

**“It turns life upside down”: Experiences of parents
in the personal care of a child hospitalized for cancer**

**“Cambia la vida de un día para otro”: Experiencias de madres y padres
al cuidado personal de un hijo/a hospitalizado por cáncer**

**“Muda a vida de um dia para o outro”: Experiências de mães e pais
no cuidado pessoal de uma criança internada por câncer**

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Abstract: Objective: To understand the meaning attributed by parents to the experience of being with their hospitalized child in an oncology unit of a public hospital in Chile. Methodology: Interpretative research paradigm, Van Manen’s hermeneutic phenomenological approach. In-depth interviews were conducted with 10 participants and the narratives were analyzed by means of a thematic analysis with selective reading approach. The article was approved by the ethics committee of the Pontificia Universidad Católica de Chile. Results: The experience of hospitalization meant “It turns life upside down”; this outcome was shaped by two structures: 1) “When they give you the diagnosis your world falls apart”, which contains difficult moments such as the hospitalization when they receive the diagnosis, the moments when the child suffers, life-threatening situations, the tiredness of mothers and fathers and the changes that affect the family, and 2) “Receiving a helping light during hospitalization”, which describes the importance of a quiet physical space, a health team with a caring treatment and sharing experiences with other parents. Conclusions: Hospitalization represents a transformation in the life world of parents, it is vital that the health team attends to the physical and emotional needs that derive from this change in the space and relationships they experience.

Keywords: cancer; parents; hospitalization; oncology service.

Resumen: Objetivo: Comprender el significado que atribuyen los padres y madres a la experiencia de estar junto a su hijo hospitalizado en una unidad de oncología de un hospital público de Chile. Metodología: Paradigma de investigación interpretativo, enfoque fenomenológico hermenéutico de Van Manen. Se realizó una entrevista en profundidad a 10 participantes y las narrativas se analizaron mediante un análisis temático con enfoque selectivo de lectura. El artículo fue aprobado por el comité de ética de la Pontificia Universidad Católica de Chile. Resultados: La experiencia de hospitalización significó

“cambiar la vida de un día para otro”; este resultado se conformó por dos estructuras: 1) “Cuando te dan el diagnóstico se te derrumba el mundo”, que contiene momentos difíciles como la hospitalización en que reciben el diagnóstico, los momentos en que el hijo/a sufre, las situaciones de riesgo vital, el cansancio de las madres y padres y los cambios que afectan a la familia, y 2) “Recibir una luz de ayuda durante la hospitalización”, que describe la importancia de un espacio físico tranquilo, de un equipo de salud con un trato cariñoso y de compartir experiencias con otras madres y padres. Conclusiones: La hospitalización representa una transformación en el mundo vida de los padres y madres, es vital que el equipo de salud atienda las necesidades físicas y emocionales que derivan de este cambio en el espacio y relaciones que estos vivencian.

Palabras clave: cáncer; padres y madres; hospitalización; servicio de oncología.

Resumo: Objetivo: Entender o significado atribuído pelos pais à experiência de estar com seu filho hospitalizado em uma unidade oncológica de um hospital público no Chile. Metodologia: Paradigma de pesquisa interpretativa, abordagem fenomenológica hermenêutica de Van Manen. Foi realizada uma entrevista aprofundada com 10 participantes e as narrativas foram analisadas utilizando uma análise temática com uma abordagem de leitura seletiva. O artigo foi aprovado pelo comitê de ética da Pontificia Universidad Católica de Chile. Resultados: A experiência da hospitalização significou “Muda a vida de um dia para o outro”; este resultado foi moldado por duas estruturas: 1) “Quando você recebe o diagnóstico, seu mundo desmorona”, que contém momentos difíceis como a hospitalização quando recebem o diagnóstico, momentos em que a criança sofre, situações de risco de vida, cansaço das mães e dos pais e mudanças que afetam a família, e 2) “Receber uma luz de ajuda durante a hospitalização”, que descreve a importância de um espaço físico tranquilo, uma equipe de saúde com um tratamento cuidadoso e compartilhando experiências com outras mães e pais. Conclusões: A hospitalização representa uma transformação no mundo da vida dos pais, é vital que a equipe de saúde atenda às necessidades físicas e emocionais que surgem desta mudança no espaço e nos relacionamentos que eles experimentam.

