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RESEARCH ARTICLE

PARENTAL EXPERIENCE OF CHILDREN WITH SICKLE CELL DISEASE: A QUALITATIVE STUDY

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Abstract

Background: Sickle Cell Disease (SCD) is a painful disease with long-term transfusion therapy, hydration, hydroxyurea therapy, and primary care parents are severely affected psychologically, socially, cognitively, and economically. This study evaluates the parental Perspectives on the Challenges of Pediatric Sickle Cell Disease.

Method and Material: The qualitative phenomenological method was used to determine the parents' experiences. The study sample included 12 parents who met the inclusion criteria. Individual interviews, an introductory information form and a semi-structured interview form were used for data collection. The data were analyzed with Colaizzi's seven-step method.

Results: The mean age of the parents was 44.83±6.08 (min. 34; max. 54); the children were 14.58±3.20 (min. 8; max. 18). Four themes of the interviews were established: psychosocial distress, family relationship, managing pain, and financial burden. Parents stated that their child experienced feelings such as stress, unhappiness, fear of death, demonstrated reluctance to attend check-ups, maternal attachment and constraint. Moreover, parents said that their other children were also affected emotionally exchibiting jealousy and loneliness. For pain management in children, parents reported using non-pharmacological strategies such as encouraging balloon blowing, providing massages, applying hot water bottles to affected areas, and assisting their children with hot showers. Parents also experience economic burdens, primarily due to transportation costs for hospital visits and the increased nutritional needs of both their children and themselves.

Conclusions: The results of the study revealed that the parents who have a child with SCD experience several psychological problems, social isolation, difficulty in pain management and large financial cost to health services. Both the healthcare system and medical professionals should be aware of the challenges faced by parents of children with sickle cell disease (SCD) and provide them with appropriate support. It is recommended that interventions be planned and implemented in a way that maximizes the quality of life of children and their families.

Keywords: Sickle cell disease, qualitative study, parents, experience.

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INTRODUCTION

Sickle cell disease (SCD) is an autosomal recessive blood disorder that causes severe anaemia and crises.[1] Sickle haemoglobin (HbS), which is partially or completely deoxygenated, replaces normal adult haemoglobin (HbA). It is the most common haemoglobinopathy in the world. However, it is more common in the Mediterranean, Caribbean and African region. In our country, it has been observed that the incidence of SCD is higher in some regions. The region where the research was conducted (Çukorova region) is the one where SCD is the most common.[2,3] Screening in our country revealed that Hg SS is present in 15.3% of individuals. A study conducted in the Tarsus region revealed that Hg SS was present in 0.43% of individuals, carriage was observed in 8.61%, and the Hg S gene frequency was 9.07%.[4] In SCD, clinical signs/findings are seen depending on the location of the molecular disorder. The most acute symptoms of the disease occur during periods of exacerbation, called crises. These crises can occur in any part of the body. They can be of short or long duration.[1] Signs and symptoms seen during a crisis include fever, abdominal pain, severe pain (called painful crisis), weakness, paleness, shortness of breath, vision problems or blindness (if the retina is not adequately supplied with red blood cells), yellowing of the skin and eyes, delayed growth and puberty in children, and infections. Other clinical findings include pallor, weakness, fatigue, jaundice, enlarged liver and spleen (not seen in the first five years and in adults due to auto splenectomy), systolic heart murmur, cardiomegaly, tissue hypoxia, maxillary hypertrophy, short stature, delayed growth, enuresis, and impaired or delayed sexual development.[4] In addition to these, psychological problems such as sleep disorders, fatigue, anxiety, depression and suicide attempts have also been reported. Bone marrow transplantation can be curative in SCD, but it is rarely used due to a lack of suitable bone marrow donors and complications.[5] Therefore, treatment is usually symptomatic and preventive. This includes long-term transfusion therapy, hydration, hydroxyurea therapy and pain management.[6] Primary care parents are severely affected physically, socially, cognitively and financially throughout the disease and treatment process.[7-12]

The literature reports that parents of chronically ill children experience significantly more stress than parents of healthy children.[13-15] A limited number of studies on this topic have shown that caring for a child with SCD is both stressful and challenging for parents.[16,17] Parents of children with SCD have been reported to have negative effects on their mental health and work performance, employability, and socio-economic status.[8,9,12-18] In addition, the disease has been shown[19,20] to hurt family dynamics, including difficulties in maintaining family relationships and meeting the needs of other family members. Therefore, the parents accompanying the child receiving SCD treatment need supportive care to carry out the treatment and care of their children. The treatment and care process for the child may be disrupted if the supportive care needs of their parents are not identified.[21-24]

The lived experiences of parents caring for children with Sickle Cell Disease in Turkey need to be better understood. The use of the 'in-depth interview' method, one of the qualitative research methods in the research, will be an opportunity for in-depth assessment of parents' feelings, thoughts and perceptions about their experiences. This research was warranted due to the high prevalence of sickle cell disease (SCD) in the region where the study was conducted, which represents the most affected area in the country. To date, no study in our country has explored the experiences of parents of children diagnosed with sickle cell disease (SCD) using a qualitative research approach. The aim of this study was to examine and understand parental experiences related to the disease process and its impact on family life.

