Research

Views of Parents of a Child Diagnosed with Autism Spectrum Disorder on Burnout: A Meta-Synthesis Study

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Abstract:

This research aims to analyze the views of parents of children diagnosed with autism spectrum disorder (ASD) regarding their burnout using a meta-synthesis method. A total of 456 articles published between 2010 and 2023, using qualitative methodologies, were analyzed, examining 10 studies. Google Scholar, DergiPark, ERIC, EBSCO, EBCSCO Academic Search Ultimate, Elsevier, SCOPUS, Web of Science (WOS), and Wiley databases were used for study selection. The subject headings and keywords used in the searches were: 'autism spectrum disorder, parent, family, burnout, child, perspective, qualitative research. Content analysis was the preferred method during the data analysis. Using content analysis, the sampling methods, research purposes, data collection tools, and results obtained in the studies were examined. The identified data were interpreted based on frequency and occasionally presented using tables and graphs. The findings were categorized under identified themes based on the collected data. The studies examined within the scope of the research were evaluated as a whole, and five themes were reached: getting support, isolation, disruption of daily routine, anxiety, and emotional outbursts. The study's conclusions also provide recommendations for educators, parents, and future research directions.

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INTRODUCTION

Autism Spectrum Disorder (ASD), which emerges in early childhood, is characterized by difficulties in behavior, communication, and child socialization (American Psychiatric Association, 2000). The definition of ASD in DSM-5 is as follows: abnormal social approach and reciprocal lack of speech; inability to share interests, emotions, or affect; failure to initiate or engage in social interaction; experiencing social-emotional confusion, inadequacy in verbal and nonverbal communication, abnormalities in eye contact and body language, lack of understanding and use of gestures, minimal facial expressions and nonverbal communication for social interaction, difficulties in adjusting behavior according to different social situations, difficulties in sharing imaginary play or making friends, lack of interest in peers, deficits in forming, maintaining, and understanding relationships (American Psychiatric Association, APA, 2014). These individuals often follow routines of observing spinning objects, tend to play with spinning objects, create unique internal worlds for themselves, have established routines, and experience behavioral problems when their routines are disrupted. They are individuals who do not enjoy hugging and avoid being touched (Koca, 2019).

Autism spectrum disorder, first defined by American psychiatrist Leo Kanner in 1943, is a neurodevelopmental disorder that appears in early childhood (Goldson, 2016; Verhoeff, 2014). In 2012, when the Centers for Disease Control and Prevention (CDC) published data from 2008, ASD was observed in 1 out of 88 children among all ethnic and socioeconomic groups (CDC, 2012). While the World Health Organization stated in March 2022 that approximately 1 in 100 children has ASD (WHO, 2022), according to the 2009 data from Guidance and Research Centers (RAM), 10,811 individuals in Turkey were diagnosed with ASD (Tüfek & Sarı, 2016). Approximately 80% of children diagnosed with ASD can obtain scores of 70 or below on the Wechsler Intelligence Scale for Children (WISC-R), and some individuals with ASD may excel in various fields (music, mathematics, etc.) (Bodur & Soysal, 2004). Individuals with ASD persistently repeat actions that give them pleasure and happiness in various areas (Çolak et al., 2016). Although these individuals are similar to their peers in terms of physical development, they may exhibit behaviors such as walking on tiptoes, spinning around themselves, and grinding their teeth while showing inadequacy in situations requiring fine motor skills such as holding eating utensils and using scissors. Because of their weak imitation skills, they may learn certain movements related to gross motor skills (e.g., dancing and swimming) later (Kurşun, 2018; Karacasu, 2019).

In accordance with the diagnostic criteria provided in DSM-5, it is important to implement necessary measures and intervention plans for these individuals from early developmental stages. Early diagnosis is crucial in reducing problem behaviors, enhancing social communication, facilitating school adjustment, and improving peer relationships among individuals diagnosed with autism (Kal, 2020). To establish an early diagnosis, the

primary caregivers of the child, usually the parents, play a vital role. Learning that their child has ASD can lead family members to experience stress, burnout, helplessness, and depression, negatively affecting family harmony and making it difficult to accept the diagnosis (Akbey & Kalaycı, 2016; Akmaniş, 2010; Kaya, 2017).