Palavras-chave: câncer; pais e mães; hospitalização; serviço de oncologia.

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Introduction

Childhood cancer is a global health problem. According to estimates from the Global Cancer Observatory, in 2020 approximately 280,000 children and adolescents were diagnosed worldwide. ⁽¹⁾ In Chile, childhood cancer is the second cause of death in children, with an average of 516.8 new cases per year and with an overall survival rate of 73.5 % 5

years after the cancer was diagnosed ⁽²⁾ which is similar to high-income countries. ⁽³⁾ Treatment in Chile is directed by the National Childhood Cancer Program (or PINDA in Spanish), which has 11 integral health centers, 4 partial centers, and 5 support centers where children receive different therapies and treatment of complications. ⁽²⁾

Childhood cancer therapies are intense and require frequent and prolonged hospitalizations. ⁽⁴⁾ For this reason, in numerous hospitals around the world, children and adolescents are with their parents during hospitalization, thus adhering to the World Health Organization (WHO) recommendation that states that all children should be with their caregivers as a fundamental right. ⁽⁵⁾ Furthermore, the emotional trauma suffered by hospitalized children and adolescents who are separated from their mother and father, ⁽⁶⁾ the stress caused by hospitalization, ⁽⁷⁾ as well as the beneficial effect that parental involvement has on parental and children anxiety levels during the hospitalization process ⁽⁸⁾ are widely recognized. Separation of parents and their children has become more important with the current pandemic situation, where the presence of caregivers at the hospital was restricted, limiting the possibility providing family-centered care. ⁽⁹⁾

On the other hand, recurrent hospitalizations cause extended periods of stress in parents due to the activities assumed as caregivers, the social stigma that this serious disease entails and the need for emotional support that the sick child demands. ⁽¹⁰⁾ Hospitalization also has repercussions on the family level, causing an imbalance in child care between both parents and changes in couple relationships, ⁽¹¹⁾ forcing a reorganization of family tasks. ⁽¹²⁾

Considering the wide impact of hospitalization on children and adolescents, some pediatric hospitals have taken the family-centered care model as a reference, which emphasizes the importance of listening to parents' concerns, building trust, and valuing the knowledge they have about their child. ⁽¹³⁾ In Chile, the monitoring and continuous care of mothers and fathers during hospitalization in oncology units is a phenomenon that has emerged in less than a decade, ⁽¹⁴⁾ and it still counts with few studies at the national level, which has posed new challenges for nursing professionals. Therefore, the research question from which this article emerge was: how do mothers and fathers live the experience of being with their hospitalized child in an oncology unit?

To answer this question, we conducted a research based on Van Manen's experiential phenomenology or phenomenology of practice. This research approach has been used by some authors to understand the experience of people living serious health problems such as cancer ⁽¹⁵⁻¹⁸⁾ and is applicable to the aim of this research because it allows a detailed description and better understanding of the world that parents live during their experience of the hospitalization of their children due to cancer.

Max van Manen, a Canadian social scientist and educational philosopher, developed the phenomenology of practice, which is an approach that seeks to answer questions about how people act in everyday life situations. ⁽¹⁹⁾ The "of practice" part refers to the meaning and practice of phenomenology in professional contexts, as well as the practice of phenomenological reflection in contexts of everyday life. ⁽²⁰⁾ Van Manen's vision regarding the phenomenology of practice is that it can make accessible the non-cognitive (pre-reflexive) dimensions of practice, what is pre-reflexive is the original experience, that is, the immediate contact with the world before becoming conscious to the subject.

Methodology

The experience of parents was explored with the interpretive paradigm, using a phenomenological design with a hermeneutical approach according to Van Manen,⁽¹⁹⁾ which highlights that phenomenology of practice is a type of research “that addresses and helps professional practices”,^(20 p17) and in this way it “maintains an attentive attitude to the ways in which human beings experience and are aware of the world”.^(20 p58)

Van Manen's approach is guided by four existential themes, which are structures of experience that allow us to interpret the interviewee's *lifeworld*: lived space (*spatiality*), lived time (*temporality*), lived body (*corporeality*), and lived relationship (*relationality*). These themes enable us to contextualize the human experience of the participants and integrate the meanings in a medium to base the human experience. This process is carried out in an iterative process of reflection, listening to the participant and weaving his lifeworld from the present and future situations that he relates around his experience and his relationship with other human beings. The preparation of the research question was framed in the phenomenological methodology that aims to capture the meaning of the phenomena as they come to the consciousness of the interviewee. To attain this, an initial open question was conceived in order to generate comprehensive knowledge regarding the experience lived by mothers and fathers in relation to the hospitalization of their children in an oncology unit based on their own experiential reports.

