



The experience of grandparents of children hospitalized in Pediatric Intensive Care Unit*

A experiência dos avós de crianças hospitalizadas em Unidade de Terapia Intensiva Pediátrica
La experiencia de los abuelos de niños hospitalizados en Unidad de Terapia Intensiva Pediátrica

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ABSTRACT

Objective: To understand the experience of grandparents of children hospitalized in pediatric intensive care units. **Method:** This was a qualitative study based on the symbolic interactionism theoretical framework and the grounded theory as methodological framework carried out with grandparents of children hospitalized in the pediatric intensive care unit of a teaching hospital in a city in the state of São Paulo. Data were collected by means of participatory observation and semi-structured interviews, and analyzed following the open and axial codification stages of grounded theory. **Results:** Nine grandparents were interviewed. Two phenomena were identified: "finding themselves inside a storm" and "fighting to be the anchor of the family", which explain the suffering experienced and support role developed by grandparents during the hospitalization period. **Conclusion:** Grandparents develop an important family support role during the crisis. Therefore, family care strategies must be developed to include this generation of the family, who are increasingly present and participatory in several healthcare settings.

DESCRIPTORS

Child, Hospitalized; Grandparents; Family Relations; Pediatric Nursing; Intensive Care Units, Pediatric.

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INTRODUCTION

Pediatric intensive care units (PICU) are a stressful environment for families, who find themselves vulnerable “to the hostile environment, real and imaginary threats, a team that has the power over their child, and the rupture that families suffer in their structure”⁽¹⁾.

Family dysfunction due to hospitalization in intensive care units is experienced by all family members and may be intensified by uncertainties that follow critical and emerging changes in the child’s health – sources of stress include: insecurity related to the intensive care environment, such as alarms and equipment, and communication with the team; caregivers’ role; child’s health condition; and alterations caused by the illness⁽²⁻³⁾.

Child hospitalization results in the reorganization of family roles and duties, which relies primarily on the help and support of grandparents. Several studies have identified grandparents as important parts of the family support network during the entire period of hospitalization⁽²⁻⁴⁾.

Human longevity has increased, and consequently, family relationships have changed, especially intergenerationally, “where grandparents become grandparents at younger ages and experience this role for a longer time”. In this new setting, they are more active and participatory in their families⁽⁵⁾.

Studies about the experience of grandparents when faced with a grandchild’s illness, whether acute or chronic, show alarming data about their suffering⁽⁵⁻¹⁰⁾. The intensity of the suffering can be understood as multiple sufferings: for the ill grandchild, for the other grandchildren, for their children, their family, and finally, their own suffering⁽⁷⁻⁸⁾.

This suffering is associated with the illness of a loved one, and in this context, feeling impotent in the face of the illness, standing by as a witness of the suffering and being unable to ease it or prevent the illness⁽⁷⁻⁸⁾. However, “grandparents are not usually considered a part of the family affected by suffering in the context of a serious illness”⁽⁶⁾.

Understanding that the hospitalization of the child in the PICU is highly stressful, affects all family members in several ways, grandparents among them, and considering the greatest participation if grandparents in the daily care of the child and family routine in our society, the objective of the present study was to understand, from the grandparents’ perspective, the experience of having a grandchild hospitalized in the PICU.

METHOD

This was a qualitative study based on the symbolic interactionism theoretical framework⁽¹¹⁾ and grounded theory⁽¹²⁾ methodology. Data collection was carried out in a 12-bed PICU of a teaching hospital in a city in the state of São Paulo, Brazil.

A total of nine grandparents were interviewed. The following inclusion criteria were adopted: grandchildren hospitalized for at least 24 hours and grandparents who actively participated as family members. Grandparents who were permanent legal guardians were excluded. Table 1 presents the main characteristics of the participants. To ensure anonymity, fictitious names were attributed to the participants.

Chart 1 – Characteristics of the participants – Campinas, 2016/2017.

