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ORIGINAL ARTICLE

Persistence in the Face of Ecological Challenges: A Phenomenological Study of Parents of Children With Disabilities in Turkey

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Abstract

In this qualitative study, we aimed to reveal the psychological experiences of parents of children with disabilities in Turkey. A focus group interview was conducted with nine parents (one father and eight mothers) of children with Autism spectrum disorder, Down syndrome, and developmental disabilities who were selected using criterion sampling. The psychological experiences of the parents included themes of anxiety, avoidance, guilt, burnout, and the child-centered life and self-neglect. Parents' experiences are affected by familial, social, cultural, and economic factors. The results indicated that parents' experiences need to be approached from ecological systems theory. We suggest the use of an ecological perspective in the investigation and determination of parents' experiences and in the provision of clinical approaches to helping parents overcome challenges.

Keywords Children with disabilities · Parents of children with disabilities · Ecological systems theory · Phenomenological research

Parents of children with disabilities experience many psychological problems, such as depression (Koca et al., 2019; Pinquart, 2018), anxiety (Dykens et al., 2014; Ülker Tümlü et al., 2017), despair (Tavakolizadeh & Ghochani, 2018), stress (Drogomyretska et al., 2020; Savari et al., 2021), and distress (Rayan & Ahmad, 2018). Additionally, parents of children with disabilities are at higher risk of depression and anxiety compared to parents of typically developing children (Scherer et al.,

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2019). The majority of studies have focused on individual interventions rather than the contexts in which these problems develop (e.g., Dykens et al., 2014; Feinberg et al., 2014). Individual interventions yield improvements in symptoms; however, a number of studies have shown that the change is not permanent (e.g., Eikeseth et al., 2015; Gallagher et al., 2018). Regardless of the intervention, parents' complaints such as hopelessness, helplessness, and despair may continue (Akdoğan, 2016).

In addition to individual factors, many environmental, cultural, and educational factors influence the well-being of parents of children with disabilities (Marshall et al., 2018; Rodrigues et al., 2019; S'lungile et al., 2015). The psychological experiences of these parents and their concrete problems are intertwined and may manifest as psychological difficulties or mental health distress. For example, the psychological symptoms such as hopelessness and helplessness and physical complaints such as stomachache, headache, and sleeplessness displayed by these families are related to social exclusion (Akdoğan, 2016). The unique nature of parents' psychological experiences and interrelated factors (Akdoğan, 2016; Aplin et al., 2018) make individual and/or symptom-oriented intervention inadequate. Therefore, their psychological experiences need to be addressed more broadly so they can be better understood. Bronfenbrenner's (1979, 1986) ecological systems theory (EST) allow a holistic approach to the experiences of parents (Algood et al., 2011; Widyawan et al., 2020).

Literature Review

Ecological Systems Theory

According to Bronfenbrenner (1979, 1986), social, cultural, and political factors influence the development of individuals (who are shaped by the environments in which they interact). Therefore, EST provides a perspective that helps understand the individual within the framework of their contextual, and environmental interactions.

In EST, the individual's experiences are evaluated in the following four interacting subsystems, each of which includes the previous one: microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). The *microsystem* includes social structures, such as family, friends, neighbors, and bosses (Brack et al., 2011), with whom the individual communicates directly, as well as social media contacts (Arnold et al., 2012) with whom the individual interacts directly. *Mesosystem* refers to the effects of two or more social structures in which the individual is not directly involved. The interaction of these structures influences the individual's experiences (Bronfenbrenner, 1986). The *exosystem* is defined as "one or more settings that do not involve the developing person as an active participant but in which events occur that affect, or are affected by what happens in that setting" (Bronfenbrenner, 1979, p. 237). *Macrosystem* is the outermost layer. It includes cultural factors, political policies, and social and economic structures the indirectly affect the individual (Bronfenbrenner, 1986).

Rationale for the Study

Various factors explain the continuation of problems and the insufficiencies of individual counseling in these areas (Akdoğan, 2016; Tümlü & Akdoğan, 2019a). Disability is not always a temporary condition; it may last a long time or forever (Shah & Trivedi, 2017). Therefore, parents' social support needs are also continuous; however, this support is usually insufficient (Akdoğan, 2016). When a child with disabilities requires continuous care and educational support at home, concrete consequences such as job loss can occur in the lives of some parents (Bainbridge & Broady, 2017). Children with disabilities affect how their families function (Cuzzocrea et al., 2013). When one parent provides the majority of childcare, it may lead to consequences such as problems between spouses (Akdoğan, 2016), low marital satisfaction, and divorce (Daroni et al., 2018). In addition, parents face social prejudices and exclusion (Akdoğan, 2016; Haraz, 2019; Tümlü & Akdoğan, 2019a), in which case, sociocultural factors may create obstacles for the children to receive appropriate education (Brydges & Mkandawire, 2020). For example, educators can also exclude children with disabilities. Many studies have suggested that school authorities, teachers, and parents of peers frequently complain about the miserable or inappropriate behaviors of these children (Bakhshi et al., 2017; Tümlü, 2019; Yazar, 2021). Due to these prejudices, some parents may even perceive the school environment as a threat to their children's social integration (Brydges & Mkandawire, 2020). However, parents need social resources that their children can utilize, and parents need to take advantage of their legal rights (Yazar, 2021). Though social exclusion is a result of current circumstances, it also impacts the affected person's future prospects (Haraz, 2019). As a result, prejudices may lead to children's failure to benefit sufficiently from the educational environment, even if they are present therein.

