



The life of mothers of children with Autism: A grounded theory study

La vida de las madres de niños con autismo: un estudio de teoría fundamentada

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Received: 01/20/2022 Accepted: 04/19/2023 Published: 05/12/2024 DOI: <http://doi.org/10.5281/zenodo.11260914>

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Abstract

Raising a child with autism as a “lifelong developmental disorder” creates unique and countless challenges in all aspects of mothers’ lives that affect their meaning of life and sense of existence. As a part of more extensive research, this study aims to explore these mothers’ life processes. This qualitative study was conducted with a grounded theory approach. Participants included 12 mothers and 2 fathers of children with autism. They were first selected by purposeful maximum variation sampling, which turned into theoretical sampling. Data were collected using 14 semi-structured interviews and 4 observations. Corbin and Strauss’s (2015) analytical approach was used for data analysis. The core variable in this study emerged as “trying to achieve balance,” which consists of five main categories: “despair,” “ambiguity,” “neutralization,” “child management,” and “relationship management.” Clearly, all interviewees repeatedly talked about instability and non-balance and fluctuations in different stages of life and trying to achieve balance in their lives and those of their families. This study’s findings help develop theories and models of care regarding the provision of quality care and the development of knowledge in this field. Therapists, health managers and policymakers can use these findings to provide appropriate social support services to mothers of children with autism spectrum disorders and help mothers manage these children properly and effectively.

Keywords: Qualitative research, Autism Spectrum Disorders, Mothers, Children

Resumen

Criar a un niño con autismo como un “trastorno del desarrollo permanente” crea desafíos únicos e innumerables en todos los aspectos de la vida de las madres que afectan su significado de vida y su sentido de existencia. Como parte de una investigación más extensa, este estudio tiene como objetivo explorar los procesos de vida de estas madres. Este estudio cualitativo se realizó con un enfoque de teoría fundamentada. Los participantes incluyeron 12 madres y 2 padres de niños con autismo. Primero fueron seleccionados mediante muestreo intencionado de máxima variación, que se convirtió en muestreo teórico. Los datos fueron recolectados mediante 14 entrevistas semiestructuradas y 4 observaciones. Para el análisis de datos se utilizó el enfoque analítico de Corbin y Strauss (2015). La variable central de este estudio surgió como “tratar de lograr el equilibrio”, que consta de cinco categorías principales: “desesperación”, “ambigüedad”, “neutralización”, “gestión de niños” y “gestión de relaciones”. Claramente, todos los entrevistados hablaron repetidamente de inestabilidad, desequilibrio y fluctuaciones en las diferentes etapas de la vida y de tratar de lograr el equilibrio en sus vidas y las de sus familias. Los hallazgos de este estudio ayudan a desarrollar teorías y modelos de atención relacionados con la prestación de atención de calidad y el desarrollo del conocimiento en este campo. Los terapeutas, administradores de salud y formuladores de políticas pueden utilizar estos hallazgos para brindar servicios de apoyo social apropiados a las madres de niños con trastornos del espectro autista y ayudar a las madres a manejar a estos niños de manera adecuada y efectiva.

Palabras clave: Investigación cualitativa, Trastornos del espectro autista, Madres, Niños.

Chronic diseases among children have increased continually in recent decades¹. Children with chronic diseases make up a large group in society. According to available statistics, half of the world's children suffer from one or more diseases and need special care. Among these, especially disorders that affect the mental and psychological dimensions of the child are of paramount importance, and autism is one of the most prominent of these disorders². Autism Spectrum Disorder (ASD) is a group of disorders with similar symptoms such as autistic syndrome, Asperger syndrome, and childhood disintegrative disorder, which is characterized as abnormal development, impaired quality of social interaction and communication, behavioral disorder, and decreased child adjustment and ranges from mild to severe symptoms³. The prevalence of ASD is estimated by the World Health Organization (WHO) at 1 in 160 children worldwide⁴, with the Center for Disease Control (CDC) estimating the prevalence of autism at 16.8 per 1,000 children (1 in 59 children) in 2014 in the United States which increased to 18.5 in 2018 (1 in 54)⁵.

