## Much More Than Parenting: Psychosocial Problems Experienced by Mothers of Children with Special Needs and Coping Methods: A Qualitative Study

Ebeveynlikten Çok Daha Ötesi: Özel Gereksinimli Çocuğu Olan Annelerin Yaşadıkları Psikososyal Sorunlar ve Baş Etme Yöntemleri: Nitel Bir Çalışma

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#### ABSTRACT

The aim of this study was to evaluate the psychosocial problems experienced by mothers with children with special needs and their coping methods. In this study, in which qualitative research method was used, in-depth individual interviews were conducted with 17 mothers. Criterion sampling method, one of the purposeful sampling methods, was used to reach the sample group. Interviews continued until data saturation was reached. All interviews were recorded with a voice recorder and then transcribed. The data of the study were analysed using thematic analysis The study was conducted and reported method. according to the COREQ checklist. Within the scope of the study, three themes (Emotions and reactions, Experiences during the process, coping) and six subthemes (Emotions, reactions, primary problems, secondary problems, dreams/desires, coping methods) were obtained. As a result of the study, it was determined that mothers experienced many psychosocial difficulties and could not use healthy coping methods in the face of difficulties. It can be said that there is a need for psychosocial empowerment of mothers and teaching healthy coping methods.

**Keywords:** Child with special needs, Mother, Psychosocial problem, Qualitative study

#### ÖΖ

Bu çalışmada özel gereksinimli çocuğa sahip annelerin yaşadıkları psikososyal sorunlar ve baş etme vöntemlerinin değerlendirilmesi amaclanmıştır. Nitel arastırma vönteminin kullanıldığı bu calısmada, 17 anne ile derinlemesine bireysel görüşmeler yapılmıştır. Örneklem grubuna ulaşmak için amaçlı örnekleme vöntemlerinden ölcüt örnekleme yöntemi kullanılmıştır. Görüşmeler veri doygunluğuna ulaşılana kadar devam etmiştir. Tüm görüşmeler ses kayıt cihazı ile kaydedilmiş ve daha sonra yazıya dökülmüştür. Çalışmanın verileri tematik analiz yöntemi kullanılarak analiz edilmiştir. Çalışma COREQ kontrol listesine göre yürütülmüş ve raporlanmıştır. Araştırma kapsamında üç tema (Duygu ve tepkiler, süreç boyunca yaşanan deneyimler, baş etme) ve altı alt tema (Duygular, tepkiler, birincil sorunlar, ikincil sorunlar, hayaller/istekler, baş etme yöntemleri) elde edilmiştir. Çalışma sonucunda annelerin psikososyal olarak birçok zorluk yaşadıkları ve zorluklar karşısında sağlıklı baş etme yöntemlerini kullanamadıkları saptanmıştır. Annelerin psikososyal açıdan güçlendirilmesine ve sağlıklı baş etme yöntemlerinin öğretilmesine ihtiyaç olduğu söylenebilir.

Anahtar Kelimeler: Özel gereksinimli çocuk, Anne, Psikososyal problem, Nitel çalışma

#### **Key Points**

\*In this study, in which psychosocial difficulties were evaluated from the perspective of mothers with children with special needs, important outputs related to the process were obtained.

\*Within the scope of the study, it was determined that mothers had many psychosocial difficulties and could not use healthy coping methods.

This study was approved by Giresun University Social Sciences, Science and Engineering Sciences Research Ethics Committee. Ethics Committee decision dated 04/09/2024 and numbered 8/16. This study was presented as an oral presentation at Firat University International Women's Studies Conference on 14-16 October 2024.

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## INTRODUCTION

A child is expected to come to the world healthy and grow up, but the special needs that occur at birth or after birth create a lot of burden on the happiness and order of the family.<sup>1</sup> An individual with special needs is a person who has physical, mental, sensory limitations due to a developmental or acquired problem and needs special care and education apart from their peers.<sup>2</sup> Having a child with special needs is a difficult process that creates changes in family life and negatively affects living standards. The person most affected by this struggle is the mother who takes care of the child.<sup>3-4</sup> Due to the burden of care, caregivers face many problems such as postponing their own needs, reducing their social relationships, health problems. economic problems, deterioration of family relationships, and decreased quality of life.<sup>5</sup> However, while parents act according to the needs of the child, they also have to meet social roles and expectations.<sup>6</sup>