Families providing care for individuals with ASD can experience emotional and informational gaps and struggle with depression, confusion, obligatory sacrifices, and marriage problems (Arslan, 2020). After receiving a diagnosis of ASD for their child, parents begin to develop various concerns about their child's future. Stress and anxiety increase in family members, and as the child's behavioral problems become evident in social settings, a decrease in social relationships begins, and loneliness emerges. On the other hand, according to the findings of various studies, some families try to develop themselves more to support their children 's problems and find happiness in small things (Foo et al., 2015; Yassıbaş, 2015). Research conducted with parents of children diagnosed with ASD reveals that due to the physical differences of ASD children compared to their peers, as well as their different behaviors in social situations, parents experience labeled, anxious, and depressive feelings (Yassıbaş, 2015). A meta-analysis study conducted by Green et al. (2013) also identified that parents of children with disabilities experienced problems such as stress, lack of support services, and labeling. When examining the conducted research, it can be seen that parents of children with ASD experience different problems and may need support services to overcome these challenges. Although various studies provide information to practitioners and researchers about support and intervention services for families of individuals with disabilities, there is a scarcity of research specifically targeting families of individuals with ASD. In this context, analyzing research conducted with parents of children with ASD is important for both parents and researchers to understand how these studies are conducted. Therefore, this study aims to analyze articles conducted with parents of children diagnosed with autism in Turkey between 2010 and 2022 regarding methodology, findings, and conclusions. The relevant literature shows that parents, especially mothers, fathers, and primary caregivers, of individuals with ASD experience significant disruptions in their lives. The most significant impact is stress. If this stress is not managed, it can adversely affect caregivers' health. Many studies have shown that caregivers are at risk in this regard (Montes & Halterman, 2007). Studies in the relevant literature indicate that as stress levels increase, burnout also increases (Biçki, 2016; Çengelci, 2009; Yüzer et al., 2010; Kurşun, 2018).

Caregivers of children with ASD may experience burnout symptoms due to stress. In a study conducted by Tunçel (2017) with mothers of children diagnosed with ASD, significant differences were found in emotional burnout levels according to the degree of autism and the rate of autism symptoms. In a study conducted by Valenti et al. (2014), therapists providing care to children diagnosed with ASD, who were selected as

participants, were reported to experience more intense burnout than those providing care outside this field.

Purpose of the Research

Due to the diagnosis of ASD in children, parents may experience burnout. To reduce and alleviate burnout in these families' daily lives and enhance their quality of life, there is a need for various interventions and supportive plans. Therefore, it is essential to identify the extent of burnout experienced by parents of children diagnosed with ASD. When examining the international and national relevant literature, the significance of qualitative research in determining the burnout of parents with children diagnosed with ASD is increasingly recognized in this research. To gain a general understanding of the burnout experienced by these parents, it is necessary to evaluate the differences and similarities among these studies within the context of qualitative research. Qualitative research is primarily exploratory research used to uncover trends in thought and opinions and dove deeper into the problem.

Upon reviewing the relevant literature, no meta-synthesis study has been found concerning the burnout of parents of individuals with ASD. A detailed analysis of the criteria expressed in the study is expected to shed light on future research in this area. This research combines and evaluates qualitative studies on parents of individuals with ASD to comprehensively understand their burnout. The meta-synthesis method is preferred for this purpose. Meta-synthesis research involves a systematic, in-depth examination of qualitative studies on a specific topic (Polat & Ay, 2016). In this study, by examining the burnout of parents with children diagnosed with ASD in detail, the sense of burnout related to having a child with ASD can be explained. Exploring and explaining this feeling from various angles will reveal the experiences that parents undergo during this process. This will assist practitioners in the field in understanding parents' experiences and thus contribute to developing family education programs and parental intervention-support programs.

Synthesizing different qualitative studies related to the burnout of parents with children diagnosed with ASD from a broad perspective will provide diverse insights to professionals working in this field. In this meta-synthesis study, the objectives are identifying studies related to the burnout of parents with children diagnosed with ASD in the relevant literature, examining the identified studies according to predetermined criteria, and synthesizing the findings obtained from these studies. In the scope of this general objective, the following questions have been attempted to be answered:

1. How are the distributions of these studies in terms of the type of index in which they were published
2. What is the chronological distribution of these studies?
3. How are these studies distributed based on research methods?
4. How are these studies distributed based on sampling methods?

5. What data collection tools were used in these studies?
6. What are the common themes identified across these studies?
7. What are the common findings in the results of these studies?
8. What are the differences in the findings of these studies?

METHOD

Research Design

In this study, a method known as meta-synthesis (thematic content analysis), a type of content analysis, has been chosen. Meta-synthesis involves bringing together groups of studies centered around a particular context, analyzing and synthesizing them to develop a new conceptualization based on the primary factors explored in the research (Schreiber et al., 1997). Dinçer (2018) emphasizes that content analysis is both a research method and an analysis technique, and it is important to detail the process in studies employing it.

Meta-synthesis is considered a research method within the domain of content analysis. It involves examining and interpreting qualitative studies related to a specific topic or chosen field using a qualitative understanding (Çalık & Sözbilir, 2014; Gül & Sözbilir, 2015; Polat & Ay, 2016; Walsh & Downe, 2005). Polat and Ay (2016) mention that terms like 'meta-study,' 'thematic content analysis,' 'meta-ethnography,' and 'qualitative meta-analysis' can describe meta-synthesis studies. In meta-synthesis studies, qualitative research studies on the same topic are systematically examined and interpreted using templates, tables, and diagrams to highlight their similarities and differences (Gül & Sözbilir, 2015). Meta-synthesis studies aim not to produce a single conclusion but to reconcile the conflicting situations identified in the studies. Rich and in-depth interpretation of the examined studies is essential; hence, limiting the number of articles to around 10-12 is recommended (Bondas & Hall, 2007).