Most studies show that raising a child with ASD creates unique and countless challenges to all aspects of parents' life⁶. These parents experience more stress than parents of children with normal development⁷. Also, caregivers of children with ASD often suffer from mental health disorders, especially anxiety and depression^{8,9}, and most of them, compared to caregivers of children with normal growth, show a lower quality of life and well-being and higher levels of stress¹⁰. Depending on their personality structure, mothers of children with autism are more likely to feel responsible or sometimes guilty. On the other hand, they spend most of their time and energy on the child¹¹. These mothers focus all their efforts on normalizing the structure and process of the family and are involved in the care process with all their energy, regardless of their capacity. They try to look good and hide their suffering. Numerous physical problems (insomnia, fatigue, headache, back pain, anorexia, indigestion and palpitations) and emotional problems (feelings of despair, hopelessness, anger, stress, anxiety and depression) have been reported in the lives of these mothers¹²⁻¹⁴.

Numerous problems and challenges caused by the child's illness affect the meaning of life of mothers of children with autism and their sense of existence; such that these mothers have a lower quality of life than other mothers of children with other mental problems and compared to the two groups of mothers of deaf children and mothers of children with learning disabilities, these mothers have a lower score on the scale of hope and mental health^{15,16}.

So far, many studies have been conducted on parents of children with ASD with a grounded theory approach exploring different aspects of the lives of mothers and fathers. Roquette Viana et al. investigated the parenting of children with ASD with a grounded theory approach and aimed at exploring the processes and feelings of parents during their encounters with children through interviews with 9 couples. They dealt with the process of adapting to the problems of raising a child with ASD in the context of society¹⁷.

Ilias et al. explored the resilience of mothers and fathers of school-age children with ASD using a grounded theory approach and semi-structured interviews. The findings of this study emphasize the stresses and risks experienced by parents during child rearing and finally address the protective processes of parents against stress¹⁸. Several studies in other countries have also explored the experiences of mothers of children with ASD with a grounded theory approach^{12,19}.

In Iran, although studies have been conducted on the life experiences of mothers of children with ASD to examine mothers' needs, stresses and challenges in caring for children with ASD²⁰⁻²², all these studies have been phenomenological. Conducting grounded theory qualitative research can shed light on parts of the hidden aspects of these mothers' lives. Explaining the life process of these mothers can help to better understand the needs, challenges and issues around them so that nurses, doctors and policymakers can use it as a guide to provide key strategies to improve and enhance the life process of mothers of children with autism.

In Iranian culture, mothers tend to be responsible for caring for a child with autism more than other family members. Because the life process of these mothers is not well known according to our society's social and cultural conditions, the present study was conducted to "Explore the life process of mothers of children with autism".

This study was carried out to explore the life process of mothers of children with autism with a qualitative research paradigm and grounded theory approach²³. Grounded theory has a strong connection with symbolic interactionism. Symbolic interactionism refers to the fact that the members of a society influence the social self-development of each individual in that society²⁴.

1. Research Setting and Participants

The study setting in the present study is autism education, treatment and rehabilitation centers in Tehran province, Iran. As in other qualitative studies, in the present study, sampling was first purposive with maximum variation. Gradually, data analysis and new questions continued with theoretical sampling²³.

A total of 14 participants, including 12 mothers of children with autism and 2 fathers, participated in this study based on inclusion criteria. There were also four observations of the participants' mother-child interaction in the center or at home. The main participants were mothers with a child up to 18 years of age with a definite diagnosis of autism (at least two years must have passed since diagnosis and care) and without other physical and developmental disorders who had been referred to education, treatment and mental rehabilitation centers, under the supervision of Tehran province Welfare Organization. Interviewees also had no history of drug abuse, psychological disorders and known chronic illnesses.

2. Data generation methods

Initially, unstructured and semi-structured interviews were used to generate data and get a more complete and deep understanding of the phenomenon under study. This study interviewed 14 participants including 12 mothers of children with autism and 2 fathers. The interview began with an open-ended question, "Explain how one day of your life is with your child with autism" The content of each interview was tried to cover the purpose of the research based on the content expressed by the participants and by asking progressive and clarifying questions. Based on the participants' answers, they were asked to answer questions such as "Please explain more about this" and "What do you mean?" to clarify their statements. Similar questions were sometimes asked in different ways to expand the depth of the data so that each time the participant would ponder more and recall new things. The average duration of the interview was 90 minutes based on the circumstances and situation of the participants. However, to remove the ambiguities in

the data and complete them, and generally, to increase the clarity of information and categories, two participants were interviewed again to clarify the ambiguities.

