Objective: analyzing the perceptions of mothers of children with cancer living at a house for support during their children treatment.

Method: a descriptive and an exploratory study of qualitative approach. The data production was conducted through interviews with 11 mothers, between May and July 2010. The data analysis occurred by pre-analysis, the exploration phase of the material, coding and listing of units of meaning and categorization. The research project was approved by the Research Ethics Committee, CAAE No 0218.0.000.146-10. Results: after the analysis process, three categories emerged << Path taken since the discovery of the child's illness >>; << Faith and possibility of death >> and << Living in home support >>.

Conclusions: the cancer diagnosis in the child generates disruption of family routine and change in the mother’s role; home support facilitates access to treatment of the child.

Descriptors: Nursing; Neoplasms; Caregivers; Child Care.
INTRODUCTION

Cancer is characterized by cells’ uncontrolled growth those invade tissues and organs, and may spread to other body regions. It is an important cause of morbidity and mortality in Brazil since 2003 malignant neoplasms are formed as the second cause of death in the population and the fifth among the population of one to 19 years old.\(^1\)\(^3\)

It is noteworthy that childhood cancer is studied separately from cancer in adults; it presents differences in the primary site, histological origins and clinical behaviors. Pediatric tumors have shorter latency periods, often grow quickly and are more invasive; on the other hand, there is a better response to treatment and has good prognosis.\(^2\)\(^4\)

North American studies show that in patients younger than twenty years old, leukemias are among the most common types of cancer (31,4%), in sequence, tumors of the central nervous system (17,6%), lymphomas (12,4%), soft tissue (7,1%) , the sympathetic nervous system (6,6%), kidney (6,3%), bone (5%) and others (4,5%). Each year, in Brazil, 12 to 13 thousand children under age 14 are affected by some form of cancer, and of these, about 70 % could be considered cured, depending on early diagnosis, age and type of neoplasm.\(^5\)\(^6\)

Considering the complexity of cancer, it is important that treatment should be done in specialized centers, including the following modalities: clinical, through the use of chemotherapy with antineoplastic; radiotherapy which destroys tumor cells employing ionizing radiation; immunotherapy, which stimulates the immune system; and a bone marrow transplant to replace the diseased marrow cell from a healthy donor; in addition to surgical treatment.\(^7\)

The moment of discovery of the diagnosis of childhood cancer is stressful, tense, covered in uncertainty and leads to a painful process in the lives of the family members. It is the experience with the disease and their meanings, as well as worries about the future and fear of death that causes changes in the dynamics and family relationships.\(^8\)\(^-\)\(^10\)

Family and child were facing problems: long periods of hospitalization, readmissions, aggressive therapy side effects, difficulties related to separation from family members during hospitalization, interruption of daily activities, limitations in understanding the diagnosis, financial misfit, anguish, pain, suffering and the constant fear of death possibility.\(^9\)\(^\)\(^11\)

During the treatment of children with cancer, it is observed that caregivers may show: losses at work, in their studies, in sleep patterns, mood, sex life, appetite, plans for the future physical and mental health, personal care, social life among others.\(^12\)

Family of children with cancer deserve special attention in the biological, psychological, social, economic and spiritual spheres; making a part of the social support that assists therapy, along with friends and the hospital. Health services, supported in new care paradigms, consider the family beyond the needs of the child, increasing the dimension of care.\(^13\)

Family members need to receive social support, which is a process of interaction between people or groups of people who establish bonds of friendship and information beyond the material, emotional, affective support, contributing to the reciprocal welfare highlighting the role that individuals can play in solving everyday situations in times of crisis, eg , the treatment of children with cancer.\(^13\)

The Brazil owns charities, aimed to support cancer patients and their families and the Brazilians give a part of their free time to work in hospitals, nursing homes and institutions.\(^14\) An example of charity are the homes to support children with cancer, offering the opportunity for specialized treatment without the need for hospitalization, featuring an outpatient therapy. However, children and adolescents, accompanied by the mother, father or other adult, start living in a “home away from home”.\(^14\)

Already the damage for caregivers of children with cancer is countless and can further increase when the treatment occurs away from home, because the referral hospitals located in large urban centers. Living in a different environment with different people and cultures and in a stressful situation such as the diagnosis of childhood cancer, can generate conflicts, fears and insecurities that if only they are exposed and ears by the multidisciplinary team can help.

OBJECTIVE

- To analyze the perception of mothers of children with cancer living at home to support their children during treatment.