Also, a sociodemographic questionnaire was applied to characterize the participants according to their age, sex, nationality, education level, occupation, residence region, occupation, health insurance, marital status, and number of children. In the questionnaire, information about the child was also asked: age, diagnosis, time from diagnosis to interview and stage of treatment. It was also recorded the number of hospitalizations in which the interviewee performed the role of main caregiver.

Participants

The study was carried out in a pediatric oncology unit of a public pediatric hospital in Santiago de Chile, between October 2018 and May 2019. Although there is vast evidence in other countries about the impact of hospitalization on parents of children with cancer, in Chile, a country where the National Childhood Cancer Program has been running for 34 years, no published studies were found that describe the experience of parents during hospitalization in these health centers.

Mothers and fathers of children with cancer who were treated in the oncology unit were invited to participate. The inclusion criteria were being over 18 years of age, being father or mother of a child under 15 years of age with cancer, being the main caregiver, expressing their willingness to participate and having a pass from the unit psychologist, this last criterion safeguarding the non-maleficence of the investigation. Parents or mothers whose child was in a situation of cancer relapse, palliative care or in the intensive care unit at the time of the interview were excluded, considering that the interview could cause some damage to them.

Procedure

Parents who met the inclusion criteria were provided written information about the study by the unit psychologist. Those mothers and fathers who agreed to participate authorized the delivery of their contact information to the research team. These parents were contacted by telephone by the main researcher, and the time and place of the interview was coordinated. It should be noted that the researchers did not previously know the participants or have any relationship with them.

Data collection

The interviews were conducted privately in a room at the hospital or at the participant’s home, according to the preferences of the parent, in order to secure an environment of comfort and confidentiality for the in-depth interview.

For each participant, on the agreed date the informed consent was read and signed along with the application of the sociodemographic questionnaire. Subsequently, the main researcher conducted the in-depth interview, which was audio-recorded and lasted 50 minutes on average. The interview had a script that began with the question: How have you lived the experience of being with your son/daughter hospitalized in the oncology unit? Following the methodology proposed by Van Manen, during the interview detailed questions derived from the responses of each participant were asked to deepen the narrative of their experience. This script was previously piloted with a mother from another hospital.

Information analysis

For the characterization of the participants the data obtained in the sociodemographic questionnaire was tabulated and statistical measures were computed such as average, minimum, maximum. To carry out the analysis of the interviews, the process proposed by Van Manen,⁽¹⁹⁾ was followed: each interview was literally transcribed and analyzed through a thematic analysis with a selective reading approach⁽²⁰⁾ (Figure 1).

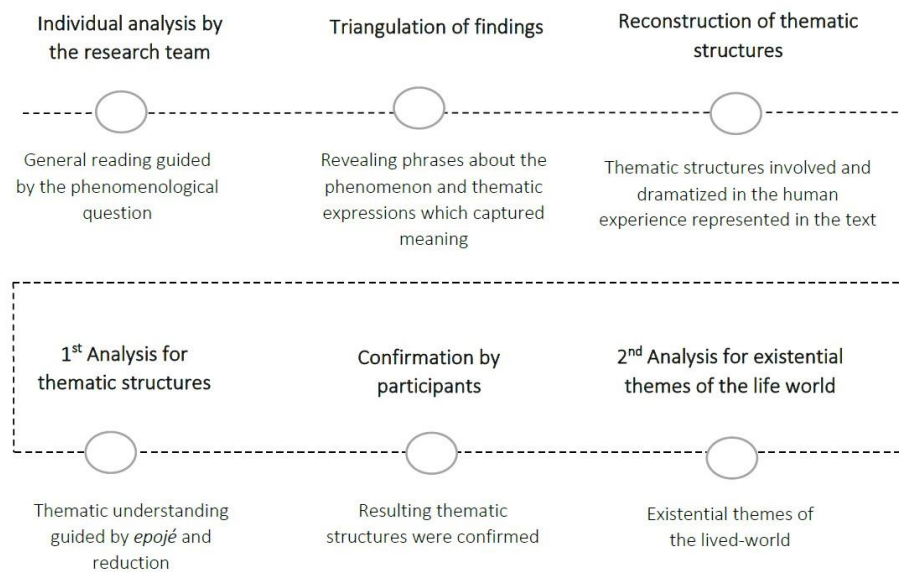


Figure 1. Thematic analysis with a selective reading approach based on Van Manen. Source: Own elaboration (2022)