The review of counseling literature revealed that the psychological experiences of parents of children with disabilities need to be examined in a more holistic and comprehensive manner with consideration of personal, familial, cultural, and economical factors (Akdoğan, 2016). The aim of this study was thus to reveal the psychological experiences of the parents of children with disabilities and the dynamics of these experiences from their perspectives.

Research Question

The main research question that guided this descriptive phenomenological inquiry was: "What are the psychological experiences of parents of children with disabilities?" The results of this study can help counseling services for parents of children with disabilities become more holistic and comprehensive.

Method

Research Design

In this study, the descriptive phenomenological design led by Edmund Husserl was used to reveal the experiences of parents of children with disabilities and the

meanings they attribute to these experiences (Chao et al. 2018). This method focuses on what individuals know and their interpretations thereof (Christensen et al., 2015; Creswell, 2012; Ersoy, 2016). In this context, the main purpose is to describe the perceptions and experiences of individuals (Ersoy, 2016). The data were obtained from a focus group interview. A focus group interview is usually conducted with six to 10 people with similar experiences; it is a preferred data collection technique because it provides the opportunity to collect different perspectives and benefit from the interaction between participants (Patton, 2014).

Participants

In phenomenological studies, the participants are individuals who have experience in the research area and can explain their experiences (Christensen et al., 2015). We used the criterion sampling method to select participants. This sampling method is based on the principle that people who meet the predetermined criteria are included in the study (Patton, 2014). Our participant criteria included the following: (a) being the mother or father of a child with a disability, (b) having the ability to explain personal experiences, and (c) volunteering to participate in the study. In this study, to provide a safe group environment and support the volunteer participants (Creswell, 2012), a preliminary interview was conducted with each participant by a counselor who works in the institution where the group interview was conducted, and the purpose of the group interview was stated to the participants. Participants' demographic information is presented in Table 1.

Context of the Study

The study was conducted at a university-affiliated research institute where special educational support is provided to children 0–8 years of age diagnosed with Autism spectrum disorder, a developmental disability, or Down syndrome. Specialists and academicians in special education and counseling work at the institution. Intensive individual and group training are provided to children 5 days a week, and educational evaluation and follow-up studies are completed thereafter. Parents are involved in their children's educational processes and, if necessary, can benefit from the services of the institution through individual and/or group counseling.

Data Collection

The study followed a three-stage process: before the interview, during the interview, and after the interview. The opinions of a rehabilitation counseling specialist (hereinafter, external reviewer) were used to ensure our objectivity and to increase the quality of the study at each stage.

Before the interview, a semistructured focus group interview form was prepared in line with the purposes of the interview. Eight open-ended questions were initially included based on the literature and external reviewer's professional opinions and

Table 1 Participants' Demographic Information

No	Nickname	Gender	Age	Highest educational level completed	Marital status	Current work	Child's type of disability
1	P1	Female	42	Bachelor's degree	Married	Cleaning worker	Autism spectrum disorder
2	P2	Female	44	Community college	Married	Nurse	Down syndrome and developmental disability
3	P3	Female	38	Master's degree	Separated	Housewife	Autism spectrum disorder
4	P4	Female	38	Bachelor's degree	Married	Housewife	Autism spectrum disorder
5	P5	Female	39	Primary school	Married	Housewife	Down syndrome
6	P6	Female	37	Primary school	Married	Housewife	Down syndrome
7	P7	Female	32	Master's degree	Married	Housewife	Developmental disability
8	P8	Male	38	Master's degree	Married	Teacher	Autism spectrum disorder
9	P9	Female	30	High school	Married	Technical painter	Autism spectrum disorder

experiences. However, in accordance with the reviewer's suggestions, some questions were combined and the number of questions was reduced to six.

The interview form contained the following questions for exploring the psychological experiences of parents: "What are you experiencing because of having a child with disabilities?" "Can you compare your life before and after the birth of your child?" "What would you do differently now if you did not have a child?" "What are you experiencing in your relationships (with spouse, friends, relatives, neighbors) because of your child?" "As an individual, how do you allocate time to yourself?" "What are your expectations for the future?".

It is important that the environment is nonthreatening and that the interviewers are experienced in conducting focus group interviews so they can be effective (Patton, 2014). Furthermore, it is recommended to have two people, one in the role of a moderator and the other in the role of an observer, during the focus group interview process (Creswell, 2012; Patton, 2014).

During the interview process, the first author of this study became the moderator due to his experience with qualitative research and being moderator in focus group interviews, and the external reviewer was involved in the interview process as a participant observer. The interviewers introduced themselves and indicated the purpose of the interview. We explained that the data obtained from the audio-recorded interview would be kept confidential, and that the data analyzed after the interview would be shared with the participants if they wished. The parents were informed that additional individual interviews would be conducted with them if needed. We conducted a single-session focus group interview. The interview lasted 59 min.

After the interview, we conducted an evaluation interview with the help of the external reviewer. Based on the reviewer's notes, observations, and opinions and the moderator's observations and opinions, we confirmed the quality of the interview and initiated the analysis stage. After the evaluation interview, we concluded that the data were sufficient. Therefore, we did not need any additional individual interviews.

Data Analysis

Our data analysis was an inductive framework (Creswell, 2012). The inductive analysis process we used consisted of six steps (see Fig. 1) that do not always occur in a linear sequence (Creswell, 2012).

