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Stress and coping strategies among parents of children with cancer at Tikur Anbessa Specialized Hospital paediatric oncology unit, Ethiopia: a phenomenological study

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ABSTRACT

Objective This study explores sources of stress, conditions that help reduce stress levels and coping strategies among parents of children with cancer receiving chemotherapy at Tikur Anbessa Specialized Hospital (TASH) in Ethiopia.

Design A qualitative phenomenological approach was used.

Setting Parents of children receiving chemotherapy at the TASH paediatric oncology unit.

Participants Fifteen semistructured in-depth interviews were conducted with nine mothers and six fathers of children with cancer from November 2020 to January 2021.

Results Sources of stress related to child's health condition as the severity of the child's illness, fear of treatment side effects and loss of body parts were identified. Parents mentioned experiencing stress arising from limited access to health facilities, long waiting times, prolonged hospital stays, lack of chemotherapy drugs, and limited or inadequate information about their child's disease condition and treatment. Other sources of stress were insufficient social support, stigmatisation of cancer and financial problems. Conditions decreasing parents' stress included positive changes in the child's health, receiving cancer treatment and access to drugs. Receiving counselling from healthcare providers, getting social support and knowing someone who had a positive treatment outcome also helped reduce stress. Coping strategies used by parents were religious practices including prayer, crying, accepting the child's condition, denial and communication with health providers.

Conclusion The main causes of stress identified by parents of children with cancer in Ethiopia were the severity of their child's illness, expectations of poor treatment outcomes, unavailability of cancer treatment services and lack of social/financial support. Measures that should be considered to reduce parents' stress include providing psycho-oncological care for parents and improving the counselling available to parents concerning the nature of the child's illness, its treatment, diagnostic procedures and treatment side effects. It may also be helpful to establish and strengthen family support groups and parent-to-parent communication, improve the availability of chemotherapy drugs and offer more education on coping strategies.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative interview data offered contextualised and detailed insights into parental stress, conditions influencing it and coping strategies.
- ⇒ Data collection was performed at the paediatric oncology unit of Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia, which is the country's primary oncological care unit.
- ⇒ Because participants were selected purposively, the characteristics of the sample may limit the transferability of the findings to other populations.

INTRODUCTION

Every day, 700 children are diagnosed with cancer worldwide,[1] and the estimated number of childhood cancer cases in 2015 was 397 000. Globally, 43% of childhood cancer cases are undiagnosed, with the highest prevalence of undiagnosed cases in African countries.[2] Despite dramatically improved survival rates (80%) in high-income countries, cancer remains the leading cause of death among children younger than 19 years old.[1] When compared with the published data for developed countries, the available data on childhood cancer survival in developing countries are incomplete and limited but indicate that survival rates are on the order of 10%–30% and are thus much lower than in developed countries.[2–5] Accordingly, the childhood cancer survival rate in Ethiopia is believed to be below 20%[6] and shortages of chemotherapeutic agents, treatment facilities and skilled health professionals are common challenges in paediatric oncology.[6 7]

Both parents and children are affected by the psychological stress associated with childhood cancer.[8] As noted by Lazarus and Folkman, stress is a specific relationship between a person and their environment that the person considers beyond their capacity and harmful to their well-being. Stress perception varies from person to person; what is stressful to one person may not be stressful at all to another.[9] Similarly, the American Psychiatric Association defined stress as a sense of being overwhelmed that may be linked to worry, depression, exhaustion and lethargy.[10] Stress affects people of every age, sex, race and situation, resulting in both physical and psychological health problems.[11]

Parenting stress is an aversive psychological response to the strains of being a parent that occurs when parents cannot meet the demand of parenthood such as having adequate information, the ability to provide care and the level of competency of doing so.[12] Stress is commonly experienced by parents of children with serious illnesses such as cancer. Accordingly, a comparative study conducted by Pollock *et al* found parents of children with cancer exhibited more severe physiological symptoms of stress than parents of healthy children.[13] Several studies have also found that parents of children with cancer experienced significant levels of stress related to their children's condition.[14–17] Both fathers and mothers may develop parental stress, although there is evidence of higher levels of stress among mothers than fathers.[17–20] Moreover, parents of children who survived cancer report feelings of stress for extended periods after their child's recovery.[16 20]

Several studies have investigated sources of stress among parents of children with cancer. Parental stress has been linked to the duration of the child's disease following diagnosis,[14 16 17 21] the severity of the family's financial problems,[14] fear of death, the impact of the disease on the child's life,[21] the child's age at the time of diagnosis,[21 22] and the diagnostic and treatment procedures used in cancer therapy.[13] Previous studies have also shown that parents use different strategies to cope with their child's cancer and that the choice of strategy affects the family's adaptation to the child's condition.[23] Two types of coping strategy have been distinguished: problem focused and emotion focused. Problem-focused coping involves resolving or taking action to change the source of stress, whereas emotion-focused coping focuses on reducing or managing emotional stress.[24] Sutan *et al* reported that parents used problem-focused coping strategies more than emotion-focused ones to handle a child's cancer diagnosis.[25] Another study on parents of children with cancer described emotion-focused coping strategies such as praying, adhering to religious obligations, getting support from family members and meeting other parents of children with cancer.[25] Known problem-focused coping techniques include seeking information, consulting medical experts and seeing psychiatrists.[26] The types of coping strategies used by parents also depend on the phase of the child's cancer.[22 27]

Research on parental stress and coping strategies in oncology care in developing countries such as Ethiopia is scarce. Despite the relatively high burden of childhood cancer in Ethiopia,[28] the paediatric oncology unit of Tikur Anbessa Specialized Hospital (TASH) is the only unit in the country providing comprehensive treatment for paediatric oncology patients. Therefore, many parents are required to travel long distances from every corner of the country and stay in Addis Ababa for extended periods to get treatment for their children. Since this study is the first of its kind, an explorative qualitative approach was adopted to identify causes of parental stress with direct implications for clinical practice and the development of effective interventions. The aims of this work were thus to identify sources of stress, conditions that help reduce stress levels and coping strategies for managing stress among parents of children with cancer in Ethiopia. To guide the work towards this objective, three research questions were formulated:

Research question 1: What are the sources of stress among parents of children with cancer in Ethiopia?

