

Research Article

The Experiences and Needs of Mothers' of Children with Cancer in Coping with the Child's Disease

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Abstract

Purpose: To describe the experiences and needs of mothers of children with cancer in coping with the child's illness.

Participants and setting: Five mothers of children with cancer were recruited from Tallinn Children's Hospital and Estonian Association of Parents of Children with Cancer in autumn 2020.

Methodologic approach: Design of this study is qualitative, empirical, and descriptive research. Semi-structured interviews were used to collect data and inductive content analysis was used to analyse the data.

Findings: The mothers' experiences of coping with a child's disease included health-related experiences, material aspects, and changes in lifestyle, support systems and contact with professionals. The mothers' needs in dealing with the child's disease included the mother's emotional needs, the support of other family members, and the need for various support systems and services.

Implications for nursing: Nurses could help mothers of children with cancer by sharing sufficient information, teaching medication, and providing emotional support and understanding.

Knowledge translation:

- If nurses understand experiences and needs of the parents, it allows more quality and patient-centred health care services.
- Nurses can educate mothers in medication administering to the child and provide emotional support.
- It is recommended to form communication groups of parents, where parents with similar diagnoses could share experiences.

Keywords: Cancer; Coping; Child; Need; Experience

Introduction

Malignant tumours have become one of the main causes for mortality and morbidity following cardiovascular diseases across the world [1]. Tumour diagnosis was received approximately by 19.3 million people in 2020 and almost 10 million people died from malignant tumours [2]. About 4 million new cancer cases were diagnosed in Europe in 2020, and 1.9 cancer-related deaths were registered [3]. Cancer is often considered a disease among the elderly; however malignant tumours may be diagnosed among children and young adults [1]. Forty eight new malignant tumour cases were diagnosed among children in Estonia in 2019 [4].

It is exhausting to be a parent of a child with cancer diagnosis. The parents need to cope with the disease, invasive treatment, and

insecurity about child's health and future during the treatment. The parents experience a lot of psychological stress, symptoms of Post-Traumatic Stress Disorder (PTSD) and depression may occur. In addition, the treatment process has a financial effect on the family [5].

Looking after children with cancer may cause anxiety, anger, helplessness, and guilt for the close ones, but depending on family's strength and patient support system not all people need external psychological help. Less anxious parents are able to help, support the child more and to understand the disease [6].

Costa et al. [7] researched mothers' experiences when in palliative care with a child with cancer. Some mothers had to leave their jobs or schools or to stop their daily activities, since they agreed to give up everything for the child and be with them during several stages of their treatment. Mothers took care of the routine, so that doctors' appointments were possible and treatment, that the child would have necessary medications and ensured care at home. There were changes towards other family members living with a child with cancer because others had to adapt new habits and hospital routines. Changed way of life resulted in some parents being less time at home and it influenced other children in the family because they received less attention.

Child's disease is emotionally difficult for every parent. It means a major change in family's way of life. The child needs more attention and care, and parents need information helping to manage new situation [8]. As about additional help, parents of children with

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a chronic disease mentioned that child minders are needed the most, then support people for children, and information about the child's disease, help options and organizing way of life, psychological counseling, rest breaks, free time, financial support, and help relating to their own health problems [9].

Most parents of children with cancer express that they would like to receive all possible information about the diagnosis of their child, incl. prognostic information, because they find this information personally relevant and important for decision-making. Yet, many parents have unclear expectations on treatment results and some feel that they did not receive enough information to cope with the child. Unclear understanding of prognosis may influence decisions of treatment options [10].

The purpose of the research is to describe the experiences and needs of mothers of children with cancer in coping with the disease.

Materials and Methods

Study design

Current research is qualitative, empirical, and descriptive. Qualitative research contributes on better understanding of human systems by acquiring knowledge [11]. Qualitative method is appropriate to research this phenomenon because not many have researched experiences and needs of mothers of children with cancer in coping with, and this method helps to understand the phenomenon more effectively. Empirical research is a paper compiled based on experiment, practical observation, or measurements [11]. Empirical research was selected because interviews are conducted for research, resulting in descriptions of various statements, patterns, feelings, and attitudes.