Observation was another fundamental method for collecting data in the present study and enriching and validating interview data.

3. Ethical considerations

Ethical considerations were observed by obtaining the permission of the Ethics Committee of Iran University of Medical Sciences (IUMS) and presenting it to the research environment, determining the time and place of the interviews with the consent of the participants, explaining the research objectives and the purpose of using voice-recorder to the participants, and obtaining permission to record the interviews. Confidentiality of information was met by removing the participants' names and removing any mark that makes it possible to identify participants.

4. Data Analysis

Data analysis was performed simultaneously with data collection and based on the guidelines recommended in five interwoven stages²³⁻³⁷.

5. Data Trustworthiness

To ensure the study's rigor, Lincoln and Guba's four criteria to establish trustworthiness, including credibility, transferability, dependability, and confirmability, were used²⁵. To do so, maximum variation sampling, prolonged engagement, peer debriefing and adequate interaction with the participants were used, and the supervisors verified all the stages of coding and categorization steps. Member checks were used to ensure participants' agree

ment with the findings. The context of the study and the decision trail were explained in detail to increase its transferability. The experts also audited the process of the study.

Striving to achieve balance

The central concept in this study is “striving to achieve balance.” All the participants clearly and repeatedly pointed to imbalances, instabilities and fluctuations in their life and acknowledged that they are constantly trying to achieve balance in their lives and families. This prominent theme consists of five main categories: “despair”, “ambiguity”, “neutralization”, “child management” and “relationship management”. (Table 1).

Table 1: Main categories and subcategories of “Striving to achieve balance”

Core variable	Main categories	Subcategories
Striving to achieve balance	Despair	permanent self-conflict
		Mental devastation
		Parenting Tension
		Care pressure
	Ambiguity	Internal conflict
		Worrying about the future
	Neutralization	Being with another
		Kindness to oneself
		Seizing (grabbing) the opportunities
	Child management	General planning
		Management of the affected child
		Protection of healthy children
		Protection of the affected child
	Relationship management	Creating social bubble
		Control

a) Despair

After the diagnosis of the child’s illness, the life of this group of mothers faced extensive and sudden changes. The mothers entered a new phase of their lives without any preparation and were placed on the difficult path of living with these children. The mothers experienced despair at different stages of their life with a child with autism. The subcategories are listed in Table 1.

a-1) Permanent self-conflict

All mothers experienced many mental conflicts before and after the illness diagnosis and while caring for the affected child. Many of them were looking for the cause and the why of this incident and had been blaming themselves for this illness for a long time; throughout their life with the affected child, they missed the past life and constantly compared the child with other children and their healthy children.

a- 2) Mental devastation:

Prolonged exposure to life’s challenges with a child with autism and high anxiety levels led to physical and mental intolerance and reduced motivation in many mothers.

“I feel like a robot that receives orders and obeys them. I have no motivation to start changing,” said the third participant.

a-3) Care pressure:

Having a heavy responsibility, lack of time for oneself, and the complex nature of the illness increased the pressure of caring for mothers and ultimately caused a feeling of helplessness and despair.

The fourth participant said: “Most of the time, I am alone with my son, and I have to carry out all the responsibilities; both the housework and child care, taking the child out and to class and keeping him busy almost take all my time and this is not an easy job.... ”

a-4) Parenting tension:

While living with the affected child, much stress was inflicted upon the mother from the affected child, spouse and others, which increased the pressure and feeling of helplessness in the mother. These were seen in the mothers’ interviews.

The eighth participant (husband) states in this regard: “having noticed my daughter’s illness, my wife paid much less attention to my eldest son or me and kept arguing with me about the fact that we diagnosed my daughter’s illness late, and these arguments and disputes caused distance between us. My wife tried very hard to convince me to help her, but she did not succeed, which is why she always did the work of our affected daughter alone, which hurt her day by day ...”

b) Ambiguity

Another major category in the study is ambiguity. Throughout their lives and in the face of an affected child, the mothers face a world of questions and ambiguities about their autistic child, which causes them to become frustrated and incapacitated over time, despite their efforts to maintain balance and stability in the process of life. This main category includes the subcategories; “Internal conflict” and “Worrying about the future.”

b-1) Internal conflict:

Misconceptions about the illness of the affected child and the constant occupation of the mother’s mind with the affected child and healthy children have caused mothers to be constantly in internal conflict with themselves and face many questions and thoughts in their minds every day.

b-2) Worrying about the future:

In addition to the mental conflicts that the mothers had in mind about the current situation of the child, fear and worry about the future of the affected child and its impact on the future of education and marriage of healthy children led to many mental conflicts and ambiguities for which resulted in nothing but despair and helplessness of the mother.