Research question 2: What conditions helped reduce the stress levels of parents of children with cancer?

Research question 3: What coping strategies do parents use to manage the stress associated with childhood cancer?

METHODS

Study setting and approach

We conducted a qualitative phenomenological study among parents of children being treated for cancer at the paediatric oncology unit of TASH in Addis Ababa, Ethiopia. Ethiopia is Africa's second most populous country, with a population of more than 100 million people.[29] According to data from the hospital's administration, TASH is the country's largest tertiary university teaching hospital, with a capacity of over 800 beds. The paediatric oncology ward has 26 beds and is staffed with haemato-oncologists, haematopathologists, residents and nurses. Data from the unit's registry indicate that it provides inpatient and outpatient services for around 500–600 children with cancer annually.

To explore the 'lived experience' of parents of children with cancer being treated in the paediatric oncology unit, we conducted an exploratory qualitative study using a phenomenological approach.[30] Lived experience refers to a representation of the experiences and choices of a given person and the knowledge they gain from these experiences and choices.[30] Semistructured in-depth interviews were conducted in which parents were encouraged to direct and shape the discussion in accordance with their own experiences, views and particular concerns.

Participant selection

Following the recommendations of Grossoehme and Moser and Korstjens,[30 31] we purposely selected 15 parents of children with cancer visiting the paediatric oncology centre at TASH. In addition to these recommendations, we also considered data saturation to ensure that the number of study participants was adequate. Data saturation was evaluated based on informational redundancy, meaning that it was considered to have been achieved once no new information or categories emerged from the

Box 1 Interview discussion guide

1. Tell me about your experience as a parent who has a child with cancer.
2. What did you find hard when you learnt that your child had cancer?
3. What has been hard for you during your child's cancer treatment?
4. What things do you do to cope with your child's cancer/cancer treatment?
5. How do you evaluate your current level of stress compared with when you first heard that your child had cancer?

data and additional interviews no longer generated new categories.

The principal researcher (LD) recruited the participants with the help of nurses working at the unit. Factors considered during participant selection were the ages of parents and children, residence, time since initial diagnosis and cancer treatment stage. Parents of children diagnosed with any type of cancer and being treated in either the paediatric oncology unit or the outpatient department were considered eligible for inclusion. Parents of critically ill children and those with known mental health problems were excluded. All parents invited to the study agreed to participate.

Interviews

Interviews were conducted by the primary author (LD), who was not part of the child treatment team, with assistance from one note-taker (DB). The researcher used the interview guide presented in box 1, which was developed by the research team based on the chosen research questions. Before actual data collection, the designed interview guide was pretested by interviewing three parents of children with cancer who were not included in the sample. The authors then discussed the guide based on these preliminary interviews and made modifications to improve clarity and understandability. A series of prompts were used to encourage participants to clarify or expand on their responses, such as 'What else was hard?', 'Can you tell me more?' and 'What else have you done?'. In addition to verbal communication, facial expressions and other non-verbal responses of the participants were recorded by making field notes to improve understanding of participants' responses. The interviews were conducted from November 2020 to January 2021 in locations where the respondents felt comfortable. Their duration ranged from 12 to 23 min. All interviews were audio-recorded. Interviews were transcribed verbatim in the original languages (Amharic and Affan Oromo) and then translated into English. The translated transcripts and the field notes made by the author (LD) and the note-taker were used for analysis.

Data analysis

Data were analysed using the inductive purely data-driven thematic analysis method.[32] Despite conducting an extensive literature search, we found no similar study done in the study area. Therefore, we did not want to use any prespecified dimensions of stress or coping strategies in order to avoid preconceptions that might obscure, reframe or leave invisible key themes. Instead, we decided to allow information on stress sources and coping strategies to emerge from the raw data. The analysis involved an iterative process of listening to the interviews, reading the transcripts, assigning codes and finally identifying patterns in the material. To this end, the authors and research assistants first read the transcripts independently several times. Texts were then broken down into meaningful units consisting of key phrases from the transcripts. These meaningful units were then condensed and labelled with codes, which were developed inductively as they emerged from the data. Codes identify features of the data that are pertinent to the research questions and organise data into more concise ideas that can subsequently be grouped into topics. The identified codes were then sorted into different categories and codes with a high degree of agreement between the coders were discussed and sorted into subthemes. Finally, the subthemes were organised into overarching themes. Representative quotes for each theme are presented in the Results section below. The analysis process was performed using ATLAS.ti V.8 software.

