



An Explanation of the Concept of the Care Burden of Family Caregivers of Children with Autism Spectrum Disorder from the Perspective of Family Caregivers

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Abstract

Background: Autism spectrum disorder (ASD), characterized by challenges with social skills, repetitive behaviors, speech, and nonverbal communication, has greatly affected family caregivers, leading to subjective and objective care burdens on them.

Objectives: The aim of this study was to explain the care burden of family caregivers of children with ASD from the perspective of family caregivers.

Methods: In this qualitative study, 14 family caregivers were purposefully selected. The data were collected using semi-structured, in-depth interviews. The coding of the data was performed using MAXQDA 10 software, and then the data were analyzed by the content analysis method.

Results: After the data coding, 266 codes were obtained, which were then classified into three main categories, including context and background, health factors (physical and mental health), and social support (formal and informal support).

Conclusions: The results of the study showed that family caregivers bear the caregiving and mental burden of taking care of their autistic children. Besides adding to our body of knowledge and understanding of the problems encountered by caregivers, this study showed that the caregiving burden can be reduced by providing social support for the caregivers of autistic children.

Keywords: Autism Spectrum Disorder, Caregiver Burden, Caregivers

1. Background

Autism spectrum disorder (ASD), formerly known as infantile autism, is characterized by challenges with social skills, repetitive behaviors, speech, and nonverbal communication. The prevalence of ASD (the diagnostic and statistical manual of mental disorders-fifth edition [DSM-5]) is reported to be 15 to 20 per 10,000 individuals. The prevalence of autism has been reported in Iran at 6.26. In other words, 1 out of every 59 live births has ASD (1-3). As we know, care is part of the duties of caregivers. However, the many limitations of individuals with ASD might require long-term and comprehensive care, forcing the caregivers to spend much time taking care of these children. This will lead to a significant increase in the burden on family caregivers and on their physical and

mental health (4).

A family caregiver is a person who has a very close emotional relationship with the care receiver; s/he can be a member of the patient's family and is usually a close person who provides assistance for and takes care of a child, an elderly person, or a person with an acute or chronic illness and receives no money in return (5). The term "care burden" refers to the strain or load borne by a person who cares for a chronically ill family member. Zarit et al. (as cited by Ezzat et al.) states that the care burden might affect various aspects of the social, health, and economic status of the caregiver and the quality of his/her life (6). A study by Dykens et al. showed that caregivers of children with autism had more psychological distress than caregivers of children with other neurodevelopmental

disorders. These individuals experience psychological distress in the form of stress, financial and social problems, mental problems, and health disorders (7).

The care burden on family caregivers of children with ASD is such that it affects the quality of their lives. These individuals complain about the financial burden imposed on them, which could be due to the expenses of long-term care and rehabilitation services provided for children with ASD, in addition to the loss of job opportunities. Caregivers say that caregiving is a time-consuming task that can reduce their time for social interactions. Additionally, their normal lifestyle changes and their social relationships move toward isolation (8). Caregiver's involvement with an autistic child from birth to the end of his/her life, its chronic and lifelong nature, the onset of the disease from birth, aggressive behaviors of the child, severe symptoms of autism, communication problems of autistic children, and their learning difficulties put heavy pressure on family caregivers. These features lead to long-term stress and many physical, mental, social, marital, economic, and health problems and reduce the quality of life of family caregivers of children with ASD. All of the aforementioned problems necessitate carrying out this study (9).

Moreover, additional comorbid disorders complicate the situation for caregivers of autistic children. Comorbidity is the presence of one or more additional conditions often co-occurring with a primary condition. Comorbidity describes the effect of all other conditions an individual patient might have other than the primary condition of interest and can be physiological or psychological. Epilepsy, psychiatric/behavioral complaints, and gastrointestinal disorders are common comorbidities of ASD, especially in subjects with intellectual disability (ID) (10). Among other problems in family caregivers, we can refer to the negative impact of an autistic child on other family members. Siblings of autistic children experience negative effects, such as feelings of loneliness, isolation, low levels of prosocial behavior, and decreased self-esteem (11).

