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Challenges and Needs of Iranian Parents While Seeking Help for their Adolescent with Anorexia Nervosa: An Interpretative Phenomenological Analysis

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Abstract

Introduction: Early diagnosis and treatment are crucial for the recovery of adolescents with Anorexia Nervosa (AN), and parental involvement plays a pivotal role in early intervention. Therefore, the present study aimed to explore Iranian parents' challenges before and after seeking out professional help for the treatment of their adolescent with AN and what they required during this process.
Method: Through purposeful sampling, 15 parents of adolescents with AN from several cities of Iran participated in this qualitative study. Data was gathered through online in-depth semi-structured interviews in Google Meet platform between July 2022 and October 2022, and was analyzed using Interpretative Phenomenological Analysis.
Results: Overall, seven group experiential themes emerged from the interviews. The challenges included four main themes: lack of mental health literacy, misdiagnosis or delays in eating disorders recognition, lack of eating disorder specialists and centers, and parental burnout. In addition, the needs consisted of three main themes: familiarity with eating disorders, parent management training, emotional and societal support.
Conclusion: Iranian healthcare providers can consider the challenges and the needs of parents identified in this study to provide the best practice for the diagnosis and treatment of pediatric AN with minimum potential deficits.

Keywords: Adolescent, Anorexia Nervosa, Parents, Qualitative Research

Introduction

Eating Disorders (EDs), particularly Anorexia Nervosa (AN), are among the psychiatric disorders that are complex, potentially life-threatening characterized by an excessive preoccupation with the weight and shape of the body that significantly impact physical and psychosocial functioning and quality of life [1, 2]. The lifetime prevalence rates of AN might be up to 4% among females and 0.3% among males [3]. The prevalence of eating disorders among children and adolescents in Iran based on DSM 5 was 0.89 [4]. In another study, Iranian girls (16.6%) were more likely to report extreme dietary restriction than boys (12.0%) while the occurrence of other ED behaviors did not differ by gender [5].

Anorexia Nervosa (AN), is among the psychiatric disorders that benefit considerably from earlier recognition, diagnosis, and treatment [1, 2]. More significantly, recovery from an AN becomes much less likely the longer the symptoms have persisted before seeking treatment [6]. Adolescents with AN are less likely to seek help than adults due to their age [7] and the ego-syntonic nature of eating disorders that they perceive AN as part of their true self rather than a disorder that requires treatment [8]. Accordingly, previous studies have demonstrated that parents play a pivotal role in initial recognition [9] and the treatment of pediatric eating disorders [10, 11].

Nevertheless, even if they come to recognize the ED symptoms, they often encounter barriers to seeking professional help in healthcare systems [12], as there are sometimes either insufficient ED screening and diagnostic measures or ineffective and potentially detrimental treatment offer made by professionals [13]. By accessing professional help, they are often able to avoid common interpersonal reactions that can adversely impact outcomes such as accommodating to the illness and reacting with high expressed emotion (overprotection and hostility) [14].

In many countries, Family-Based Treatment (FBT) is usually the first-line intervention offered to parents whose adolescent has an ED diagnosis [15], and there are specialized services and trained psychotherapists to provide help for such families. As a result, larger increases in parental self-efficacy and decreases in maternal criticism have been shown to predict greater weight gain[16] for adolescents in FBT and to enhance treatment outcomes for this population [17, 18]. Although in Iran, several studies have highlighted the effectiveness of particular treatments for adolescent ED [19, 20], there is still a lack of consensus on both time-efficient screening measures and therapeutic culturally-accepted interventions for this population. Moreover, In Iran, with no identified evidence-based reasons, there is a lack of official pediatric treatment centers to provide family interventions such as FBT or parenting support groups for adolescents with ED. Meanwhile, such families remain neglected and under-recognized with widespread confusion and misunderstanding in seeking out therapeutic resources and receiving potential psychological treatments. Furthermore, current general treatment services in Iran do not often provide distinctive care pathways for the majority of ED families and they are roughly left in a blind corner. Thereby, seeking help becomes a complicated challenge in the recovery journey of Iranian adolescents with ED, including AN [21].

The existing literature on the experiences of parents of adolescents with ED is extensive and focuses particularly on the obstacles and facilitators to interventions received in the pediatric eating disorder system [11]. Previous research has established that the chief obstacles to parents seeking help for their adolescent with ED seem to be comprised of both internal (normalization of early ED symptoms and attributing symptoms to normal adolescent development [22]; guilt, self-blame, and other negative emotions about the role that parents play in the occurrence of ED [11, 23]) and external aspects (being discouraged from healthcare professionals and offered interventions) [24].