Trustworthiness

Trustworthiness in qualitative studies depends on transferability, credibility, dependability and confirmability.[24 33] Credibility was established by having the primary researcher stay at the study site for an extended period to become familiar with the setting, by receiving continuous comments from peers during peer debriefing, and by using negative case analysis. Dependability was established by thoroughly describing the methods that were used, maintaining meticulous records of interviews and documenting the analytical process. To confirm that the interpretations of the findings were derived from the data rather than a figment of the investigators' imagination, all events that occurred in the field, personal reflections to the study and phenomena that arose during the investigation were recorded along with relevant aspects of the researchers' personal history. The investigators were sceptical or in doubt if the information felt incorrect and tried to create rapport and trust through prolonged attachment with the informants. In addition, data source triangulation was used. To facilitate the transferability of research findings, a thick description was used which involves elucidating all the research processes. In addition, purposive intensity sampling was used to focus on key informants with particular knowledge about the issues of interest to maximise the depth of the findings, and maximum variation purposive sampling was performed when selecting study participants.

Patient and public involvement

No patients were involved.

Table 1 Characteristics of the interviewed participants

	Mothers		Fathers		Total	
Variable	**Median**	**Range**	**Median**	**Range**	**Median**	**Range**
Parent’s age	32	25–41	30.5	28–40	32	25–41
Child age in years	5	2–13	3.5	<1–12	4	<1–13
Time since diagnosis in months	7	1–48	2.5	1–12	5	1–48
Total number of children parents have	3	1–5	4	1–8	3	1–8

RESULTS

Participant characteristics

Interviews were conducted with 15 parents (nine mothers and six fathers) aged from 25 to 41 years. Eight participants (five mothers and three fathers) came from urban parts of Ethiopia and 10 had three or more children. Six parents had no formal education (four mothers and two fathers), four (two mothers and two fathers) had attended primary education, three (two mothers and one father) had attended secondary education and two (one mother and one father) had attended university/college. Four of the participants were unemployed. Six of the children were boys. The ages of the children with cancer ranged from 10 months to 13 years, and the time since diagnosis varied from 1 month to 4 years. Table 1 summarises the participants’ characteristics.

The interview analysis identified the following overarching themes:

1. Sources of stress.
2. Conditions that reduce stress.
3. Coping strategies.

These themes and the subthemes are presented in table 2, and figure 1 shows how they are related.

Theme 1: sources of stress

Parents were asked to describe their major sources of stress following their child’s diagnosis. Twenty-two codes were identified from their responses and grouped into five categories: (a) parents’ understanding of cancer, (b) child health related, (c) health facility related, (d) social/financial support related and (e) witnessing others’ bad experiences (table 2).

Parents’ understanding of cancer

Some parents stated that they had no knowledge or understanding of cancer before their child’s diagnosis. Furthermore, some parents expressed their understanding of cancer in terms of the curability of the illness, the severity of the disease, treatment duration and the importance of early treatment (see table 3).

A father from a rural part of Ethiopia indicated that he knew nothing about cancer before his child’s diagnosis. Similarly, when asked to describe cancer, a mother from a rural area said, “I had no information about this disease before. I had sometimes heard it mentioned in the media but I do not have anything to say about it.” Another mother also stated that she had only heard the term ‘cancer’ when people talked about it.

Other respondents described cancer as a severe and horrible disease and were uncertain about whether it could be cured. One mother said, “… my child’s illness is a terrible disease. I know it hurts people very severely. I also know that it may or may not be a curable disease.” Another mother said, “It is a horrible disease. I heard it is a severe and challenging disease.” A father from Addis

Table 2 Sources of stress, conditions decreasing stress and coping strategies among parents of children with cancer

Themes	Subthemes/codes	
Sources of stress	a. Parents’ understanding of cancer	
	b. Child health related	
	▶ Acquiring the disease at an early age ▶ Fear of cancer relapse ▶ Fear of treatment side effects ▶ Clinical manifestations of the child	▶ Having a child with a severe/lifelong illness ▶ Worsening of illness
	c. Health facility related	
	▶ Waiting time before starting treatment ▶ Long hospital stays ▶ Unavailability of chemotherapy drugs	▶ Referral to TASH ▶ Receiving inadequate information
	d. Social/financial support related	
	▶ Lack of social support ▶ Financial problems ▶ Disruption/cessation of child’s schooling	▶ Effects of peer influence ▶ Parents’ working conditions
	e. Witnessing others’ bad experiences	
Conditions decreasing stress	a. Child treatment related	
	▶ Experiencing side effects less than anticipated ▶ Hope for a positive treatment outcome	▶ Knowledge about treatment side effects ▶ Starting treatment
	b. Hospital related	
	▶ Perceived good care ▶ Counselling from health providers	▶ Trust in health providers ▶ Short distance to hospital
	c. Social related	
	▶ Financial support ▶ Discussions with other parents ▶ Receiving care for children at home	▶ Witnessing positive outcomes for other children ▶ Social support
Coping strategies	▶ Praying ▶ Discussions with other people/parents ▶ Crying	▶ Accepting the child’s condition (ie, doing nothing) ▶ Denial

TASH, Tikur Anbessa Specialized Hospital.

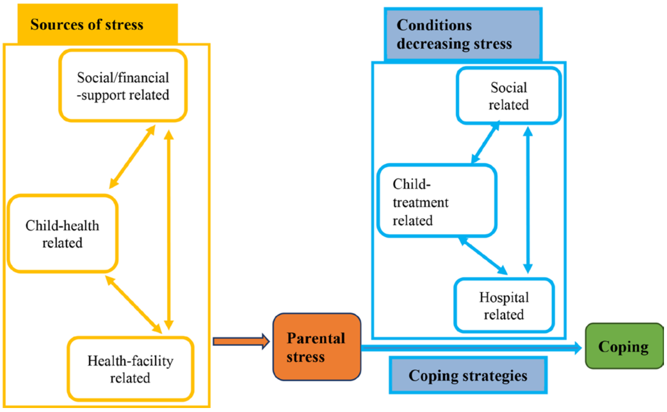

Figure 1 Relationships between sources of stress in parents of children with cancer, conditions that reduce their stress and the coping strategies that they adopt.