Due to the increasing number of qualitative research studies in education, the need to evaluate these studies collectively has led to the emergence of meta-synthesis studies in education (Polat & Ay, 2016). Although there are a substantial number of qualitative studies in the field of special education, there is a lack of meta-synthesis studies (Boshoff et al., 2016; Corcoran et al., 2015)

According to Clemmens (2003), while meta-analysis reduces and interprets quantitative research results through averages, meta-synthesis works conversely by interpreting the uniqueness of individual studies and integrating them to make qualitative research results more comprehensive. This study aimed to synthesize and interpret information about the burnout of parents with children diagnosed with ASD to achieve a higher-level understanding. Therefore, meta-synthesis was chosen as the method for this research.

Boshoff et al. (2016) conducted a study synthesizing qualitative articles on families' experiences in advocacy. This meta-synthesis study involves three important steps: (a) screening studies, describing identified results, identifying most frequently used themes, (b) synthesizing similar findings beneath these themes, and (c) labeling and defining the

synthesis appropriately and comprehensively presenting the findings. Noblit and Hare proposed seven steps for the meta-synthesis process (as cited by Mohammed et al., 2016).

These steps are

a) Identifying the Focused Topic of the Research

b) Deciding on Relevant Studies for the Topic

c) Reading and re-reading Selected Studies in Detail

d) Establishing Relationships among Selected Studies

e) Identifying the Similarities and Differences Among Selected Studies

f) Synthesizing Common and Diverse Aspects

g) Interpreting the Synthesized Data

This study considers the systematic meta-synthesis stages proposed by Noblit and Hare (1988).

a. Identifying the Focused Topic of the Research

Within the scope of the study, the focus topic and its framework were initially determined. The research topic was identified as burnout experienced by parents of individuals with ASD after their children 's diagnosis. The sample group included only parents (mothers and fathers), and the study did not include other caregivers or family members, such as siblings, grandparents, or other relatives.

b. Deciding on Relevant Studies for the Topic

After determining the research topic, searches were conducted in Google Scholar, DergiPark, ERIC, EBSCO, EBCSCO Academic Search Ultimate, Elsevier, SCOPUS, Web of Science, and Wiley. During the database search, both Turkish and English keywords were used, including the phrases "autism mother," "autism father," and "autism parent burnout,". After reading the abstracts of the 456 studies between 2010 and 2023, 10 articles were selected for inclusion based on predetermined criteria. After determining the inclusion criteria of the articles, the researchers identified the articles. The inclusion criteria for the articles are given in Table 1.

Table 1. Inclusion criteria for articles

CRITERIA	INDICATORS
Scope of this article	Burnout of parents whose children have ASD
Participants	Mother, father, and parent
Content	Parents′ feelings of burnout about their children diagnosed with ASD
The research method	Application of the qualitative research methods in research (phenomenology, case study)

c. Reading and re-reading Selected Studies in Detail

Then, the researchers read the selected articles in detail. The entire process of reading and excluding articles is depicted in Figure 1, and the PRISMA flow diagram was used to illustrate the detailed steps of the meta-synthesis process (Moher et al., 2009).