The following inductive analysis steps were employed in this study: (a) audio records were transcribed precisely by the first author and checked by the second; (b) the first author reviewed the transcription in the context of the research questions, determined the major themes, transferred them to the NVivo 12 program, created codes, and presented the obtained codes to the second author, sequentially; (c) in the thematization process, we conducted six team meetings and reached a consensus on three categories, 13 themes, and 23 subthemes, and in the fourth meeting, we reached a consensus on three categories, 13 themes, and 20 subthemes; (d) in the fifth meeting, we decided to categorize the experiences of parents under five main themes (i.e., anxiety, avoidance, guilt, burnout, and the child-centered life and self-neglect) and six subthemes (i.e., anxiety about the labeling and exclusion of the child; anxiety about the future of the child; avoidance of establishing relationships with friends, neighbors, or relatives; avoidance of going to collective places; self-guilt for being an inadequate parent to the child with disabilities; and self-guilt for not allocating equal time to their children without disabilities) under the guidance of the external reviewer; (e) in the sixth meeting, we recognized that the experiences included in the themes were influenced by the ecological contexts in which the individuals were involved and that they affected each other, and we concluded that the parents' psychological experiences could be evaluated within the framework of the EST (Algood et al., 2011; Widyawan et all., 2020); (f) while reporting the results, we included direct quotations from the participants' statements regarding the themes and subthemes, and to ensure the data's accuracy, we provided member checking by sharing each quotation via email with the participant to whom it

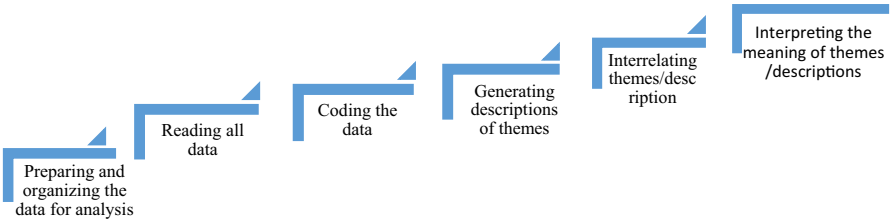


Fig. 1 The Qualitative Process of Data Analysis

belonged; and (g) participants were numbered from one to nine (P1–P9), quotations were listed in italics together with the participant numbers and minute intervals, and unrelated parts of a quotation were shortened with ellipses.

Researcher Roles and Trustworthiness

As counselors and counselor educators, we started this study by discussing and recording our counseling experiences with parents of children with disabilities. We concluded that each parent of children with disabilities has their own unique experiences, and these experiences should only be evaluated within the context of the parents' subjective perceptions and contexts. This conclusion led us to understand the nature of these experiences and produce solutions through a descriptive phenomenological design. In this context, our study focused on providing the components of credibility, transferability, consistency, and confirmability (Connelly, 2016; Guba, 1981; Merriam, 2013; Patton, 2014). Credibility is related to whether the data reflect reality (Guba, 1981; Merriam, 2013). In this study, we performed a sufficient literature review and utilized various theoretical views to ensure credibility. During the data collection and analysis processes, we considered multiple perspectives and reported the findings in detail. In addition, the facts that we work with the parents of children with disabilities and are experienced in conducting qualitative research support the study's reliability.

The extent to which the results obtained in qualitative research can be applied to different situations is related to their transferability (Merriam, 2013). In this study, theoretical knowledge ensures transferability, and we worked with appropriate participants and collected detailed descriptive data. The extent to which the results obtained in qualitative research are similar with the data collected is discussed under the concept of consistency (Guba, 1981). In this study, we present a detailed explanation of how the data were collected and the codings were created and how they were related to the results and the participants' interviews with us to ensure consistency in this process. Confirmability corresponds to ensuring objectivity in qualitative research (Guba, 1981; Merriam, 2013). The focus group interview was conducted systematically, and the process was recorded to support this study's confirmability. Furthermore, we consulted with an external reviewer to prevent our possible data blindness within the scope of the study. In addition, we provided member checking to ensure confirmability (Patton, 2014). Finally, including the exact statements of the participants in the presentation of findings supports the study's confirmability.

Results

The purpose of this study was to reveal the psychological experiences of parents of children with disabilities and the dynamics of these experiences from their own perspectives. *Personal*, *familial*, *cultural*, and *social status* factors emerged as the

dynamics of parents' experiences. Because the results showed that psychological experiences developed in context with various environmental, cultural, and educational factors and were also related to each other, it was necessary to evaluate them within a holistic framework. To this end, we concluded that Bronfenbrenner's (1979, 1986) EST could be used as an appropriate tool to explain the parents' experiences. Our results are presented next.

Parents' Experiences and Their Dynamics

We observed that the parents' psychological experiences and their dynamics were consistent with the EST. Accordingly, we created Fig. 2 to show the parents' experiences and their dynamics within the EST framework. Then, we graphed each theme from the same perspective in Fig. 3.

In Fig. 2, parents and their experiences are at the center of the ecosystem. The microsystem includes individuals with whom parents interact. The mesosystem includes parents' individual and structural relationships. The exosystem includes individuals and structures in the parents' microsystems. The macrosystem includes the social structure, norms, values, and culture in which an individual lives along with state policies. The parents' experiences are categorized under five main themes: anxiety, avoidance, guilt, burnout, and the child-centered life and self-neglect. Figure 3 illustrates the themes and sub-themes.

