

Original Article



Lived Experiences of Parents of Children with Celiac Disease: A Descriptive Qualitative Study

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ABSTRACT

Purpose: Celiac disease (CD) is one of the most prevalent food-related illnesses in children, with a global prevalence of approximately 1.4%. CD can create an emotional burden, particularly on mothers, who are mainly responsible for managing challenges related to adherence to a gluten-free diet, high food costs, and food problems in schools and social areas. There is a gap in the literature, and parental experiences of raising children with CD should be explicitly examined. This qualitative study sought to provide insights into the experiences of parents raising a child with CD in the Turkish context.

Methods: This study used a descriptive qualitative research methodology and conducted individual semi-structured video-based dyadic interviews with 19 parents.

Results: Participants experienced both challenges and motivators through management of their children's CD. Analyses of the interview transcripts through the data uncovered three main themes focusing primarily on parental concerns: (1) parental challenges in child's disease management, (2) supportive care needs, and (3) parental expectations.

Conclusion: A multidisciplinary team should approach the child and family immediately after diagnosis, and facilities should support parents with continuing education and psychological, financial, and social assistance.

Keywords: Celiac disease; Gluten-free diet; Parents; Qualitative research; Life experiences

INTRODUCTION

Celiac disease (CD) is an inherited autoimmune condition that affects the small intestinal mucosa, resulting in incomplete gluten absorption [1]. CD is one of the most prevalent food-related illnesses in children, with a worldwide prevalence of approximately 1.4% [2-4]. According to the 2021 data from the Ministry of Health in Turkey, the incidence of CD varies between 0.3% and 1%, and the number of patients diagnosed is 138,230. Children in the 0-14 age group constituted 52,022 [5]. The traditional Turkish diet relies heavily on gluten-containing grains such as wheat. Bread is a staple in Turkish cuisine, and wheat-based products such as bulgur, a cracked wheat, are commonly used. Many traditional Turkish desserts and pastries are also made with gluten-containing doughs [6]. CD can only be managed by strictly adhering to a gluten-free diet (GFD) to prevent future complications and malignancies [1,7,8]. In addition to being complicated and expensive, a GFD can

be restricted in social circumstances, leading to difficulties in disease-management for parents and children, especially in the early stages [7-9]. Celiac can create an emotional burden, particularly on mothers, as they are mainly responsible for managing challenges regarding adherence to a GFD, high food costs, and food problems in school and social arenas [2,10]. There is a gap in the literature, and parental experiences of raising children with CD should be explicitly examined [11]. Little is known about the experiences of parents who have children with celiac [2,9,10,12]. Thus, this qualitative study sought insights into the experiences of parents raising a child with CD in the Turkish context. Sharing parents' experiences of daily problems, expressing their potential challenges, and becoming aware of possible support systems may increase their adaptation to the disease and improve their coping skills. This may also guide other parents experiencing similar challenges.

MATERIALS AND METHODS

Study design

This study adopted a descriptive qualitative research methodology focused on understanding the overall everyday lived experiences of individuals. It provides a broad view of what might be shared experiences among all the participants. This design offers comprehensive insights into particular phenomena and is widely used in areas where little is known about the subject under investigation [13-15]. Thus, this design was chosen to examine straightforward descriptions of the experiences and perceptions of parents of children with CD. Individual face-to-face interviews were conducted to describe the overall landscape by having parents describe their experience of raising a child with CD.

Setting and sample

The study was advertised on social media groups. Potential participants contacted the researchers via email or phone. Interviews were conducted between November 2022 and February 2023 and recorded using an Internet-based audiovisual conferencing platform (Zoom; Zoom Video Communications, Inc.). To be eligible for the study, one had to be a parent of a child who met the following criteria: (1) at least 2 years of age, but not more than 18 years old; (2) have a diagnosis of CD at least 6 months ago; and (3) be following a GFD.

Data collection

This study was approved by the Kastamonu University Institutional Review Board (IRB# 10/20) in October 2022. The procedures used in this study adhere to the tenets of the Declaration of Helsinki. After obtaining informed consent from eligible participants, the researchers initiated in-depth individual online interviews. The researchers formulated interview guidelines (**Supplementary 1**) through expert evaluation of the research purpose, population, and literature search. A semi-structured interview guide was used to conduct the interviews. The interviews were guided by nurse researchers who had received training in semi-structured interviews and used objective, non-leading language to maximize data integrity. The planned interview duration was 45–60 minutes [16,17]. The interviews lasted from 34 to 62 minutes, averaging 47 minutes each. Data saturation occurred when the narrative data started to repeat itself and future interviews stopped producing new materials helpful in answering the study topic [18,19]. At the end of the interview, each participant was compensated with a 100TL (approximately 4\$) grocery store gift card.