This process began with the general reading of the interviews by each of the researchers, separately, guided by the phenomenological research question.

Subsequently, the researchers triangulated their findings by highlighting the revealing phrases of the phenomenon and capturing the phenomenological meaning through thematic expressions or through phrases in the text that were particularly evocative.⁽²⁰⁾ Collectively, the researchers manually coded the narratives, recovering the thematic structures dramatized in the human experience represented in the text, guided by the existential themes of the lifeworld according to Van Manen. Then, they formulated a thematic understanding from the narratives, respecting *epojé* and reduction. To determine the number of interviews, the criterion of data saturation was applied; the three researchers observed data saturation in the eighth participant so two more interviews were conducted, compiling a total of ten interviewed participants. Lastly, the final thematic structures containing the unveiled phenomena were shared by telephone with the participants, who confirmed that they felt identified with the findings.⁽¹⁹⁾

During the investigation, compliance with the methodological rigor proposed by Guba & Lincoln⁽²¹⁾ was ensured. Credibility was safeguarded by returning the description of the phenomenon to the participants and their acknowledgment of the experience. Confirmability was accomplished by describing in the research the steps of the information gathering and analysis process, which led to the thematic structures. Dependability was achieved by basing the resulting thematic structures on the words of the subjects that reflect their experience, a process that was built by triangulating the process of analysis of the interviews between the three researchers and using the actual words of the participants in the thematic structures. The transferability of this study is fulfilled with the clear characterization of the participants and the context where the research is carried out.

In addition, it was approved by the Science Ethics Committee of the Faculty of Medicine of the Pontifical Catholic University of Chile and the Research Unit of the Hospital where the study was carried out.

Results

The research involved 10 main caregivers. Two mothers refused to participate in this study for reasons related to the care of their sick child. The sociodemographic characteristics of the participants were described in Table 1. For this study, 8 mothers and 2 fathers, whose ages were between 22 and 44 years, were interviewed. All were Chilean, the educational level was middle or high school predominantly (70 %) and a high percentage of parents had a paid employment before the diagnosis of their children (80 %). Marital status was predominantly single (80 %). A third of the participants lived with their children and partner, another third with their child and extended family, and another third only with their child. Notably, a high percentage of parents (70 %) had more than one child at the time of cancer diagnosis.

Table 1. Characteristics of the 10 parents interviewed between October 2018 and May 2019 in a public hospital in Santiago de Chile

Participant code	Age	Sex	Educational level	Occupation	Marital status	Living with	Number of children
Participant 1	34	Female	High school	Pharmacy assistant	Single	Daughters	2
Participant 2	44	Female	High school	Housewife	Single	Daughter	1
Participant 3	27	Female	Middle school	Housewife	Single	Daughter and couple	2
Participant 4	22	Female	Elementary school	Farmer	Single	Son and partner	1
Participant 5	35	Male	Technical	Constructor	Married	Daughter and couple	2
Participant 6	21	Female	High school	Housewife	Single	Mother and children	2
Participant 7	37	Male	High school	Carrier transport	Single	Alone	1
Participant 8	34	Female	Elementary school incomplete	Street vendor	Single	Children and mother	3
Participant 9	43	Female	Technical education	Preschool teacher	Divorced	Children	3
Participant 10	38	Female	Technical education	Nursing assistants	Single	Children and mother	2

Source: Own elaboration (2022)

Regarding the characteristics of the children with cancer (Table 2), the ages ranged from 1 to 13 years with a median age of 5 years. The predominant diagnosis was Leukemia (60 %), followed by Nervous System Tumor (40 %). All were in active treatment phase and had been diagnosed on average 6 months before the interview. Prior to the interview, the participants had been with their children fulfilling the role of main caregivers between 2 and 22 hospitalizations.