Figure 1. PRISMA flowchart
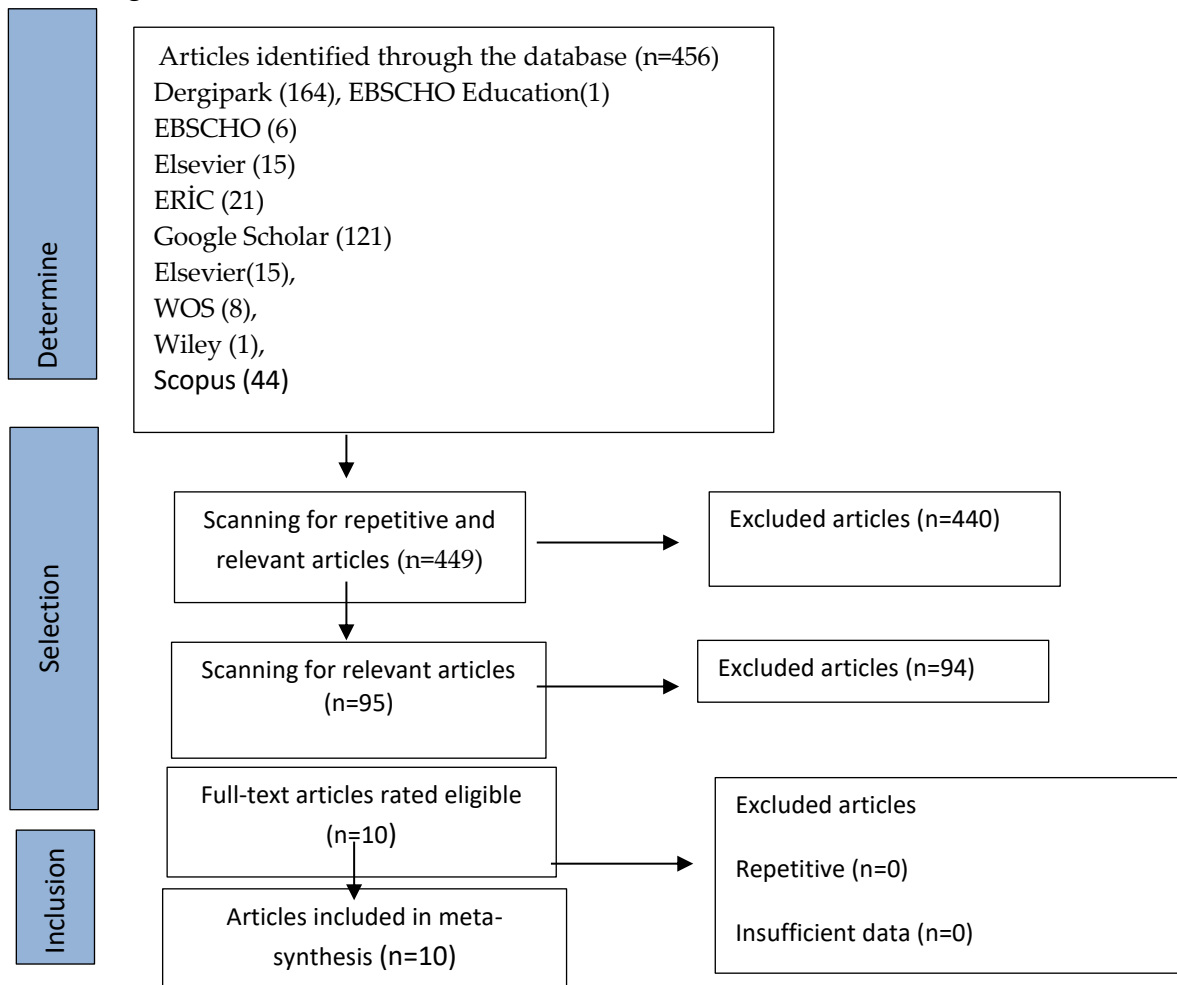
Following this process, 456 articles were identified, and their methodology sections were closely examined. Articles that were conducted using phenomenological and case study methods were included in the research scope. During the detailed reading process, the researchers encountered instances where they had differing opinions regarding certain concepts in the methodology section. The conflicting article was re-read and thoroughly examined in such cases, considering the differing perspectives. After this thorough examination, consensus was reached on the inclusion of 10 articles that aligned with the predetermined inclusion criteria. These 10 articles were subsequently read and examined in detail to ensure their suitability for the research.

d. Establishing Relationships among Selected Studies

The researchers designed a template to analyze and compare the selected articles systematically. This template encompassed the research title, aim, questions, sampling methods, participant characteristics, data collection tools, data analysis methods, findings (similar themes/different themes), and quotations. The researchers manually coded the

articles using this template, and inter-coder agreement was established through comparison and consensus. The consistency between the researchers' and the expert's (special education specialist) comparisons was examined. The reliability of the research was calculated using the formula Reliability = agreement/(agreement + disagreement) * 100, which was recommended to be at least 80% by Miles and Huberman (1994). In this study, the inter-coder agreement was 90%.

e. Identifying Similarities and Differences among Selected Studies

After coding the articles based on the established template, the researchers compiled and examined their similarities and differences. Table 2 illustrates the template used for this purpose.

Table 2. Template used to identify similarities and differences

Source	Data collection	Data analysis	Sampling	Method	Participant
Lamba, et al., 2022	Semi-structured interview form	Content analysis (Thematic analysis)	Purposeful and a snowball	The case study	17
Ghanouni, et al., 2021	Semi-structured interview form	Content analysis using NVIVO	Purposeful	The case study	22
Keville, et al., 2021	Semi-structured interview form	Thematic analysis	Purposeful	Phenomenology	6
Sulaimani, et al., 2022	Semi-structured interview form	Content analysis (Thematic analysis)	Purposeful	Phenomenology	15
Tümlü, et al., 2021	Semi-structured interview form	inductive analysis	Criteria sampling	Phenomenology	9
Anclair et al., 2014	Semi-structured interview form			Single-Subject	2
Koydemir et al., 2010	Semi-structured interview form	Content analysis	Snowball	The case study	13
Efeoğlu, et al., 2020	Semi-structured interview form	Content analysis using NVIVO	Snowball and Criteria	Phenomenology	8
Toper, et al., 2021	Semi-structured interview form	Content analysis using Maxqda 2020	Purposeful	Phenomenology	10
Yamoah, et al., 2022	Semi-structured interview form	Content analysis	Snowball	Cross-case analysis	5