Ababa stated that cancer was ‘the most challenging and complicated disease’.

Parents also discussed the time needed to complete treatment for cancer and compared it with that required for other diseases. One parent from Addis Ababa said cancer is a complex disease because its treatment takes a long time. He explained the situation by saying, “… the disease itself is not something that heals within a short period. This is why cancer is a very difficult disease.”

Child health-related stressors

Parents mentioned several sources of stress relating to the child’s health condition. These included acquiring the disease at an early age, the child showing signs of delayed development, fear that the child’s cancer might relapse, fear of treatment side effects, considering the child’s condition to be severe and life-threatening, having a child with severe clinical manifestations, fear of the illness worsening and fear of the child losing body parts. Parents also stated that they did not expect cancer to occur at an early stage of life and that having a young child with cancer was stressful because they feared that their child might not tolerate either the illness or the available treatment. In addition, parents were stressed because the child developed signs of developmental drawbacks. For example, one mother stated, “the illness worried us because unlike other children of her age, she could not see or grasp anything.”

Table 3 Descriptions of cancer provided by parents of children with cancer

Question	Responses from parents
What is cancer for you? How do you describe cancer?	▶ Lack of information – Do not know anything – Never heard about cancer before – I have no information – Know only the name ▶ Severity – Severe and challenging disease – Horrible disease – Uncertainty about cures for the disease – Terrible disease ▶ Duration of treatment – Long duration of treatment – Needs early treatment

The side effects of treatment were another cause of stress expressed by parents. Parents were worried about the side effects of treatment based on either their own experiences or expectations based on knowledge of others’ experiences. A mother of a child who had received his second round of chemotherapy said, “Yes, I am worried about the side effect of the drug. They (health providers) already told me about the possible side effects. Since my child is very young and small, I do not know whether he is going to tolerate the side effects or not.” Another mother stated that she became stressed after receiving information about another parent’s child experiencing treatment side effects due to fear that her child may respond similarly.

Regarding his child’s sickness, one father said that the child’s inability to breast feed was a leading cause of his stress and mentioned it as a major symptom of his child’s illness. Discussing a deterioration in his child’s health, a father from Addis Ababa who had stayed in the hospital for more than 6months said, “after we were to finish chemotherapy and getting ready to be discharged, the child developed a new health problem and stayed for three more months. This was stressful for the child, me, and my family.”

Parents also mentioned fear of death as a source of stress. A mother from an urban town outside Addis Ababa stated, “When I look at his face, I may find him looking weaker. I become most stressed when he refuses to eat foods or breastfeed because of his weakness.” A mother of a daughter who visited the centre for a routine check-up after completing chemotherapy revealed that her biggest worry was fear of her daughter dying. The main reasons for this were that she witnessed her neighbour die from cancer and that people had told her cancer is an incurable disease.

Fear of their child losing a body part was another major cause of stress for parents. A mother commented, “I accepted the removal of the eye because I felt it is better to lose one of her eyes than losing her. But I felt very bad that my baby lost one of her eyes.” A father of a baby girl who was afraid of his daughter losing her leg stated, “I am not sure about her leg. I saw a boy in this room whose leg was amputated because of cancer. So, I am worried that this might happen to my daughter.”

Health facility-related stressors

Parents mentioned five stress-causing conditions that related to health facilities. These included long waiting times for diagnosis and starting treatment, long hospital stays, limited drug availability, being referred to TASH and receiving inadequate information.

Long waiting times for diagnosis and starting treatment

The long waiting time associated with diagnostic procedures and starting treatment was repeatedly stated as being stressful. Parents mentioned that conducting diagnostic procedures had taken a significant amount of time; one father said that he had spent more than 2 weeks in Addis Ababa for a single diagnostic procedure. Most parents mentioned that their child's health had deteriorated while waiting because they could not receive treatment before the diagnosis was confirmed. A father from the Afar region added that the prolonged waiting time made it impossible to find anywhere to spend the night despite having enough money to pay for accommodation because hotels were unwilling to rent a room to a family with a sick child. Another father from the Amhara region said he was concerned about finding a place to stay until their next appointment; as he put it, "after we left the hospital, she got sick and it was difficult for us to return to this hospital. I am worried because getting back to this hospital is very difficult."

Long hospital stays

Parents also mentioned the long duration of their child's hospitalisation as a source of stress. For example, when asked what made his stress worse, a father answered, "my child's inability to recover quickly." He added, "unlike other diseases, you cannot get treatment only once and go home with your child to continue your work. You cannot think like that. The treatment takes a very long time. That creates many burdens." A mother from Hawassa town said that her prolonged stay in the hospital made her worry about the two children she had left at home; she said, "When we heard we should take him to Tikur Anbessa quickly, we did not consider who would look after the other children. We stayed at this hospital for 45 consecutive days. We were concerned about what would happen to the children left at home if we stayed here any longer."