The purpose of this study was to explain the concept of the care burden of family caregivers of children with ASD from the perspective of family caregivers. Since the researchers sought to obtain the views of family caregivers of autistic children, a qualitative method was used for carrying out this study, and interviews were conducted so that they could express and describe their situation. Qualitative research seeks to provide a rich understanding of certain aspects of human behavior through studying specific cases. Qualitative research is capable of describing and comprehending human beings from their own understanding, avoiding any external and

unarticulated theoretical entities. It is a valuable approach to describe the experiences and perspectives of human life and helps understand human experiences (12). The primary focus of this study was to gain a comprehensive understanding of the care burden experienced by family caregivers of children with ASD from the caregivers' own perspective. Although the care burden is widely acknowledged, there is a lack of in-depth exploration into the subjective experiences, challenges, and emotions faced by caregivers in their caregiving role. Therefore, the main problem addressed in this study is the need to explain the care burden of these caregivers by directly examining their perspectives. By analyzing the caregivers' accounts, the study aimed to uncover the unique difficulties they encounter while caring for their children with ASD. The study also sought to investigate the various contributing factors to the care burden, including contextual and background factors, physical and mental health issues, and the availability of social support. Ultimately, the objective was to gain valuable insights that can inform the development of effective interventions and support systems, with the ultimate goal of reducing the care burden and enhancing the well-being of family caregivers of children with ASD.

2. Objectives

The purpose of this study was to explain the care burden of family caregivers of children with ASD from the perspective of family caregivers.

3. Methods

3.1. Design

The present study is an inductive qualitative content analysis. The content analysis method was used in this qualitative study. Qualitative content analysis is a method of analyzing written, spoken, or visual messages. It is a systematic and purposeful way to describe a phenomenon. This method allows the researcher to examine the subjects in order to get a better understanding of them. In qualitative content analysis, raw data are summarized based on inference and interpretation, and then they are coded into categories and subcategories (13, 14).

3.2. Participants

This study was conducted in specific settings that granted access to family caregivers of children with ASD. The Autism Spectrum Disorder Association in Hamedan province, Iran, was chosen as the research environment to recruit participants for this study. The study population

comprised family caregivers who were responsible for caring for children diagnosed with ASD. The participants were selected using a targeted method. Maximum variation in terms of age, gender, religion, socioeconomic status, level of education, and area of residence was also applied in the sampling process.

In the current study, a predetermined number of participants was not available. The researcher decided on data saturation and reaching a comprehensive understanding of the intended concept (with judgment and consultation within the research team) by considering a combination of repetitive codes, paying attention to receiving fresh data after conducting new interviews and ensuring a minimum of nine family caregivers and a maximum number of participants (more than nine) to be interviewed. The researcher continued the study until reaching data saturation and achieving a comprehensive understanding. Ultimately, a total of 14 participants, including 9 mothers and 5 fathers, were included in the sampling process using purposeful sampling. The inclusion criteria for the participants in this study were carefully established. First, the participants were required to have a child diagnosed with ASD, as confirmed by a specialist in the field. Additionally, caregivers who actively sought rehabilitative services for their autistic child at the Autism Association Center in Hamedan were eligible to participate. The age of the child with autism needed to be under 14 years. Finally, caregivers were expected to possess the ability to establish effective communication and express themselves well.

Autism spectrum disorder is classified into three levels based on a doctor's diagnosis. These levels, ranging from level 1 to level 3, are based on the amount of support individuals with ASD require and the impact of their symptoms on their daily functioning. Level 1 represents individuals who require some support (mild), level 2 indicates those who need substantial support (moderate), and level 3 encompasses individuals who require very substantial support in various areas of their lives (severe). Sampling continued until data saturation was achieved. Data saturation occurs when the researcher reaches a point where no new information is obtained from further data (15) (Table 1).

3.3. Data Collection

For this study, an ethics code was obtained from the National Committee for Ethics in Biomedical Research at the School of Pharmacy, Nursing, and Midwifery in Shahid Beheshti University of Medical Sciences, Tehran, Iran. Furthermore, sampling permission was granted by the Vice-Chancellor for Research and Technology of Shahid Beheshti University of Medical Sciences, and then they

were submitted to the Vice-Chancellor for Research and Technology of Hamadan University of Medical Sciences to obtain the contact number of participants and interview them for the study. The sampling started on 26.09.2020 and ended on 19.03.2021.