Sample and setting

Estonian Association of Parents of Children with Cancer and Tallinn Children's Hospital were contacted to find the subjects. Inclusion criteria for the subjects were: participant's child is diagnosed with cancer; the subject is the mother of this child; the subject lives in Estonia; subject speaks and understands Estonian; subject agrees to participate in the study voluntarily.

Initially eight mothers agreed to participate, five of them finally replied to the questions, contact with one of them was lost and two mothers did not reply to the call. Mean age of the active participants was 36; the youngest was 24 and the eldest 40. All subjects lived in Estonia. Civil status of mothers varied, one of them was single, and other had living partners. One of the subjects was spiritually orthodox; others did not belong to any religious groups. Two subjects had higher education, one basic education, one secondary education and one applied higher education. Three mothers of five went to work and one of unemployed mothers was studying. Four of children with cancer were male and one female. Mean age of children was six, the youngest was four and the eldest was nine years old. One family had a single child, other families had two children.

Data collection

Data were collected in autumn 2020. Representatives of Tallinn Children's Hospital and Estonian Association of Parents of Children with Cancer forwarded the contacts of agreed parents to the researchers who contacted these parents to agree suitable timing and place for the subjects. It was initially planned to conduct interviews live but due to COVID-19 face-to-face meetings were cancelled. Therefore, the subjects received interview plan *via* e-mail, which allowed them to

reply to the questions in a written form and at most suitable time for them. There were five respondents. The answers of subjects varied in lengths, the shortest was 2 A4 pages and the longest 2.5 A4 pages.

Interview structure is most widespread of data collection in qualitative research. The interviews may be unstructured, semi-structured or structured. Semi-structured method is based on open questions; this method allows the interviewer to address important and personal topics within a short time [12]. Semi-structured interview was used for this research data collection (Table 1).

Sample size is sufficient if additional interviews do not allow identifying new conceptions, it is named data saturation; to find out about saturation analysis is performed simultaneously with data collection [13]. Data saturation was not achieved in current research, since three mothers of initial eight left the study.

Data analysis

Normal content analysis is used to analyse qualitative data, it can be inductive or deductive. Inductive approach is used if to move from specific to more general, so that specific cases are observed and combined into greater whole or general statement [14]. Current research used inductive approach because there was not much data about this topic prior.

Systematization process of qualitative data included open coding, categorisation, and abstraction. It is common for qualitative research that data collection and analysis takes place simultaneously [11]. Abstraction means wording general description of research issues by generalizing categories. Similar subcategories are united to categories, which form main categories [14].

Researches read the answers of the subjects in detail and added them all to the file, where the subjects were marked with a code (mother 1, mother 2, etc...). After that collections of ideas corresponding to research issues were found and marked. These were simplified and general simplified expressions formed substantive codes. Subcategories were formed after, which consisted of similar substantive codes. Subcategories formed categories with similar criteria, which formed two main categories. Table 2 illustrates categorisation process.

Ethical considerations

Credibility of research is increased by clear connection between the data and results. Therefore, detailed description of analysis process is necessary, when presenting results. One may use quotations to increase credibility of the research, but it should be ensured that people are not recognized based on their sentences [14]. Codes are used for subjects' quotations in research, so that subjects cannot be recognized. Plagiarism is avoided by appropriate in-text and full references for other authors' ideas. Texts of interviews were stored in personal laptops of the researchers, no one else could access their laptops, and documentation was destroyed after the end of the research.

Current research uses questions for semi-structured interview, based on earlier research papers. Permission to conduct research was received from Tallinn Health Care College (No 1-16/139, issued on 02.06.2020), and from Research Ethics Committee of the National Institute for Health Development (Decision No 396, issued on 07.07.2020). Researchers sent informed consent form to the subjects before conducting the research; the form was signed digitally by the participants.

Table 1: Interview plan.