f. Synthesizing Common and Diverse Aspects

Using the template created in Table 2, the researchers marked similarities and differences among the selected articles. The researchers examined and classified the articles' distinctive and shared characteristics based on this template. These classifications helped identify themes, which were further analyzed to determine common themes. Two special education experts and the researchers coded the data collected. The agreement between the researchers' and experts' coding was examined, and it was found that the agreement rate increased from 80% to 90% after discussions and agreements. After the coding process, the codes were integrated into the templates, and the templates were finalized based on the analysis process of the articles by the authors.

g. Interpretation of Synthesized Data

The findings section extensively elaborates on the final step of interpreting the synthesized data.

RESULTS

The articles included in the research were examined within the scope of the criteria determined within the scope of this research. While examining the articles, similarities, and differences in terms of the purpose of the research, the participating group, data collection techniques and tools, and the techniques preferred in data analysis and findings were revealed. Each of them is explained under a separate heading in the Findings section. Within the scope of this research carried out with meta-synthesis, the articles discussed within the scope of the research were evaluated as a whole, and themes were formed.

Study Purposes

Table 3. Purpose of the studies included in the study

Purpose of this research	Research
To reveal the experiences of children of mothers with ASD regarding labeling.	Sulaimani, et al., 2022
To reveal the parenting experiences of parents of children with ASD	Keville, et al., 2021
To reveal the experiences of individuals with ASD regarding receiving health services	Ghanouni, et al., 2021
Exploring the difficulties and support mechanisms of mothers of children with ASD	Lamp, et al., 2022
To reveal the burnout of families with children with ASD and examine cognitive behavioral therapy's effect.	Anclair et al., 2014
Investigating the effect of having a child with ASD on children	Koydemir et al., 2010
To reveal the psychological experiences of families with children with ASD	Tumlu, et al., 2021
To reveal the changes in themselves and their children because of the	Efeoglu, et al., 2020

employment of these children through their families' experiences.

To reveal the experiences of families with children with ASD regarding their psychological and social difficulties	Toper, et al., 2021
To reveal the role of social support in reducing burnout in parents of children with medical complexity.	Yamoah, et al., 2022

Analysis of the Participants in the Study

When the studies included in the research are examined, it is seen in Table 4 that the number of participants is between 2 and 22. It is also observed that there are mothers who undertake primary care among the participants in the study.

Table 4. Number of participants in the studies

Research	Number of participants	Parent
Lamp et al., 2022	17	Mom
Ghanouni et al., 2021	22	Mom
Keville et al., 2021	6	Mom
Sulaimani et al., 2022	15	Mom
Tumlu et al., 2021	9	Mother and father
Anclair et al., 2014	2	Mom
Koydemir et al., 2010	13	Mom
Efeoglu, et al., 2020	8	Mother and father
Toper et al., 2021	10	Mother and father
Yamoah et al ., 2022	5	Mom

Data Collection Tools and Data Analysis Methods of Studies

As seen in Table 5, a semi-structured interview form was used because data were collected through interviews, one of the qualitative research methods. In addition to the semi-structured interview form, some studies also have a demographic information form (Ghanouni et al., 2021; Koydemir et al., 2010; Sulaimani et al., 2022; Toper et al., 2022; Yamoah et al., 2022). When we look at the data analysis methods of the studies, we see that content analysis methods are used in most of the studies. Content analysis programs such as NVIVO and MAXQDA have been used in some research while performing content analysis (Efeoğlu et al., 2020; Ghanouni et al., 2021; Toper et al., 2021).

Table 5. Data collection tools and analysis methods of the studies

Research	Data collecting tools	Data Analysis Method
Lamp et al., 2022	Semi-structured interview	Content analysis (Thematic analysis)
Ghanouni et al., 2021	Demographic information	Content analysis using NVIVO
	Semi-structured interview	
Keville et al., 2021	Semi-structured interview	Thematic analysis (Interpretive phenomenological analysis)
Sulaimani et al., 2022	Demographic information	Content analysis (interpretative phenomenological analysis)
	Semi-structured interview	
Tumlu et al., 2021	Semi-structured interview	inductive analysis
Anclair et al., 2014	Interview form	
Koydemir et al., 2010	Demographic information	Content analysis
	Semi-structured interview	
Efeoglu et al., 2020	Semi-structured interview	Nvivo 12 Plus
Toper et al., 2021	Demographic information	Maxquda 2020
	Semi-structured interview	
Yamoah et al ., 2022	Demographic information	Content analysis
	Semi-structured interview	

The data collection technique, the interview method, is very effective in revealing the participants' perspectives, experiences, feelings, and perceptions about the researched subject (Patton, 1987). The research shows that the interview method is preferred to understand the psychological processes and burnout of the parents because their children are diagnosed with ASD.