Data analysis

The interviews were transcribed verbatim using a voice-to-text converter. Two researchers listened to the original recordings and verified their transcriptions. Data management and analysis were performed using MAXQDA (VERBI Software, 2021). A thematic approach was used for data analysis. An initial coding framework was created by coding the first five interview transcripts, which were expanded as the study progressed. New codes were added as new themes emerged, and similar or overlapping categories were collapsed. The researchers then reduced the number of categories and concentrated on a small group of concepts and relationships. Following this, the main themes and subthemes were identified as both researchers met repeatedly during the analytical period to evaluate, debate, and check their understanding of the developing categories. Any disagreements over interpretation were settled by consensus, and the specifics of the results are described in the present work. Two researchers and one external qualitative research expert participated in collaborative discussions on the themes and thematic descriptions. This approach improved the methodological rigor regarding credibility and helped reexamine, reinterpret, and reformulate the thematic narrative of the occurrences [20,21].

RESULTS

The study included 19 parents of children with CD. The majority of the sample can be characterized as educated, middle-aged, married mothers of two children. Parents mostly live in urban areas, have a nuclear family structure, and do not experience difficulties in accessing healthcare. Additionally, only two parents received training about CD after their child was diagnosed. The majority reported that they experienced problems accessing gluten-free foods and following a GFD. **Table 1** provides detailed information about the demographic characteristics of parents and their children.

Analyses of the interview transcripts showed three themes that describe the parents' experiences: (1) parental challenges in the child's disease management, (2) supportive care needs, and (3) parental expectations. The ten subthemes within these three themes are summarized in **Fig. 1**. The themes and subthemes are further characterized below.

Parental challenges in child's disease management

Parents believed that they had difficulties managing the child's disease, especially in the early stages of diagnosis. One mother believed that, although it becomes smoother with time, their "children have always been felt incomplete..." (P3). Under this theme, three subthemes emerged from the parental perspective: familial, social, and institutional challenges (**Fig. 1**).

Table 1. Demographics of parents (n=19) and their children with celiac disease

Features	Values
Age (yr)	38±2.3 (26–55)
Sex	
Female	16 (84)
Male	3 (16)
Marital status	
Married	19 (100)
Other	0 (0)

(continued to the next page)

Table 1. (Continued) Demographics of parents (n=19) and their children with celiac disease

Features	Values
Occupation	
Civil servant	3 (16)
Self-employment	3 (16)
Housewife	12 (63)
Other	1 (5)
Educational status	
Bachelor's degree and above	9 (48)
High school degree	8 (42)
Middle school degree	2 (10)
Economic status of the family	
Income less than expenses	3 (16)
Income equals expenses	4 (74)
Income more than expenses	2 (10)
Social security	
Yes	15 (79)
No	4 (21)
Residence	
Urban	15 (79)
Rural	4 (21)
Family type	
Extended	3 (16)
Nuclear	16 (84)
Number of children	
1	4 (21)
2	11 (58)
3	4 (21)
Other family members diagnosed with celiac	
Yes	6 (32)
No	13 (68)
Presence of non-parental caregiver in the home	
Yes	3 (16)
No	16 (84)
Child ever hospitalized for celiac exacerbation?	
Yes	6 (32)
No	13 (68)
Difficulty in accessing health care	
Yes	7 (37)
No	12 (63)
Difficulty in accessing gluten-free foods	
Yes	6 (32)
Partially	12 (63)
No	1 (5)
Difficulty in following a gluten-free diet	
Yes	4 (21)
Partially	8 (42)
No	7 (37)
Receiving any training about illness/nutrition after diagnosis	
Yes	2 (10)
No	17 (90)
Child age (yr)	10±4.14 (4–18)
Time since diagnosis (yr)	4±2.65 (1–10)
Sex of the child	
Girl	9 (47)
Boy	10 (53)
Child is attending school?	
Yes	17 (90)
No	2 (10)

Values are presented as mean±standard deviation (minimum–maximum) or number (%).