Name	Age Grandparent	Gender	Maternal Paternal	Child’s age	Cause of child hospitalization	No. of hospitalizations in PICUs	Days of hospitalization at the time of the interview
1. Severino	54	M	Maternal	1 month	Bronchiolitis	1	12 days
2. Marta	59	F	Maternal	1 month	Post-CA	1	1 day
3. Genivaldo	57	M	Maternal	1 month	Post-CA	1	1 day
4. Madalena	48	F	Maternal	3 months	Bronchiolitis	1	40 days
5. Antônia	66	F	Paternal	3 months	Bronchiolitis	1	40 days
6. Regina	49	F	Maternal	8 months	Cardiac Surgery	1	2 days
7. Lucia	67	F	Maternal	8 months	Lung malformation	3	30 days
8. Cassia	51	F	Paternal	2 years	Exogenous intoxication	1	8 days
9. Conceição	48	F	Paternal	2 years	Primary immunodeficiency and Sepsis	3	40 days

Data collection occurred from May 2016 to March 2017 and was carried out by means of participatory observation recorded in a field diary and through interviews.

Candidates were accessed and approached by the main researcher before or after the grandparent visited their grandchildren in the PICU. The researcher provided information about the study and the informed consent form, and the participants were only included in the study after signing this form. Next, a place and time of preference were chosen by the participants for the interviews.

First, a genogram was used to understand the grandparent’s family structure, which is part of the Calgary Family Assessment Model⁽¹³⁾. The interviews were based on a single guiding question: “Tell me about your experience with your grandchild hospitalized in the PICU”. On the basis of the answer to this question, new questions were formulated to achieve a more in-depth understanding of the ideas expressed.

The interviews were fully recorded in digital audio and later transcribed, all with the participants’ consent. They lasted between 7 and 30 minutes.

The data were analyzed comparatively and constantly, following the axial and selective codification stages, according to grounded theory methodology. Data collection ended following the analysis process, while the study was being developed. The theoretical sample consisted of the identification and selection of individuals based on the gaps, with the aim of maximizing chances to discover variations among concepts and turn the categories dense⁽¹²⁾.

The study was approved by a research ethics committee under protocol no. 1.511.788 and respected all ethical principles of the current legislation, according to standards proposed by the Resolution CNS 466/12. All participants were informed about the study and signed the informed consent form.

RESULTS

The experience of the grandparents can be described and understood by means of two phenomena: “finding themselves inside a storm” and “fighting to be the anchor of the family”.



Figure 1 – Phenomena and categories - Campinas, 2016/2017.

For grandparents, the presence of grandchildren in the PICU inevitably refers to death, which generates uncontrolled anguish and apprehension. They had never experienced the situation of having someone so close to them in a PICU, and from their perspective, this hospital environment is only intended for patients who are dying – for whom there are no other treatment options.

As grandparents interact with elements of their grandchildren’s own illness and their critical, unstable, and unpredictable condition, they realize how much the illness imposes limitations onto their grandchildren, and how vulnerable, weakened, and even changed they are due to the severity of the illness. Seeing them so different from who they are is shocking for grandparents.

This feeling also involves the experience of being a grandparent. The participants defined this role as involving a different and much greater love when compared with what they felt for their own children. Therefore, when such a dear and beloved grandchild is exposed to a condition such as the

The dimensions of the experience will be presented next.

The first phenomenon, “finding themselves inside a storm”, represents the first interactions involving the hospitalization of a grandchild in a PICU and can be compared to a storm in the high seas – it introduces a storm to the grandparent’s life, because it involves meanings attributed to the PICU, as well as interactions that lead to more turbulence. This phenomenon is represented by the following categories: “being hit by the possibility of their grandchild’s death”, “finding themselves surrounded by suffering”, and “a horizon obscured by uncertainties and isolation”.

The category “being hit by the possibility of their grandchild’s death” represents the beliefs and meanings attributed to the PICU, illness, and grandchild, and involves the following subcategories: “believing that the PICU is a place to die”, “suffering the impact of realizing the severity of the grandchild’s illness”, and “heartbreak at seeing their grandchild so ill”.

PICU, these grandparents “become heartbroken to see their grandchild so ill”.

I was very afraid, I thought she was going to die when they told me she was going to the ICU... If she has to return to that place, I wish I could go in her place. Ana [granddaughter] was like this, one day you knew she was feeling well, and, suddenly, she was not well anymore (Madalena).