Moreover, there is a relatively small body of literature concerned with the needs of parents, specifically parents of adolescents with AN, whereby the illness has a significant negative impact on both an emotional and physical level [25]. In one qualitative study, parents emphasized the need for an individualized and personalized approach to treatment that would help their adolescent find their own way of recovery [12]. There is also evidence that parents needed the doctors to take their concerns seriously and have timely follow-ups. Furthermore, they needed treatments that had a focus on psychological aspects of their adolescent's illness (i.e., anxiety and distress) because most treatments primarily addressed physical aspects, such as rigidly emphasizing weight gain [11].

Despite previous research findings into the lived experiences of parents of adolescents with ED and AN outside Iran, little is known about the Iranian parents' experiences while coping with their adolescent's problems related to AN and seeking out help and resources. AN is a serious and potentially life-threatening disorder associated with high mortality rates and with severe impacts on the well-being of adolescents' families [26, 27]. If left untreated, adolescents with AN are at an increased risk of developing major physical, psychological, and social difficulties and, in extreme cases, mortality [14]. Therefore, early recognition and intervention play crucial roles in adolescent AN treatment[28]. Nevertheless, regarding the significant role of parents in the recovery process, so far, Iranian parents have been among under-represented groups in the Iran-based ED research papers, and to date, their lived experiences in terms of challenges and needs have still not been empirically investigated.

Given the central role of parental involvement [29] and early intervention as the key indicators of adolescent AN symptoms recovery, the overall objective of the current qualitative research was to explore these parents' challenges and needs via in-depth semi-structured interviews. Accordingly, the current study's specific aims were to gain insight into: 1. Obstacles encountered by parents before they decide to seek professional help 2. Parents' major challenges in the process of diagnosis and treatment offered by professionals 3. Essential needs felt by parents in both diagnosis and treatment processes and to what extent these needs were met.

Method

The study population comprised parents of adolescents with AN who resided in one of the cities of Iran and were recruited via word of mouth, letters to clinicians, and online advertising through *Instagram*. Meanwhile, the sampling strategy was purposeful sampling.

The inclusion criteria were: 1. being a parent of an adolescent with AN aged between 11 and 18 and with the primary symptom of restriction and weight loss that had resulted in the child's Body Mass Index (BMI) between 14 and 18, at any time over the past year, 2. adolescents being assessed by a clinical psychologist and a psychiatrist, and being diagnosed with AN according to DSM-5 criteria [30], 3. parents being able to verbally communicate their experiences in an interview. Families in which the adolescent or parent had an intellectual disability were ineligible and excluded.

Initially, parents were asked to complete an online demographic survey and if they met the preliminary inclusion criteria (i.e., age, the presence of AN symptoms, BMI), they were provided with information about the study through a detailed written pdf file and a 30-minute video call to build a relationship and reassure the eligibility. Full disclosure of the purpose of the study, the potential benefits and risks associated with participation, and the confidential nature of information obtained in the study were explained to them. If they agreed to participate, were required to give a written and informed consent, and then the diagnostic interviews were scheduled. The diagnostic interviews included more detailed questions to check the AN symptoms, comorbidities as well as family history.

Finally, after the diagnostic stage, semi-structured in-depth online interviews between 50 to 60 minutes including open questions and open-worded prompts were conducted.

Google Meet platform was used in this study and interviews using a digital platform enabled the participants across the country to benefit from the convenience, comfort, and mobility as well as overcoming the possible challenges such as geographic barriers associated with participating in the research.

The interviews were conducted between July 2022 and October 2022, and data saturation was achieved by the fifteenth interview with almost no further new insights.

In this study, Interpretative Phenomenological Analysis (IPA) [31] was used to proceed with both the data collection and analysis stages [32]. IPA is a qualitative method concerned with the detailed exploration of people's lived experiences and how they make sense of their personal and social world [33]. Smith et al. [31, 33] have made several modifications to the IPA terminology in describing the data collection and analytic process. Hence, in this study, the same suggested steps and terminology based on the new conceptualization have been implemented. The interview guide was designed based on the instructions suggested by Smith and Nizza [31] and consisted of seven main questions. All the interviews were audio-recorded and a verbatim transcript of each interview was produced in the Word Software and included all semantic information.