The sampling method of the studies

The sampling methods used in the studies are given in Table 6. When the sampling methods of the studies are examined, the purposeful sampling method is preferred in most studies.

Table 6. The sampling method of the studies

Research	Sampling Method
Lamp, et al., 2022	Purposeful and snowball sampling
Ghanouni , et al., 2021	Purposeful, convenient sampling
Keville , et al., 2021	Purposeful sampling
Sulaimani et al., 2022	Purposeful sampling

Tumlu et al., 2021	Purposeful sampling
Anclair et al., 2014	Convenience sampling
Koydemir et al., 2010	Snowball sampling
Efeoglu, et al., 2020	Snowball sampling and criterion sampling
Toper, et al., 2021	Purposeful sampling
Yamoah , et al ., 2022	Snowball sampling

The purposeful sampling method is the random inclusion of participants in the research according to certain criteria (Patton, 1990). Depending on the purpose of the research, this type of sampling was mostly preferred because it allows for in-depth research by selecting information-rich situations.

Common Points Regarding the Findings of the Studies

When the findings of the articles included in the research were examined, the common findings in the 10 studies that examined parent burnout were determined and made into themes. When the articles included in the study are examined in Table 7, there are five common findings.

Table 7. Common findings of the articles

Articles	Common findings
Yamoah et al., 2022; Tumlu et al., 2021; Lamp et al., 2022	Getting support
Yamoah et al., 2022; Tumlu et al., 2021; Toper et al., 2021; Efeoglu et al., 2020; Sulaimani et al., 2022	Isolation
Tumlu et al., 2021; Toper et al., 2021; Efeoglu et al., 2020; Anclair et al., 2014	Disruption of the daily routine
Efeoglu et al., 2020; Ghanouni et al., 2021; Sulaimani et al., 2022; Anclair et al., 2014	Anxiety
Keville et al., 2021; Efeoglu et al., 2020; Ghanouni et al., 2021; Anclair et al., 2014	emotional outbursts

The parents of children diagnosed with ASD experienced burnout and witnessed different life experiences along with this feeling. These life experiences were thematized by reading the articles in the context of common findings.

Getting support

The first theme determined after reading the studies is 'getting support .'Individuals with ASD receive support to protect their psychological resilience because their parents experience burnout (Lamba et al., 2022; Tümlü et al., 2021; Yamoah et al., 2022).

In the study by Lamba et al., 2022, many participants mentioned the support they received from therapeutic services. It was stated that they received support from support groups and that they did not feel alone at this point. It also stated that they can share their experiences and ideas through support groups. Below is a quote from a participant:

"…These people have really helped and supported us emotionally, at least, emotional support knowing there is someone else out there, you are not alone… I would go and try and get advice and try to do the same. So it really helps a lot…"

There are different preferences in terms of support groups among the participants of the research conducted. For example, some mothers stated that they felt supported through online groups on Facebook or by establishing close bonds in private groups (Lamba et al., 2022).

Tumlu, et al. (2021) showed that parents share their experiences as support and use social support as support teams. There is a similar finding in the study by Lamba et al., 2022, it shows that parents prefer social support groups more than support. At the same time, the need for financial support was emphasized in this study. State policies and economic conditions also appear to affect parents significantly in burnout. Below is an excerpt from one of the participants in the study:

"If the situation of these special children is good financially and socially, you can take these children for a walk and take them everywhere. . .However, people are sad because they don't exist… our disabled people have no rights; they have no legal rights. They do not give them anything, that is. . . Wherever you go, they close the door for you."

Yamoah et al. (2022) divided the types of social support into four subcategories: church support, practical support, mental health support, and rest/childcare support. The study's findings showed that active participation in the types of social support is critical in alleviating parental burnout and feelings of isolation. Participants underlined the importance of receiving mental health support at various stages of their parenting journey. In addition, the participants stated that they sought mental health support to address parental burnout. Participant 3 talked about how much the counseling services helped him. She realized how easily she could get an appointment whenever she wanted. An excerpt from Participant 3 is as follows:

"Even though we have not used the service recently, I know I can easily set up an appointment and talk to them, which has been a huge help'.

Isolation

Efeoglu et al. (2020) stated that a factor that triggers burnout in parents is that they experience isolation in shock, denial, and acceptance processes after being diagnosed with ASD. In addition, in this process, it is seen in a quote from one of the participants that the most affected in the family are the mothers:

"…with autism, the mothers are the most affected in the family. Fathers are still out and about during the day, but women are more oppressed under this burden. They are disconnected from their surroundings. Because people do not understand you, they are not doing exactly what you are

suffering from, they are not aware of it. In the meantime, the woman has to stay home; she cannot take her child anywhere easily."