METHODOLOGY

Research Design

A qualitative phenomenological approach was employed to explore the lived experiences of parents of children with sickle cell disease (SCD). This methodology enables a deep understanding of individuals' subjective experiences and meanings.[25] Data analysis was conducted using Colaizzi's seven-step method, which ensures a systematic and rigorous examination of the participants' narratives. This scientific approach ensures the authenticity and rigorous evaluation of data according to scientific standards.[26]

Sample

This study was carried out from November 2022 to December 2023 at a hospital located in Mersin province, Turkey. The study population consisted of 35 parents of children diagnosed with sickle cell disease (SCD). Interviews were conducted with 12 parents, at which point data saturation was achieved—indicating that no new themes or information were emerging from the subsequent interviews (Morse, 2015). The inclusion criteria were: (1) volunteering to participate in the study, (2) being over 18 years old, (3) having no communication problems (visual, auditory or mental), (4) having a child who has been receiving care in Sickle cell disease, and (5) speaking Turkish.

Data Collection Tool

The introductory information form: The form created by the researchers consists of questions about age, gender, children, education, employment status, and the economic status of the family.

The semi-structured interview form: This form was prepared after a review of the literature[8,9,12] and expert opinions about its suitability were obtained from ten experts. Corrections were made according to their suggestions, and then a pilot study was carried out. Three parents were chosen from the study population for the pilot study, and they were excluded from the study sample. The interviews were carried out and the suitability and comprehensibility of the questions were evaluated with help of experts in the field.

Data Collection Procedure

Written informed consent was obtained from the parents before the interviews, explaining the purpose of the study, usefulness, the time for the interview and that an audio recording device would be used. The individual interviews with the parents who agreed to participate in the study took place in the patient meeting room of the unit to ensure a quiet and comfortable environment. The parents filled out the introductory information form prior to the interviews. Then, the interviews were carried out using the semi-structured interview form. The interviews were recorded with a voice recorder. The interviews were concluded when data saturation was achieved (when the participants' statements started to resemble each other). Each interview lasted 45-60 minutes. All interviews were conducted by the same researcher.

Data Analysis

The sociodemographic data were analyzed using SPPS 22.0 software. They are presented as numbers and percentages. Colaizzi's seven-step method was used for analyzing the data. In the first step, audio-recordings were saved. Each written transcript was read multiple times by both authors. In the second step, important statements about the experiences of the parents were determined from among transcripts. In the third step, significant expressions were formulated. In the fourth step, the formulated meanings reflecting experiences of the parents were grouped into clusters of three common themes. In the fifth step, the basic structure was defined for the experiences of parents. In the final step, the findings were confirmed by contacting the participants again.[26] MAXQDA was used for coding and creating themes.

Ethical Considerations

Ethical approval was obtained from the Scientific Research and Publication Ethics Committee of a university with the decision number 2022/18. The names of the participants were kept confidential, and the nurses were identified with codes (P1, P2, P3...).

RESULTS

The demographic characteristics of the parents and children

The descriptive characteristics of the parents are shown in Table 1 and children are shown in Table 2. The mean age of the parents was 44.83±6.08 (min. 34; max. 54) and for the children 14.58±3.20 (min. 8; max. 18).

Content Analysis

The four themes that were obtained from the study were psychosocial distress, family relationship, managing pain, and financial burden.

Psychosocial distress

This theme consists of the sub-themes and codes of family (stress, fear, restlessness, sadness, unhappiness, uneasiness, depression, future anxiety, uncertainty, fear of loss, despair, not wanting to think, acceptance, regret, guilt, burnout and loneliness), child (stress, unhappiness, fear of death, surrender, maternal attachment, limitation) and sibling (jealousy and loneliness) (Figure 1). The code-subcode hierarchical map of parents' experiences regarding the emotional effects of the disease is shown in Figure 1.