Data collection involved conducting semi-structured, in-depth interviews with the family caregivers to gather information. In this study, the researcher was the interviewer. Open-ended questions were used during the interviews to allow the caregivers to freely express their experiences and perspectives. The average duration of these interviews was between 40 and 55 minutes. Due to the limitations imposed by the coronavirus disease 2019 (COVID-19) pandemic, all interviews were conducted over the telephone. Additionally, three complementary interviews were conducted via e-mail in a written format. Informed consent was obtained from all participants who received consent forms via e-mail or letter. They signed the forms to indicate their willingness to participate in the research and returned them to the researcher. Before each interview, the researcher began with general questions, allowing the participants to speak freely about their experiences. The researcher then directed the interview to clarify the concept under study by asking follow-up questions. These follow-up questions were based on the information provided by the interviewees and included in-depth interview questions, such as "can you explain more?", "what do you mean?" and "can you give an example so that I can better understand what you mean?". All conversations during the interviews were recorded, and the confidentiality of the conversations was explained to the participants. The participants were informed that they could ask for clarification if they did not understand a question.

Demographic information, including age, gender, marital status, relationship to the child, child's age, level of autism, caregiver's occupation, child's history of other illnesses, number of family members, and child's gender and age, was recorded for the participants. The order of the interview questions was not fixed and could be adjusted based on the interview process and participant conditions.

During the interviews, a brief and general introductory conversation was conducted to create a sense of comfort for the participants. Open-ended questions related to the research topic were used to facilitate the discussion and allow for broad responses. For example, family caregivers were asked to describe a typical day of caring for their child. Follow-up questions were asked to delve deeper into the details provided in the initial response. Exploratory questions were used to obtain more in-depth information, such as requesting further elaboration, examples, and explanations based

Table 1. Demographic Characteristics of the Participants

Row	Gender	Age (y)	Marital Status	Occupation	Income Level	Relation to the Child	Number of Family Members	Caregiver's Education Level	Child's Age	Child's Gender	Medical History	Level of Autism Diagnosed by a Specialist	Length of Interview
1	Female	42	Married	Housewife	No problem	Mother	4	B.A.	8	Female	No	Mild	55
2	Female	30	Married	Housewife	Acceptable	Mother	3	Diploma	4	Male	No	In between	50
3	Female	47	Married	Housewife	Not sufficient	Mother	4	Diploma	7	Male	No	Mild	53
4	Female	32	Married	Housewife	Not sufficient	Mother	3	Under diploma	5	Male	Impaired concentration and attention	Mild	57
5	Female	38	Married	Housewife	Not sufficient	Mother	3	Diploma	6	Male	Mental disorder, hyperactivity	Severe	45
6	Female	35	Married	Housewife	Not sufficient	Mother	3	Under diploma	8	Male	Hyperactivity, epilepsy	In between	50
7	Female	47	Married	Housewife	Not sufficient	Mother	5	Under diploma	2	Male	Hypothyroidy	Severe	52
8	Female	33	Married	Housewife	Not sufficient	Mother	3 Pregnant	Diploma	8	Male	Mental disorder, muscular dystrophy, epilepsy	Severe	55
9	Male	45	Married	Music instructor	Acceptable	Father	3	Diploma	6	Male	Impaired concentration and attention	Mild	50
10	Female	40	Married	Housewife	No problem	Mother	2	B.A.	4	Male	Gastrointestinal disorders	In between	51
11	Male	43	Married	Driver	Not sufficient	Father	3	Under diploma	6	Female	Epilepsy, mental disorder	Severe	45
12	Male	38	Married	Teacher	No problem	Father	3	B.A.	5	Female	Hyperactivity, mental disorder	Severe	40
13	Male	38	Married	Unemployed	Not sufficient	Father	2	B.A.	5	Male	Hyperactivity	In between	47
14	Male	42	Married	Engineer	Not sufficient	Father	1	B.A.	7	Male	Gastrointestinal disorders	In between	50

on the participants' experiences. Some techniques, such as silence, echoing the participant's statements, and using affirming words, were employed to enhance the quality of the interview. At the end of each interview, the participants were given the opportunity to share any additional thoughts or topics they wished to discuss. They were also informed about the possibility of follow-up interviews or the need for further clarification if necessary.

After each interview, the recorded audio was carefully listened to, transcribed word by word, and coded using MAXQDA 10 software at the earliest possible opportunity.

The following main questions were asked from family caregivers:

- What problems do you encounter when caring for an autistic child?

- In which part of your life do you feel caring pressure the most?

- Can you describe a day of caring for your child?