Topic	Interview questions
Introductory questions related to the subject	Age
	Marital status
	Level of education
	Working status
	Spirituality/Religiosity
Questions about the diagnosed child	Gender
	Age when diagnosed
	Current age
Questions regarding the family	Number of children
	Age of siblings
Questions for the interviewee on experiences in coping with the child's disease	Which problems have you experienced since your child was diagnosed with cancer?
	How did your family adapt with the disease and changed way of life?
	What/who has helped you and your family to manage the situation?
	In which way have your relations changed within the family?
	Please describe help and support you have received during and after your child's treatment process.
Needs of the interviewee relating to coping with the child's disease.	Which possible health problems have you experienced regarding supporting your child's coping with?
	What is important to you relating to supporting your child?
	Which are your needs relating to supporting your child's coping with?
	Which additional help/support is necessary?
	Describe your needs for additional help and support.
Summary	How else could one support you to help your child?
	Is there anything else you would like to share with relating to your experiences?

Table 2: Categorisation process.

Collection of ideas from database	Substantive code	Subcategory	Category	Main category
"Major problem financially..."	Serious financial issue	Experiences relating to financial issues	Experiences relating to way of life and material aspects	Mothers' experiences in coping with the child's disease
"...how to manage financially..."	Management of money			
"I was on sick leave, a child home from kindergarten."	The child did not go to the kindergarten	Experiences regarding changes in a way of life		
"Luckily we could spend more time at home."	More time at home			

Results

Mother's experiences in coping with the child's disease

Main category, Mothers' experiences in coping with the child's disease was formed by substantive codes, which formed 15 subcategories and these four categories, which had experiences relating to material aspects and way of life, links to health, various support systems and specialists' support. Table 3 explains mothers' experiences in coping with the child's disease.

Experiences relating to way of life and material aspects

Mothers wrote that new situation was financially problematic for them, and they had difficulties in making the ends meet.

"It was major financial problem. At first, I was afraid of how to manage financially. As time passed by, it was finally solved".

Some respondents had not changed the way of life, yet some other mothers noted that way of life were constantly changing. The subjects found that priorities had changed and some of them lived a day at the time. It was emphasised that they could spend more time at home and the child did not attend kindergarten.

"I was on a care leave, the child stopped going to kindergarten and we spent 8 months between home and hospital. Luckily, we spent more time at home".

"Disease and treatment are unpredictable; therefore we have chosen to live a day at the time. We never know how child's condition is tomorrow. Therefore, a way of life is constantly changing".

"Priorities have changed. Minor problems are irrelevant now".

Most mothers had adapted the situation, but there was a mother writing that she had adapted the situation but not accepted it.

"This disease cannot be adapted and accepted 100%".

"We have adapted but not accepted".

"The family adapted well; this is new normality for us".

Mothers experienced that lack of information was most problematic. No people with similar background were found to ask tips or help. One of the mothers informed that she was not given enough information how a way of life was continuing. There were many questions after receiving the diagnosis but one of the mothers still solves the issues and is looking for answers even three months later.

"I did not know where to find people with similar problems to talk to. What is going to happen? What will happen to the child?"

"Many questions occurred, and I am still solving them now, three months after the diagnosis".

"Not enough information and help was given, in which way it will be functioning".

One of the mothers highlighted that administering tablets was a major challenge and the situation was more difficult because the nurses and doctors did not understand it, and nurses working at hospitals were unable to give tips, which could have helped. It was also mentioned that situations are rapidly changing during treatment and therefore quick solutions are necessary.

"Giving pills was a great challenge and nurses and doctors did not understand it and it made it all worse".

"I got argued because the pills were not administered on time, although I had tried to convince, threaten, and smooth the child for 2 hours to take them".

Table 3: Mothers' experiences in coping with the child's disease.