Many of the parents stated that their children experienced stress, fear, restlessness, sadness, unhappiness and uneasiness during the flare-ups of the illness. "It will be a bit emotional now, but if something happens to me, there is no one to take care of me because his siblings are also male, so we are a little worried about that, of course, it is a little different when it is a son." (P12) Another parent said, "It's sad because you can't do anything, you can't do anything, you just try to make him live in better conditions." (P10) Another parent said, "My worries did not end as a mother, you know, there is a mother who is constantly anxious with questions about clothing seasonal changes, keeping her away from strenuous work, drinking water, did she take her medication. After all, I have been trying to do whatever I can to prevent her from suffering from pain for years." (P2)

One of the parents stated that their child had difficulties during the treatment and care process and suffered from depression. "Coming and going made us exhausted. My wife became a migraine patient due to these problems, she cannot sleep day and night due to headaches, she is depressed now, it is not easy." (P3)

Almost all of the parents stated that their children experienced anxiety about the future and uncertainty due to the illness process. "There is a lot of anxiety about what will happen when we are hospitalised, this feeling is always present..." (P7) In addition, some parents stated that they were afraid of losing their children and therefore felt helpless. "You can't do anything, you just try to make him live in better conditions." (P10)

Two parents stated that they did not want to think about the disease at all. "Sometimes I don't even want to think about anything, I mean, when we think about it, we get stressed and our psychology deteriorates, so we don't think about it at all." (P12)

The majority of the parents stated that they experienced burnout due to the treatment and care process of the disease. "...you cannot be happy while he/she is suffering, you cannot be happy, it is an exhausting process, sometimes you feel exhausted...." (P10) Another parent said, "As a parent, I mean, the guilt that passes through us, I mean, God knows first, but this disease is something that can happen to anyone, but you can be diagnosed earlier and know what the child has, but we didn't know, I don't know if it was our ignorance or what." (P5)

Some parents expressed that they felt regret and guilt because their children were sick. "Sometimes there is regret, how can I describe it, I wish I had them tested earlier, I wish they were like healthy children." (P8)

Most of the parents reported that the disease also affected their children psychosocially. The majority of the parents stated that their children experienced negative emotions such as stress and unhappiness. "He thinks that he will not live very long, he does not have a very active social life because of the pain he is already experiencing, yes, he goes to school, but he always has pain that makes him unhappy and brings him negativity." (P10)

One parent stated that his child had fear of death. "My son says, 'Mum, don't give me the medication, I'm going to die,' I say, 'Son, don't say that, God is great, everything is in God's hands, take care of yourself,' I tell my son..." (P9) Two of the parents stated that their child no longer wanted to go to treatment appointments. "He was fed up, we were having difficulty going to the hospital, he said he did not want to go, he had a painful crisis again before he could overcome the psychology there, it was very difficult." (P5)

Another parent stated that her child did not want to be separated from her mother during the hospitalisation process. "My daughter's moodiness was sometimes very bad, her requests do not end, she wants her every request to be done during periods of flare-ups, she wants me to be with her all the time... she expects a lot of love, she wants me to be with her all the time." (P11)

Two of the parents reported that the disease also affected their other children psychosocially. "We were leaving the older brother, we were leaving him with my mum, he was spending time with his cousins, but the child felt lonely, we had to be there for the young one but it affected the older one for a while. He was jealous of his brother, you get disconnected from everything." (P3) Some of the parents stated that their other children were jealous of their siblings and that their other children were left alone and felt lonely. "It was bad for my son, he spent his childhood alone, his mother was not always with him, you become more dependent on the child. He thought that I was leaving him and he was jealous of his brother, saying why are you going with him..." (P7)

Family relationship

This theme includes care burden (difficulty, lack of knowledge about the disease, difficulty in hospital conditions, sacrifice, protective attitude), deterioration in family relationships (problems experienced by the child [pain, weakness, fatigue, dizziness, limitation of mobility, avoidance of cold, school absenteeism, decrease in academic success, avoidance of stress], negative effects on their own health, inability to take care of the other child]),social support (inadequate social support, spouse, relatives, friends, psychologist), and social isolation (Figure 2). The code-subcode hierarchical map of parents' experiences regarding the effects of the disease on the family process is shown in Figure 2. The parents stated that their care burden increased due to the illness of their children and they experienced hardships. "My children are twins, I used to go with one of them and stay for a week. You are at home for 2 days and go with the other one for a week. They had a grandmother, I had to leave one of them there, I had no one else to leave them with, one of them was crying behind me when I was leaving, whichever one I went with, things like that are very difficult, I mean, it is very difficult to explain it, you need to experience some things." (P8) In addition, one parent stated that they did not have enough information about the disease. "At that time, I did not know that he had a painful crisis, I learnt that he had a painful crisis while coming to Mersin..." (P4) The majority of the parents stated that they make sacrifices for their children. "I try to do whatever I can so that he/she does not suffer from pain." (P2) Some parents reported that they showed an overprotective attitude towards their children. "We try to do what he/she says so that he/she does not get stressed." (P12)