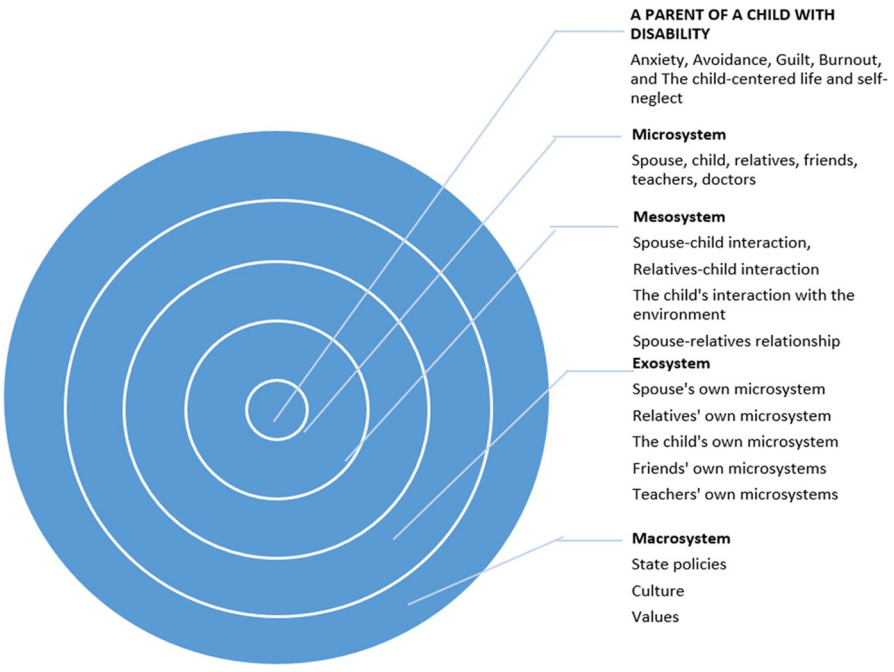


Fig. 2 Ecological Systems Theory Related to Parents of Children With Disabilities

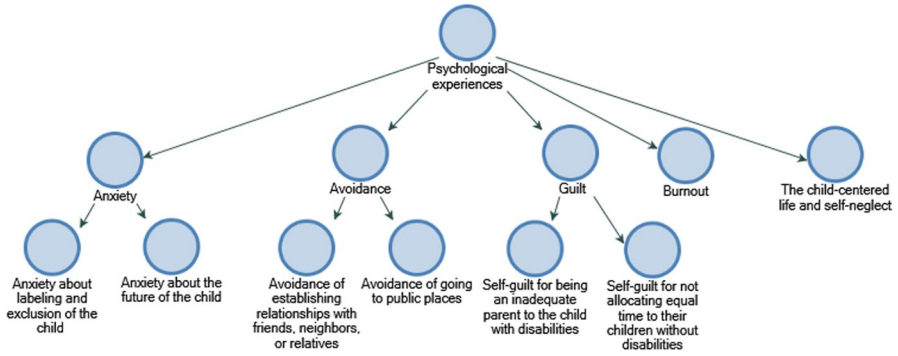


Fig. 3 Psychological Experiences of Parents of Children With Disabilities

Anxiety

We identified two subthemes: anxiety about the labeling and exclusion of the child and anxiety about the child's future. The parents expressed anxiety about the fact that their children will be labeled and excluded by their peers or by the families of these peers. One parent expressed this anxiety clearly:

> We also have mental fatigue, we are constantly on tenterhooks. What are we experiencing? We are constantly experiencing anxiety about whether the child will be labeled from outside. We always have to explain to the child. We have to stand behind her/him constantly to ensure that she/he comes together with her/his peers. (P8, 01:34–02:00)

This parent attributed the reason for these concerns to the negative perspective that may be exhibited by children's peers and the families of these peers: "We have to take shelter against mothers who can prevent them from coming together with their peers" (P8, 02:00–02:40).

This parental anxiety is fed by their children's relationships with their peers at the mesosystemic level. The parents were disturbed by these relationships but felt an obligation to regulate or intervene in them. The parents revealed that anxiety regarding the labeling and exclusion of their children at the micro level also has sources at the macro level. Indeed, a number of parents argued that the labeling or exclusion of their children by others is related to their lack of knowledge:

> My child is mildly autistic. A little bit little bit . . . but but people see him as normal. Then they are surprised when they see some oddities, the need to explain is very troublesome in that sense, to say something or the truth constantly, sometimes to interpret by changing and so on. All of these are bothering. Frankly, as Mrs. M. has explained just now, severe cases come to the mind, and they immediately stick the label. (P2, 22:12–23:19)

Another subtheme is anxiety about the child's future. The parents experienced anxiety about their own deaths or about what would happen to their children if they

could no longer provide support. We observed anxiety that the children would face various compelling experiences, ranging from economic difficulties to physical violence:

> Yeah, they ask me, "Why do you work?" I am saying my pension will be left to the child; the child will not need anyone. He will not even need his own brother. . . Am I big on cleaning up the mess of everyone? But I'm just striving for him. But if his own uncle does that, then if something happens to me, maybe he's going to beat him up. What will he do? Will he throw him aside? Maybe he will not look after him. Maybe his aunt will push him away; maybe she will say that he could not come. You cannot know, you see, people's future anxiety. (P6, 20:46–22:16)

Relationships at the mesosystemic level are the source of the parents' anxieties about their children's futures. To remove this negative perspective, the parents needed arrangements in social areas, but they were hopeless about this. Therefore, anxiety about the child's future is the product of both mesosystemic and macrosystemic structures.