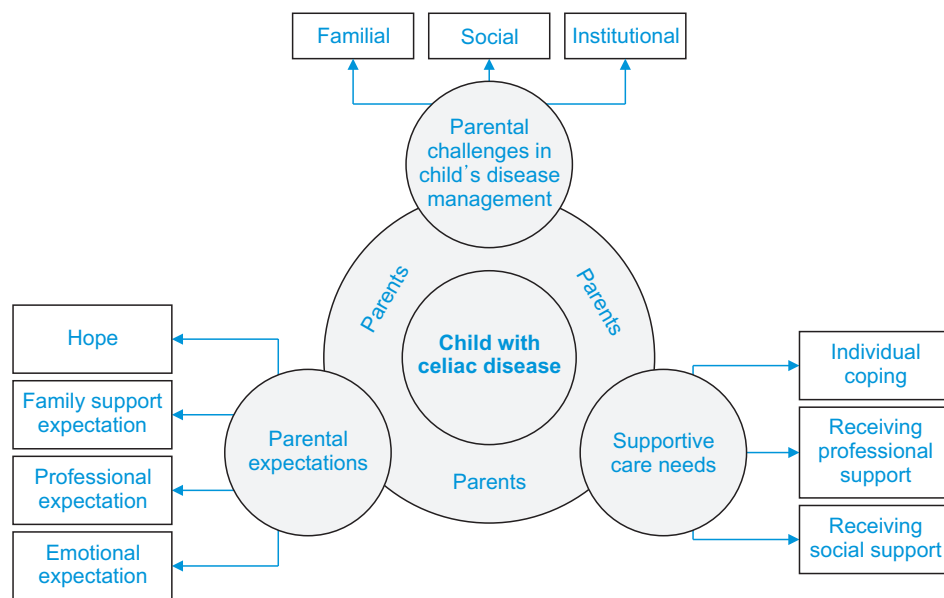


Fig. 1. Effective factors of celiac disease management.

Immediately after the diagnosis, many parents began to experience familial difficulties, such as preparing meals for multiple family members and providing justice for siblings who were and were not diagnosed with celiac. One mother explained her predicament in preparing gluten-free food: “My first experience was bread...I struggled a lot, but made an effort and put it in the oven with great excitement. Something mind-blowing came out, like concrete. When I saw it, I cried...” (P15). It was overwhelming for parents to take precautions to avoid cross-contamination by separately cooking and eating utensils for gluten-free foods, and ensuring thorough cleaning of all surfaces. As one mother said: “...a complete change of the kitchen, a change in the way you eat...is a very tiring process, materially and spiritually” (P8). Another mother talked about how planning meals, grocery shopping for gluten-free ingredients, and preparing homemade alternatives are time and energy-consuming: “(cooking) takes 4–5 hours of my day...” (P10). Parents also mentioned feeling emotionally depleted during their efforts to ensure their children’s health and wellbeing. Most inquire about being enough or not: “The (role of the) mother is vital, how can I raise this child, I involuntarily question myself, will I be enough?” (P4). Parents may often be concerned and afraid about their child’s future, such as university years, marriage, having a child with CD, or the diagnosis of another disease, such as diabetes. One mother said: “Can he live without me?...I always have these questions in my mind” (P9). Balancing parental responsibilities among siblings may also be challenging. A mother said: “I feel unfair to him (without celiac) as he is only eight and wants to eat outside. Sometimes, we neglect him while thinking about other (with celiac). His father took him to eat outside; I don’t know if we are unfair to the other (with celiac) while feeding him (without celiac) secretly” (P14).

Parents experience social challenges in engagement, with food being the central aspect. They felt apprehensive about accepting invitations to dine at others’ houses and restaurants. In addition to concerns about accidental gluten exposure and difficulties in explaining their dietary needs to others, gluten-free options are usually scarce. One father said: “As a family, we loved to eat out, but now he can’t eat outside because limited restaurants offer gluten-free (dishes). I still ache when I pass by a patisserie” (P2). Society’s pressure is another complaint

of a father: “I can’t allow my son for any of the activities. People say ‘there is nothing wrong with trying once, nothing happens from a tiny piece?’ I can’t trust (society)” (P3). CD was often misunderstood or unrecognized by the general public. This lack of understanding has led to misconceptions regarding the severity and impact of the condition. Parents found themselves constantly explaining the nature of CD to friends, family members and others, which “exhausts the most” for them. A lack of support and understanding from society may lead to burnout, as one mother complained: “When we go to my friend’s house, they think we did not like their food and we are rude (she is crying)” (P1).