Table 2. Characteristics of the children of the participants

Participant code	Child's age	Diagnosis of the child	Time from diagnosis to interview	Stage of child's treatment	Hospitalizations with the caregiver interviewed
Participant 1	10	Acute lymphoblastic leukemia	7 months	End of consolidation	9
Participant 2	13	Acute lymphoblastic leukemia	7 months	End of consolidation	8
Participant 3	3	Ganglioneuroblastoma	2 months	Half Treatment (2/4 chemotherapies)	4
Participant 4	5	Acute lymphoblastic leukemia phi(+)	7 months	End of consolidation	4
Participant 5	2	Acute lymphoblastic leukemia	2 months	Start of consolidation	3
Participant 6	1	Central nervous system tumor	3 months	5th cycle chemotherapy radiotherapy	5
Participant 7	1	Acute myeloid leukemia	2 months	Start of consolidation	2
Participant 8	12	Acute lymphoblastic leukemia	5 months	End of consolidation	3
Participant 9	13	Teratoma brain tumor	4 months	Half of the treatment	4
Participant 10	4	Medulloblastoma	24 months	End of treatment	22

Source: Own elaboration (2022)

The account of the experience lived by mothers and fathers during the hospitalization of their child in an oncology unit was analyzed, giving rise to the thematic structures whose results are summarized in Table 3.

Table 3. Summary of results

Central thematic structure	Secondary thematic structures	Thematic substructures	Thematic expressions	
"It turns life upside down"	When they tell you the diagnosis, the world collapses	The hardest part of all was hearing the diagnosis	Associating the word cancer with death, not understanding how the disease works Feeling like the world is collapsing when you hear the diagnostic The first hospitalization was the biggest shock Freezing in the first hospitalization, not being able to hear anything, not knowing what to do Not wanting to assume the diagnosis, thinking that it is a mistake	
		The hardest thing is to see a child who suffers	Suffering to see her daughter exposed to painful procedures Feeling sorry to see that your child is sedated It is terrible to witness your daughter lying in bed from chemotherapy	
		Seeing a child in ICU is devastating.	Fear that your child will go to the ICU because you will not be able to be with him Seeing other children dying in the hospital brings back the possibility of your daughter's death Serious situations generate uncertainty that makes you assess your daughter's recovery from a different perspective	
		Being there in the hospital routine is exhausting	Spend most of the personal time taking care of your daughter Being alone in the hospital room is hard. An emotionally tiring experience due to the constant complications that prevent discharge Spend less time with his other children	
		Dealing with changes that affect the rest of the family	On top of physical fatigue is the change in the relationship with my other son Cancer is a disease that impacts the lifestyle of the entire family Move to live in Santiago so that your child receives treatment and leave the rest of your family Be the main pillar of the family	
		Receiving a help light during hospitalization	The hospital facilities gave me some peace of mind	The oncology unit a protected space that allows your daughter to express her emotions The oncology unit is a comfortable and clean place which provides you with safety Oncology rooms create an intimate environment for mother and child, which supported improving communication
			The nurses give love and a light when everything is dark	Feeling the health care team's concern for the details towards the children gives us peace of mind as parents The oncology unit: a nice surprise, the professionals were waiting for us Feeling supported by the health care team at leaving my home behind The nursing team gives love to your child and that is essential
			Help each other between mothers by sharing the experience	Advice from other mothers encourages me to keep going The other mothers who arrive go through the same despair, I am able to transmit them strength Feeling recognized, hearing that other people admires you as a mother

Source: Own elaboration (2022)

Figure 2 shows the main structure of the results, and it is titled “It turns life upside down”. It contains 2 secondary structures: “when they tell you the diagnosis, the world collapses” and “receiving a helping light during hospitalization”. The first structure brings together the difficult experiences that mothers and fathers live in caring for their child during hospitalization, and these meanings are grouped into 5 thematic substructures that narrate complex moments such as “the hardest part of all was hearing the diagnosis”, “the hardest thing is to see a child who suffers” and “seeing a child in ICU is devastating”. This structure also contains the personal impact of hospitalization which is shown in “being there in the hospital routine is exhausting” and “dealing with changes that affect the rest of the family”. The second structure is positioned behind and in contact with the first one, since it was observed as an element that appeared simultaneously with the difficult moments narrated by the participants and it is entitled “receiving a helping light during hospitalization”. This second structure contains 3 substructures that were “the hospital facilities gave me peace of mind”, “the nurses give love and light when everything is dark” and “we help each other between mothers by sharing our experiences”.