The first participant said: “I say to myself that because of my affected daughter, will anyone come to my house

and propose to my healthy daughter? Or, if my healthy daughter is pregnant, how do I know she will not give birth to such a child? I often say that what will happen to the education and marriage of my affected child? ... I am very worried about their future."

C) Neutralization

This main category was one of the mothers' important strategies against feelings of despair and ambiguity. It led to "striving for balance" as this study's core category, in which mothers tried to improve their situation and that of their families by taking a series of measures.

c-1) Being with another:

The mothers tried to reduce their stress and mental pressure and gain positive energy by spending time with their families and enjoying being with their healthy children and the affected child. Some of them tried to reduce their stress by having contact with their peers.

The tenth participant said in this regard: "On the contrary, having communication with these families is very good because it makes us share our experience and appreciate the good things around us more ..."

c-2) Kindness to oneself:

The findings showed that accepting the reality of the child's illness, being realistic, trying to control grief, paying attention to oneself, and taking some measures to gain positive energy have made mothers calm down and improved their ability to deal with problems properly.

The fourth participant said, "I try to accept my son's illness and say that this is part of my destiny. I find so much relief by reading books, albeit little or sometimes writing. Now it seems in a way that if my son does not exist with all his weaknesses and inadequacies, I don't exist..."

c-3) Seizing (grabbing) the opportunities:

After gaining positive energy and achieving peace and self-confidence, mothers could overcome their feelings of weakness and inadequacy to some extent, appreciate what they have, and use the smallest opportunities to improve their mental and physical condition.

The first participant says in this regard: "Late at night, it is a very good time for me to do the work that I like with more freedom, of course, if any energy is left for me, for example, I read a book, or I spend time with my phone ...or, when I take my older daughter to school, I take the opportunity to walk a little and I like it ..."

d) Child management

The study's findings showed that despite all the worries, stresses and doubts that mothers had about the future and the present of their healthy and affected children, which caused them mental distress, they tried to manage the affairs of their healthy and affected children.

d-1) General planning

The sixth participant says in this regard: "When my daughter returns home from school, we all have lunch together, and then I listen to my daughter's words about school and her class ... I often set my schedule to have dinner ready at 9 o'clock so that we all can have dinner together ..."

d-2) Management of the affected child:

One of the most important stresses of mothers in daily life is interaction with the affected child. They always tried to choose appropriate approaches in dealing with the child's abnormal behaviors by planning the affairs of the affected child daily, as well as educating the child and following his treatments.

In one of the observations in the educational center for children with autism, mothers' efforts and treatment of their autistic children were observed. In the second observation, it was reported: Mothers eagerly brought their children, often entering the center on time and fixing the time of their next visit with the secretary. "Sitting next to me was a mother who brought her 10-year-old daughter, lovingly stroked her daughter's hair and was practicing with her how to hold a pencil ..."

d-3) Protection of healthy children

The mental preoccupation of the mothers with their healthy children and their concern about a healthy child's injury prompted mothers to take steps to desensitize healthy children and satisfy them.

The fifth participant said: "My daughter's school counselor helped us learn to pay special attention to my older daughter, no matter how little but we tried to pay attention to her. ... There were many times when my older daughter got bored so that we would take her to park in order for her to be away from home environment for a moment."

d-4) Protection of the affected child

The findings showed that lack of public and family knowledge of autism and fear of stigma on the affected child led mothers to use strategies such as hiding the affected child from others and limiting relationships to protect them and keep themselves calm.

The fourth participant said: "I usually do not have any contact with anyone but my family because they often have children. When they come to our home, either they do not play with my daughter or my daughter does not play with them, and most of the time, my daughter suffers. That's why I prefer not to have contact with them ..."