The analysis of data also followed the processes and steps for IPA's idiographic approach [31, 33], whereby at the beginning, a single analysis of each transcript was performed by making exploratory notes (commenting on what was important) in their margin. In the second stage, deep engagement with the data was conducted by which experiential statements (a concise summary of what emerged as important in the notes) were formulated with a more analytic and interpretative approach. Following the third stage, the lists of experiential statements were printed out on a separate piece of paper and were repositioned on a board. Thereafter, the connections together with similarities were found and experiential statements were clustered. At the final stage, the related groupings were put together to form larger clusters and then the table of group experiential themes of all the transcripts was produced with each theme having two to three experiential subthemes leading to a cross-case analysis, common patterns, and high-level connectivity between cases.

In order to evaluate the credibility of the research findings, two strategies of peer review (an external check of the research process by two other psychologists) and member checking (taking data and interpretations back to the participants so that they could judge the accounts' accuracy) [34] were carried out.

Moreover, the dependability of the research was enhanced through intercoder agreement [34], by which two independent coders analyzed the transcript data.

Results

The eligible participants included 15 parents between 37 and 54 years (M age = 46.2 years, 13 mothers and 2 fathers) who had female adolescents of 11–18 years old (M age=15.6 years) diagnosed with anorexia nervosa. Only two parents were based in Tehran (13.3%) and the majority of them resided in other cities (86.6%). The duration of the disorder ranged from 7 to 32 months (M duration= 15 months) which are quite significant figures. A more detailed description of the participants' demographic information is given in Table 1.

Table 1. Demographic Information about Parents and their Adolescents

Parent	Age	Education	City	Adolescent's Age	BMI	Duration of disorder (month)
1. mother	46	BA degree	Esfahan	15	16.4	8
2. mother	44	BA degree	Hamedan	13	17.1	9
3. father	49	BA degree	Hamedan	14	17.0	9
4. mother	50	BA degree	Karaj	16	16.9	12
5. mother	43	BA degree	Tehran	15	16.0	10
6. mother	51	Diploma	Varamin	16	17.2	14
7. mother	48	BA degree	Tehran	18	15.4	9
8. mother	46	BA degree	Mashhad	18	16.1	18
9. father	54	PhD degree	Rasht	17	17.4	26
10. mother	37	MA degree	Esfahan	13	14.5	7
11. mother	50	Middle school	Kermanshah	17	15.2	32
12. mother	41	BA degree	Kermanshah	18	17.3	7
13. mother	38	MA degree	Arak	11	15.3	10
14. mother	48	BA degree	Karaj	17	17.0	28
15. mother	49	Diploma	Saari	16	16.2	30

The results presented in this research used the Smith and Nizza [20] IPA idiographic approach. Overall, the analysis yielded seven group experiential themes each with two or three subthemes (Table 2).

Each main theme and its subthemes are described below in turn and illustrated by participants' relevant quotations and indicated by their study ID number (e.g., P1: Parent1).

Table 2. Group Experiential Themes and Subthemes that Emerged from Parents' Isnterviews

Challenges	
Themes	**Subthemes**
Lack of mental health literacy	Lack of public awareness of eating disorders among families Normalization of early symptoms Lack of access to accurate native information resources
Misdiagnosis or delays in eating disorders recognition	Lack of knowledge of eating disorders among healthcare providers Parents switching from one doctor to another
Lack of eating disorder specialists and centers	Lack of appropriate local eating disorder services Professionals offer ineffective or misleading therapeutic advice
Parental burnout	Feelings of guilt, bafflement, helplessness and emotional exhaustion Parents find themselves in predicament with no clear road map
Needs	
Themes	**Subthemes**
Familiarity with eating disorders	Psychoeducation about anorexia and its causes Reliable therapeutic options
Parent management training	Quick refeeding tips Parent-child interaction skills
Emotional and societal support	Self-soothing strategies knowing other similar parents' experiences

Challenges:

- Lack of mental health literacy
  - Lack of public awareness of eating disorders among families

P2: "I hadn’t heard about such a disorder at all and I didn’t know that it might have been a mental problem."

  - Normalization of early symptoms

P8: "My husband and I thought our daughter had chosen a healthy diet and she had been exercising to just get fit and even sometimes my husband got happy and used to praise her that she didn’t eat junk food anymore. I also had this impression that picking on her body shape was just a normal transient adolescence-related sensitivity and nothing else. "

  - Lack of access to accurate native information resources

P1: "You cannot imagine how many times I searched on the internet to figure out what this disorder is like. The information on our Farsi websites was too ambiguous. Everyone had written about the devastating nature of this disorder. No one had provided solutions. They had all written about anorexia being incurable with no particular medication. I was totally overwhelmed and hopeless when reading such articles."