> Now this will be over, it will be an elementary school. God knows whom he will come across in elementary school. Maybe, he will be pushed aside, they will say, "This kid does not stay quiet." Only with rehabilitation, he will have two hours per week, so what? Nothing, you know, I don't know. Normally, they have prepared a draft of a law, but it probably has not gone through. (P6, 17:04–17:33)

Avoidance

We identified two avoidance subthemes: avoidance of establishing relationships with friends, neighbors, or relatives and avoidance of public places. The first subtheme revealed that the parents avoided social settings due to the concern that their children will exhibit uncertain negative behaviors and, therefore, be excluded by others.

> We do not have the concept of "guest" and do not go to friends' anymore. You know, we go, and he breaks something during the visit, he does not stay quiet . . . he will make noise;, something will happen. Maybe he won't do anything, but you do not go with the anxiety that he will do; you stay at home. (P6, 55:55–56:23)

In this example, the parent's microsystem includes a relationship between the guest (friends, relatives) and child. The microlevel anxiety is fed by the dynamics in both the mesosystem (interaction between the child and peers) and the exosystem (interaction between the child's peers and others). In other words, the parents thought that their children's behavioral problems would negatively affect relationships with individuals in their microsystems.

The second subtheme of avoidance showed that, as in close social relationships, behavioral problems that the child exhibits or will exhibit are the basis of an

avoidance of collective places. The parents stated that they have encountered reactions in social arenas when their children exhibited behavioral problems; therefore, they do not want to go to collective places:

> Even pressing a simple button in a tram used to become an event. Certainly, I'm going to push that button, when someone else pressed the button, he used to get angry . . . certainly, he wants to sit by himself, he doesn't want to give his place to someone else. The elders say, "My daughter, lift the child" he says, "I will sit," I say he wants to sit, I scuffle with them. . . there were times when I said it would have been better not to get on. (P6, 52:56–53:32)

Avoidance due to possible negative social reactions causes negative reflections on spousal relationships, too:

> My spouse, G., and I went to a shopping center at a crowded time. Naturally, G. became uneasy; it was very crowded and noisy . . . He is a child who moves very slowly while walking on the stairs; this time, my spouse began to look impatient. We had to deal with my spouse. You know, leave him alone;, he will go slowly. We had to quarrel; we will come after you: you go. (P2, 54:53–55:42)

These examples demonstrate that the interactions between parents and their spouses and children at the microsystemic level are affected by relationships at the mesosystemic level. Meanwhile, individuals in the exosystem are also affected by the macrosystem, which includes microsystems within their contexts and society's lack of knowledge of or attitudes toward disabilities. Therefore, avoidance is affected by factors from the microsystem to the macrosystem.

Guilt

The theme of guilt has two subthemes: feeling guilty for being an inadequate parent to the child with disabilities and feeling guilty for not allocating equal time to their children without disabilities. No matter how much effort they make, the parents still felt guilty because they thought that they could not fulfill their responsibilities to their children. One parent was deeply concerned that not doing so will cost them more:

> Sometimes you can't allocate time for your child, and then you fret until the evening. I should have done that, I wish I could do this, now I will do it better. . . Then you feel guilty until the morning, I was going to do it;, why haven't I done it. (P9, 30:45–32:25)
> Maybe we don't prefer, now that breathing is like relieving my own conscience. If I do something on my own, or if I don't fulfill my responsibility, it will be like I have left something deficient. You think that this deficiency will cost even greater, maybe. (P2, 29:40–32:43)

The parents' efforts to eliminate their guilt could even become irrational:

> What if even the book you're reading isn't about your child? I'm sitting next to him while I'm reading. I'm reading a book while he is sleeping. I'm sitting next to him. . . But since it is not related to the child, even in that, I'm successful both in reading and feeling guilty. (P2, 29:40–32:43)

Parents who feel guilty for being inadequate are in conflict with individuals in their own microsystems. They are affected by the dynamics of the mesosystem involving the interaction of these individuals with each other and by the dynamics experienced by each of these individuals in their own microsystems. All of these are linked to insufficient health, education, financial support, a lack of knowledge of society, and dependency on the inadequacy of state policies at the mesosystemic level.

The parents' guilt might not only be due to being inadequate parents to their children with disabilities but also to not allocating equal time to their other children who have no disabilities. This sometimes arose spontaneously, and sometimes from the attitudes of the other parent:

> My spouse says, "You favor the older boy; you distinguish him. You discriminate between the children." I say that this is not true. I say that our little boy is a bit aggressive, but he can handle everything by himself, but the older one (with autism) is not like him. . . Now, for example, while the little boy is eating his meal, the older one will stay hungry if I don't feed him. So, you are obliged to feed him. . . But then I worry whether I neglect the other one too much. (P9, 37:16–38:03)

Although guilt seems to be experienced at the microsystemic level, it develops within an ecosystemic structure. Based on the participants' statements, the guilt seems to be originating from reactions of their spouses at the microsystemic level (which are due to a typically developing child–parent relationship at the mesosystemic level.) Moreover, it is nourished by the microsystemic experiences of the other parent, namely through the exosystemic layer.