Some of the parents stated that their social support was insufficient during the treatment and care process of their children. "You cannot get support from anyone, visits are forbidden anyway, no one can stay with him except me. Previously, when I was working, I used to stay at night and my father used to stay during the day after work, but now they don't allow him anymore. Since the department we stay in is haematology, there are patients with leukaemia, they do not allow double companions because the infection increases." (P10) Some parents receive support from their spouses, relatives or friends. "I get support from my family at work, my parents, my mother and father in law, my sister-in-law, even my neighbours are very helpful at times like this, thanks to the fact that we are very united." (P11) One parent stated that he received support from a psychologist during this process. "I was getting support from psychologists and psychiatry, I was using psychiatric drugs and then my child started to use them. I started to use them after my child's illness. You use them when you feel stuck, you can't leave them halfway so you have to get psychiatric help." (P5)

The majority of the parents stated that the problems experienced by their children affected family relationships. Parents reported that their children experienced a range of symptoms and challenges, including pain, weakness, fatigue, dizziness, restricted mobility, sensitivity to cold, frequent school absenteeism, reduced academic performance, and difficulty coping with stress."It is good if he takes care of himself, but he does not come out to the cold or heat so he doesn't get tired. Fatigue and weakness appear suddenly; he loses strength in his hands and feet and enters a painful crisis. In those moments, we feel helpless and unsure of what to do." (P7) Another parent said, "My daughter's psychological state was not good, she had dizzines sso she faced difficulty going to and from school. It affected her lessons, she was falling behind in her lessons." (P4) Another parent said, "He is very affected by cold weather, when he stays outside, when he is in a bad mood, and when he moves too much. We are usually more careful in the winter months during seasonal transitions, but inevitably the pain starts." (P6)

Two of the parents stated that their own health was negatively affected due to the difficulties in the treatment and care process of their children and that they suffered from migraines. "Coming and going was exhausting, we were miserable, half of the time until the operation was spent in hospitals. We could not take care of the young child, he stayed with his aunt for 5-6 months. My wife suffered from migraines due to these problems, she cannot sleep neither in the day nor at night due to the headache, she is depressed now, it is not easy." (P3) Parents with other children stated that they were less focused of their other children during this period. "It affected the older brother, even though we were leaving him with my mum and he was spending time

with his cousins he feels lonely, we have to be there for the little one, but it affected the older brother for a while. He was jealous of his brother, you are disconnected from everything, your life should be at home but the hospital becomes a part of your life too." (P7)

More than half of the parents stated that they experienced restrictions in their social lives. "There are many negative aspects because you cannot be happy while she is suffering, you just cannot be happy, so it is an exhausting process. It also affects you socially, sometimes you stay in the hospital for days, you don't see anyone, the child is your only focus, you have a restricted social life." (P10)

Managing pain

This theme consists of the sub-themes of drinking water, balloon blowing, massage, hot water bag, hot shower, chewing/blasting gum, diet and analgesic use (Figure 3). The code-subcode hierarchical map of parents' experiences regarding the painful crisis method of the disease is shown in Figure 3.

It was determined that parents controlled their children's pain by making them drink plenty of water, blowing balloons, massage, hot water bags, hot showers, chewing/blasting gum, diet and analgesics use during the pain crisis. A parent said, "According to the information I received from our doctor, depending on the severity of the pain, I can take them to the hospital immediately, and sometimes we can get over it at home. For example, when he says that my foot hurts, my knee hurts, I immediately apply pain cream, I give painkillers, I immediately set the time, I give painkillers alternately every 3 hours, I make them drink plenty of water, I cook chicken soup, I cook meat soup, I give fruit, milk and eggs, we can overcome it in 2 days. We inflate balloons very often, especially when I make him chew gum and I ask him to inflate the gum, and in that way we exercise his lungs." (P11) Another parent said, "We were using hot applications, we were taking a shower or hot massages, we were putting clothes on, I was rubbing him all the time because there was pain coming from the bone." (P5) Another parent said, "I try to give as much water as I can without medication, water is very important for him, I massage the places where he has pain, and sometimes we use a hot water bag to ease the place where he has pain. What I emphasize most of the time is that he should drink at least 2.5 liters of water a day." (P2)

Financial burden

This theme consists of the sub-themes of transport, treatment and care, and increased daily expenses (Figure 4). The code-subcode hierarchical map of parents' experiences regarding the economic burden of the disease is shown in Figure 4.