Subcategory	Category
Experiences relating to financial problems	Experiences relating to way of life and material aspects
Experiences relating to changes in a way of life	
Experiences relating to adaptation	
Experiences relating to receiving information	
Experiences relating to changes in treatment process	
Experiences relating to mother's physical health	Experiences relating to their health
Experiences relating to mother's mental health	
Experiences relating to ill child's health	
Experiences relating to family support	Experiences relating to various support systems
Experiences relating to friends'/acquaintances support	
Experiences relating to support from various organisations	
Experiences relating to specialists' support	
Experiences in family relationships	Experiences in relationships
Positive experiences relating to staff	
Negative experiences relating to staff	

"Situations are rapidly changing during treatment and some of these need quick solutions".

Experiences relating to health

As of physical complaints, tiredness, lack of energy, back pain and problems related to inactivity were mentioned.

"Tiredness is the greatest /.../ Feeling of inability to help now and quickly your child".

"Unless some back pain and problems caused by inactivity".

Parents emphasised that it was mentally challenging to cope with and there was additional stress due to medication administering to the child. Also, mood swings, anxiety, panic attacks and personal problems occurred.

"I got argued if pills were not taken on time... It was tremendous additional stress".

"Mood swings, too".

"Anxiety, panic attacks, mental health problems".

One child had had mental health problems, stressed and the process and disease had made them tired.

"With child's anger, irritability, physical touch, speech and being awake /.../ fall asleep within the second -in kindergarten, now at school".

Experiences relating to various support systems

Mothers expressed that there was support and help from the family. And yet, there was a mother that said that the husband did not help, and relationships had some extra tension.

"Relationship with my man was very tense at the beginning because I felt he did not support me".

"My mum has always been the best support, and father of the child helped also".

Mothers wrote that their friends helped a lot, they could talk to them, they listened to them, also parents in the same situation helped, and they could provide tips and help.

"Talking to other parents at hospital helped a lot, their children had been there".

"Communication with friends was very good; they helped to keep my mind somewhere else".

Mothers replied that help and support was provided by local municipalities and from the Estonian Association of Parents of Children with Cancer. Mothers value existing help and support.

"Estonian Association of Parents of Children with Cancer has been very helpful; they were always there in case of questions or problems".

"Local municipality helped with getting benefits".

Mothers received support when needed. Families were supported by chaplains, support person, family therapist, rehabilitation centre helped with therapy and counseling.

"Chaplains visiting hospitals were very helpful".

"Support person has helped family's welfare".

"A year of family therapy turned our relationship stronger as ever".

Experiences in relationships

Interviews revealed that receiving difficult diagnosis adds tensions to everybody and a lot of stress occurred within the family, but it all strengthened relationships and mental help helps to improve communication if necessary. Some mothers still emphasised that relationships did not change, or people become more opaque.

"Relations within family did not change".

"More opaque"

"Family relationships definitely became better, connection stronger".

"At first relationship with my man became very tense.... But a year in family therapy changed our relationship stronger than ever".

Some mothers had highlighted that hospital staff provided them with safety feeling and they were grateful.

"I am grateful for those who support and help. Support groups created at hospital and doctors create good and safe feeling".

One mother informed that she could not be with her child before the surgery and when the child woke up, she could not be with her. She also experienced that nurses and doctors did not understand her difficulties, especially in administering tablets, and staff had no ideas how to improve the situation.

"...where little child has to wait for the surgery without the mum and waking up is also without the mum in the waking up room".

“Lack of understanding of nurses and doctors/.../ I got argued when pills were not taken on time /.../Also nurses had no ideas what to offer”.

Mothers' needs in coping with the child's disease

Main category, Mothers' needs in coping with the child's disease “was formed by substantive codes, which were grouped into nine subcategories, which formed three categories; emotional needs in coping with the child, needs relating to other family members and needs for different supporters and services. Mothers' needs in coping with the child's disease are explained in Table 4.

Mother's emotional needs in coping with the child

Mothers wrote that mental support, help, and understanding were important, to have someone to rely on, support and share problems and ideas with. Some informed that they had desired more support and trust from hospital staff.

“Surely help, support and understanding for me /.../ to rely on someone and talk about my ideas/problems”.