Burnout

The Parents parents strive strove to get their childrenschildren's' situations accepted in their social settings. They experienced intense fatigue and burnout due to this:

> Now I have entered a new environment. . . I can make acquaintance with people newly so that I can explain the child and myself and prepare the necessary environment again. But we couldn't always be prepared; this means I'm going to experience it all the time. These are exhausting for me . . . Not only me, not just my child, not just relatives, but it is required to prepare the whole world. (P2, 04:15–04:54)
>
> The immediate vicinity is also included in this. I live with my parents; they are very old, and they have to use hearing aids, but they don't use them. They're the people with whom my son first wants to contact . . . Although I have warned them a lot, they find the things that he says wrongly cute and repeat

them. They don't pay attention to the child's sleeping and waking times. This makes me tired. (P2, 11:24–12:19)

The statements indicate that the judgmental and even accusatory attitudes of others associated with the child also play important roles in parental burnout:

So every year, these report events turn into a torture for us. I mean, go to that doctor. . . when I was getting a report last year, the child was grumpy a lot, but the doctor was saying, "I am first going to take in patients who have an appointment." He didn't let us in, although he saw us in that situation. Then the child started to cry, so I cried as well. . . And when we entered, he said, "You shouted, shouted, was it worth it?" What can the child understand? (P3, 08:54–09:32)

State policies and economic conditions are also important factors in burnout:

If the situation of these special children is financially good, socially, you can show them around, and take them everywhere. . .But people are upset because there is no… our disabled people have no rights, no legal rights. They don't give anything to them, so. . . wherever you go, they close the door in front of you. (P1, 14:39–15:27)

Burnout is experienced in the context of the EST. The parents' interactions with their spouses, relatives, children, or neighbors in their microsystems—the mesosystems of these individuals, which include their interactions with children, and the dynamics of each of these individuals' own microsystems—feeds this experience. In addition, certain macrosystemic dynamics, such as state policies, economic conditions, cultural attitudes, and a lack of knowledge of children with disabilities feed parental burnout.

The Child-Centered Life and Self-Neglect

The last main theme was the parents living a child-centered life and neglecting themselves. The parents' statements showed they had almost symbiotic relationships with their children:

I'm so attached to the kid, I would not say 'attached to,' now this has become a bit like adhesion. I have adhered to the kid so much that I don't want to leave him to anyone because I think that he can't express himself, can't tell, can't meet his needs, and there may be other consequences. And I'm always after the kid. (P2, 27:24–28:40)

The parent who lives a child-centered life also keeps themselves away from their profession, and this causes them to be pessimistic about the future:

I want to do my profession very much, but now I have two children, there is no-one I can leave them to, there is no-one I can trust, and I cannot do my profession, and this causes me to lose my ability in my profession. And in the

> future, I won't be able to work in this profession. Just when I say the children have saved themselves, this time, it will not be possible for me to do this profession. (P9, 41:56–42:00)

As with other experiences, a child-centered life and self-neglect are also shaped ecosystemically. Underneath this parenting attitude is the perception that they cannot get sufficient support at the microsystemic level. The relationship parents establish with their spouses, relatives, or neighbors, and the relationships these people have with each other cause parents to live child-centered lives both at the microsystemic and mesosystemic levels. A child-centered life can also cause parents to abandon their work life at a macro level.

The Relationships of Experiences with Each Other

In this study, the parents' experiences were related to each other. The parents used expressions concerning the fact that their psychological experiences develop in cause-and-effect relationships. For example, anxiety forms the basis of a child-centered life and self-neglect. Because the parent is concerned that their child will not be able to meet their own needs and cannot receive support, the parent leads a child-centered life (see P2, 27:24–28:40).

There is also mutual determinism between feeling guilt and living a child-centered life. It can be seen that an individual feels guilty when they take time for themselves due to anxiety and that they lead a child-centered life and tend to neglect themselves (see P2, 29:40–32:43). The participants' statements revealed that anxiety and avoidance are also related. Parents avoid establishing relationships with friends, neighbors, or relatives because of concerns that their children will be labeled or excluded (see P6, 55:55–56:23). The avoidance behavior of parents appears to be the product of a child-centered life, based on one point of view: "I'm done with visits, sightseeing, socialization. Never, there isn't. I mean, I'm only interested in my kid" (P6, 33:27–34:28).

A child-centered life is fed by anxiety, and it brings about burnout. In this context, the negative perspectives of others affect parents' anxiety and burnout:

> She took E. to the park. My E. is a bit active, she tripped, and my mother fell. She hit her head slightly. My brother sent me a message and said, "May God give you patience because you deal with this crazy child." I said, I'm done, I'm done. If my brother does this to me, what do the rest do? Yeah, they ask me, "Why do you work." And I say, "My pension will be left to the child, the child will not need anyone. He will not need even his own brother." (P6, 20:46–22:12)

Discussion

In line with the findings of other studies, the results of this study reveal that parents of children with disabilities experience anxiety (Bujnowska et al., 2019; Sheikh et al., 2018; Ülker Tümlü et al., 2017), avoidance (Atchison & Goodwin,

2019), guilt (Ziapour & Khosravi, 2020), and burnout (Anclair et al., 2018; Sánchez-Rodríguez, 2019) and often lead child-centered lives (Akdoğan, 2016; Chou et al., 2013; Rodrigues et al., 2019). In this respect, the results provide additional empirical data for the literature. The psychological experiences of parents are the products of family interactions, close and distant relationships, and social, cultural, and economic factors; moreover, all of their experiences are related to each other within the framework of the EST. Therefore, from the EST perspective, it is necessary to give these parents psychological help.