It is like twice the love, it is greater. However, when they are ill, is also worse, because we feel their pain... It is more with grandchildren, I think that if it were my son, I would not be as worried as I am with Laura [granddaughter] (Conceição).

For grandparents, this situation triggers suffering and anguish from all angles. Therefore, the category “finding themselves surrounded by suffering” consists of the following subcategories: “suffering for the grandchild”, “for their child”, “for their family”, “for other children hospitalized”, and “for themselves”. The suffering that the grandparents described to the researchers was intense and multiplied.

The subcategory “suffering for their grandchild” involves something that goes beyond “heartbreak at seeing their grandchild so ill”. This is when grandparents receive the news of the hospitalization and feel a break in the hopes and dreams associated with the meaning constructed around the love for their grandchild and their role as grandparents. This suffering pervades the entire hospitalization period, and not only the time when they realize the severity of the illness.

Grandparents also experience this turbulence under the parental dimension, “suffering for their child”, when they have to watch their adult children experience such a painful and difficult situation – which they themselves did not experience when they were parents of small children. Watching their child suffering the impact of having a critically-ill child and being unable to do something to change this situation is devastating.

These grandparents also suffer when they realize the impact of their grandchild’s illness and hospitalization on other family members.

During the daily routine inside the PICU, grandparents interact with the stories of other people. By witnessing the difficult experiences of other children hospitalized, their families, and their care routines that are sometimes more serious – end up “suffering for other children hospitalized”.

Therefore, grandparents suffer intense and multiplied pain, sometimes reaching moral and physical spheres – pain that can be expressed through deep feelings of sadness and physical pain, which limits daily activities, such as adequately feeding themselves, sleeping and resting, and even working. *Laura’s illness impacted the family. Then, because we are very attached to her, everybody suffers, everybody is worried, and this is very difficult* (Conceição).

I was suffering along with all those children, because we see their health condition, the tubes, and each case was more difficult than the other. Everything was frightening. What scared me the most was watching all those children in that condition, suffering (Antonia).

When I heard the word ICU, I started to tremble, I was sick, I did not sleep, I was up pacing around all night long, I was worried. It was terrible. I even had to take medication because I could not sleep. I get stressed because she is my first granddaughter. That is why I lost all my immunity, my hand swelled and my skin broke, I could not work, I was going to sew, do things, but I could not, I could not do anything for almost a month (Conceição).

The category “a horizon obscured by uncertainties and isolation” represents the needs of grandparents when experiencing their grandchildren’s hospitalization in the ICU that result from new interactions with this environment, in addition to the meaning previously above, as the ICU as a place for death. This category includes the following subcategories: “worried all the time”, “afraid of the unknown”, “feeling impotent”, “not having information about the grandchild’s health condition”, “not being allowed to be in the ICU”, and “suffering in silence”.

The grandparents start interacting with unknown elements in the PICU, with themselves, and with their grandchild, thus attributing resulting in the construction of a new real meaning to the unit. In this process, they interact with alarms, equipment, devices, and care routines that, while still not well understood, become a source of uncertainty, fear, and suffering.

In this context, they see themselves as mere witnesses of the whole suffering of their grandchildren and family, remain in the unit witnessing the suffering, not being able to do anything for their grandchildren, not being able to do anything to help or change the course of the illness.

Needs not met are sources of pain and suffering. The subcategories “not being allowed to be inside the PICU” and “not having information about the grandchild’s health condition” were reported by the grandparents as one more suffering factor: the feeling of exclusion. Most of the grandparents interviewed were not allowed to be inside the PICU at some time of the hospitalization period and only received information about their grandchildren through their children; therefore, they were not satisfied and wished to be included by the healthcare team.

All this suffering and concern is silenced, because not only do they lack room to talk about their pain and suffering, grandparents also believe that their suffering should not be greater than that of the child’s parents, and that they should not bother or worry them more. Therefore, they suffer in silence.

I saw her [granddaughter] the day she got out of surgery, and she looked like a small Christmas tree, full of things hanging from her (Regina).