“It is necessary that nurses/doctors trusted the parent”.

Parents felt that somehow, they need to cope with, and they need to hold on. It was mentioned that they need to be brave enough to ask for help and support.

“The road is full of obstacles, but you need to be strong and hold on bravely /.../ you must not be afraid of and ask for help and support”.

Mothers highlighted the need of confidence regarding treatment process, which should be explained as early as possible, the way how everything is going to function.

“It is important that treatment was responded and doctor's confidence on performed treatment”.

“To explain early what is planned and when”.

Research revealed that some mothers have forgotten their own needs, also right questions had not been found.

“I have forgotten my own needs”.

“I often do not know which questions to ask and needs to find”.

Mother explained that free time is necessary sometimes to have a rest and be more efficient for the child. Also, another mother highlighted that need relating to supporting the child is simple sleep.

“Perhaps if I could have some free time to charge my batteries to be stronger for the child /.../ Tiredness is the greatest”.

“Sleep... ”.

Needs relating to other family members

Mothers confirmed that ensuring the feeling of safety is essential, so that the child would feel themselves fine. One mother highlighted that one should take time to conduct unpleasant procedures, and there is a need to be next to the child before and during the procedures. One mother replied that administering pills need to be practiced step-by-step, so that the child would get used to accept the situation.

“That they would have feeling of safety”.

“It is very important to be with the child during unpleasant procedures or before the surgery... it is also important to take time for unpleasant procedures so that the child would be ready for it /.../

Practicing step-by-step would have been much easier”.

Questions were arisen how to organize education, can the child spend time with other children and do same activities or not. It was also written that it is important to stay positive and to lead the child to be positive.

“How to reorganize current life to provide the child with necessary conditions for the treatment. How to organize education? How much can they be with other children and feel themselves as ordinary child (can run around and have fun)?”

“To stay calm, support and lead them to positive way of thinking”.

Mother highlighted that there is another child in the family whose wishes and needs are in the background even if unplanned, and in case there is unexpected situation, and then there is a problem that can spend time with this child then.

“Most of all I need some therapy to another child because it affects them, too and even if not to want, their needs and wishes are in the background”.

“What happens if I must go to hospital with the child unexpectedly? Who can come to another child? How to divide myself, so that the other child would not feel left out?”

Need for various supporters and services

Most subjects confirmed the need for mental support and additional support from psychologist, family, or counsellor. One mother noted that had problems with medicine administration that it would be supporting to have a Facebook group, where advice could have been asked from other parents. She also wrote that nurses need training on child psychology, so that staff knew how to behave with children and use another approach.

“Possibly a shrink and family support”.

“The need for mental counseling and support /.../ Good mental health counselor”.

“I would have liked that Facebook group”.

“Nurses need child psychology training”.

One mother explained that since the child left kindergarten, she had to take a care leave paper. Other mother needed more time and she separately noted that needed someone at home to cook. Since disease may be mentally and physically challenging, one mother wished training how to relieve stress and tension practically. It was separately listed that to support a child there are needs for medication, transportation, and support services.

“I need someone at home to cook”.

“I took a care leave, child left the kindergarten”.

Table 4: Mothers' needs in coping with the child's disease.

Subcategory	Category
Need for understanding and support	Mother's emotional needs in coping with the child
Need to be strong and brave	
Need for confidence	
Ignoring mother's own needs	
Need for personal time and rest	
Needs relating to the ill child	Needs relating to other family members
Needs relating to other children in the family	
Need for various supporters	
Need for various services	Needs for various supporters and services

“...practical training to relieve tensions”

“... Drugs, transportation, support service”.

Discussion

Research results revealed, which are the experiences and needs for mothers of children with cancer in coping with the child's disease. Cernvall et al. [5] noted that parents experience a lot of psychological stress; they might experience PTSD and symptoms of depression. Additionally, treatment process affects the family financially. Current research demonstrated in results that the subjects had experiences regarding way of life and material aspects. Not all respondents changed their way of life, there were some that changed their priorities and minor problems were unimportant. Authors of research find that child's disease changes daily life of the family and problems have another perspective.