The following follow-up questions were asked from family caregivers:

- What effect has caring had on your health and your family?

- How has caring affected different aspects of your life?

3.4. Data Analysis

Inductive qualitative content analysis was used for data analysis. In this method, the researcher is like an interpreter who reads the data to find their meaning and, after finding them, codifies, classifies, and organizes the data. This process continues until the meaningful categories are connected to each other and show their themes. The process of content analysis was carried out using the Kyngäs et al. model, and the data were analyzed in three stages, including preparation, organization, and reporting. In the preparation phase, in order to gain a comprehensive understanding of the phenomenon under study, all interviews were transcribed word by word, and then they were read several times. In all the interviews, propositions and codes were selected as the unit of analysis and meaning, respectively. The researcher tried to find the meaning of the data and to understand what has happened and what is understood from this meaning in general. In the organization phase, some measures, such as open coding, subcategory formation, and abstracting,

were performed to achieve categories with a higher level of abstraction (16).

3.5. Trustworthiness

For the robustness of the study, the four criteria of credibility, dependability, confirmability, transferability, and authenticity were used. Several techniques, such as long-term researcher's interaction with data and participants and control by members, were used. For this purpose, after coding, the interviews were given to the participants to review and confirm the researcher's interpretation. The process of data analysis and category extraction was reviewed and approved by the members of the research team (second and third authors), who are members of the nursing faculty and experts in qualitative research. The selection of participants was performed with maximum sampling variance in terms of gender, level of autism, income, and education (Table 1) and continued until data saturation. Moreover, to increase confirmability, all stages of the study, including data collection, coding and analysis, and access to the main categories, were recorded in writing (17).

3.6. Ethical Considerations

The research was approved by the National Committee for Ethics in Biomedical Research at the School of Pharmacy, Nursing, and Midwifery at Shahid Beheshti University of Medical Sciences. This study was extracted from a dissertation with the ethics code of IR.SBMU.PHARMACY.REC.1398.295. First, the researcher introduced herself to the participants and explained the objectives and method of the study. The anonymity of the participants was observed. The right to participate freely in the study and to withdraw from the study at any time were explained to the participants. Signed consent was obtained from the participants.

4. Results

In line with the specific objectives of explaining the content analysis of the burden of care in family caregivers of children with ASD from the perspective of family caregivers and in interviews with participants, 266 codes were extracted in 3 main categories, namely context and background (with financial burden and social burden subcategories), health factors (with subcategories of physical and mental health), and social support (with subcategories of formal support and informal support) (Table 2).

4.1. Context and Background

The first category is the context and background, with the two subcategories of financial burden and social pressures. This category refers to economic and social problems among family caregivers. Financial and social pressures are the most frequent problems expressed by family caregivers.

The financial burden is the biggest problem for caregivers in taking care of children with autism. In this study, 64% of caregivers reported financial inadequacy, 14.5% of them had acceptable financial status, and only 21.5% expressed that they had no problem regarding financial matters. Caregivers take their children to rehabilitation classes in order to eliminate their communication and motor skill deficits. These classes impose high costs, which, due to the persistence of the problem, the classes are also permanent in order to lead the child to get more independence. In addition, caregivers complained about the high cost of para-clinical tests, such as magnetic resonance imaging (MRI) and electroencephalography. Spending much money on commuting and shrinkage of the family food basket will reduce the family caregivers' quality of life. Family caregivers who stated that they were financially inadequate were in middle- and low-income occupations; this showed that social status with job characteristics could be a predictor of income. Family caregiver No. 4 stated:

"The problem I have in taking care of my son, apart from his restlessness, is related to financial issues. We even are not able to meet our basic needs right now. Now we are worried about food. Right now, if a doctor wants to take an MRI, I have to pay 700,000 Tomans, and they do not accept healthcare insurance. It is very disturbing that I cannot take my son to the doctor and rehabilitation center regularly. Magnetic resonance imaging of the brain should be taken from autistic children regularly. It is both costly and very difficult because it is the main test, but they do not cooperate with us at all."

Regarding social pressure, caregiver No. 8 said in a statement:

"The way people look at us makes us embarrassed. They look at us with pity and sympathy. Sometimes, they say in a bad tone: 'Oh, my God, does your child have autism?'. We do not like to take our son out of the house just due to these words and looks. Due to our son's behavior, we prefer to stay home. We really feel bad when we are out of the house with our son."