Figure 2. Thematic structures of the experience lived by parents of children hospitalized in an oncology unit. Source: Own elaboration (2022)

Simultaneously to the identification of the thematic structures described above, the four existential themes of the lifeworld: spatiality, temporality, relationality and corporality were also revealed, which made it possible to reconstruct in greater depth the parents' life world coming to a broader understanding of the hospitalization experience as a life changing experience.

Each of the unveiled units and the narratives contained in them will be described below.

Structure 1: When they tell you the diagnosis, the world collapses

The hardest part of all was hearing the diagnosis

In the first hospitalization, mothers and fathers experience a shock state, marked by feelings of pain and impotence in the face of receiving a completely unexpected diagnosis of cancer of their child, which leads them to associate it with the possibility of death. In addition to this, there is change in the lived temporality, that is, a break in the perception of the future, to which is added the stress and uncertainty of communicating the diagnosis to your child.

When they tell you the diagnosis, your world collapses. At first, it was terrible, I had never set foot in a hospital!... For one, it's all new, because my daughter had never been hospitalized... New, difficult, complicated!... My daughter said: "I can't walk" ... "I want to die". I think that was the most difficult of all: listening to the diagnosis. Even though I had read it, when they told me I thought my daughter was going to die... And she also thought that (Participant 2).

The hardest thing is to see a child who suffers

During hospitalization, the pain and anguish of the children in the face of the procedures generates suffering, impotence and despair in the mothers and fathers, since they do not have the possibility of exercising a role of protection.

The first hospitalization... Seeing her, she didn't want to eat, they pricked her so much, she cried, she told me: "I want to go home, let's go, let's go! Don't poke me!". That is the hardest thing for one, to see a child who suffers because of that [gets emotional], they couldn't find his veins, that is the most painful thing for a mother (Participant 3).

Seeing a child in the Intensive Care Unit is devastating

The transfer to the intensive care unit (ICU) is one of the most difficult moments for mothers and fathers, due to the seriousness that this entails, the risk of death (representing uncertainty regarding the future) and the separation to which they are forced given the norms of this hospital unit (illustrating an important change in the relationality with the child and in the experience of space).

When she is in the ICU she has to be isolated with IVs, with a mask, intubated... And you see your child like this and it is devastating. You have never seen her like this before... After about four days that she was hospitalized, I was just able to take her in my arms, hug her, feel her close to me... And then your soul returns to your body! (Participant 5).

Being there in the hospital routine is exhausting

The frequent hospitalizations required by children in active treatment accentuate the fatigue of mothers and fathers who are taking care of them, being forced to postpone their own care such as sleeping, bathing and eating. But they are also limited in the expression of their emotions, having to maintain constant strength in front of their children.

Because you can't sleep in an armchair. Being there without being able to sleep, because at night the nurse comes in to take her blood pressure... I think all of that is the most tiring thing about being there! Being with this hospital routine. And emotional because one has to see his daughter who is there, lying on a bed! That she doesn't want to eat, that she feels bad, that she doesn't feel like it... So, it's complicated! (Participant 2).

Dealing with changes that affect the rest of the family

Hospitalization causes physical distancing in the family and alters its routine, which is why mothers and fathers see their relationships with their partners and especially with their other children affected. Mothers especially report dealing with a double presence, in which, in addition to the burden of caring for the sick child, they are required by the children who are at home. This is more intense in those mothers and fathers who must move from the city to another so that their sick child can receive treatment.

Now I am the bad mom deep down, trying to be here, lifting this kid's spirit. My other daughter tells me that I don't love her, that with this thing about Fabián, the only one I love is Fabián. I feel that Fabian's sister is suffering from horrible depression, she calls me crying that she is doing badly at school, that she loves her brother, that she is very sorry and on top of that her mother is not there and neither her father's support! This is more difficult for her! So I also have to deal with that (Participant 9).