Many factors, such as insufficient social support (Cohen et al., 2015), social prejudices (Munyi, 2012), and the nature of children's disabilities (Akdoğan, 2016), can affect parents' child-centered lives. Therefore, parents experience many challenging stress factors resulting from having children with disabilities, and although this situation causes burnout (Sánchez-Rodríguez, 2019), it obliges a child-centered life. The participants' statements show that a child-centered lifestyle is based on feelings of anxiety and guilt and this situation results in burnout (see P2, 29:40–32:43). Likewise, anxiety brings about avoidance, and this leads the parent to limit their life with the child (see P6, 55:55–56:23). In this example, there is a close relationship between feeling anxiety and guilt and living a child-centered life to get rid of these feelings. Here, eliminating anxiety or guilt seems possible only by building a non-child-centered life. For example, including the other parent in the counseling process and ensuring that they help their spouse will prevent parents from feeling anxious or guilty about their children and save the parents from living child-centered lives.

When anxiety is considered from an EST perspective, the individual experience originates from the parents' fears that their children will be labeled or excluded. Therefore, the anxiety develops in a social context. In other words, the dynamics of the relationships in the parents' mesosystems feed their feelings of anxiety at the microsystemic level. The dynamics are also shaped by macrosystemic factors, which include higher-level structures such as a lack of knowledge of society, inadequate state policies, and cultural prejudices (see the Anxiety section). Similarly, avoidance is closely related to the parents' anxiety and social positions (Aktürk & Aylaz, 2017). Parents who experience anxiety that society will exclude their children keep themselves out of social life (see the Avoidance section).

Parents show avoidance out of fear that others will judge them (Atchison & Goodwin, 2019). In brief, parents use avoidance to shield themselves from social prejudices. Therefore, parents avoid communicating and interacting with others (Atchison & Goodwin, 2019), and others avoid interaction with them (Mazumder & Thompson-Hodgetts, 2019; Saccà et al., 2019) and exclude them (Gilson et al., 2018). Concrete social and cultural factors lead to anxiety, as supported by other studies (Falk et al., 2014; Marshall et al., 2018). To help parents cope with this anxiety, social awareness needs to be increased and the parents' individual coping mechanisms need to be strengthened.

Feelings of guilt also develop within an ecosystemic structure in a similar manner. Parents experience guilt because they hold themselves responsible for their children's disabilities (S'lungile et al., 2015). However, we found that parents, especially

those who tend to avoid social arenas, feel that they are inadequate, despite their excessive efforts related to their children, and this can lead to feelings of guilt (see the Guilt section). We argue that this experience is based on not receiving the necessary support from exosystemic structures. In fact, the participants' statements indicate that they experience difficulties in finding social support (see P2, 29:40–32:43). In this example, it is necessary to study the factors that influence this feeling rather than studying the feelings of guilt directly. For example, enabling parents to develop realistic expectations about their children (Akdoğan, 2016) and investigating social support resources (Cuzzocrea et al., 2016; Lu et al., 2015) seem to be much more functional solutions than studying the feelings of guilt directly.

Parents' burnout is facilitated by factors originating from the nature of the disability and higher structures, such as the attitudes of their families, society, professionals, cultures, and economies (see the Burnout section). In this sense, burnout also develops in a context appropriate for EST. The results of our study indicate that professional attitudes are extremely important in parental burnout (S'lungile et al., 2015; Zuckerman et al., 2015). Parents do not feel safe unless they receive support from professionals regarding their anxieties about their children's disabilities (Zuckerman et al., 2015). Therefore, social support resources at the microsystemic level and structures at the macrosystemic level are important in eliminating or preventing burnout. The results show that the sense of burnout needs to be addressed within the context in which it develops during the counseling process. The counseling process must be supported by informative consultancy services. This may include informing parents about their child's disability, increasing their awareness of their social and legal rights, and supporting them in developing their abilities to defend their rights.

A significant result of this study was the determination that parents of children with disabilities lead child-centered lives and often neglect themselves. Although a child-centered life seems to be the personal preference of the parent experience at the microsystemic level, the results suggest that this experience also develops within the framework of the whole ecosystemic structure. Mothers, in particular, perceive inadequate social support from their spouses at the microsystemic level and from society and the state at the macrosystemic level. This seems to be closely related to a continuation of traditional parenting roles. As has frequently been emphasized in the literature, childcare is particularly located at the center of the mothers' lives (Akdoğan, 2016; Chou et al., 2013; Rodrigues et al., 2019).

Considering that the majority of the participants in this study are mothers, their experiences are also related to the role of motherhood. Unlike the mothers involved in the study, the only participant father's statement supports this determination: "Turkish mothers are overprotective... They don't let the kid do anything on his own. I'm not like that, parents also need to breathe" (P8, 42:00–43:30). This indicates that counselors may want to allocate an important part of the counseling process to developing division of labor. To this end, family or couple counseling may be preferred to individual counseling. Given that the majority of the participants are mothers, it is possible that mainly mothers experience the psychological difficulties we studied. Therefore, one way to prevent mothers from leading child-centered lives is to involve fathers more in the counseling process. At this point, the necessity of including both parents in the counseling processes emerges. An individual

with disabilities affects the functioning of the whole family and their relationships with society (Akdoğan, 2016; Reichman et al., 2008; Tümlü & Akdoğan, 2019b), so the intervention must also involve the whole family. Indeed, the most important factor contributing to parents' satisfaction is adherence to family-centered principles (Jansen et al., 2013).