Tark et al. [6] noted that in addition to anger taking care of the close ones may cause helplessness, grief, and guilt. 40% to 70% cancer patients' caretaker's symptoms of depression occur. Analysis of research revealed that subjects of the research had problems with physical and mental health. Several parents had experienced tiredness, lack of energy, anxiety, and panic attacks.

Turner-Sack et al. [10] noted that parents would like to receive all possible information about diagnosis of their child, also prognostic information, because it plays a major role in decision-making, but many have unclear expectations regarding treatment and too little information how to cope with the child. This research also revealed that mothers desire as much information as possible and early explanation how everything is about to function. It was also highlighted that feeling of safety should be ensured regarding treatment process. Authors of current research state that parents could plan their life more effectively if there are early explanations how the process is functioning and to give an overview of support systems opportunities.

Metsla [8] has written that disease is emotionally exhausting and changes in family daily life are implemented, also parents need detailed information to cope with the new situation. Current research revealed that adaptation takes time and effort should be made to change way of life because more time is dedicated on the child with diagnosis, also one should not forget other children and should pay attention to them.

Costa et al. [7] mentions that after the diagnosis of the child many mothers must quit their jobs or school or to give up daily activities because they agreed everything to be next to the child during various stages of treatment. Mothers also took care of the routine that all medications are available and doctor's appointments are on time. Mothers also took care of cooking and hygiene. Authors of current research expressed that some mothers had to take a care leave paper to stay home with the child and live in a moment because they never knew what the child's health status could be next day. They stated in needs category that they need someone to cook, take care of medications and transportation.

Kallaste et al. [9] has written that additional help regarding child minders and support people is needed, also mental counseling and a psychologist, it was added that more free time, rest breaks and financial support are needed. Results of this research revealed that most subjects desired more time and rest to keep their head straight. Also, childminders are needed, especially in case of more than one

child in the family and the mother has no time for everyone. Financial fears occurred because there were many costs regarding the treatment. More mental support or training how to cope with stress is necessary. Authors find a support system is needed for the families received cancer diagnosis.

Limitation of the research was limited number of parents, not everyone that agreed to participate in interviews did participate in research and data saturation did not occur. Sensitive topic encumbered finding the subjects, since mothers might have it difficult to share their experiences in coping with the ill child's disease, on the other hand influence of COVID-19 pandemic, which hindered conducting immediate “face-to-face” interviews.

Implications for nursing

Results of the research are introduced to nurses and doctors of Tallinn Children's Hospital to implement these in practice. If health care employees understand experiences and needs of the parents, it allows more quality and patient-centered health care services. The subjects had pointed out that nurses need training on child psychology, so that health care workers knew how to behave with children and use different approaches. As mothers had also problems with their own mental and physical health due to child's disease, they needed more mental support, help, and understanding. Nurses could help mothers of children with cancer by sharing sufficient information and educating mothers in medication administering to the child. The authors of research suggest forming communication groups of parents, where parents with similar diagnoses could share experiences.

Conclusion

Mothers' experiences in coping with child's disease included experiences relating to health, material aspects, changes in a way of life, help from support systems and encounters with specialists. Although some mothers experienced that hospital staff provided them with safety feeling and they were grateful, the others experienced that nurses and doctors did not understand their difficulties and they desired more support and trust from hospital staff.

Mothers' needs in coping with the child's disease included mother's emotional needs, support from other family members and needs for various support systems and services. Some mothers complained lack of information, they needed confidence regarding treatment process, which should be explained as early as possible. In particular, they would have needed help in medication administering to the child. The subjects had pointed out that they need more time for rest and the childcare would also be necessary. The mothers have also a need for more mental and financial support. The support system is needed for the families. In the future, awareness of health care employees about supporting parents of children with cancer could be researched more in the frames of national quantitative research, which enables to improve the quality of health care services.

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