Lack of drugs

Regarding issues related to chemotherapy, parents said they were worried because they were uncertain about the outcome of their child's treatment and because chemotherapy drugs were not regularly available at the hospital. They also added that the drugs were very expensive and that some were hard to find even in private drug stores. A father commented:

> Not all prescribed drugs are available in this hospital. You need to buy from private drug stores. This creates its own burdens. First of all, drugs are not available even in private drug stores, and secondly, they are expensive if we can find them. This can be a cause of stress, and it is very stressful.

Referral to TASH

Parents who came from outside Addis Ababa described being referred to a tertiary hospital like TASH as a source of stress. Because TASH is Ethiopia's highest referral hospital, parents interpreted a referral to TASH as an indication of the seriousness of their child's illness. The other reason parents described referral to TASH as stressful was its high patient load, due to which the parents feared that admission, receiving treatment and other services would take a long time. A mother from Hawassa town stated her husband was also scared and lost hope when the child was referred to TASH. She said, "After confirming the diagnosis, they referred us to Tikur Anbessa Hospital. No family member had been treated at Tikur Anbessa before, but it is a scary place to be as we have heard about it." She stated that she considered the hospital a frightening place because of the negative information she had heard about it from mass media and other people; as she put it, "Yes, we were scared when we heard the child was referred to Tikur Anbessa Hospital. Then we came here, and our stress got worse when they confirmed our child's diagnosis of cancer."

Receiving inadequate information or no information at all

Parents of children with cancer reported that the information they obtained from healthcare providers was inadequate or that they received no information at all. Moreover, they said that when health providers did supply information, it consisted only of general and non-specific descriptions of the child's illness and its treatments. Information about why the child needed a specific drug, the side effects of drugs, the future effects of the disease and what to expect concerning the child's illness was highly desired but rarely provided. This lack of information and clarity caused stress. A mother of an under-5 girl who was receiving chemotherapy for the fifth time stated, "They only tell me the frequency and time to take the drug. They did not clearly tell me about the benefit or side effects of the drugs my child is taking." She also added that health providers only gave general information, such as saying that chemotherapy may have some side effects without specifying what side effects should be expected. A father of a newly diagnosed infant daughter said, "… different investigations were performed, including a CT scan, and they just said there was a tumor on her kidney, but they could not specify whether it is cancer or not. During the investigation process, I got so worried because no one was responsible for telling us about the child's exact diagnosis."

The lack of information about the side effects of treatment also aggravated parents' stress levels. A father said that some of his stress could have been prevented if he had been informed about the treatment's side effects:

> They told me that the only way to treat the child was through cancer medication called chemo, but they did not explain to us the adverse effect of this medication, such as loss of appetite or other side effects. Because of this, we were shocked and had to run to the emergency by the time she started to show these side effects.

He added, "we were worried because of the side effects of the medication, but if they had told us at the beginning of the treatment, that might make things better."

Social/financial support-related stressors

Social and financial factors were another source of stress mentioned by patients. Stressors in this category included a lack of social support, financial problems, parents' previous bad experiences, disruption or cessation of the child's schooling, peer influence on parents and parents' working conditions. Stress relating to a lack of expected social support and financial problems was mentioned more frequently than other factors.

Social support: parents reported a lack of social support from families, significant others and friends as a cause of stress. The most frequently mentioned stressor in this context was concern about a lack of support for children who had been left at home. A mother of a daughter who came from a rural part of the country and had left two of her children at home mentioned that people were not providing enough support. She was concerned that it was difficult to get people to help, especially during crop harvesting time. She stated, "all my worry is about the children I left at home. I always think who is going to prepare and give them food? I worry about whether they are eating breakfast or can get lunch? I am also worried about whether they get enough food."

Social support can also take the form of financial support. Accordingly, two parents discussed social support in terms of financial assistance provided, and one father associated it with a lack of assistance with farming. A mother reported that she was very stressed because she and her partner had no relatives or anyone else to support them financially, so they had to cover all of the expenses related to treatment and living costs by themselves. A father from a rural part of the country also expressed worry about who would harvest his crops and look after his cattle. The lack of a social network and social interactions was also mentioned as a source of stress.

Another source of parental stress relating to social issues was disruption or cessation of the child's schooling and the associated effects on the child's relationships with their peers. Illness and treatment procedures often forced children to discontinue their schooling or to fall one or more grades behind their friends. A mother from Addis Ababa said, "She discontinued school three times. The discontinuation of the school was stressful." She also added, "answering questions from other people about why she is still in grade four while her friends are in grade seven gives me bad feelings, but we cannot do anything about it."

Financial problems mentioned by respondents were related to overall living expenses, living expenses in Addis Ababa, overall treatment costs and the cost of buying chemotherapy drugs. Parents stated that expenses associated with the child's sickness made covering living expenses harder than before. A mother from Addis Ababa whose child had completed chemotherapy remembered the time when her child was first admitted saying, "In addition to my kid's admission, I had to search for something to eat. By that time, I was so stressed and confused." Another mother described living on just her husband's salary; their child's illness worsened the family's financial situation. She said, "my husband is the only one who has a job. It is not easy to live with his salary alone. There are different kinds of payments to make like rent, transportation, and so on. It is very hard."

In addition to the overall cost of treatment, costs associated with transportation, diagnostic procedures and other hospital-related costs were mentioned as sources of stress. One mother from rural Ethiopia said, "someone may not have adequate money, but a lack of money to pay for a child's treatment is worrisome. I am afraid that my child may not get treatment because of a lack of money. I am worried about that." A father also said, "Here for your child's treatment, you need cash to buy things like drugs and pay for lab investigations. You cannot get treatment for the child without money. This by itself is stressful for me." Regarding the cost of chemotherapy, one mother said, "I did not forget the bad feeling I had when the doctor told me to buy an expensive drug."