4.2. Health Factors

The category of health factors with two subcategories of physical and mental health refers to the problems that

Table 2. Categories, Subcategories, and Codes^a

Categories	Subcategories	Codes
Context and background	Financial burden; social burden	High costs of rehabilitation classes (20); insurance limitations (11); high hidden costs (8); expensive drugs (8); problems in daily commute (13); special food costs (5); shame and embarrassment caused by their autistic child (8); autism label (12); isolation and loneliness of caregivers (13); decrease in quality of life (21)
Health factors	Physical health; mental health	Caregiver's fatigue (34); mental stress imposed on the family (30); stress and depression of caregivers (21)
Social support	Formal support; informal support	Lack of medical-educational and care centers (14); lack of government support for individuals with autism (23); interruption of social interactions (25)

^a The numbers in front of each code indicate the frequency of that code, that is, the number of repetitions of that code by the family caregivers of children with autism.

occur during care. Caregivers suffer from physical and mental problems while caring for an autistic child. The subcategory of physical health refers to some problems, such as fatigue, illness, and sleep disorders. Other physical health problems include back pain, migraine headaches, indigestion, and fatigue. Family caregiver No. 7 stated:

"I think the difficulty in caregiving means the tiredness that comes from care, and I think I am very tired of taking care of my son. I am both mentally and physically tired. I cannot lift him anymore. He is heavy, and I have back pain. I have not left the house since a few months ago. I do not want to see anyone at all. I am constantly crying at home."

The subcategory of mental health refers to the problems that the care burden imposes on the caregiver's psyche. A family caregiver No. 13 said:

"Physically, it has not caused any problems, but we are mentally disturbed. We are constantly under stress because we think about our child's future, and at every stage of his growth, one concern arises; for example, whether we should take him to a preschool assessment center or not. We are more worried about the future of our son. Can he achieve independence or not? We are under great psychological pressure. Our minds are constantly occupied with our son's autism."

4.3. Social Support

The third category includes two subcategories: Formal and informal support. Formal support means support provided by the government in the form of financial support and expert support. Informal support means support provided by others, friends, acquaintances, and relatives and can play an important role in the mental health of family caregivers. Family caregivers complain that society does not support them financially and socially. Caregivers expect the government to provide financial subsidies for children with autism. Individuals with autism do not have special healthcare insurance, and autism is not recognized as a rare disease. There are no schools or facilities dedicated to taking care of children

with autism. Caregivers who are unable to take care of their children are forced to take their children to welfare centers for mentally retarded children. No special education for autistic children is provided in these places. In addition, the autistic child's specific behaviors limit the social interactions of their family caregivers and lead them to isolation. Caregivers feel lonely and isolated from society when dealing with others, and they feel that they are excluded from society. The family caregiver No. 14 stated:

"We are very upset that the people around us do not understand us. They look at us as if we have leprosy. They say: "Oh my God, what has caused this? Really? Is there no cure for it?!" Or they say: "Well, you must have done something wrong during your pregnancy that has made your baby like this!" Believe me, these words and their compassion and pity drive us crazy, and we do not like to take our son out of the house just because of these words and looks. We are very upset about the way they look at us. I mean, they look at us with pity and sympathy. This is very annoying. Our son is so restless that practically he cannot be taken out at all."

The family caregiver No. 14 added:

"I have divorced my wife, and when I want to go to a friend's house for one night, there is no place to take care of my son just for one night. We have no interaction with our relatives because my son is very naughty, and no one welcomes us."

Caregiver No. 6 stated:

"It is very upsetting to be at the service of your child all the time. I cannot go anywhere without my child. I cannot leave my child with anyone because no one will accept to take care of him. We even have problems in taking our child to dentistry. He is so restless that they have to take him to a specially equipped room for a simple filling. The people do not welcome us anywhere. The government does not provide any help or support."

5. Discussion

The process of taking care of a patient with ASD poses many problems, from the heavy financial burden to negative attitudes of other individuals and lack of support for the families of these children in society. Negative experiences among family caregivers are unavoidable even in caregivers who are socially and financially well off, and these experiences change throughout the child's development and impose a different burden on family caregivers depending on the child's skills, education, and development (18, 19).

