.27% for care burden was predicted in these mothers .

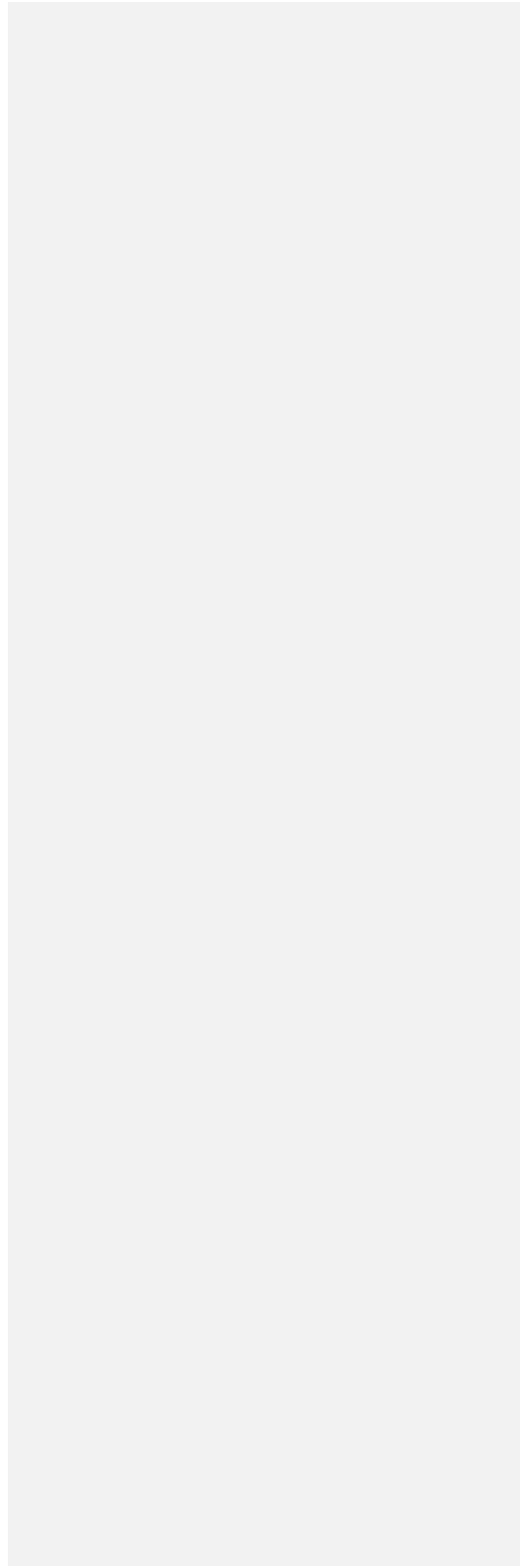
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Table1. The participants' demographic characteristics and caring burden scores

Demographic variables		Number (%)	Occupational burnout Means \pm SD	P. value
Mother's age (Year)	24-33	31(19.10)	65 \pm 1.31	0.721**
	34-44	72(65.45)	64 \pm 1.63	
	45-55	17(15.45)	64 \pm 1.57	
Mother's education	illiterate	3(2.73)	62 \pm 1.26	0.892**
	Primary	7(6.37)	62 \pm 1.78	
	Diploma	65(59.10)	62 \pm 1.43	
	Bachelor	23(20.90)	62 \pm 2.01	
	Master's degree and higher	12(10.90)	62 \pm 2.42	
Mother's Job	Self-employed	31(28.18)	61 \pm 1.65	0.021**
	Employee	24(21.82)	69 \pm 1.39	
	housewife	55(50.00)	60 \pm 1.37	
Marital status	Married	97(88.18)	62 \pm 2.01	0.82*
	Divorce	13(11.82)	63 \pm 1.72	
Number of children	1	38(34.55)	64 \pm 1.97	0.017**
	2	45(40.90)	69 \pm 1.31	
	3 and more	27(24.55)	73 \pm 1.32	
Number of children with autism	1	96(87.27)	69 \pm 1.47	0.92*
	2	14(12.73)	70 \pm 1.87	
Sex of children	boy	78(70.90)	67 \pm 1.53	0.77*
	girl	32(29.10)	69 \pm 1.97	
Children's age	6-8	37(33.64)	67 \pm 1.67	0.018**
	9-11	47(42.73)	71 \pm 1.24	
	12-14	26(23.63)	74 \pm 1.86	
Level of autism in children	High performance	58((61.82)	64 \pm 1.76	0.012*
	Low performance	42(38.18)	72 \pm 1.38	

*Independent t-test
 **ANOVA test

Table 2. The means and standard deviations of the participants' caring burden, coping strategies and parental bonding scores

<i>Variable</i>	<i>Dimension</i>	<i>Means ±SD per dimension</i>	<i>Total Means ±SD</i>
<i>Caring burden</i>	physical	64.32±1.88	64.74±2.57
	mental	65.16±2.63	
<i>Coping strategies</i>	Direct confrontation	67.31±3.22	68.81±2.76
	Self-control	69.98±2.13	
	Seeking social	68.87±3.41	
	Support	71.21±2.33	
	Responsibility	70.24±2.61	
	Avoidance	68.18±2.27	
	Problem-solving	66.31±3.45	
	Positive re-evaluation	68.42±2.33	
<i>Parental bonding</i>	Caring	44.31±1.42	45.51±1.88
	Extreme support	46.71±1.78	

Table 3. The predictor variables of caring burden in mothers of children with autism in pandemic COVID-19

<i>Variable</i>	<i>Unstandardized coefficients</i>		<i>standardized coefficients</i>	<i>T</i>	<i>P-value</i>
	<i>B</i>	<i>Standard deviation</i>	<i>β</i>		
<i>Coping strategies</i>	-0.744	2.62	-0.794	-3.42	0.001
<i>Parental bonding</i>	0.708	2.21	0.768	3.28	0.001
<i>Mother's job</i>	0.313	2.27	0.377	2.98	0.031
<i>Number of children</i>	0.295	2.76	0.310	3.21	0.034
<i>Children's age</i>	0.642	2.31	0.661	1.87	0.042
<i>Level of autism in children</i>	0.651	1.53	0.672	1.43	0.039
Adjusted R2: 81.27%					

For Review Only



Nurussakinah Daulay <nurussakinah@uinsu.ac.id>

Thank you for submitting your review of Manuscript ID NOP-2021-Aug-1354 for Nursing Open [email ref: ENR-SW-6-f]

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Diana-Lyn Baptiste <onbehalf@manuscriptcentral.com>

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