METHOD

This is a qualitative, exploratory and descriptive study. The qualitative research is related to a level of reality that cannot be
quantified, seeking to understand and explain the dynamics of social relations, working with a universe of beliefs, values, attitudes, meanings. This method enables researchers to uncover and interpret the different ways of experiencing the world.\textsuperscript{15}

The study was conducted in a nonprofit home for support to children with cancer. The population of eleven mothers of children with cancer living in the home support located in the district of Barão Geraldo, in the city of Campinas, in the State of São Paulo / SP.

The home support of the Association of Parents and Friends of Children with Cancer and Blood Disorders - (APACC, in Portuguese) was created on October 7\textsuperscript{th}, 1992, by parents and some friends who treated their children at Boldrini Hospital in Campinas, created from living with families of patients who came from distant places who had financial difficulties to remain outside and continue the treatment. APACC are housed in patients between zero and twenty-five years old, in cancer treatment in hospitals in Campinas and needing an accommodation. They are entitled to an escort at no cost, to the accompaniment of psychologists, social workers, occupational therapists and other volunteers willing to contribute to their recovery.

APACC became on July 8\textsuperscript{th}, 2010; the fourth Ronald McDonald House in Brazil. From a long process of analysis and adjustments, the institution was licensed to receive an international certificate of Ronald McDonald House Charities - RMHC, becoming part of the worldwide program that aims to provide "a home away from home" for young patients undergoing treatment and their families. The guest house has the capacity to serve 56 patients and their families. It occupies a building area of 1,281 m\textsuperscript{2}, in Bosque das Palmeiras. There are 28 rooms and 112 beds, 16 baths, playroom and computer room. In 2009, went through infrastructure reforms, which resulted in a new laundry room and a modern industrial kitchen, a dining room with 40 seats, taking capacity to prepare and serve up to 120 people comfortably per meal.

After approval by the Research Ethics Committee of the Faculty of Medical Sciences - UNICAMP, under protocol No. 046/2010, began collecting data from the consent of the mothers by signing the consent form, from May to July 2010.

The interview can be seen as a social encounter, permeated with empathy and intersubjectivity.\textsuperscript{15} The same occurred with the guiding question: "How is it for you to live in this house for support during your child's treatment?"

It was defined the sample by the repeatability of the data, from the historical perspective and the theoretical domain of the researcher that new ideas could be added, favoring new coding thus the transcription of the speeches and pre-analysis occurred concurrently with each interview.

The data analysis occurred through the pre-analysis phase material exploration, coding and listing of units of meaning and categorization.\textsuperscript{15}

RESULTS

The data were analyzed and three categories emerged: \textless{} Path taken since the discovery of the disease \textgreater{}, \textless{} Relying on faith and dealing with the possibility of child's death \textgreater{} and \textless{} Living in home support. \textgreater{}.

DISCUSSION

In category \textless{} Path taken since the discovery of the disease \textgreater{} when talking about this, the mothers brought about the early signs and symptoms that occurred before the definitive diagnosis, examinations and treatments performed, the current situation of the child and the amazing diagnosis of cancer, as seen below:

\begin{quote}
He was sick with a high fever, purple spots on the body and went to the pediatrician [...] he said, mom, I without their hands on him, I think he's a very serious disease. I did not know what he was doing, I was crazy! My life collapsed (M1).

When I heard that he was sick, the doctor called me and my husband, [...] gave me bring the results and found that leukemia is ALL, it seemed that opened a hole and I fell inside (M2).
\end{quote}

Living the diagnosis of cancer of the child is an unexpected and unplanned experience; the role of mother shall be modified to construct a new role due to the disruption of the family routine. When you notice that your child is threatened, the mother is faced with the need to establish a priority for its life, this will be the focus of her concerns and around which all decisions should be taken.\textsuperscript{16}

The childhood cancer treatment usually involves invasive procedures, aggressive and side effects that cause many uncertainties and threats in children's lives and their families.\textsuperscript{16} It is observed in the discourses that treatment brings feelings of fear and loss, especially during preceding the diagnosis, a sense of uncertainty by waiting for a possible diagnosis of cancer in their child, is evidenced in the following excerpt:

\begin{quote}
At the hospital there is no conversation, the doctors are very doubtful, and you do not
\end{quote}
always have someone to talk to, someone who understands you, to be guided, to give you support, sometimes we feel anxious, that suffering. The result out soon, the doctor says that your child has and to treat it right and you can go home, it is very tiring (M3).

It becomes clear that mothers need a team supporting them, providing care and being able to explain in detail and through intelligible language, everything will be done during the treatment of the child so that the moments of adaptation and acceptance to this therapy are lived in a less painful manner. As noted below:

I like it here, I like also the hospital, doctors there treat you very well, you know? When I arrived, education, nurses, doctors, they explain everything right […] (M4).