Both mothers and fathers reported leaving jobs because of their child's illness, and the loss of employment was another source of stress. For example, one mother said, "I was working at a private institution. She gets treatment every week, but they did not give me permission to leave every week. It was challenging to work, so I left the job." Many parents also said that having to cease work due to their child's illness had contributed significantly to their financial problems.

Witnessing others' bad experiences

Witnessing bad experiences at a hospital or at home, including witnessing death, the loss of a body part or other adverse outcomes of childhood cancer, increased parents' stress and made them fear that their child might suffer a similar fate. One mother said:

> When I see a child's death in the ward, I lose hope and feel my child might be the next one …When I see their health deteriorate, I feel bad inside. I sometimes cry when I hear that a child has died, and I feel very depressed.

Some parents stated that during their hospital stay, they did not see or hear about any child whose health had improved after starting treatment. This increased their level of stress because it made them lose hope in the possibility of successful treatment. A father with a newly diagnosed baby daughter commented: "Everything I hear is not good. When I see other patients, the treatment took a long time, when I see their condition, I understand that it is going to be very difficult. I cannot tolerate this." Similarly, a mother of a baby boy stated: "I never saw anyone completely cured. When we ask others, they tell us they were here for a long time, for three months, four months, and they are still coming again and again. We did not see a child that was completely cured."

Theme 2: conditions decreasing stress

Parents identified 14 factors that helped to reduce their level of stress, which were divided into three groups: (a) child treatment-related factors, (b) hospital-related factors and (c) social factors.

Child treatment-related factors

The commencement of treatment, experiencing hope for a positive treatment outcome, knowledge about treatment side effects and the child experiencing fewer side effects than had been anticipated were mentioned as factors that reduced parental stress.

In Ethiopia, the process of referring patients from primary hospitals to tertiary hospitals like TASH takes a long time. Accordingly, many of the interviewees had spent a lot of time waiting for the referral process to be completed before their child could receive treatment. The ending of this wait and the commencement of treatment were therefore a significant stress-relieving factor. For example, one mother said, “as my child took her treatment for the first time and I heard she has a chance to heal, I became calm.”

Positive treatment outcomes, or hope for such outcomes, was also associated with reduced stress. Parents stated that they became less stressed after receiving information about the possibility of a positive treatment outcome and observing improvements in their child’s health. A mother commented:

> At first, I thought her illness had no treatment (cure), and she has no hope of surviving. When I saw her getting well from time to time, I got some relief.

Hospital-related factors

Parents mentioned that their level of stress decreased because they felt healthcare providers took care of their children. One mother who stayed at the treatment centre for 12 days stated, “I have great hope that he will be cured after completing the treatment because the health providers are following the child very closely. He is also getting the drugs appropriately.”

Having a good relationship with staff also helped reduce parents’ stress levels. One parent commented, “There was a doctor I met at the unit, and I considered him like my brother. He told me that my child had a good chance of survival. After that, I became much more hopeful.”

The respondents mentioned that although staff had high workloads, they tried to provide emotional support to the parents. A mother of a child attending follow-up appointments 8 months after completing chemotherapy described the relationship between patient load and healthcare providers’ efforts by saying “they will help you when you are stressed. Sometimes they grumble, they may be stressed out when there are too many people. By this time, you may feel forgotten. But usually, they also empathize with you, they are good for me.”

Social factors

Parents reported that witnessing positive treatment outcomes for other children admitted to the hospital had helped to reduce their stress levels. Parents described that before coming to the hospital, they thought childhood cancer was not a common phenomenon and was something that had only happened to their child. However, parents reported that knowing this disease can happen to anyone and getting a chance to meet and talk with other parents reduced their level of stress for two reasons. First, seeing other children with more complicated conditions helped parents feel that their child was in a better condition than others and could therefore have a better chance of survival. Second, witnessing and hearing testimony from other parents about a child improving after receiving treatment reduced parents’ fears of losing their child. Discussing childhood cancer with other parents also reduced parents’ level of stress. The influence of these factors is demonstrated by the following quotations:

> At first, I thought my child was the only one to develop a disease like this at this early age, but when I came here, I saw many children with the same health problem as my child…. when I saw some improvement of the health condition of other children, this helped my stress to decrease from time to time. (a mother of a daughter)

> There were other very severe diseases. When I saw other complicated illnesses and myomas, I considered my child’s illness to be better than the others. (a single mother)

> I like to ask all people about their experience. And they told me they were in the same position when they first came to this center, but now their child has improved greatly … I also saw a child who had a similar illness to mine but was now showing clear improvement. This helped me to hope that my child will also get well. (a mother of a baby boy)

Receiving financial support was another major stress-reducing factor. One mother said that her level of stress decreased significantly after receiving support from a charity that covered the cost of the child’s treatment and their living expenses. A father reported that he received financial support from different people, including some he did not know, which helped him to cover some of the child’s treatment costs. Another mother said that having the children’s grandmother look after other children who had been left at home helped her not to worry about them.

Theme 3: coping strategies

Praying and religious beliefs, crying, accepting the child’s condition and doing nothing, having discussions with health providers and denial were commonly mentioned as coping mechanisms for parents of children with cancer. Many parents said that once they learnt the diagnosis and the seriousness of their child’s illness, they felt that the only thing they could do was pray. A mother stated, “I cannot do anything. I will be stressed for the time being, and then I pray. I pray for his mercy to cure my child. … I can do nothing more than pray for His mercy. What else I can do about it?” Similarly, a father said, “we get solace from the word of God. We know there are always challenges in life, and we try to overcome them with God’s help.” Another mother commented, “I pray to God. I say, ‘You gave me this disease please give us the cure too’. … all I can do is pray. What other option have I? Nothing.”