Parents stated that they experienced economic difficulties due to the treatment and care process of their children, transport expenses and the increase in daily expenses. "When we were travelling to and from Diyarbakır, sometimes we were in need of even one lira, we borrowed money. When we were first diagnosed, we used to go on the 15th of every month, sometimes they would hospitalise us for 10 days. After the surgery in 2017, he is not the same as before, but his treatment continues. When my husband was not working, we were having a hard time, we needed money to come and go. For 2 years, I travelled back and forth, but it was not possible, I had to rent a house, I settled in Mersin and now I am renting a house." (P4) Another parent said, "We were travelling from Silopi, it is 12 hours from here to there, we took the bus in the evening and we were here in the morning, so we were coming and going with our own means. The first treatment was done in Silopi when she was 6 months old, then they referred us to Diyarbakır Faculty of Medicine, where she was diagnosed. Then we came to Mersin when my eldest daughter got sick." (P2)

DISCUSSION

This study was carried out to determine the experiences of parents of children with SCD about the disease process. Four themes were identified: psychosocial distress, social life, family relationships, financial burden. Our study definitively showed that parents experience a range of intense emotions, including stress, anxiety, restlessness, sadness, unhappiness, unease, depression, fear of the future, the unknown, fear of loss, helplessness, preoccupation, acceptance, regret, guilt, burnout, and loneliness. Parents also stated that their child was experiencing feelings such as stress, unhappiness, fear of death, refusal to attend check-ups, reluctance to leave the mother and constraint.

Parents also confirmed that their other children were affected emotionally. Jealousy and loneliness are two examples. Caring for a child with sickle cell disease has a significant impact on caregivers. While most are afraid of losing their child due to complications of the disease, some are also worried about another child being born with SCD. Parents of children with SCD face significant psychological challenges. These problems are caused by many factors, including the disease itself and the treatment it requires, such as long-term transfusion therapy, hydration, and hydroxyurea therapy. It is reported in the literature that parents of children with SCD have high psychological burden.[10,12-15,18,24,27] Our results are in line with those in the literature. This integrative review has identified key areas for the development of a holistic nursing intervention to support parents and promote their ability to cope successfully with their condition. Furthermore, genetic counselling programmes were included in this integrative review. The objective of genetic counselling is to ensure a comprehensive understanding of the disease's implications, to enhance awareness of the disease's risk and potential transmission, to alleviate anxiety, to ensure informed decision-making, to prevent hereditory abnormalities to children, and to facilitate informed family planning choices. In conclusion, it is clear that genetic counselling was an effective nursing intervention. It helped the parents deal with their problems more positively and find ways to cope with their situation.

The present study revealed that parents experienced a high caregiving burden, strained family relationships, and inadequate social support. Parents were found to have difficulties in balancing work, school and other life activities due to their high care burden. They were found to face shortcomings in balancing the relationship between their children. Existing literature confirms that when parents experience a high caregiving burden, their social engagement is adversely affected, and they frequently limit both their own activities and those of their children to meet caregiving demands.[7,10,16] Furthermore, studies have shown[11,27,28] that siblings may unintentionally feel jealous or neglected due to the extra attention their parents give to the child with SCD. In this study, most parents reported that there was no one around to provide social support. One parent whose children were both diagnosed with SCD said that they were desperately in need of social support because their hopital stays could last up to a week and that sometimes the other child with SCD had to stay home alone since it wasn't in need of medical care like the first one. The literature indicates that parents of children with sickle cell disease often experience social isolation and a lack of support. Furthermore, they may face increased domestic conflicts, which in some cases contribute to marital strain or the risk of divorce. Therefore, the difficulties experienced by children with sickle cell disease and their parents have been linked to the lack of knowledge and negative attitudes towards sickle cell disease in society, especially among parents.[13,22,29] Therefore, there is a need for public awareness campaigns about inherited blood disorders like SCD and additional training for individuals should be repeated at regular intervals.

Vaso-occlusive crises cause pain in children diagnosed with sickle cell anaemia. This situation makes the daily life of parents even more difficult. To manage this process, parents use non-pharmacological methods as well as pharmacological treatment. In our study, parents have their children blow balloons, give them massages, apply a hot water bottle to the painful area, and have them take a hot shower. Furthermore, their children were seen to be trying to increase their fluid intake. Smith et al.[30] reported in their study that parents mostly used hot applications and massages to manage their children's pain. Pain management at home is very important for children. Parents of children with SCD play an important role in reducing their child's pain. For this reason, it is believed that parents should be provided with training in non-pharmacological pain management. Similarly, it has been reported that taking warm showers and using hot water bottles is an effective method of managing pain in children with SCD.[31,32] The study by Amin et al.[23] concluded that non-pharmacological pain management provided to parents was effective in increasing their level of knowledge. In addition, it is suggested that it is necessary to educate parents not only theoretically but also practically in order for the child to experience less pain. Parents of children with sickle cell disease (SCD) are often confronted with challenges such as frequent hospital visits, prolonged hospitalizations, and recurrent bacterial infections.[33,34] Particularly for parents from lower socio-economic