Toper et al. (2021) stated that there are serious changes in the daily routines of parents of children diagnosed with ASD. These changes in daily life and the changes in some usual situations lead to burnout in parents. Here is an excerpt from one participant's interview:

"I finished my work life instantly. I finished my social life, so I had no social life until I founded this association. So I was with my son 24 hours a day."

Tumlu et al. (2021) stated that parents engage in avoidance behavior because of the anxiety of experiencing social exclusion due to their children with ASD. The study concluded that these parents experienced social isolation with avoidance behavior, which negatively affected their burnout.

Sulaimani et al. (2022) reported that the parents included in the study experienced isolation because they experienced avoidance and embarrassment after the diagnosis.

Yamoah et al. (2022) concluded that the dominant theme related to parental burnout was the isolation experienced by the parents. Most participants stated that they felt lonely, sad, unable to receive social support, and thus experienced isolation.

Disruption of Daily Routine

Anclair et al. (2014) concluded that children and mothers with ASD lead a routine and social life at home, and the mother's burnout was seriously affected by the disruption of daily routine.

Efeoglu et al. (2020) concluded that as individuals with ASD grow up and their educational life ends, the increase in closure and the onset of introversion have negative effects on the daily routine of these individuals and their families. It has been found in the study that the routines of the families of these individuals who experience tantrums are disrupted, and their care becomes more difficult. The direct quotes of some participants because of the interviews are as follows:

"Children, you get through that period somehow at a young age, but when they become adults, everything becomes much more difficult" (A1, Dad)

…when he is closed at home, the children 's obsessions increase and their irritability and tantrums increase." (A5, Mother)

Tumlu et al. (2021) revealed that parents of individuals with ASD avoid social environments because they fear that their children will display ambiguous negative behaviors and therefore will be ostracized by others. For this reason, they disrupt their daily routines. Here is an excerpt from the interviews of a participant:

"We no longer have the concept of guests; we don't go to visit friends. Something breaks during the visit when we go, and he does not stay silent. It will sound; maybe you won't do anything

with the fear that something will happen, but you don't go with the anxiety that you will; you stay at home."

Anxiety

Efeoglu et al. (2020) stated that one of the biggest concerns of the parents of individuals with ASD is that they do not know how their children can sustain their own lives after their death due to the excessive dependence of the autistic child on the family. A1 and A8 expressed their concerns about the future of children as follows.

"…everyone's biggest fear is what will this child be after me, to whom will he entrust it? Even if it is a sibling, it carries it to a certain extent. That is people's biggest fear." (A1, Father)

"…I used to think every night when I went to bed. I wonder what will happen in the future. For example, I am still affected [cries]. Maybe it's us today, but what will happen tomorrow…it's a very difficult thing." (A8, Mother)

Ghanouni et al. (2021) reported that participants did not receive financial, social, or psychological support while living with the diagnosis of ASD and that this created anxiety for both adult children with ASD and themselves.

In the study by Anclair et al. (2014), it was concluded that they experienced anxiety because of their children's behavioral problems. It is stated in the research that they experience burnout along with negative emotions such as anxiety, worry, and sadness.

Sulaimani et al. (2022) revealed that after the diagnosis of ASD, their children experienced cultural stigma, difficulty in accessing resources, and anxiety due to reactions to the child 's diagnosis, which triggered mothers ' anxiety. Research participant mothers said they were worried about their children 's underdeveloped language skills. At the same time, mothers stated that their children 's lack of attention triggered their anxiety. One of the mothers:

She stated this point clearly when she said that *"seemed as if she was unaware of what was going on around her, as if she had not heard, and was not even aware of the danger"*. Seven of the fifteen mothers interviewed were concerned that their children 's inability to develop appropriate behavior hindered their social and emotional development. mother 5 claimed she was worried because her son "*moved his head strangely, turned quickly, and moved excessively" (*Sulaimani et al., 2022).

Emotional Outbursts

It is seen that parents experience emotional outbursts because of the burnout they experience with their children. It is possible to encounter mothers who commit suicide because of severe family conflicts, family break-ups, divorce, and burnout syndrome (Efeoğlu et al., 2020). Participant A7 expressed this situation as follows:

"…many of our mothers have reached the level of suicide and committed suicide. This rejection and, of course, some fathers did not accept it; divorces were difficult, families were broken because such things were always too heavy for families." (A7, Mother)

DISCUSSION and CONCLUSION

This study aims to evaluate the studies conducted with the phenomenology and case study design, which is one of the qualitative research methods, on the burnout of parents with a child diagnosed with ASD in the national and international literature, with the meta-synthesis method covering 2010–2023. The studies examined within the scope of the research were evaluated as a whole, and five themes were identified: getting support, isolation, disruption of daily routine, anxiety, and emotional outbursts.