  - Misdiagnosis or delays in eating disorders recognition
  - Lack of knowledge of eating disorders among healthcare providers

P5: " Once, we went to a psychologist and she told us my daughter's symptoms were quite normal as an adolescent and she mentioned there had been a recent trend at schools whereby adolescents including my daughter fell in love with Korean actors and singers and tried to model themselves after them in terms of their body shape and behaviors, therefore, there was nothing serious to get worried about. That's why we quit the treatment for a while and the symptoms got worsen than before."

  - Parents switching from one doctor to another

P10: "We changed three to four doctors and three psychologists. None of them could help my daughter and they just made her more sensitive. Whenever I suggest another professional, my daughter doesn’t want to visit any psychotherapists at all".

- Lack of eating disorder specialists and centers
  - Lack of appropriate local eating disorder services

P3: " I do not know why there is no center for such important disorder here in our town. Finally, we decided to come to Tehran, and eventually a child and adolescent psychiatrist could diagnose my daughter's anorexia and he started the medication and referred us to a psychotherapist."

  - Professionals offer ineffective or misleading therapeutic advice

P9: "The psychologist who used to talk to my daughter was really inexperienced. The psychologist encouraged my daughter to go for a walk even though she had excessive exercises at that time or to drink low-fat milk as a healthy diet. They were all disastrous and for a while, we wanted to sue her for her wrong tips which had worsened my daughter's obsessions with food and eating."

- Parental burnout
  - Feelings of guilt, bafflement, helplessness, and emotional exhaustion

P4: " I feel I have no more power to take care of my child. Sometimes I blame myself for her condition and I feel extreme guilt. Meanwhile, I am really confused and feel out on a limb. There were days that my daughter was suffering from severe physical weakness and sudden faints. I could see how much hungry she was but she used to refuse to eat food. She was depressed and as a mother, I could not do anything for her. The medication, therapy, nothing really could help her..."

  - Parents find themselves in predicament with no clear road map

P15: "We have tried so many ways and solutions but none of them responded well. I am too depressed and confused at the moment and I do not know what else I can do for her."

Needs:

- Familiarity with eating disorders
  - Psychoeducation about anorexia and its causes

P13: "I'm very curious to know what are the common symptoms of this disorder and its causes. Sometimes I think genetics is important but I am not sure... I really wonder how and why it started. As a parent, I need this to be clarified. The psychiatrist prescribed the medications with no explanations... "

  - Reliable therapeutic options

P6: "I need to know is there really a definite and reliable cure for this disorder. As I told you, we have gone to several doctors and their advice was not the same. Everyone told us something different to do and some of them just worsened the situation."

- Parent management training
  - Quick refeeding tips

P11: "We need someone to offer us tips as soon as possible on how to persuade our daughter to eat normally just like in her past."

  - Parent-child interaction skills

P7: "I need someone to guide me on how to interact with my daughter so as not to upset her. I know I have so many mistakes in my parenting and I need to know how to avoid these pitfalls and finally resolve our conflicts."

- Emotional and societal support
  - Self-soothing strategies

P12: "Sometimes I am fed up and I find my anxiety difficult to manage. That's why I think I need to learn how to soothe my nerves."

  - knowing other similar parents' experiences

P14: "You know there were times I felt we were totally a different and weird family, coping with an illness that nobody had heard of or experienced before. As a parent, I needed to get understood and to see that I was not the only one. I believe no one better than similar parents can deeply understand us. I wish there was an opportunity such as a group to see and interact with other parents and hear their experiences, challenges and their suggestions. "

Discussion

The present study aimed to investigate common challenges and needs while Iranian parents begin help-seeking, particularly in a context in which there is a lack of specialized ED centers; thereby, making their voices heard. With respect to the parents' challenges, consistent with the literature [9, 22], it was found that one of the initial obstacles to getting help was lack of mental health literacy among families.

Mental health literacy is mainly associated with several components such as recognizing early symptoms of a disorder, and awareness of how to seek out help and treatment options [35]. It appeared that families had no idea of what an eating disorder is and this often led to the normalization of anorexia symptoms and delayed help-seeking. Although eating disorder symptoms among Iranian adolescents have been reported to be quite common, with girls and boys demonstrating regular extreme dietary restriction with 16.6% and 12.0% respectively [5], there have been few attempts to raise public health awareness of eating disorders among families specially through Farsi websites, guidelines, and educational videos.

Another important finding is that when parents eventually began to seek professional help, they struggled with healthcare providers' misdiagnosis, underdiagnosis, or delays in recognizing ED symptoms; similar to the challenge expressed by parents in other studies [11, 12]. This result may be explained by the fact that eating disorders are seen as rather uncommon relative to other physical and mental health problems [13]. However, this lack of familiarity and knowledge among professionals may pose serious threats to vulnerable patients, making parents switch from one doctor to another and lose faith in healthcare professionals. Thus, it seems that national attempts supported by Iran's Ministry of Health should be made to provide physicians, dieticians, and psychologists with professional training for carefully detecting ED and using appropriate screening measures when they encounter suspicious signs and symptoms as well as offering necessary referrals and therapeutic supports.