groups, this was the biggest problem identified. They emphasised that they often run out of money, as they have limited time to be productive, their work efficiency decreased and it is difficult to find employment. In this study, the socio-economic level of the parents is identified as low. The parents face financial difficulties related to the treatment process of the disease. In addition, the parents stated that their children were absent from school for long periods of time due to frequent hospital visits. In Turkey, the treatment of sickle cell disease is covered by the healthcare stystem, but parents are negatively affected economically due to reasons such as transportation to the hospital and the nutritional needs of their children and themselves. Oluntuya et al.[35] reported that some parents in Nigeria sold their assets and belongings and took out loans to cover hospital bills. Similarly, Sims et al.[12], Kuerten et al.[14], and Kilonzi et al.[22] stated that parents had difficulty in performing their jobs and almost went bankrupt due to hospital bills, which resulted in financial hardship.

Limitations

The results of this study will contribute to the literature on sickle cell disease. However, it has some limitations. The study was conducted in a single center; therefore, it cannot be generalized. The demographics of the participants and the study setting limit generalisability to the overall population of parents of children with SCD in Turkey. In addition, two major earthquakes occurred in the country during the study period, affecting 11 provinces. The province where the study was conducted during these earthquakes is very close to the region. For this reason, the training of university students was conducted online and as a result the data could not be collected between 6 February and 9 October 2023 because the students (the researchers who collected the data) couldn't attend university.

CONCLUSION

Sickle cell disease is a major public health problem. It is a chronic condition and a burden on families. The results of the study showed that parents of a child with SCD experience a range of psychological problems, social isolation, difficulties in managing pain, and high financial costs to healthcare services. The study also highlighted parents' experiences and identified their specific needs as well as the treatment and care processes for their children. In this way, the children's and parents' health demands can be better understood and met. It is therefore important that the health care system and its professionals are aware of the implications these families face and adequetly support them. From the beginning of treatment and care, parents need to understand the guidance given by health professionals. Therefore, it is anticipated that the findings of this study will contribute to improving the quality of care and overall well-being of parents of children with sickle cell disease (SCD). Accordingly, interventions aimed at enhancing the quality of life for both children and their families should be carefully planned and effectively implemented.

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ANNEX

TABLE 1. Sociodemographic characteristics of the parents.

	Age	Living place	Family type	Education level	Occupation	Spouse educational status	Spouse's occupation	Income status	Consanguineous marriage
K1	41	District	Nuclear family	Primary School	Housewife	Primary School	Carpenter	Income is equal to expenses	No
K2	49	Province	Nuclear family	Primary School	Housewife	Primary School	Car fixer	Income is equal to expenses	No
K3	51	Province	Nuclear family	Primary School	Housewife	Primary School	Concierge	Income is equal to expenses	No
K4	34	District	Nuclear family	Primary School	Housewife	Primary School	Truck driver	Income is equal to expenses	No
K5	54	Province	Nuclear family	Primary School	Housewife	Primary School	Retired	Income is less than expenses	No
K6	46	District	Nuclear family	High School	Secretary	High School	Textile chef	Income is equal to expenses	No
K7	50	District	Nuclear family	Housewife	Housewife	Primary School	Driver	Income is equal to expenses	Yes
K8	47	District	Nuclear family	University	Sales consultant	High School	Retired	Income is equal to expenses	No
K9	40	District	Nuclear family	Literate	Housewife	Literate	Retired	Income is less than expenses	No
K10	36	District	Broken family	High School	Housewife	High School	Machine chef	Income is equal to expenses	No
K11	46	Village	Nuclear family	Primary School	Housewife	Primary School	Driver	Income is equal to expenses	No
K12	44	Village	Nuclear family	Primary School	Housewife	Primary School	Farmer	Income is less than expenses	No

TABLE 2. Sociodemographic characteristics of the children.

Participant	child's age	Number of siblings	Which child is the child receiving treatment?	Age at first diagnosis	Bone marrow transplantation status	Stem cell transplantation attempt
K1	17	4	2	2 age	No	No
K2	18	3	3	1 age	No	No
K3	9	2	1	In utero	Yes (1 time)	Yes (1 time)
K4	16	6	2	6 months	No	No
K5	16	3	3	1 age	Yes (1 time)	No
K6	15	2	2	7 age	No	No
K7	16	2	2	2 age	No	No
K8	18	2	1	1.5 age	No	No
K9	15	6	6	7 months	No	No
K10	14	1	1	At birth	No	No
K11	8	3	3	8 months	No	No
K12	13	3	1	7 months	No	No

FIGURE 1. Psychosocial distress code-subcode sections model.