The process experienced by mothers of children with special needs is unique. When mothers give birth to a child with special needs, the loss of the ideal child they experience causes them to grieve. The loss experienced is actually the loss of the ideal child designed in dreams. This situation may cause intense grief and mourning in mothers and its effects may last for a lifetime.<sup>7</sup> Mothers with children with special needs sacrifice their own needs and wishes and experience burnout due to undertaking the primary care of their children.<sup>8</sup> Mothers struggle to meet the extra needs of housework, work and the child and experience more stress, conflict, health

# **Type of Research**

Qualitative method was used in the research. Throughout this research, the Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed, and a report was prepared accordingly.<sup>13</sup>

problems, etc. In this process, mothers do not share their problems with others and even hide their true feelings. This makes it difficult for them to adapt healthily.9 Accordingly, future helplessness, anxiety, fear, exclusion, loneliness, disappointment, rebellion, regret, self-blame, and hopelessness are observed in mothers.<sup>10</sup> Studies have reported that parents with children with special needs have more parenting stress and psychological problems.11

The difficulties faced by families with children with special needs and the care needs of the child differ according to the degree of special needs. The important thing here is to minimise the dependency of the child in care, education and health needs. Recent studies have reported that services for children with special needs should not be limited to the child, the family should also be included in the system, their problems and needs should be identified, and services should be provided accordingly.<sup>12</sup>

Literature frequently focuses on the problems experienced by mothers, but the number of studies on how they cope with these problems is quite limited. In this study, it was aimed to evaluate the difficulties experienced by mothers with children with special needs and their coping methods. It is thought that the findings obtained regarding the problems experienced by mothers and coping methods will be guiding in producing alternatives for empowering mothers against problems, planning and teaching healthy coping methods.

## MATERIALS AND METHODS

## **Population/Sample of the Research**

The population of the study consisted of mothers of children with special needs receiving services from a special education and rehabilitation centre located in the north of Turkey. The sample of the study consisted of mothers of children with special needs who met the inclusion criteria and agreed to participate in the study. Criterion sampling method, one of the purposeful sampling methods, was used to determine the sample. In the criterion sampling method, all situations that meet predetermined criteria are taken into consideration. Criteria/criteria can be created by the researcher, or a pre-prepared list of criteria can be used.<sup>14</sup> Inclusion criteria were a) agreeing to participate in the study, b) Being a mother with a child with special needs c) having the cognitive competence to answer the questions posed.

## **Research Design**

This study was conducted between 6-8 September 2024 using an inductive qualitative design. Face-to-face in-depth individual interviews were conducted with 17 mothers who agreed to participate in the study.

## **Research Team and Reflexivity**

The research team is working as an active faculty member in the nursing school. She has a doctorate in psychiatric nursing. She has received training in qualitative research methods.

## **Data Collection**

Data were collected in a Special Education and Rehabilitation Center in northern Turkey. A semi-structured interview form was prepared by the researcher in line with the relevant literature. The form consists of two parts. The first part includes questions about the mothers' age, educational status, economic status, physical/mental illnesses, etc. The second part consists of five basic open-ended questions to be used in the semi-structured interview. The questions in the semistructured interview form were discussed with the mothers face-to-face individually.<sup>15</sup>

In the interviews, open-ended questions were asked about the psychosocial problems of having a child with special needs and coping methods, and mothers were asked to describe their experiences on the subject and asked, 'Can you explain your answer a little more?' and 'What do you mean by this?' All interviews were conducted by the (first author). The interviews were recorded with a voice recorder and then transcribed verbatim by the researcher. Five basic questions were used in the interviews.

## Analysing the Data

Colaizzi's seven-stage phenomenological analysis method was used to analyse the qualitative data obtained from the interviews.<sup>16</sup> Since the study was based on an inductive approach, no categories were defined in advance. In the first stage, the interviews were transcribed, and the interview texts were read independently and repeatedly by the researcher and a faculty member experienced in qualitative research. Thus, it was tried to understand what was explained in the data. Important statements in the interview texts were selected, reorganised and expressed in general terms. Then, the data that were tried to be explained in the statements were identified and analysed. The researcher and the other evaluator formulated and confirmed the meanings by discussing until they reached consensus. Then, they identified and а organised the themes into main and subthemes. The themes and sub-themes of the research were developed with clear expression. The accuracy of the themes and content was strengthened by presenting the findings of the research to the participants. In addition, by including the statements of the participants, the reader was able to verify the interpretation and analysis of the data.<sup>14</sup>