Children with cancer caregivers have physical and emotional distress as a result of activities performed, including time for activities directed to care for and monitor the wear of the child in its path in search of life itself. The mother accompanies her sick child more often in hospital admissions. It is clear that the mother needs to be heard by professional team, after all, it can help reduce the stress caused by the treatment the child is receiving.17

Caring for the sick child appeared in the interviews as the sole responsibility of the mother, must weight, as if there is another possibility, which can be seen below:

[...] I was here three months just taking care of my son, because he has to take care of, right? […] Just left me, the boat touched just for me […] but it’s son of us and we have to take care, do what? (M5).

But you go to live anyway, has no choice, it must be so, it must be so and we have to accept to be (M6).

It is necessary that mothers of children with cancer have access to resources that help them understanding everything that is happening with their children during the disease process, such understanding will ultimately help them coping with painful situations involving cancer treatment kids.16

The mother is considered the base of family structure and under her control she is creating and raising children, caring for the home and the health of family members. She is characterized as the primary caregiver, defined as the person family with moral duty to stay with the child during its treatment and feel an obligation to care for the child, since the child elects her as the protector of the family. Believes that no one is as prepared as she to care for and protect her child.17

For category “Relying on faith and dealing with the possibility of child’s death” faith appeared as a coping strategy, this happens before the mobilization of natural resources for purposes of handling stressful situations, consisting of the interaction between organism and environment.

Faith is an attitude of hope, open to future consummations; its construction occurs through experiences on interpersonal relations and to settle in life, requires a personal choice. Can be regarded as comprehensive and independent of any religion, since it appears, for example, before a health treatment, focused on the belief in the efficacy of the same.18-19

This strategy can be supported not only in religion but also in recognition of helplessness before pain, suffering, illness and impending death. The determination of God can arise in trying to find a cause that may have produced the child’s disease. As shown below:

God puts certain things in our lives […] I put here, huh? The folk’s going, getting through all. Just have faith in God, God helps us (M2).

I cannot explain, it’s so hard, but … surrender to God and move on […] Because as I always say, we have to have the support of the physician, but first is God, always put God first (M7).

Mothers rely on the idea that this process is due to the will of God and rely on Him to leave their children alive and healthy so they do not lose hope during the treatment of their children.

Even relying on faith, mothers at some time during treatment, find themselves facing the possibility of death for their children, according to the speech below:

I do not want my son to die, I want him to stay with me and I take his side (M5).

Sometimes you have photos at home that my son looks and says mom, that died here, that died here, that died here. Mother! I’m still alive, will I die too? […] I said: no, you will not die (M1).

Cancer is a frightening disease that carries with it the stigma created by society, the death sentence. Child is synonymous with joy, and future growth, so death is coated with special cruelty. You can see that mothers end up denying the possibility of death, to themselves and to their children. For them it is very difficult to prepare for the death of his son, since this fact represents a reversal of the natural order of life, after all it is expected that the sons bury their fathers.19

Mothers may also feel threatened by his son’s death, when faced with the death of a child suffering from the same illness of his
son, this occurrence creates a devastating
effect on them, meaning an immense pain
that can affect your ability to remain in
equilibrium M1. As mentioned during his
speech:

Had a little baby here, I took care of my son
and hers too, and she went to the
transplant and the patient died, was in
Rondônia. [...] And ... she's gone and made
a huge missing in my life [...] I even speak
good that she died there and so I did not see
her suffering, you know (M1).

The last category was “Living in home
support”, in which mothers leave their homes
to accompany the child in treatment.

A life crisis can be triggered by a cancer
diagnosis. This situation brings changes in
routine, functions, and behaviors performed
by the child and the family roles, the
normality of life before the disease is altered
from its discovery and marked by anxiety and
care of the mother and the rest of the
family.

The need for follow-up treatment of the
child away from home brings a redefinition in
the role of mother and family: household
chores are left aside due to change to support
house in another city; healthy children feel
ignored as attention is focused on the sick
child, and being a mother happens to be
prioritized in relation to being a wife, this
separation and new family routine can be
disastrous. Parents and children occupy a
background on the relationship between
mother and child with cancer.

The experience of the mother to remain in
a support house, away from the familiar
routine, pegged the situation of caring for a
sick child, generates feelings of sadness:

 [...] It is sad for me to stay away from my
family [...] (M5).

It's hard, you know? I have to leave my
family [...] feel really missed my family, my
home, my father, my mother (M7).

 [...] Because no one asks for an overnight
pro child is sick, or to be in a house that is
not her, to leave her routine (M3).