You know the meaning of impotence. I felt impotent... you watch, you know, and you can’t do anything (Antonia).

The little baby [granddaughter] is in very bad conditions and we can’t do anything. (Marta)

Today, the doctor said that she would only give information to the mother, she made it very clear that she would not talk to me. The only thing I wanted was to receive the information from the doctor herself, not from my son or from Renata. (Cassia)

We, as grandparents, do not have anybody to talk about our concerns. Nobody in this place talks to us. I cannot talk about my concerns with my children because I have to give them support (Genivaldo).

The second phenomenon, “fighting to be the anchor of the family”, represents the grandparents’ movement to not succumb to the first phenomenon. Consequently, they take on the role of family pillars, or those who will do anything necessary to ensure that the ship – the family – is safe. Recognizing themselves as non-protagonists of the experience, grandparents believe that their role must be performed in the backstage. While developing this role, they search for external resources to remain strong and not succumb to suffering. The phenomenon includes the following categories: “working in the backstage to provide support”, “seeking strength to steady the ship”, and “keeping hope in better days”.

Grandparents provide the family with support throughout the entire hospitalization period, such as financial aid and taking on backstage roles to maintain daily activities. This includes taking care of the healthy siblings, stay in the hospital, or perform activities necessary so that parents are able to remain in the hospital.

Grandparents recognize that the autonomy for decision-making about all things regarding their grandchildren belongs to the child's parents. Therefore, they understand that their role is better performed from the backstage. The category "working in the backstage to provide support" means giving support so that whoever is in charge of the situation is able to do their best.

In addition to the activities performed in the backstage, the subcategory "providing support to their child" is how they take care and also keep their children strong during hospitalization. Grandparents remain present, are constantly concerned, and try to say supportive things to their children – with the purpose of not letting them give up or succumb to the storm.

Grandparents provide support not only to their children, but to the entire family; even though they are intensely suffering, they do not show it to their children and other family members. Not only do they not want to worry their children, but they also believe that, when showing strength in the middle of a crisis, they can encourage other family members.

I try to help with everything I can, sometimes with gasoline. I give them gasoline money so they can come here. I also come and stay with her, as I did today (Lucia).

I also have to take care of Alice [sister of the hospitalized granddaughter]. Right now, I am not only being a grandmother, but also a mother, because I have to educate her, call her attention when necessary, take care of her, and give her love while her mother is absent all the time (Madalena).

I must be strong. There is one moment when I cannot be shaken. Because I cannot let the others be shaken too. That is because right now, I have to be the head of the family. So, I think I have to show them strength, you know? (Genivaldo).

The category "seeking strength to steady the ship" represents the resources that the grandparents have and seek out when facing their grandchildren's hospitalization. It is composed by subcategories "seeking support in faith", "searching for information about the grandchild's health condition", and "seeking out new relationships".

Regardless of the religion, the subcategory "seeking support in faith" refers to the grandparents' search for support in faith or in church and its spiritual leaders, in addition to finding a purpose or meaning for their grandchildren's hospitalization and suffering.

Receiving information about the grandchildren's health condition and prognosis was identified as of utmost importance by the grandparents. Therefore, they are "searching for information about the grandchild's health condition". However, in addition to the need for information, grandparents also need to feel embraced by healthcare teams.

Grandparents search for new resources and interactions during this time of crisis, searching for new relationships. These new resources can be found through the help, shoulder and solidarity of partners, friends, and other family members – even strangers who show an interest in the child's illness and the family's situation.

I believe that all things are possible for God, and the proof is there [pointing to her granddaughter in the crib], who is getting better. And I tell you, she was born again (...) God uses what we most love, in His way, to teach us, and I told Milena: "I want you to talk to God" (Madalena).

I had never seen her [granddaughter] that way, but when the doctor told me "she is well, I don't want to see you crying", I gave him a hug and he said it again "I don't want to see you crying". This was a thank-you hug that was very important to me. I felt embraced by him (Regina).

People are helping us, we are organizing a bingo to help her. The whole city was touched with Laura's illness [granddaughter], people I have never met in my life appear at my doorstep to help. Some people give us money, others bought bingo cards, or brought bingo prizes... Everybody is concerned, trying to help somehow (Conceição).