Structure 2: Receiving a helping light during hospitalization

The hospital facilities gave me some peace of mind

When analyzing the spatiality of the experience, mothers and fathers report that the oncology unit has furnished rooms with individual bathrooms that provide a comfortable and intimate physical space that favors coexistence and privacy with their child.

At first I did not expect that, in the oncology unit, he would have his room, his cradle, his TV. That is still a good thing! What impressed me the most was the facilities here! I never thought that they were so modern, that they seemed a luxury hospital, that gave me a bit of peace of mind, because I think that, if it had been something like old and gloomy... It would have been worse mentally and hospitalized for so long! I think that mentally it helps with something (Participant 7).

The nurses give love and light when everything is dark

Mothers and fathers value the nursery team during hospitalization, who transmit hope and concern, by keeping them informed and involving them in the care of their child, especially in hospitalizations that are repeated over time. In addition, these professionals

create an understanding and loving environment for their children wearing nice clinical scrubs, using kind words, and playing games with them.

The nurse who received me told me: “Mommy, I understand what is happening, we always see this, after a while it will be better, the children come out of this”. So, when you see everything dark, that little window, that light helps a lot. And in general, the nurses are very affectionate, very caring, very understanding with them (Participant 1).

We help each other between mothers by sharing our experiences

The mothers point out that sharing their experiences, crisis situations and doubts regarding their child’s illness with other parents in the unit allows them to feel welcomed by each other, especially during the first hospitalization. These helping relationships are built especially by mothers who have lived more hospitalizations as main caregivers.

Being alone in the room... It’s difficult [she gets emotional]. The sharing, talking about the experience, that the other mother told me: “the same thing happened to my son... But rub him, so his pain will go away” is like helping each other (Participant 10).

Discussion

The continuous presence of mothers and fathers during the hospitalization of a child with cancer encompasses experiences that go beyond what happens during the hospitalization space-time. The analysis from the four existential perspectives proposed by Van Manen made it possible to find changes in space, temporality and relationships experienced by mothers and fathers since, by spending a large part of the day in the hospital, they feel that they “live” at the hospital.

When comparing our findings with the current literature, it was observed that there is agreement in relation to the fact that the unexpected diagnosis of cancer in a child had a strong impact on the parents. Qualitative studies found show a similar overall experience. Research from different countries found that the experience was like feeling the sky collapsing, ⁽¹⁶⁾ like a terrible disaster ⁽²²⁾ and as one of their most difficult and painful experiences. ^(23, 24) Among the findings reported in our study, it stands out that the vision of the corporality itself and the internal space of parents was forgotten in favor of child care, which can be linked to the current evidence that shows that caring for a child with cancer is associated with greater depressive symptoms in fathers and mothers, ^(25, 26) post-traumatic stress symptoms ⁽²⁷⁾ and that even the burden of care impacts their quality of life. ^(28–30)

In the same manner, in this research mothers and fathers report that hospitalization has effects on the close family environment. This result has also been exposed by other authors who emphasize that the family undergoes a rupture marked by the change of roles and physical distancing, ⁽³¹⁾ and that this also causes brothers and sisters to feel isolated during the hospitalization stage. ^(32, 33) Therefore, although the child and his/her caregiver suffer the direct effects of hospitalization, the family suffers indirect effects, ^(30, 34) which became evident when analyzing the changes in the relationality of the parents’ life world, which reveals how relationships with family members outside the hospital are also affected.

Another element revealed in this investigation was that the oncology unit environment constituted an important component in the parents’ adaptation process. This fact

has been described in other studies where the importance of ensuring a friendly ^(35, 36) and cheerful ^(37, 38) treatment is highlighted, along with a health care team who provides honest information ^(24, 39, 40) and the provision of adequate and comfortable physical facilities. ⁽⁴¹⁾

Finally, in the analysis of the relationality experienced, this study found that the participants considered the interaction with other mothers as a positive aspect of the new ties that are established in the hospital. This has also been evidenced in other studies where they show that mutual support between mothers and fathers who are going through the same process opened spaces to talk about disease progression and control of the adverse effects of treatment ⁽⁴²⁾ and feeling helpful by participating in their children's care. ⁽⁴³⁾

Limitations of the study

This research collects the experience of parents from a Chilean public hospital in Santiago city, so it would be advisable to expand it to hospital centers in other Latin American regions and countries and to incorporate the perspective of other family members and health care professionals, situations that would allow enriching the view of this phenomenon.