Another coping strategy reported by parents was accepting the child’s condition. One mother said, “… I said, how can I lie about what God gave me? I accepted my child’s diagnosis and started telling people the truth.” Parents also used talking to other people and friends about the child’s health condition and their stressors as a coping strategy. For example, a mother stated, “Sometimes you feel relief when you talk with other people. Some people make it easy when they talk about it. You forget about it when they tell you she will be fine; you forget about your stress for the time being.”

Parents stated that if they believed they could not change the situation and were out of options, they would cry to get relief from stress. A mother said, “I cannot do anything. I sometimes cry.” Another mother, when asked what she usually did when she was stressed, stated, “we did everything possible to get treatment and to complete treatment.” Another mother denied the truth of her child’s cancer diagnosis because she had never previously known about childhood cancer and said that she never expected her child to be diagnosed with such a deadly disease. The interviewed parents also said that discussing their child’s condition with healthcare providers helped them to cope with their situation. One father also stated that sharing his feelings and stress with the oncologist treating his child helped him to cope.

DISCUSSION

Paediatric oncology care in Ethiopia is very limited and frequently incomplete, inadequate or simply unavailable. Moreover, there is very limited palliative care for children with incurable diseases.[6 7] As in other low-income countries, healthcare is severely hindered by a lack of trained professionals,[34] insufficient supplies of drugs and inadequate health facilities.[35 36] These limitations in combination with low cancer awareness (especially in rural parts of the country) result in fear of cancer and tend to cause delays in seeking treatment.[7 37 38] Parental stress associated with childhood cancer in Ethiopia has not previously been studied in detail; this study is the first to explore causes of parental stress relating to childhood cancer, factors that help reduce parents’ stress levels and coping strategies used by parents from the parents’ perspective.

The results obtained indicate that Ethiopian parents have insufficient awareness of and knowledge about childhood cancer, which caused stress and fear. This is consistent with previous reports indicating a relationship between a lack of knowledge about cancer and stress.[7 39 40] Also consistent with earlier studies[41] is the fact that the interviewed parents said they were stressed because healthcare providers did not give them detailed and relevant information about cancer and their child’s health. This indicates that it is important to provide information and raise awareness about the disease and that strategies to help and encourage staff to give parents information about cancer could help reduce stress and promote positive provider–patient contact.[42 43]

The interviewed parents also said that getting detailed information and counselling from healthcare providers about the chance of survival, treatment duration, schedule and treatment benefits reduced their level of stress. According to previous studies on Ethiopian paediatric oncology, nearly two in five children receiving chemotherapy develop adverse drug reactions,[44 45] which indicates that parents often either see their own children suffering these side effects or witness another child struggling with them. Uncontrollable fears about the child’s death and concerns about cancer relapse are known to consume parents’ energy even after curative treatment of their child’s cancer.[46] These findings indicate a need to ensure effective information exchange between oncologists and patients,[29 47] and to develop well-designed need-based stress control and reduction interventions that are initiated at the point of cancer diagnosis, continue throughout the treatment process and remain available to the parents after the treatment is completed.[16]

In line with the previous research,[48 49] the findings of this study also show that the child’s clinical manifestations, the severity of their illness, uncertainty about disease outcomes and the risk of relapse/death were all significant sources of parental stress.[21 50 51] In keeping with this finding, the review of Vrijmoet-Wiersma *et al* identified the perceived severity of cancer and treatment as risk factors associated with post-traumatic stress syndrome and post-traumatic stress disorder.[22]

Another major source of parental stress identified in this work was the unavailability of chemotherapy drugs within the hospital and pharmacies. Some of these chemotherapy drugs were unavailable in the public hospital but available in private pharmacies. Others were simply not available in the country at all, so parents were expected to import the drugs by themselves. This makes chemotherapy drugs unaffordable and worsens parental stress.[38] This finding is consistent with the national cancer control plan of the Ethiopian Federal Ministry, which notes that no chemotherapeutic agents are included in the Ethiopian Essential Medicines List.[52] This indicates that more work will be needed from the ministry to the hospital level to increase the availability of these drugs.

Socioeconomic factors such as inadequate hospital facilities, familial financial constraints and lack of social support were also mentioned as causes of stress. Cancer treatment in Ethiopia is characterised by very long waiting times because of the limited availability of health facilities and resources; an earlier study found that the median waiting time for curative cancer treatment in Ethiopia was 150 days.[53] Parental stress was also increased by the prolonged referral process and the need for multiple hospital procedures to diagnose and treat child cancer. Parents from rural areas commented on the high cost of travelling to and living in Addis Ababa; together with the often lengthy wait before starting treatment, this increased their stress and financial difficulties. Further, as TASH is the country's only facility providing paediatric oncology care, parents from remote rural areas had limited opportunities to return home and care for other children for financial reasons and because of difficulties with transportation. Being unable to leave the ill child alone in the hospital and depending on others to take care of children who remained at home were stressful for the parents. Being unable to work while taking care of the sick child also reduced family income and exacerbated parental stress.[54] These findings confirm the increased vulnerability of low-income families with children undergoing cancer treatments[55] and indicate a need to further decentralise cancer treatment centres to peripheral parts of Ethiopia to ensure equal access to care.