Institutional challenges undermine parental management of a child’s CD. The lack of resources left parents feeling overwhelmed and unsure about how to navigate the life of a child with celiac. As one mother said: “I looked for someone to just ask what should I buy for my child (to eat)” (P8). Gluten-free options are limited in variety and availability compared to the wide range of gluten-containing products. Significantly, parents living in rural or remote areas experienced more difficulty in finding gluten-free options. One father said: “Sometimes I have to drive forty kilometers to find gluten-free products” (P3). Those products are often imported and priced higher than their gluten-containing counterparts. The increased cost strains the family’s budget, and this financial burden makes it challenging to maintain a balanced and affordable diet. While a mother explained: “Financially, the price of groceries increased five times” (P8), a father said: “We don’t follow our diet, just think about his (diet)” (P11). In addition, parents identified inconsistencies in labelling requirements that created confusion when identifying safe gluten-free options. One father said: “There are too many loopholes in our food regulations...” (P19).

Children with CD have limited school and peer interactions, and boarding schools do not provide gluten-free accommodation. One mother explained their disappointment: “He was delighted when going to kindergarten, but (after diagnosis) they withdrew him. He spent all day crying; we were sad” (P12). Children with CD are also bullied at school, as a mother explained her son’s situation: “...he was physically troubled by his friends” (P9). Thus, parents become “advocates” for their children. A mother struggled with her children’s guardians at school: “They thought celiac was a transmitted disease and did not allow their children to play with mine” (P5). Contrastingly, some parents “feel thankful” for the support from their children’s teachers.

Supportive care needs

Parents of children diagnosed with CD may experience various emotional challenges as they navigate the condition. Sometimes, parents felt guilty for passing on their genetic predisposition to their child or for not recognizing the symptoms earlier. One mother blamed herself for her child’s dietary restrictions: “I was feeding my daughter a lot of wheat germ...I wonder if it was because of me” (P16). Children, primarily teenagers, sometimes blame parents: “...my daughter blames me, thinks I’m responsible for her disease” (P11). Actively seeking appropriate support fulfills parents’ lives. Three subthemes emerged: individual coping, receiving social support, and receiving professional support (**Fig. 1**).

Individual coping is vital for parents of children with CD as they can empower their children in this way. While some parents used spiritual coping strategies: “I think belief in God is very precious...whatever Allah (God) has given me is for the best” (P5). Others compared their situation with worse chronic diseases: “There are worse diseases; like spinal muscular atrophy patients, there are children who are disabled. We see these things; at least we console

ourselves. It (CD) can be solved with diet” (P11). All parents found a way to ensure continuity of self-motivation: “There is no other explanation for this power, this divine power comes completely from motherhood” (P8).

Receiving social support is one way to gain knowledge, and parents can foster a supportive environment for both their children and themselves. Connecting with parents through community support provides valuable social support and a sense of understanding and solidarity. A mother said: “I become a member of the association. They announce brand lists (gluten-free), advise gluten-free scanner apps. They support us.” (P1). Among all parents, social media played a vital role in providing self-effort: “I completed my learning process from social media” (P15).

Receiving professional support helped parents to successfully manage their child’s disease. Half of our participants received professional psychological support after their children were diagnosed with celiac. “At that time, my psychology was seriously disturbed, and I started to beat up my child. I realized it breaks our parent-child relationship, and I sought psychological support” (P7) others explained their needs “I needed psychological support, but was not able to receive” (P1). Although not everybody receives professional support from healthcare providers, one “lucky” parent said: “I have never met such a doctor in my life...he talks for hours to comfort us, there was no scolding” (P13).