Relationship Management

What was most noticeable in mothers' interviews was the tension and anxiety that mothers of children with au-

tism experienced in dealing with others and their families in public settings. Therefore, they felt compelled to manage relationships.

e-1) Creating a social bubble

Choosing the right people to have contact with, visiting at the right time, and going to the places that cause the least worry and stress in the mother is one of the strategies that mothers use to achieve balance. In fact, mothers tried to put their relationships with others in a bubble to be more controllable.

e-2) Control

The need to have contact with others as children grow older and the need to have social relationships led to the control of relationships and contacts in order to maintain peace and protect healthy and affected children.

pendence on the mother²⁸ which negatively affects their care performance.

In addition, it has been shown that there is a direct relationship between the severity of the disorder, the deficiencies of a child with autism and the level of stress and performance of parents, so that widespread and severe deficiencies in most children with ASD compared to the problems of children with other developmental disorders are associated with a greater increase in parental problems such as decreased parental efficiency, increased stress and increased physical and mental problems^{29,30}. Concerns and worries of these mothers, such as disrupted relationships between family members and the mother's not having enough time and energy to care for her husband and other family members, have also been supported in previous studies with parents of disabled children²⁷. In fact, divorce has been reported to have happened in such families more than in families without disabilities³¹⁻³³. In addition, even for parents who are not divorced, raising a child with autism is usually associated with lower marital satisfaction than for parents with healthy children³³, all of which affect the mother's sense of existence and ability to care and lead to low self-esteem and the inability of the mother to care for the child.

Another issue in the current study is that mothers are faced with many questions about child illness, internal conflict, and concerns about the future of healthy children, which illustrates the category of ambiguity in this study. Misconceptions about the affected child's illness and the mother's mental occupation with the affected and healthy children are among the issues reported in the present study, which led to internal conflict in the mother. Previous studies have also reported that parents have specific beliefs about children with autism, and many believe that the symptoms of the illness will decrease as the child grows older or hope that the illness will be treated with medical advances^{34, 35}.

In this study, the mothers particularly prioritized the needs of their children with ASD. They focused on dealing with the challenges of caring for a child with ASD, which led to performance problems in other family members. Other studies have also reported reduced time spent together in the family; This way, one parent stays with a child with autism, and the other spends time with normal children; However, parents were very concerned about the healthy siblings of a child with autism, and many of them felt guilty about it because most of their attention was focused on the child with autism³⁶⁻³⁸.

Some parents also stated in other studies that the siblings of a child with autism commented on the lack of attention from their parents, such as "you are always paying attention to the brother with autism," and expressed jealousy in various ways^{37,39,40}.

The mothers in this study were concerned about the future of the affected child. These findings were also sup-

Discussion

Despair and helplessness are one of the main categories of this study, which include subcategories of constant self-conflict, mental devastation, parenting tension and care pressure. In this study, all mothers were the main caregivers of the affected child. In addition to their main responsibility of caring for and coordinating the work of the affected child, they were also responsible for other daily activities at home, such as housekeeping, caring for other family members and meeting their needs. These multiple responsibilities had a negative effect on the mother's spirit and health, and due to the constant tensions caused by the abnormal behavior of the affected child and the tensions created in relationships with the spouse and others, feelings of helplessness and low self-esteem increased in mothers, leading to disability and helplessness in them.

Other studies support the current findings. In the present study, mothers talked about not having time for themselves, which led to care pressure, comparable to the findings of other studies. According to a study by Smit et al., it was reported that mothers of children with autism spend more time during the day caring for their children than mothers of healthy children and have much less leisure time than other mothers. Also, stressful events and tiredness make arguing with children and spouses in the lives of these mothers inevitable²⁶⁻²⁷. The present study's findings also indicated care pressure due to the complex and difficult nature of the child's illness, which was supported by other studies. In this regard, it has been reported that mothers of children with autism very quickly suffer from stress and emotional turmoil due to high exposure to potentially dangerous and unpredictable behaviors of these children and their functional de-

ported by other studies, as previous studies have shown that parents become skeptical about their child's future with the abnormal growth of the child. These children's high dependence on their parents repeatedly raised concerns about when they would no longer be able to care for the child; these concerns include the child's ability to be independent and to acquire the most basic survival and self-care skills in the future^{9,39}.