# **Reliability of the Research**

In a qualitative study, reliability means that the researcher observed the study case as it happened and was as unbiased as possible.<sup>17</sup> The reliability of the study was assessed using Lincoln and Guba criteria. Lincoln and Guba reliability is recommended for reliability, confirmability, transferability, and authenticity criteria.<sup>18</sup> (1) Reliability was ensured through peer control, long-term participation, selection of participants with different experiences, member control, and control. Long-term interaction external between the participants and the researcher was ensured to help the researcher gain the trust of the participants to understand the research area and to achieve a better result. (2) All interviews were recorded and transcribed with a voice recorder to assess the reliability

of the findings. The coding and data analysis of the interviews were evaluated by the researcher. In addition, an expert opinion from outside this study was obtained to confirm the quality of the coding. (3) To check for verifiability, a rich description of the data was provided to enable the data to be evaluated by an external observer and to ensure a clear understanding of the research process. (4) Maximum diversity sampling, accurate of participants, sampling identification method, and time and place of data collection increased the transferability of the data. (5) Informed consent was obtained from all participants regarding authenticity and efforts were made to develop a sense of trust in them. The method of the research was also explained to the participants. The research report was presented to the participants.

## **Ethical Aspects of the Research**

This research was approved by Giresun University Social Sciences, Science and Engineering Sciences Research Ethics Committee (Decision dated 04/09/2024 and numbered 8/16). Informed consent was obtained from the participants before starting the interview. Recordings and transcripts were stored on a password-protected device (PC). The study was conducted in accordance with the Declaration of Helsinki and the ethical standards of the National Research Committee. Before the study, the purpose and subject of the study were explained to the participants, and they were informed that their information would personal remain confidential, the records obtained would not be shared and would be used only for scientific purposes.

## **RESULTS AND DISCUSSION**

The mean age of the mothers was  $39.45\pm5.26$ , 47.05% were university graduates, 94.11% were housewives. The

mean age of the children was  $7.88\pm3.26$ , 88% were male. It was found that 58.82% of the fathers were labourers and 52.94% of the families had poor economic status (Table 1)

**Table 1. Descriptive Characteristics of the Participants** 

Participant Age number Age	Mother's	Family	Child'	Gender		<b>Parents' occupation</b>		
	Education level	economic situation	s age child		Child's condition	Mother	Father	
P.1.	48	Primary School	Bad	12	Male	Mentally disabled	Housewife	Worker
P.2.	44	University	Medium	4	Male	Autism	Laborant	Worker
P.3.	42	Primary School	Bad	7	Male	Mentally disabled	Housewife	Worker
P.4.	39	University	Bad	4	Male	Autism	Housewife	Officer
P.5.	39	University	Medium	5	Male	Speech-language disorder	Housewife	Officer
P.6.	39	University	Medium	6	Male	Atypical autism	Housewife	Officer
P.7.	43	University	Bad	9	Male	Speech-language disorder	Housewife	Worker
P.8.	35	University	Bad	5	Female	Autism	Housewife	Worker
P.9.	36	University	Bad	7	Male	Down syndrome	Housewife	Worker
P.10.	43	High school	Medium	5	Male	Mentally disabled	Housewife	Officer
P.11.	41	High school	Bad	7	Male	Down syndrome	Housewife	Worker
P.12.	36	Middle school	Bad	5	Male	Autism	Housewife	Worker
P.13.	38	Middle school	Good	4	Male	Speech-language disorder	Housewife	Self employmen
P.14.	38	High school	Bad	7	Female	Speech-language disorder	Housewife	Worker
P.15.	30	University	Good	3	Male	Speech-language disorder	Housewife	Shopkeeper
P.16.	33	High school	Good	4	Male	Autism	Housewife	Shopkeeper
P.17.	35	Middle school	Medium	13	Male	Atypical autism	Housewife	Worker

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As a result of the analysis, three main themes (Emotions and reactions, experiences during the process, coping) and six subthemes (Emotions, reactions, primary problems, secondary problems, dreams/desires, coping methods) were obtained (Table 2).