Families with a child diagnosed with autism spectrum disorder (ASD) often face significant challenges that can lead to burnout. Seeking support is essential for these families as it can provide them with the necessary resources, guidance, and emotional relief. However, finding the appropriate support can be quite challenging. Navigating through various therapies, interventions, and educational options is time-consuming and emotionally tiring for parents. In addition, financial constraints and limited access to special services further increase the stress of seeking support (Akbey & Kalaycı, 2016; Anclair & Hiltunen, 2014). Raising a child with ASD often comes with significant financial burdens. The costs of therapies, interventions, residency training, and medical treatments can accumulate quickly. These financial pressures can cause additional stress and anxiety for families struggling to provide the best care for their children while managing their financial responsibilities.

Burnout experienced by families with children with ASD can significantly affect parental well-being. Constant demands on giving care, managing behavior, and advocating for children's needs can lead to physical and mental fatigue. Parents may neglect their self-care, leading to health problems and emotional tension. Stress associated with burnout can affect marital relationships, parenting dynamics, and overall family functioning (Clemmens, 2003; Kal, 2020).

Isolation is a common experience for families with children with ASD. The unique needs and behaviors associated with ASD can make it difficult for families to attend social events and meetings or even perform simple daily chores. As a result, parents feel isolated from their friends, extended family, and society, leading to loneliness and disconnection. It was concluded that others' lack of understanding of the requirements of raising a child with ASD contributed to this isolation by depriving parents of a support network. Families with children with ASD may face stigma and judgment by society. Strangers may misinterpret compulsive behavior because of inadequate parenting, leading to feelings of shame and isolation. This social misunderstanding may contribute to burnout by preventing parents from seeking help or discussing their struggles openly (Lamba et al., 2022; Keville et al., 2021; Kurşun, 2018).

Routine is often a cornerstone for managing the needs of children with ASD. Disruption of daily routines can cause increased stress for both the child and the family.

Simple tasks, such as switching from one activity to another or dealing with unexpected changes, can trigger increased anxiety. This deterioration contributes to parental burnout by creating a continuous cycle of stress and unpredictability (Montes & Halterman, 2007; Sarcan, 2019). Anxiety is a common problem in families of children with ASD. Parents may worry about their child 's future, education, social interactions, and general well-being. The need to anticipate and manage potential anxiety triggers in their children can negatively impact their mental health. The uncertainty surrounding the effectiveness of various treatments and interventions can lead parents in a constant state of anxiety. Parents may also experience emotional outbursts because of the overwhelming stress and frustration they face. These emotional moments can strain family dynamics and lead to feelings of guilt or helplessness.

Burnout experienced by families with children with ASD is a multifaceted and complex issue. Seeking support is vital, but it comes with its own set of challenges. Addressing isolation requires increased community awareness and empathy. Managing disruptions to routines requires creative solutions and flexibility. Anxiety must be acknowledged and supported through mental health resources. Emotional outbursts require effective coping strategies and mutual understanding within the family. Families, professionals, and communities must work collaboratively to meet these challenges and provide holistic support. By improving access to specialized services, promoting inclusive environments, and fostering understanding, we can reduce the burnout experienced by families raising children with ASD.

RECOMMENDATIONS

In line with the results of the research, implications were made for educators, parents, and further research.

Recommendations for educators;

• While working with the parents of students with ASD, parents should be provided with the necessary support by an educator in case they have experienced a feeling of burnout. In this context, educators and therapists working with individuals with ASD should inform them that parents can benefit from mental health services when needed.

• Because parents see their children as inadequate in terms of skills, individuals with ASD who have special abilities can be supported in this sense and their families' burnout in this regard can be prevented.

• Parents who undertake primary care should be encouraged to participate in various activities to reduce their burnout by spending time with themselves, and in this context, the types of support should be increased.

• Better quality mental health and psychological counseling services should be provided to these parents by providing more opportunities for guidance and psychological counseling services in schools where their children are educated. Group psychological counseling services should be provided to these parents to share their negative experiences and prevent them from feeling alone in this regard.

Recommendations for further research;

• This research was carried out using the meta-synthesis method. In the meta-analysis method, qualitative research is synthesized. In this context, research can be conducted on this subject by choosing the research method meta-analysis. Thus, the interpretation of the quantitative research findings can be provided.

• In this research, articles were synthesized and interpreted. A systematic review study can be conducted on the same subject, and research that will include theses can be conducted.

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Data Availability Declaration

No Primary Data Utilized:

This study is conceptual in nature and does not rely upon primary data collection. As such, there are no datasets directly associated with the presented findings. The discussions and conclusions drawn are based on an extensive review of existing literature and analytical insights put forth by the authors.

Author Contributions

All authors, Fatih Koçak, Özge Çevik, and Hasan Kızılkaya, contributed equally to this work. They handled the conceptualization, methodology design, data acquisition, and analysis collaboratively. Each author played a significant role in drafting and revising the manuscript, ensuring its intellectual depth and coherence. All authors have thoroughly reviewed, provided critical feedback, and approved the final version of the manuscript. They jointly take responsibility for the accuracy and integrity of the research.

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