Additionally, one of the greatest challenges for parents was the lack of eating disorder specialists and centers in comparison with other existing medical and psychological national centers such as NGOs or specialized pediatric inpatient and outpatient services. This was particularly of prime importance for parents from rural regions with no or limited access to local professionals or services. This fact became more disappointing when parents came across professionals who offered misleading therapeutic options and led to symptoms' deterioration. However, research done in western countries shows that parents have highlighted the difficulty with ED services in terms of long waiting lists and timing of first connection to the ED specialist rather than the lack of them [12]. Therefore, in Iran, there is an urgent need to establish such centers and train ED psychotherapists to appropriately cater to ED families.

Moving on now to the last challenge, parental burnout seems to be the subsequent result of all those previous long-standing difficulties that parents had to endure, both in the diagnosis and treatment processes. Comparison of this finding with those of similar studies confirms that most parents described a range of negative emotions such as guilt, bafflement and helplessness in the recovery journey of their adolescent with AN [11, 12, 22]. It also appeared that these feelings became too complicated when parents did not know what to do next for the rest of the treatment process, being confused with no clear roadmap. These findings suggest that a step-by-step and unified guideline or parent-friendly flowcharts are required to clarify each feasible step contributing to their adolescent's recovery and relapse prevention.

Having discussed the main challenges of participants, it is necessary to discuss their significant needs as well. As was pointed out in the result section, parents needed to get familiar with the nature of AN and its treatment options. This corroborates the findings of a great deal of previous studies focusing on the importance of providing such families with appropriate psychoeducation [36].

Moreover, parents expressed the need for Parent Management Training (PMT), however, as soon as possible and preferably in an intensive form. Previous studies have broadly supported the central role of parents and family interventions in the treatment of adolescents with AN [37, 38]. Therefore, it is highly recommended that Iranian psychotherapists involve parents in the treatment process and provide them with evidence-based instructions, particularly about refeeding and parent-child interaction.

Emotional and societal support was another significant need reported by parents. This finding is in line with previous research [12] particularly when considering parents' burden in caring an adolescent with ED [39]. More importantly, parents demonstrated the need for knowing other similar parents' experiences, resulting in their feeling of getting deeply understood by parents in the same boat. This also mirrors those of previous studies that have examined the effectiveness of caregivers' support groups in empowering parents of adolescents with AN [9, 40].

Ultimately, there are several strengths and limitations to this study. This study is novel in Iran's context and one of the first investigations to focus specifically on the lived experiences of Iranian parents of adolescents with AN. Despite the lack of national ED centers to recruit targeted participants, researchers were successful at recruiting samples from across the country, both cities and rural communities, and the online platforms facilitated the interview process by overcoming geographical limitations. In the end, all participants were offered the opportunity to participate in an online parent coaching program based on the Schema Therapy approach. According to the limitations of this study, parents were caregivers of one type of eating disorder (i.e., anorexia nervosa) and the results may not be generalized to other eating disorders. The majority of participants were mothers, therefore, the opportunity to explore fathers' experiences was limited. Also, there may be some gender differences, since all the adolescents in this study were female and it is unclear whether the experiences of parents of male adolescents would be different from that of parents of female adolescents.

Conclusion

The current findings in this study draw our attention to the importance of considering the main challenges and needs of Iranian parents of adolescents with AN who are really underrepresented both in research and clinical settings. Iranian parents of adolescents with ED, particularly AN, are in desperate need of ED-specialized treatment centers and specialists trained in this area. It seems reasonable to assume that the availability of reliable information resources, raising awareness of clinical team members for better identifying ED symptoms, prompt referrals, as well as designing step-by-step guidelines and culturally appropriate treatment protocols and support parental groups can contribute to clarified help-seeking strategies and parents' empowerment. Further investigations are required to complement the current findings. In addition, studies on exploring parents of adolescents with other types of eating disorders are recommended to further ensure generalizability. Future research could also be undertaken to investigate the healthcare system-related gaps in supporting ED families and interviews could be conducted with healthcare providers to explore the challenges from their perspective.

Conflict of interest

The authors declare that they have no conflicts of interest.

Ethical Approval

This study was approved by the Research Ethics Committees of Shiraz University of Medical Sciences (IR.SUMS.REC.1401.212).

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