Parental expectations

Parents believed they need time and support to raise independent children. “My all expectation from my son to become independent. Now he studies in Germany alone. He goes on vacations, camping without me... All those have happened with professional support” (P5). Parents reported a lack of support from family members and healthcare providers. Four subthemes explain this theme: family support expectation, professional expectation, emotional expectation, and hope (**Fig. 1**). Parents had family support expectation: “When we go to my friend’s house, and he sees something gluten-free prepared for him, he feels that he is valued, which is what we need” (P4). Another mother said: “I take him to my hometown to visit my family. I haven’t seen special favors shown to my child. So that makes me sad. We sit and eat. He is just looking. They are insensitive toward my child” (P1). Parents also have professional expectations as most of them have similar desires from healthcare providers. When a child is diagnosed with celiac, parents want to be approached and supported as a family. Occasionally, parents were expected to be seen by healthcare providers. One father said: “I’ve waited so long, our doctor, directly starts questioning my child. He never asks how are you doing as a parent?” (P11). In addition, parents complained about how the doctors explained the diagnosis to their children. They requested a diagnosis in consultation with a child psychologist. A mother explained their experience: “You have celiac! Start your diet today! How should I explain this to my 5-year-old child now? Okay, I’m a mom, but not a psychologist” (P8). Another father said: “In the first diagnosis, it was like falling off a cliff. The doctors did not provide enough information, just gave an old, fixed list. They must be more welcoming. This a life-changing process” (P19). A mother also complained about the doctor’s approach: “Doctor told us in such a traumatic way, I tried to clear those traumas in my child first” (P5). Most parents struggled with following a diet and required consultation from a specialized dietician: “A dietician should give the treatment, but we didn’t see a dietician” (P4).

Parents sometimes had emotional expectations from others and wanted them to try to understand their lives. A mother explained: “When people learn about my child, they say, ‘Oh, what a pity.’ At that moment, I want to tear that person apart. I’ve been trying to calm my child down for years... they don’t understand as they don’t empathy” (P13). None of the participants gave up hope. They closely follow drug and vaccine studies and live with the hope of a cure being developed soon: “When I read news that the medicine would be released, I cried and prayed until the morning. My biggest hope is the vaccine will come out; I will set the table and feed my son with everything” (P1). Another mother said, “My only hope is a vaccine or medicine for celiac. Ten years ago, we could not find gluten-free flour, but now we can, even though it is expensive. It will be even better in next ten years. Maybe I’m selfish, but as the number of people with CD increases, I say Hooray! Another has been added; we are not alone” (P15).

DISCUSSION

This descriptive qualitative study examined the daily experiences of parents raising children with CD. Three main themes were identified from the data: parental challenges in child’s disease management, supportive care needs, and parental expectations. We hope that our results will increase the awareness of society and healthcare providers and guide parents of children with CD.

Parental challenges in child’s disease management

Living with a lifelong chronic disease can be a traumatic and painful experience for the entire family [22]. This study examined parents’ experiences of raising children with CD in the Turkish context. Previous studies [17,23] have reported that parents of children with CD experience significant changes and difficulties in social activities such as family gatherings, celebrations, school picnics, and eating out. Consistent with the literature, we found that children often felt different because of their need to eat a GFD [24]. The parents’ expressions revealed the profound impact of this isolation on family processes. Thus, CD is a multifaceted disease that negatively affects children, their family systems, and social life [24].

Russo et al. [2] found that a child’s CD diagnosis and accompanying GFD management affects the entire family. Our study showed that the daily lives of parents caring for a child with CD were changing, and that this was happening through struggle, effort, and sacrifice. In other studies, parents reported feelings of alienation, embarrassment, and fear of eating something that might contain gluten, whereas children with CD described this feeling as “distress” [17,25,26]. Similarly, in our study, some parents reported that their children were afraid to eat at the same table as others and were embarrassed to tell others that they had a CD.

In a study from Turkey, the authors found that mothers of patients with CD were more anxious and cautious than fathers. In that study, parents stated that doctors do not spend enough time with patients, which causes stress in coping with the disease, and that they also have difficulty finding gluten-free food in markets [27]. Our results supported these findings as our participants reported similar expectations from healthcare providers and experienced difficulties in accessing gluten-free products. In another study, mothers who felt guilty about their child’s disease experienced social isolation, pessimism, hopelessness, and low expectations [28]. Consistent with our findings, some mothers blamed themselves for their child’s illnesses. In addition, the participating parents were concerned about how the disease would affect their child’s future job, marriage, and social status [28,29].