Under the category of context and background, the biggest problem faced by caregivers was the high financial burden of autism. Autism is an inexpensive disease in and of itself and does not require much follow-up or even special medication. However, autism is associated with verbal communication disorders, which require occupational therapy and speech therapy rehabilitation classes. This rehabilitation process should continue until the end of life so that a patient with autism can enter the community. Moreover, special dietary needs are among the costs that caregivers must consider when it comes to a person with autism. Caregivers also complained about the high cost of visiting physicians and psychiatrists and receiving para-clinical services, such as MRI or electroencephalography. As one author has put it, "family caregivers of children with autism experience four burdens, including financial burden, developmental burden, time dependence burden, and emotional burdens" (20). Another study showed that 27% of caregivers experienced moderate to severe financial stress in caregiving. Studies consistent with the present study have confirmed the effect of financial stress on care burden (20-24).

Under the social pressure category, Anderson and White has observed that the majority of challenges for caregivers of patients with chronic disorders are related to emotional distress. As caregivers say, they pay less attention to themselves and ignore their own needs. Moreover, their loved one's chronic illness is painful for caregivers and causes them to experience emotional distress (25). The results of the aforementioned study are consistent with the current study's results. Family caregivers of autistic children have reported varying degrees of physical and psychological health deterioration due to caring for their autistic children.

The second category in the burden of care is health factors, which are both subjective and objective. The perceived and objective burdens of care are the physical problems imposed on family caregivers. Fatigue and problems, such as back pain and leg pain, result from

carrying an autistic child, especially in severe cases of autism. Other problems seen in family caregivers of children with autism include indigestion and digestive problems (gastrointestinal disorders). Chronic fatigue, sleep disturbances, gastrointestinal disorders, and physical health deterioration are among the physical health issues developed in family caregivers (26). The aforementioned study confirms the findings of the present study. According to family caregivers and specialists in the field of autism, psychological problems include stress, depression, and mental pressures that sometimes make them think of suicide or even harm the child. Studies consistent with the present study in Iran show that the burden of care has a greater impact on individuals' psyche than their bodies (27). The aforementioned study's results confirm the present study's results.

The third category in the study is social support, with two subcategories of formal and informal support. When family caregivers receive social support, the subjective and objective care burdens are reduced. A study showed that social support reduces isolation, despair, and hopelessness and increases life expectancy and a sense of worthiness in family caregivers, which is consistent with the present study's results (28). In the third category, family caregivers complain about inefficient education and the lack of professionals in the field of autism and believe that there is not any center to provide special education and care for children with autism. Moreover, in the field of autism, there should be a specific treatment method for each child with autism. In other words, there is no specific treatment for autism, and the therapist gives the necessary education to an autistic child based on trial and error and experience. The lack of care centers or private schools for autistic children was among the cases that severely affected the care burden of family caregivers, and no measures have been taken for it (18). Among other problems mentioned by family caregivers is the lack of informal support from society. Caregivers say that autism stigma is a problem they have encountered in society. Hogan et al. believes that autism stigma is rooted in the beliefs and values of society. For example, Chinese individuals are more ashamed of being the parent of an autistic child because they are sociable and have a collectivist culture, and the judgment of others is important to them (29).

5.1. Research Limitations

In this study, the most important constraint was the COVID-19 pandemic, which limited face-to-face access to the samples. In addition, there were limited female samples in the study, which is due to the higher prevalence of ASD among male subjects. The last restriction was the

smaller number of fathers as caregivers of autistic children in this study, leading to a decrease in the variety of samples.

5.2. Conclusions

Autism is a challenge that affects not only autistic individuals but also their caregivers. Family caregivers struggle with the subjective and objective problems of taking care of children with autism. They endure great financial burdens. They suffer from physical, psychological, and social problems. Full-time care for children with autism burns out family caregivers. Finally, this study showed that family caregivers do not receive enough social support. Moreover, by increasing formal and informal support, the consequences of the care burden can be reduced. In some studies carried out on the burden of care, it has been suggested that informal social support has a greater impact than formal social support and might reduce the care burden. However, according to the present study, in Iran, with the official, social, and financial support of the government, the care burden of caregivers of children with autism will be reduced (29).