It is difficult to be away from home. I have
three more children there too; I have no
husband [...] (M6).

Mothers end up adapting their activities to
the needs of her sick child, leaving them,
including the discontinuance of employment
when necessary so as to better meet the
demands of the child. This happened with one
of the mothers interviewed:

The only thing I have is to miss my home,
miss my service which is what I like to do, I'm
sewing, I miss my machine, right? (M7).

Besides being away from family and leave
their job, mothers also cite the difficulty of
being away from their homes and their cities.

At first I did not want at all, you know?
Would not accept being here away, right? I
never imagined that one day I would come in
this place, the problem of girl [...] (M8).

 [...] Here because it's not like the house of
the people, because the house of people we
can do what we want (M5).

In relation to living in the house, mothers
recognize building friendships as a form of
support, as speeches below:

Here is where we cry, we laugh, we do
everything [...] agent arrives without
knowing anyone, whether you stay a week
you know everybody and everybody helps
you, it's good for coexistence (M9).

I am the eldest who is here and they arrive
we will receive. There are some who come
here sad, cry and as I'm here and I already
know I'm helping, I'm only good things going
for her, right? And then, one will strengthen
the other (M4).

Friendships established among these
mothers is a resource used to meet the
situation on daily basis. The fact is that
interaction between mothers narrows and it
minimizes the burden. Through awareness
sharing experiences, and suffering from other
mothers who experience cancer in children,
there is the interest in helping and caring for
others and, from this process, they form an
extensive partnership network
strengthened.

The findings indicate that living in a home
support during treatment of his son, implies
deal with different people who came from
different places, with customs and ways of
living unmatched and these differences are
not always seen as a positive factor, as noted
below:

It is very difficult to live with a lot of
people right? Because we only have this
little life here, any little thing ... Wow! It is
a buzz back here a talk there (M1).

It is very difficult. Because we have to live
with several people, several mothers,
several parents and children (M8).

In addition of being difficult living with the
other mothers and children can generate some
feelings such as frustration, fatigue and desire
to isolate themselves amid the differences:

 [...] It becomes tiring, stressful, because
not everyone ends up doing, leaving to
some. You get disappointed, get frustrated
with people who do not collaborate [...] It
creates click (M3).

There are days when you cry, is isolated,
hay day dawns you sick, [...] we have to do
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it where it is important but sometimes tires
(M3).

Another point raised by mothers was the
financial issue. Without home support many
children do not receive treatment of cancer
due to family financial condition that would
prevent them from reaching the hospital,
according to the excerpts below:

Because we had no money, because I live far
away, I think it's my house, does not
explain, is my home here (M9).

So the house has a large infrastructure. It is
a large house, so all we need it offers [...] everything just inside the necessity of us
(M3).

Besides the emotional and intrafamilial
stress, families that have a child with cancer,
have financial difficulties due to a variety of
expenses, including long trips, lodging, time
off work, medical supplies, and sometimes
even need to borrow money to cover
additional costs.21-22

CONCLUSION

This study enabled the knowledge of
perceptions of mothers of children with
child who live in a support while treating
their child from the perspective of the
journey from the discovery of the disease, the
faith as a coping strategy to deal with the
possibility son's death, and live in a home
support.

Living the surprising diagnosis of cancer of
a child is an unexpected and unplanned
situation that ends up generating a break from
routine in the context of the family, and
especially a change in the role of the mother
until then considered the center of family
structure: one that creates and educates
children, who takes care of home and family
health. From the diagnosis of your child it
shall be the sole responsibility of caring,
which sometimes appears as an obligation,
and because of this, the need arises to change
a city, stay away from the family and to leave
the job to go to search for the child's
treatment, having to live in a home support
during treatment. All these changes are
difficult and lead to feelings of sadness,
anxiety and concerns among mothers of
children with cancer.

Mothers rely on faith as a coping strategy,
believing in God's will and that He will help
their children heal. Faith, necessarily, is not
related to religion, arises when recognizing
the impotence of the human facing pain,
suffering, illness and impending death.

The opportunity to live in a house support
facilitates access to treatment for children
with cancer, because in many cases, families
can not afford to travel and hospitalizations.
While living in the home support, the mothers
end up building friendships that end up being
a support for the difficult phase. But live with
the diversity of each person is not easy, and
can even lead to feelings of frustration, fear,
fatigue and desire to isolate themselves.

Due to all the changes and impact that a
diagnosis of cancer brings a child to the
mother's life, it is necessary to implement
strategies to support and care of a
multidisciplinary health care team in support
homes, so that adaptation to new phase and
the stress that arises during the child's
treatment are lived in a less stressful manner.

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