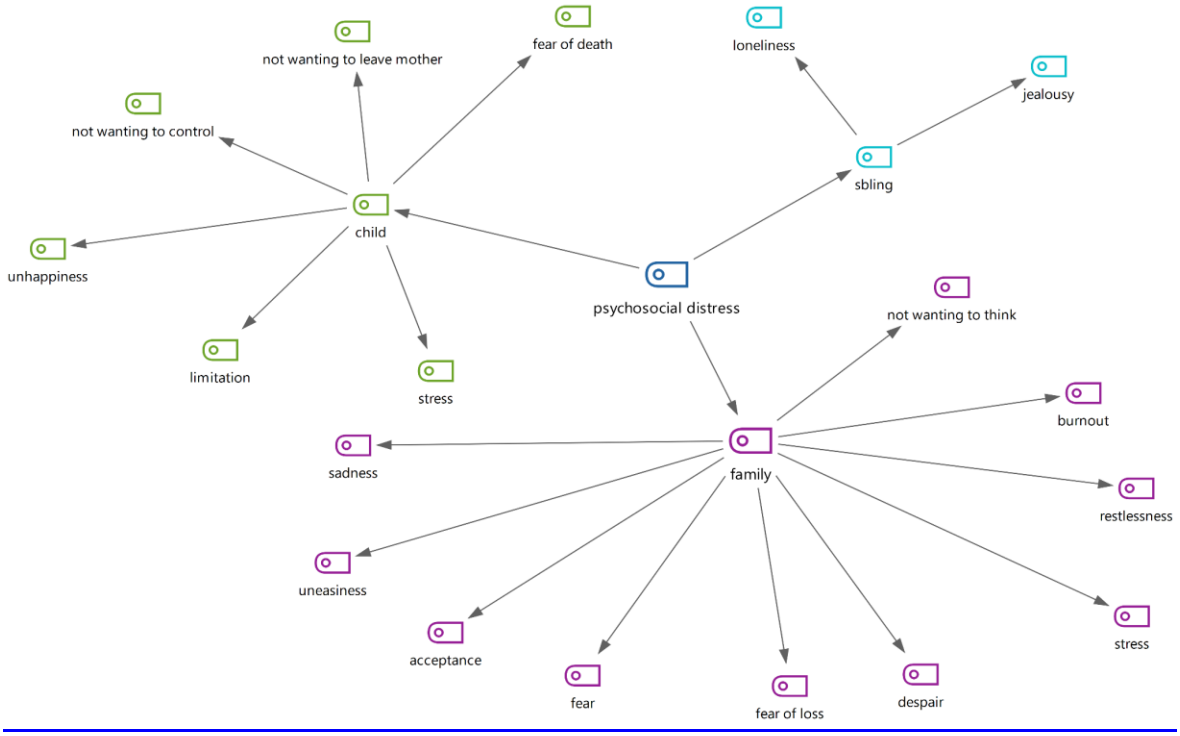

FIGURE 2. Family relationship code-subcode sections model.