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Footnotes

Authors' Contribution: Study concept and design: S. Z. A. and N. P.; acquisition of the data: N. P.; analysis and interpretation of the data: S. Z. A., N. P., J. M., and H. A. M.; drafting of the manuscript: N. P., Z. KH. M., and A. Sh.; critical revision of the manuscript for important intellectual content: S. Z. A., N. P., J. M., H. A. M., Z. KH. M., and A. Sh.; statistical analysis: N. P. and H. A. M.; administrative, technical, and material support: S. Z. A.; study supervision: S. Z. A. and N. P.

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References

- Samadi SA, Mahmoodizadeh A, McConkey R. A national study of the prevalence of autism among five-year-old children in Iran. *Autism*. 2012;16(1):5-14. [PubMed ID: 21610190]. <https://doi.org/10.1177/1362361311407091>.
- Chiarotti F, Venerosi A. Epidemiology of Autism Spectrum Disorders: A Review of Worldwide Prevalence Estimates Since 2014. *Brain Sci.* 2020;10(5):274. [PubMed ID: 32370097]. [PubMed Central ID: PMC2788022]. <https://doi.org/10.3390/brainsci10050274>.
- Tanguay PE. Autism in DSM-5. *Am J Psychiatry*. 2011;168(11):1142-4. [PubMed ID: 22193599]. <https://doi.org/10.1176/appi.ajp.2011.11071024>.
- Herrema R, Garland D, Osborne M, Freeston M, Honey E, Rodgers J. Mental Wellbeing of Family Members of Autistic Adults. *J Autism Dev Disord*. 2017;47(11):3589-99. [PubMed ID: 28861652]. [PubMed Central ID: PMC5633644]. <https://doi.org/10.1007/s10803-017-3269-z>.
- Toledano-Toledano F, Dominguez-Guedea MT. Psychosocial factors related with caregiver burden among families of children with chronic conditions. *Biopsychosoc Med*. 2019;13:6. [PubMed ID: 30899323]. [PubMed Central ID: PMC6407238]. <https://doi.org/10.1186/s13030-019-0147-2>.
- Ezzat O, Bayoumi M, Samarkandi OA. Quality of Life and Subjective Burden on Family Caregiver of Children with Autism. *Am J Nurs Sci*. 2017;6(1):33-9. <https://doi.org/10.11648/j.ajns.20170601.15>.
- Dykens EM, Fisher MH, Taylor JL, Lambert W, Miodrag N. Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*. 2014;134(2):e454-63. [PubMed ID: 25049350]. [PubMed Central ID: PMC4187227]. <https://doi.org/10.1542/peds.2013-3164>.
- Marsack-Topolewski CN, Church HL. Impact of Caregiver Burden on Quality of Life for Parents of Adult Children With Autism Spectrum Disorder. *Am J Intellect Dev Disabil*. 2019;124(2):145-56. [PubMed ID: 30835531]. <https://doi.org/10.1352/1944-7558-124.2.145>.
- Mello C, Rivard M, Terroux A, Mercier C. Quality of Life in Families of Young Children With Autism Spectrum Disorder. *Am J Intellect Dev Disabil*. 2019;124(6):535-48. [PubMed ID: 31756145]. <https://doi.org/10.1352/1944-7558-124.6.535>.
- Mpaka DM, Okitundu DL, Ndjukendi AO, N'Situ AM, Kinsala SY, Mukau JE, et al. Prevalence and comorbidities of autism among children referred to the outpatient clinics for neurodevelopmental disorders. *Pan Afr Med J*. 2016;25:82. [PubMed ID: 28292045]. [PubMed Central ID: PMC5324163]. <https://doi.org/10.11604/pamj.2016.25.82.4151>.
- Angell ME, Meadan H, Stoner JB. Experiences of siblings of individuals with autism spectrum disorders. *Autism Res Treat*. 2012;2012:949586. [PubMed ID: 22928104]. [PubMed Central ID: PMC3420668]. <https://doi.org/10.1155/2012/949586>.
- Karimi Moonaghi H, Dabbagh F, Oskouie Seid F, Vehviläinen-Julkunen K, Binaghi T. Teaching style in clinical nursing education: a qualitative study of Iranian nursing teachers' experiences. *Nurse Educ Pract*. 2010;10(1):8-12. [PubMed ID: 19251481]. <https://doi.org/10.1016/j.nep.2009.01.016>.
- Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-15. [PubMed ID: 18352969]. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>.
- Zhang Y, Wildemuth BM. Qualitative analysis of content. In: Wildemuth BM, editor. *Applications of social research methods to questions in information and library science*. Westport, Conn: Libraries Unlimited; 2009.
- Taylor ST, Bogdan R, DeVault ML. *Introduction to Qualitative Research Methods: A Guide Book and Resource*. 4th. Hoboken, New Jersey: John Wiley & Sons, Inc; 2016.