#### Table 2. Themes, Sub-themes and Codes Related to the Subject

Themes	Sub-themes	Codes
	A.Emotions	A.1. Amazement
1. Theme:		A.2. Sadness
Emotions and	"When I first learnt about it, I was very upset and questioned why it happened	A.3. Guilt
reactions	to usbut even though I accepted it in time, I blamed myself a lot, wondering if	A.4. Despair
	it was me. "(P2)	A.5. Resentment
	"I was shocked I falt nom had I amind a lot" (PA)	
	"I was shocked, I felt very bad, I cried a lot" .(P4)	A.6. Fear
	"It is an indescribable feeling, like when you are in the middle of the sea and	A.7. Indescribable
	you are looking for a life jacket."(P6)	A.8.Worry
		A.9. Incapacity
	'When I first found out, I felt anger towards the doctor, because I couldn't accept it.' (P8)	A.10.Depression
	B. Reactions	B.1. Normalisation
		B.2. Rebellion
	'Honestly, no one around me knows because we did not tell anyone because	B.3. Not accepting
	we believe it will be good' (P2).	B.4. Give thanks
	'At least he eats his own food, goes to the toilet himself, we said thank God	B.5. Disbelief
	for that'(P3)	B.6.To hope
	'I can say that it was a tragedy for me, it was very difficult to accept it, I still	B.7.To hide
	haven't accepted it' (P13)	
	A. Primary problems	A.1.Difficulty in persuasion
2. Theme:		A.2. Not understanding the
Experiences during	'Because she was always used to me in that process, when she did not get	wishes
the process	what she wanted, she was always crying and insistent and it was very difficult to	A.3. Difficulty in acquiring sel
the process	convince her.'(P3).	care habits
	The second different is a first second in the second s	
	The most difficult part is toilet training. He still doesn't say it. he also shows	A.4. Inadequate care of oth
	his requests with signs, but I can't understand them, sometimes I have a lot of	children
	difficulty.'(P6).	A.5. The burden of caring for the
	When I take care of one I feel as if I am neclecting the other As if menthing	child is solely on the mother
	When I take care of one, I feel as if I am neglecting the other. As if everything is missing'(P9).	, , , , , , , , , , , , , , , , , , ,
	B. Sekonder problems	B.1. Financial difficulties,
	I and fined have used it manufacts according and fallow up and I among	
	I get tired because it requires constant attention and follow-up and I cannot	B.2. Lack of social support
	create time for myself'(P3).	B.3. Burnout
	I have experienced a lot of social pressure. People's looks and criticisms or	B.4. Social isolation
	questions make me feel like I am inadequate, this is very difficult for a mother	B.5. Stigmatisation
		B.6. Social pressure,
	(crying)(P4).	B.7. Lack of time for oneself,
	'. We needed a lot of support when we were going through these troubles, but	
	no one provided neither financial nor moral support (crying)(P11).	B.8. Postponing or giving u
		one's wishes
	'We don't have a social life, I withdrew from society a little bit, so it actually feels like I protected myself (P14).	
3. Theme: Coping	A. Dreams- wishes	A.1. Wanting your child to lear
	'I really want him to learn to read. Apart from that, I don't plan for the future,	to read
	I'm afraid of being disappointed if it doesn't happen, so I don't dream at all'	
	(P1) (P1)	A.2. Wanting your child to b
		able to manage his/her life of
	'I would like to discover his/her special talent, for example, if it is music or	his/her own
	swimming, I would like him/her to be the best in whatever he/she is talented in,	A.3. To be able to discover you
	even if it is these, it would be perfect for me' (P6)	child's special talent
		A.4. Not dreaming
	'My only concern is that he can meet his own needs, then the income comes, I	ri. i. i i i i cu i i i i i i i i i i i i i i
	don't want to think about the future anyway, it is scary. I stopped dreaming about	
	things beyond my control' (P9)	
		B.1. Being isolated from society
	B. Coping Methods	B.2. To convince oneself
	I don't do anything special. I convince myself, I spend most of my time with	B.3. Making crafts
	him, I used to go for walks, I even gave up that, now I follow him around the	B.4. Drinking coffee
	parks"(P10).	B.5. Taking a walk
	"When I feel depressed, I go out and walk around alone, get some air and diverse a soften it feels good" (PO)	
	drink a coffee, it feels good" (P9).	
	"I wore myself out a lot, my social life ended, I reset myself for a while and I	
	don't see anyone, I'm always at home with him, I don't have the time or the	
	opportunity to do anything for myself anyway" (P6)	

opportunity to do anything for myself anyway".....(P6).

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As a result of the study, it was determined that mothers with children with special needs experienced many psychosocial difficulties and could not use healthy coping methods. The themes obtained from the study were discussed under three main headings.

# Emotions and reactions to learning that their child has special needs

Parents who learn that their child has special needs go through stages such as shock, denial, pain, depression, contradiction, anger, guilt, shame, bargaining, acceptance and adaptation. Families trying to adapt to this new process are also exposed to people's curious looks and questions.<sup>19</sup> Families experience many worrying situations in this and may hold themselves process responsible.<sup>20</sup> In the face of this situation, especially mothers are more likely to suffer psychological pain.<sup>21</sup> They experience more stress.<sup>22</sup> There are also complex emotions such as sadness, anguish, helplessness, and guilt.<sup>23</sup>

In this study, in parallel with the literature, it was found that mothers experienced many emotions and reactions such as confusion, helplessness, guilt. anxiety, rebellion. disbelief, concealment, gratitude, etc. at the same time. When it comes to the health of their children, it can be characterised as a quite normal reaction for mothers to be in a complex emotional state. However, many factors such as not knowing how to manage the ongoing process, not feeling ready for the care of their children, financial concerns, fear of stigmatisation may have laid the ground for these feelings and reactions.