The category "keeping hope in better days" shows that grandparents, even in the face of so much suffering, keep the family stable and united until the grandchildren's health condition is stabilized and they are able to return home and to the family circle. However, sometimes it is necessary to restructure the family with the child's discharge, due to new care needs related to the child's health.

During the entire hospital stay, in this process of new and constant interactions with their grandchildren, with themselves and with the PICU, grandparents construct new meanings that shift from fear of the unknown and an environment associated with death to a new perception of the PICU, as a place of salvation and necessary to their grandchildren's survival – an outlook represented in the subcategory "being familiar with and giving new meaning to the PICU".

Regarding the construction of new meanings, in some cases, the grandparents were upset by situations that were occurring before the child's admission. Thus, when observing changes in their children and family, grandparents notice the impact of hospitalization also on these relationships – both negative and positive. The subcategory "noticing positive changes in the family" represents this understanding.

Finally, until the child's health condition is re-established, grandparents understand the importance of the family unity to maintain stability and keep "the family together during the entire hospital stay".

I was very afraid of her being alone and nobody there watching her, but I saw that this was not the case. It is very important to see that she is receiving good care (...) I did not know how it worked, I was heartbroken when her mother left her. She is fine with the nurses, right? Nobody wants to stay in the ICU. You know, it would be good if we could all go home, but since I know it is necessary, at least I can see that she is receiving good care and I am more relieved (Conceição).

The maternal grandmother visits her granddaughter, she enters the room, and, realizing that her granddaughter is awake, sitting up in the crib, she stays at the doorway, smiling. Her granddaughter calls her with her hands, and “asks to be held”, and the grandmother says to one of the professionals: “I thought I couldn’t hold her in the ICU. She improved, she is well. I was afraid, but she is receiving good care” (Observation note – September 02, 2016).

This is a lesson for her [daughter]. It is not for the girl because she’s out of the woods, but she’s got to be more attentive... What happened to her daughter is a lesson for her to become better, to change and do the right things (Severino).

I try to keep the family stable – everybody, my husband, my son, my brother, everyone. I try to keep everybody together. I am also trying to give them words of comfort, those who are suffering with us (Cassia).

DISCUSSION

Grandparents are deeply involved in their grandchildren’s hospitalization and critical illness experience, and are engulfed by the storm of watching their grandchildren in severe health conditions, suffering and enduring with the help of resources and care. At the same time, they take on the role of supporting the family through this turbulent time – despite their own suffering.

The suffering and concern experienced by grandparents, together with the changes in daily living defined by the need for family reorganization due to the illness and hospitalization, intensify suffering. In the present study, this suffering was characterized by the phenomenon “finding themselves inside a storm”. It has also been found in other studies about childhood cancer, in which grandparents noticed physical and psychological manifestations of suffering, such as anxiety, depression, and reduced quality of life^(7-8,14)

Grandparents believe that keeping the family support role is more important than expressing their own feelings and suffering, thus living a situation of silenced suffering. This result was also found in grandparents who experience the premature birth of grandchildren, as well as the need for hospitalization in neonatal intensive care units – situations where they consider themselves to be the primary source of support for their children and in which their own suffering becomes irrelevant when related to the role of providing support to the new parents⁽¹⁵⁾.

The support provided by the grandparents in this context ranges according to family needs. This includes taking on the task of stabilizing and providing support to their grandchildren and family members^(5,10,15).

Keeping hope in better days has the purpose of preserving the family, which was identified in the present study by the phenomenon “fighting to be the anchor of the family”. For grandparents, this was one way to provide support, encouraging the family to keep on, by creating strategies to the “preserve the family structure, and maintain relationships that allow the family to be together, prevent conflicts, and provide support to one another”⁽¹⁶⁾, so that, together, they can prevent a collapse. Other studies have shown similar results, with parents expressing the importance of this source of support^(15,17).