16. Kyngäs H, Mikkonen K, Kääriäinen M. *The Application of Content Analysis in Nursing Science Research*. Cham: Springer; 2019. <https://doi.org/10.1007/978-3-030-30199-6>.
17. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative Content Analysis: A focus on trustworthiness. *SAGE Open*. 2014;4(1). <https://doi.org/10.1177/2158244014522633>.
18. Picardi A, Gigantesco A, Tarolla E, Stoppioni V, Cerbo R, Cremonete M, et al. Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison Groups. *Clin Pract Epidemiol Ment Health*. 2018;14:143-76. [PubMed ID: 30158998]. [PubMed Central ID: PMC6080067]. <https://doi.org/10.2174/I745017901814010143>.
19. Shivers CM, Krizova K, Lee GK. Types of strain among family members of individuals with autism spectrum disorder across the lifespan. *Res Dev Disabil*. 2017;68:42-51. [PubMed ID: 28735161]. <https://doi.org/10.1016/j.ridd.2017.07.003>.
20. Blatter S, Bliem HR, Juen BH. Empowering People with Autism. The Effect of an Integrated Daily Structure as Well as Improved Communication on the Lives of People with Autism. *Open J Soc Sci*. 2014;2(8):7-14. <https://doi.org/10.4236/ojs.2014.28002>.
21. Khougar A, Asgharnejad AA, Ranjbar H, Lotfei M, Hakimshoushtari M. [Lived Experience of the Social Suffering of the Parents with Autism Spectrum Disorder (ASD) Child]. *Soc Welfare*. 2019;19(72):243-82. Persian. <https://doi.org/10.29252/refahj.19.72.243>.
22. Saunders BS, Tilford JM, Fussell JJ, Schulz EG, Casey PH, Kuo DZ. Financial and employment impact of intellectual disability on families of children with autism. *Fam Syst Health*. 2015;33(1):36-45. [PubMed ID: 25581557]. [PubMed Central ID: PMC4355223]. <https://doi.org/10.1037/fsh00000102>.
23. Chou KR. Caregiver burden: a concept analysis. *J Pediatr Nurs*. 2000;15(6):398-407. [PubMed ID: 11151480]. <https://doi.org/10.1053/jpdn.2000.16709>.
24. Cohen SA, Cook S, Kelley L, Sando T, Bell AE. Psychosocial factors of caregiver burden in child caregivers: results from the new national study of caregiving. *Health Qual Life Outcomes*. 2015;13:20. [PubMed ID: 26246132]. [PubMed Central ID: PMC4527125]. <https://doi.org/10.1186/s12955-015-0317-2>.
25. Anderson EW, White KM. "It Has Changed My Life": An Exploration of Caregiver Experiences in Serious Illness. *Am J Hosp Palliat Care*. 2018;35(2):266-74. [PubMed ID: 28413927]. [PubMed Central ID: PMC5768253]. <https://doi.org/10.1177/1049909117701895>.
26. Piran P, Khademi Z, Tayari N, Mansouri N. Caregiving burden of children with chronic diseases. *Electron Physician*. 2017;9(9):5380-7. [PubMed ID: 29038725]. [PubMed Central ID: PMC5633241]. <https://doi.org/10.19082/5380>.
27. Pareek B, Kaur R; Meenakshi. Family Resilience and Perceived Social Support among care givers of Children with Autistic Spectrum Disorder. *Asian J Nurs Educ Res*. 2018;8(1):51. <https://doi.org/10.5958/2349-2996.2018.00012.5>.
28. Zhou T, Wang Y, Yi C. Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: Effects of self-esteem, shame and family functioning. *Psychiatry Res*. 2018;264:260-5. [PubMed ID: 29655969]. <https://doi.org/10.1016/j.psychres.2018.03.071>.
29. Hogan BE, Linden W, Najarian B. Social support interventions: do they work? *Clin Psychol Rev*. 2002;22(3):383-442. [PubMed ID: 17201192]. [https://doi.org/10.1016/s0272-7358\(01\)00102-7](https://doi.org/10.1016/s0272-7358(01)00102-7).