Another factor that may prevent parents from having a child-centered life is increasing sources of social support. Social support is a key factor in improving parents' quality of life (Rodrigues et al., 2019), and it positively affects an individual's perspective on their child with a disability (Cohen et al., 2015). One way to improve social support may be to increase the interaction and sharing between parents with similar experiences, such as by arranging focus group discussions or training programs to reduce parental stress originating from having a child with a disability (Ülker Tümlü et al., 2017). Such practices can also help parents exchange feelings with other individuals in similar situations and see each other as sources of social support.

Lastly, the findings of this study suggest that counselors need to consider not only the symptoms but also the underlying causes of these symptoms when providing counseling services to parents of children with disabilities. For example, the underlying cause of a parent's anxiety may be guilt. In this case, addressing the guilt will be much more effective than addressing anxiety. The results of this study reveal that the psychological experiences of parents must also be dealt with at a macro level. For example, if parents' avoidance behaviors are considered only on an individual basis, the intervention process may be limited to behavioral attempts that simply aim to increase the parent's willingness to enter social settings. Therefore, it is necessary to regulate not only parental behaviors, but also social structures.

Implications and Future Directions

Implications and Future Directions for Professional Counselors and Clinicians

This study reveals that the psychological experiences of parents of children with disabilities are affected both by each other and by the ecosystemic structures in which they develop. Therefore, a holistic perspective is necessary for the investigation or determination of parents' experiences and for interventions, such as counseling (Derguy et al., 2018). This study, thus, offers several implications for professional counselors currently working or intending to work with parents of children with disabilities. First, because the psychological experiences of parents of children with disabilities have unique social, cultural, educational and economic contexts, counselors need to conduct the counseling process within this context. They also need to be aware that the elimination of a psychological symptom may require improvement of the context that feeds it. In addition, counselors and clinicians need to consider that because disability is long-term and/or continuous, the problems surrounding it are also likely to be. This requires long-term planning and the delivery of counseling services for parents of children with disabilities. Furthermore, counselors need to take into account that psychological symptoms of mental health distress such as

anxiety, guilt, hopelessness, anger, social isolation, or helplessness may be associated with cultural, social, educational, or economic difficulties related to having a child with disability. In this sense, some experiences that, on the surface, seem to be the parent's preference may actually be associated with social factors. For example, avoidance may result from a fear of exclusion or a lack of social support in a child-centered life.

Second, based on the results of this study, we can say that counselors and clinicians need to focus on the main source of distress, not just the visible symptom, during the counseling process. A long-term counseling process may be useful for them to see that concrete reasons underlie psychological symptoms such as hopelessness and helplessness or that an emotional symptom is related to another psychological experience. For example, an individual's feeling of loneliness may be the outcome of social exclusion or self-blame tendencies that may be underlying a feeling of anger. Similarly, parents' avoidance and social limitations are closely associated with their fears of exclusion. Therefore, skills training to teach parents how to deal with social prejudices need to be part of the counseling process.

Lastly, the findings of this study show that the parents' psychological experiences take place in their own context; therefore, the solution is not just about the parent who has the problem. For this reason, counselors and clinicians need to use parents' social and psychological support resources as elements of the counseling process. For example, other family members and the spouse especially need to be included as much as possible in the individual counseling process. In addition to working on psychological experiences during the counseling process, informing parents is of critical importance. Thus, the results of this study show that parents' anxieties are fed by uncertainties. In this context, the counseling process also needs to include informative counseling services, including issues such as the children's disability, educational opportunities, social rights, and social resources.

Implications and Future Directions for Researchers and Counselor Educators

This study reveals that parents of children with disabilities have experiences such as anxiety, avoidance, guilt, burnout, and leading child-centered lives that negatively affect their quality of life. Moreover, the results show that these experiences are related both to each other and to the contexts in which they develop. We propose carrying out new studies with the same study pattern to gain more in-depth information about each psychological experience. In addition, we suggest that the themes we obtained from this study and the relations of these themes with each other be examined through quantitative research designs alone or mixed method designs. In addition, we recommend conducting similar studies in different cultures and making cross-cultural comparisons.

Considering the results of the study, it is necessary to create this awareness in counselor education and to support the content of education in this direction. Furthermore, in counselor education, it is necessary to approach the problems of parents of children with disabilities from a broader perspective, not just on an individual basis.

Limitations

The literature recommends holding more than one discussion session so that focus group interviews can be more effective (Merriam, 2009; Patton, 2014). However, in this study, we carried out only one session, as the participants had to take care of their children with disabilities and we could not provide care for them. In addition, focus groups typically comprise six to 10 people with similar backgrounds who participate in the interview for one to two hours (Patton, 2014). In this study, we conducted a 59-min focus group discussion with nine people. However, we think that the shortness of the interview is a limitation of the study.

Due to its qualitative nature, this study includes a small number of participants. Therefore, it is necessary to be cautious in generalizing the findings of this study (Creswell, 2014). In this context, we recommend that researchers make generalizations by taking into account the findings of similar studies. Another limitation of this study is that it is based on the results of a one-session focus group meeting due to current conditions. For this reason, there is a need for different studies that examine the themes of the psychological experiences of parents of children with disabilities. On the other hand, because we carried out this study in Turkey, the study has characteristics specific to Turkish culture and family and societal structures.

Declarations

Conflict of interest The authors declared that they have no conflict of interest

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