The findings also emphasise the pivotal importance of social support for reducing stress among parents of children with cancer. In line with previous reports,[44 56–59] parents mentioned feeling less stressed after receiving social support such as care for children who remained at home, assistance with farming, financial support and emotional support in the form of reassurance. Parents also found that discussions with other parents of children with cancer helped to reduce their stress relating to the negative effects of childhood cancer.[60] These findings indicate a need to strengthen governmental and non-governmental financial support for parents of children with cancer who lack social support. In addition, because our respondents found that peer discussions with other parents of children with cancer reduced stress, giving parents opportunities to share their experiences by creating social support networks could be highly beneficial.

Previous research has shown that parental hope is associated with better mental health as well as less severe stress and maladjustment after a child's cancer diagnosis.[61–63] In this work, parents said that they became more hopeful and started having positive expectations concerning their child's condition after meeting people with a history of cancer recovery. Conversely, in accordance with an earlier report,[64] parental stress increased after encountering other children with more complex cases of cancer. It is therefore important for healthcare providers to establish arenas for parents to share experiences but also to moderate the discussions, clearly explaining the similarities and differences between children's health conditions and possible treatment outcomes.

The interviewees mentioned only a few coping strategies that they used to manage stress. In keeping with earlier findings,[26] their strategies primarily involved emotion-focused rather than problem-focused coping. Emotion-focused strategies such as praying and religious faith, crying, accepting the child's condition, doing nothing and denial were all mentioned. Ethiopia is a deeply religious society,[29] which explains why religious beliefs and praying were mentioned as primary stress-coping mechanisms. Several other studies have also concluded that religious faith plays a significant role in facilitating coping and reducing parental stress.[65–71] Given the high religiosity in Ethiopia, these findings indicate a need to further investigate the potential role of religiosity as a source of resilience among parents of children with cancer. It also shows that healthcare providers must be respectful of and sensitive to patients' religion or spirituality.

Non-religious emotion-focused coping strategies mentioned by the participants included crying, accepting the child's condition, denial and doing nothing. As emotion-focused strategies are commonly used when dealing with uncontrollable stressors, our findings indicate that Ethiopian parents experienced hopelessness and lack of control over their situation, which may have been exacerbated by dire economic and social conditions. Emotion-focused coping activities also tend to make people distance themselves from issues, making it less likely that the stressor will be addressed.[26 72] Accordingly, one participating parent said that denial reduced her ability to secure social support. Another stated she did not initially disclose her child's condition to anyone because she did not accept the diagnosis herself. However, she also noted that she began coping with the situation better once she accepted the diagnosis and discussed it with others. Parents who use emotion-focused strategies may thus exhibit low treatment-seeking behaviour, be less likely to adhere to child treatment and accept the child's condition,[73] which could adversely affect the child's treatment process.[74] In accordance with previous reports,[73 75] seeking discussions with health providers about the child's health condition, prognosis and treatment procedures was the only problem-focused coping strategy mentioned by respondents. This indicates the importance of giving parents reliable information to help them cope with stress. Oncologist shortages might make this difficult to do, although it could potentially be achieved by increasing the involvement of nurses and social workers.

CONCLUSIONS

Childhood cancer has a significant impact on the family system, drastically changing the context within which parenting occurs. Parents of children diagnosed with cancer are profoundly affected by their child's diagnosis and the associated treatment demands. Parental stress may interfere with health decisions, attendance of clinic appointments and the parent–child relationship. This study identified several sources of stress, conditions that reduce parents' stress and strategies used to cope with stress by Ethiopian parents of children with cancer. The findings demonstrate the impact of socioeconomic and cultural factors on parents' experiences and reveal a clear need for social and economic support together with the decentralisation of oncological care within the country to ensure access to care in both rural and urban areas.

Limitations and future research

The current study has some limitations. First, interviews were only conducted with parents, so children's perspectives are missing. Future research will focus on how parental coping affects their child's coping and vice versa. Further, only one parent from a given family was interviewed. Future studies will therefore investigate dyadic coping strategies. It would also be beneficial to interview nurses and oncologists about their perspectives on parental stress, coping strategies and the ways health providers support parents. Second, despite their anonymity, some participants may have been unwilling to openly criticise healthcare providers for fear that it might negatively influence the care of their children and their relationships with healthcare staff. The purposive nature of the participant selection also limits the transferability of the findings to differing populations. Future research could also focus more on stress and coping strategies of parent groups with differing levels of education and different economic statuses. Finally, as the study was conducted during the early stages of the COVID-19 pandemic, the sampling may have been confounded by factors such as fear of infection, especially in parents of children receiving immunosuppressive treatments.

Practical implications

Unlike in many developed countries, psychosocial oncological interventions and other counselling services are largely unavailable in Ethiopia. The results presented herein could be used to develop content for such interventions. Since the number of oncologists in the country is very limited, counselling services could be provided by trained nurses and social workers assigned to the paediatric oncology unit. Our analysis suggests that this counselling should include providing information about cancer, the lack of which caused stress and fear among many of our respondents. Information about treatment and diagnostic procedures offered at TASH, including treatment of side effects, should also be provided. In addition, parent-to-parent discussions and peer support should be facilitated to help parents overcome feelings of loneliness, experiences of stigmatisation and outsidership. Finally, it will be essential to raise awareness of parental stress among Ethiopian healthcare staff and to develop policies to address and manage parental stress in paediatric oncology care to mitigate its deleterious impact.

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