Nevertheless, despite all the feelings and problems that mothers faced, they always tried to improve the situation for themselves and their families and establish stability and balance in their lives and their families. Strategies such as communicating with other peer mothers, talking and accompanying them, and establishing appropriate communication with children and the spouse revealed the main category of neutralization in the present study. These findings are supported by several studies^{3,4}. In line with this, it has been reported that despite autism in children, mothers considered their affected child to be kind, intelligent and humorous. They tried to reduce their negative feelings through continuous and unconditional love for their child³⁹. Also, other strategies of mothers to improve their situation and that of their family and neutralize the unfavorable conditions of the family in the present study are self-respect, kindness to oneself and acceptance of reality, that has been able to reduce the mother's negative feelings and enable them to think logically. Other studies have shown that parents have tried to accept the diagnosis and accept the child with autism the way it is to focus on what they can do to improve the child³⁴.

Child management is another major category of the present study. Mothers have used family management strategies to create balance and stability in their situation and that of their family. Doing housework and caring for healthy children and affected children, caring for and protecting healthy children and affected children have been among the most important mental concerns of the mother, which is consistent with the findings reported in other studies. In a way, the terms "do your best" and "never give up"³⁸ in mothers' interviews indicate the action and perseverance of parents who have devoted all their energy and time to improving the child's condition.

According to previous studies, parents also tried to improve their knowledge about autism by reading books, talking to other parents, and surfing the Internet for information⁶. Also, the sense of hopefulness experienced as their child progressed helped parents cope with the child with autism³⁸. However, they acknowledged that not everything can be changed and that some expectations of the affected child should be ignored.

It has been shown that parents' paying special attention to other children caused the affected child to be accepted by their siblings and that they helped the mother take care of the child, which gives parents more opportunity to spend time with family members and gather them together^{37,40}.

Parental strategies in these studies, adopted by many individuals, included the mother's awareness of the environment and the child's reactions, problem anticipation, early planning, and preparing the child to avoid challenging behaviors when moving between environments^{27,34}. In line with relationship management, the mothers noted the isolation of their children and hiding them, the making limitations on family relationships and communication with friends due to increased childcare responsibilities and concerns about the occurrence of possible abnormal behaviors of their children in public, which were supported by previous studies³⁶⁻³⁹. Interviews with Egyptian mothers of children with autism have shown that these mothers were willing to keep and restrict their children at home to prevent stigma and protect their affected child¹⁹. In addition to preventing destructive behaviors, these strategies have been shown to reduce stress levels in parents and children. However, despite the above measures to control child relationships, fear of stigma affects mothers' social life, so they are socially isolated. Many studies have reported that autism stigma is associated with increased psychological problems among caregivers^{27,29}. On the other hand, the need for constant vigilance increases levels of stress and fatigue, which affect their child's mood and symptoms because there is a reciprocal relationship between the positive mood of the mother and the improvement of a child's symptoms with autism³⁷⁻⁴⁰.

According to the findings, caring for these mothers is as important as or even more important than caring for a child with autism. This is important because the successful treatment of autism depends to a large extent on family care. Today, mothers' health is crucial as the primary caregiver of an autistic child. When nurses and health care providers interact with these mothers, they need to consider their fatigue factors and understand their behavioral responses. Since there is no plan for caregivers' health status and given that mental health counseling focuses mainly on the early days of diagnosis or is sporadically based on family needs, healthcare providers are expected to pay more attention to this group of mothers.

The results showed that despair, inability to care, internal conflict and fear for the future of children as they grow, despite all the strategies of the mother to achieve stability and balance, still upset the balance and stability in the family at different times and the mother is always trying to achieve balance and stability in the family. Nurses and healthcare providers should be aware that because of the lifelong nature of this illness in children, any factor that can undermine the stability of life can lead to further helplessness for these mothers.

Identifying the life process of mothers of children with autism is a step towards developing theories and models of care regarding the provision of quality care in the nursing profession and has helped to develop knowledge in this field. Therapists, managers and health policymakers can use these findings to provide appropriate social support services to mothers of children with autism spectrum disorders and help enable mothers to manage these children properly and effectively.

ACKNOWLEDGEMENT

This study is a part of a Ph.D. dissertation in Nursing at Iran University of Medical Sciences. We would like to thank all participants for their tremendous cooperation.

AUTHORS' CONTRIBUTION

All the authors met the standards of authorship based on the recommendations of the International Committee of Medical Journal Editors.

Funding: This research received no external funding.

Conflicts of Interest There is no conflict of interest in this research and article.

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