Similar to Erickson et al. [11], some of the issues that parents in our study struggled with were the impact of the disease on family life and daily management of the disease, including obtaining gluten-free food and changes in the kitchen. Additionally, experiencing financial issues in accessing complete concordance with a GFD was identical to that in the study [11]. In contrast to the United Kingdom (UK) study [11], all parents in our study talked about the difficulties in the availability of gluten-free products and the additional financial burdens associated with a GFD, which is supported by another study from Turkey [27]. In particular, they suffered because they had to go to distant stores or order online and wait for days. A study from the UK found that clear labelling and resources that make gluten-free products visible, such as the UK Coeliac Food and Drink Directory, were of great help to people with CD [12]. Although the Turkish Celiac Association has continued to work, the lack of clear regulations for CD, difficulties with labelling, and inconsistency in gluten-free packaged products were significant issues that most participants complained about and needed to be resolved quickly.

Supportive care needs

Coping can be seen as a conscious and active effort to regulate emotions, actions, thoughts, and the environment in response to stress [3]. One study found that participants brought their gluten-free foods to new places to reduce stress related to consuming gluten-free foods outdoors, which was defined as a coping technique for them [3]. In contrast, the most powerful method of coping with CD in our study was to seek refuge in spirituality and be grateful for one's condition with the thought of worse diseases. In this regard, many mothers perceived CD as easier to cope with than diabetes. In one study, a group of mothers viewed their child's condition as a divine test that had to be accepted better, in the hope that God would heal them [30]. Similar to our study, almost all participants stated that the CD was a test from God and made it easier for them to accept.

Our study showed that social media groups provide opportunities and convenience to parents. It was also found that common sharing relieved parents from preparing gluten-free recipes, obtaining them from markets, or reading content. Professional support for parents of children with CD is essential to help them navigate the challenges and complexities of managing their condition effectively. Consistent with the literature, the parents in our study stated that professional support should be increased to manage the process well, prevent burnout, adapt to a GFD faster, and feel better mentally. Therefore, there is an urgent need for specialized dietitians, psychologists, and nurses. Moreover, the family guidelines should be updated. Social media and friends may provide insufficient or misleading disease information. Health professionals should identify parents' educational and emotional needs and provide necessary guidance [30].

Parental expectations

Parents of children with CD reported the need for professional education on the disease [26]. The need for active support from health professionals was greatest immediately after diagnosis. Although stress and anxiety decrease one year after diagnosis, the disease and adaptation process to a GFD continue to affect the lives of parents and children [25]. According to one study, shared strategies for managing a GFD include reading product ingredients, labelling gluten-free flours, and having ready-to-eat snacks available [31]. All parents in our study stated that they showed outstanding self-sacrifice by constantly researching, visiting different markets, and making gluten-free snacks for their children's social events. However, they got tired and needed professional support from the beginning of diagnosis.

As with the work in the UK [11], food preparation was associated with traditional maternal roles, and domestic burden and food-related anxiety were higher in women caring for children with CD than in men in the Turkish context. In line with the literature [26], our findings showed that mothers were at the forefront of caring for children, preparing gluten-free food, and managing the disease process. At the same time, fathers financially supported the provision of gluten-free products. This shows that traditional gender roles have not changed, even in disease cases. Finally, parents had enormous expectations for ministries and municipalities to carry out social projects (such as gluten-free bazaars, events, and workshops), provide them with more financial support, and raise awareness among the general public. Similar to a previous study [31], while there were more opportunities for a GFD in urban areas, people in rural areas complained about the lack of such options. This study has some limitations. The demographics of the parents were relatively similar; therefore, they may not be representative of the entire population. In addition, the age range (4–18 years old) of the children was wide. As the age of a child increases, it may become more difficult to follow the GFD. Children's developmental stages, such as adolescence, may lead to additional parenting difficulties. Therefore, future studies should limit the age range and repeat the present study.

Conclusion

This study provides data on parents' experiences of caring for children with CD and helps to understand the psychological, emotional, economic, and social alterations in parents' lives. Parents' difficulties led to feelings of confusion, instability, social tension, and changing family dynamics since they learned about their child's diagnosis. The study emphasized that once parents took the central role of feeding the child and limited the child's responsibility in disease management, they changed routines, sacrificed, and spent endless efforts. The results also contribute to the identification of gaps in the support and care of parents raising children with CD. Health professionals must be sensitive to the psychological and social challenges faced by children living with CD and their parents over time. Institutions should provide education, interventions, and workshops to increase awareness in society.

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SUPPLEMENTARY MATERIAL

Supplementary 1

Semi-structured interview questions

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