Conclusions

In this study, through Van Manen's phenomenological approach, it was revealed how the parents' daily experience of the hospitalization of a child with cancer causes changes in all dimensions of their life world. The narratives of this research speak to the life worlds of health professionals who work daily in oncology units, suggesting improvements in different areas ranging from the relational sphere to hospital infrastructure (Figure 3).

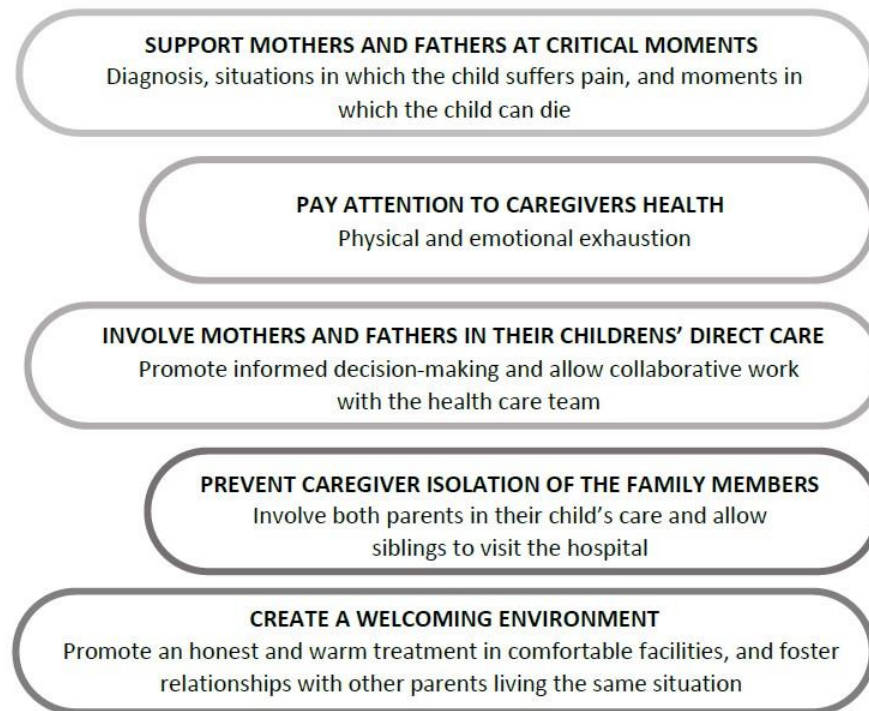


Figure 3. Recommendations for health care teams that work with mothers and fathers of children with cancer during hospitalization. Source: Own elaboration (2022)

Regarding interpersonal relationships within the hospital, one of the key findings of this research is the existence of critical moments that exacerbate parents' physical and emotional needs. In this regard, although these moments are part of the trajectory of severe pediatric disease, the same participants highlight how the kind treatment of health professionals and the new relationships of trust with other mothers and fathers help to moderate this moment of crisis. The foregoing calls for the health care team to continue deploying psychosocial support measures during moments of greatest vulnerability for mothers and fathers.

This study also reveals the impact that parental involvement and their permanent stay in oncology units have, resulting in physical exhaustion and isolation from the rest of the family members. Van Manen's phenomenological approach allowed us to visualize hospitalization as a process where mothers and fathers symbolize a crucial part of the family system, being not only an essential support for the sick child, but also actors with their own value and who are connected to the rest of the family members. That is why it is suggested that the design of pediatric hospital infrastructure must contemplate facilities that guarantee the contact between child-mother/father binomial with the rest of the family in safe conditions. The hospital should also include policies that allow for the rotation of the primary caregiver with the parent staying at home. This last point could mitigate the breakdown in family relationships and alleviate the main caregiver overload, especially in times like those experienced in pandemic context.

Finally, it is essential that both health care team and mothers and fathers continue to receive training from the institutions, so that the parents feel more empowered as caregivers and that health professionals build trust towards mothers and fathers, listen to their concerns and value their knowledge as caregivers. ⁽⁴⁴⁾ This article contributes to nursing understanding of pediatric hospitalization as a phenomenon that goes beyond the walls of the hospital where children and adolescents and their families are an interconnected network.

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