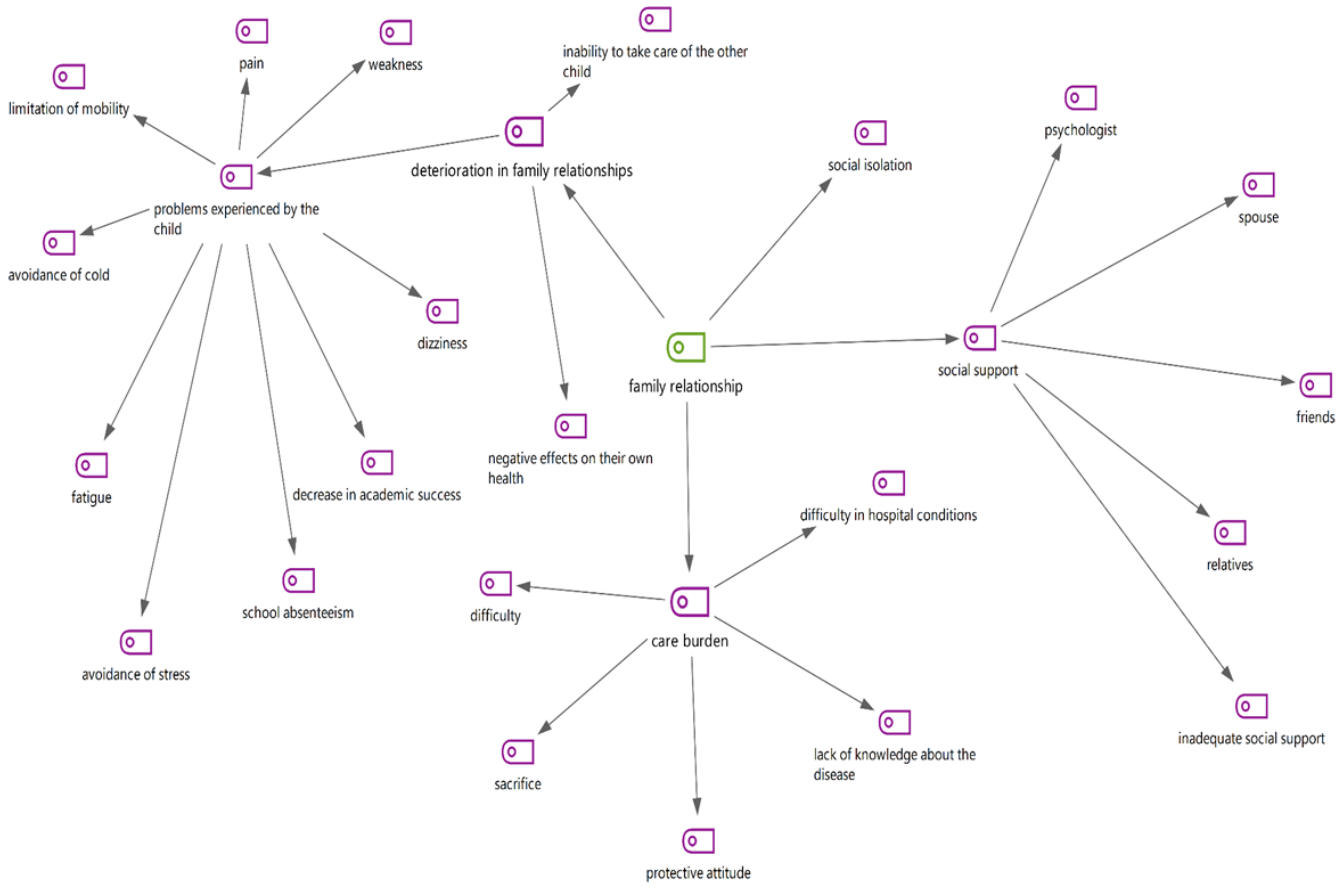

FIGURE 3. Managing pain code-subcode sections model.

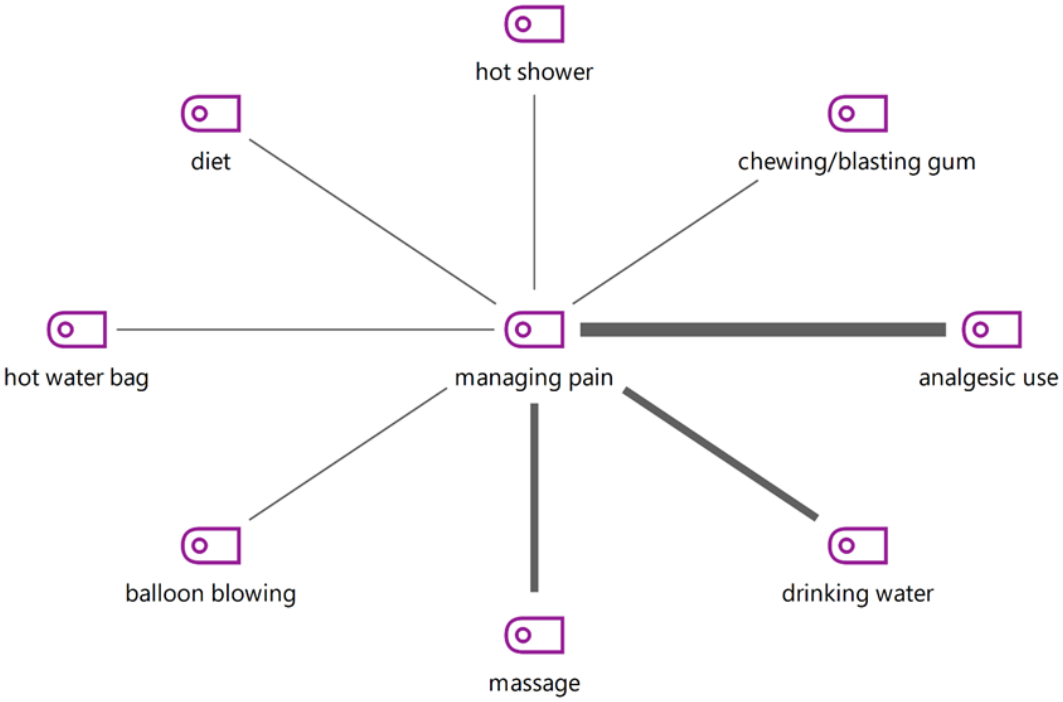

FIGURE 4. Financial burden code-subcode sections model.