# Problems experienced by mothers with children with special needs

Studies on the subject report that families with children with special needs experience many problems such as financial problems, stigmatisation, social problems, concerns about the future of the child, constant fear of injury or accident related to the child, lack of social support, material and moral problems.<sup>24</sup> In traditional societies, childcare is associated with women and the responsibility is largely delegated to women. This process creates

additional responsibility for women who cannot get support from their husbands or their environment.<sup>25</sup> It has been stated that the needs of the child with special Needs such as self-care, nutrition, education, etc. are provided by mothers.<sup>26</sup> However, individuals with special needs need help and support in many areas, including self-care. Families with low-income levels have difficulties in the face of costs and expenses. Especially mothers have difficulty in meeting the special needs of their children due to their expenses.<sup>27</sup> However, Altuğ Özsoy et al. reported that 83.6% of the families reported that the child's special needs brought additional burden to the family budget.<sup>28</sup> In another study, it was reported that families with children with special needs were mostly unemployed, poor, uneducated and socially insecure.<sup>29</sup> In another study, it was reported that as a result of increased dependency of the child on the parent, family members became dependent on the home, private life was interrupted, life satisfaction and quality of life decreased as a result of social isolation and loneliness.<sup>30</sup>

The results obtained from the study overlap with the results obtained from the literature. In this study, it was determined that mothers experienced many problems such as self-care, increased care burden, financial difficulties, inadequate social support, social isolation and stigmatisation. Within the scope of the study, factors such as the fact that a great majority of mothers are not working, many of them have poor economic status, low education levels, etc. may have paved the way for them to face more problems. In addition, the fact that the child becomes dependent on the mother due to the special needs of the child or that the care is often in the mother, limited social support, etc. factors may have caused them to experience burnout after a while and isolate themselves from society.

# Mothers' coping methods

Studies on the subject have reported that frequent application of strategies focusing on problems by parents of children with attention deficit reduces stress by increasing mental well-being, cognitive coping of parents with autistic children is associated with higher

well-being.<sup>31-32</sup> Studies have reported that coping method and social support have an impact on parental well-being. Passive emotion-focused coping style (self-blame, distancing, etc.) was found to have a negative effect on adjustment and well-being.33 It was reported that parents who reported using problem-solving coping styles were more adaptive and had lower parenting stress.<sup>34</sup> Bucuka (2022) emphasised the importance of religious coping skills and social support for mothers of children with special needs to overcome this process in a healthy way.<sup>35</sup> In Turkey, the number of studies examining coping strategies of mothers of children with special needs is limited.<sup>36</sup>

In this study, the mothers reported that they isolated themselves from society,

## CONCLUSION AND RECOMMENDATIONS

As a result of the study, it was determined that mothers experienced many psychosocial difficulties while providing care for their children with special needs (inadequacy, burnout, stigmatisation, depression, guilt, helplessness, social isolation, financial difficulties, inadequate social support, etc.) and did not use healthy coping methods to combat difficulties.

In this direction, it is recommended to plan and implement necessary training in order to empower mothers and teach alternative coping methods, and to increase the awareness of health professionals, teachers and society on the subject. In addition, it is recommended to make improvements for the

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indoctrinated themselves, did not daydream, took walks whenever they had the opportunity, drank coffee and did handicrafts as coping methods. The fact that the majority of the mothers were housewives and had to take care of their children for a longer period of time may have caused them not to spare time for themselves and to experience more burnout. In addition, many of them may not have been able to benefit from rehabilitation services to the extent they wanted due to their poor economic situation. This situation may have caused them to isolate themselves from society. In this context, it is important to implement rehabilitation programmes for mothers with children with special needs and to make plans to provide social, psychological and economic support to mothers.

needs (psychological, economic, social, etc.) in order to integrate mothers into social life.

## Limitations

The research is limited to the answers given by the participants. Another limitation is that the study was conducted in a single centre.

## **Conflict of interest**

There are no conflicts of interest related to the publication of this article.

## Author contributions

**N.G.B.;** research, conceptualization, data collection, formal analysis, editing, supervision, project management.

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