However, in order to play this role, grandparents must have their own needs met – which is essential so they can understand the crisis situation and develop their role. Some studies have been developed to better understand these needs and to define strategies to help meet them quickly and promptly. This helps lessen the suffering of grandparents, who can receive the strength and resources necessary to their own stability, and thus being able to take on their supporting role^(9-10,18).

A recent example of this movement happened in Australia, with the development of a scale to identify and measure the main needs of grandparents when they experience their grandchildren’s illness due to cancer⁽⁹⁾. This study showed that the most important need was that for information: They need information about the illness, treatment, prognosis, cure, and palliative care, in addition to information about how to better support their grandchildren and children in this situation, and where to search for help. These results corroborate the needs expressed in the present study and strengthen the need to include them in daily care practices and in the sharing of information.

The search for help for themselves includes “how” and “where” to search for emotional support, i.e, how to stay healthy and where to search for help when faced with the death of a grandchild. Contact and interaction with other grandparents experiencing similar situations were also identified as important by the grandparents, in addition to the access to a booklet or online guide with general information at the time of hospitalization⁽⁹⁾.

There are also some initiatives that aim to address these specific needs, especially that for information. In the context of childhood cancer, a booklet with information about the illness, treatment, prognosis, and procedures, and hospital routines was developed. It contains information about family and relationship management during this crisis, and how grandparents can help their children and family members in a practical way⁽¹⁸⁾.

The literature has also shown concern about the health of grandparents who actively participate in their grandchildren’s care. They tend to present poorer health and lower levels of well-being, in addition to higher levels of depression associated with various stressors. These include financial, instrumental, and disciplinary concerns regarding their grandchildren, in addition to how to maintain relationships with their own children and partners^(14,19).

When faced with the grandchild’s illness, such symptoms are intensified, especially those relative to reduced quality of life and mental health indicators. Grandparents who experience childhood cancer of their grandchildren presented higher rates of depression, anxiety, and insomnia when compared to grandparents of healthy children, as well as greater need for the use of medications for the treatment^(14,19).

Therefore, it is essential to provide specialized care and encourage grandparents to take care of their own health and to search for help. They should be instructed to address their own needs and health if they wish to provide their own family and grandchildren with support. They can also be encouraged to seek out other relationships and sources of support, which can include talking with other grandparents in similar situations and reaching out to friends, other family members, partners, and religiosity⁽¹⁸⁾.

The literature presents only a few examples of interventions that aim to prevent these effects, such as the creation of the “healthful grandparents” project. This intervention consists of nurses and social workers conducting support groups and home visits to assess health and health behaviors, followed by health education actions and the definition of goals that meet the concerns of grandparents⁽¹⁹⁾.

These interventions present promising results with regard to social relationships and physical and mental health, especially by reducing anxiety levels and depression symptoms⁽¹⁹⁾.

Similarly, to provide support to grandparents during a family crisis in the context of neonatal hospitalization, researchers carried out intervention groups that addressed the topics requested by grandparents. This involved sharing information about their grandchild’s health, procedures, prognosis, and how to provide competent support to the entire family, by helping, sharing, defending, and protecting its members – especially their own children⁽¹⁵⁾. This strategy also allows them to interact with grandparents in similar situations, sharing their personal experiences and providing mutual help among them⁽¹⁵⁾.

As shown in the present study and in the literature, grandparents consider their supporting role more important than addressing their own needs⁽¹⁵⁾. Therefore, grandparents tend to silence and put aside their own suffering and needs.

However, such needs, represented by the categories “finding themselves surrounded by suffering” and “a horizon obscured by uncertainties and isolation”, also include their own health care. These cannot be neglected, because by attending to their own needs, they have more strength to take on the supporting role in their family during this experience.

The grandparents’ source of support, represented by the categories “keeping hope in better days” and “seeking strength to steady the ship”, involves external resources and

forces that support grandparents to keep steady in their role, and also to be able to resignify the entire process.

Specific support interventions directed at grandparents, which range from booklets to discussion groups, can be effective to strengthen those who take on the role of being the main support of families during crises, preserving their stability and integrity.

CONCLUSION

The present study provided a deeper understanding of the PICU hospitalization experience for families, from the perspective of grandparents. They experience a journey of intense and multiple suffering when faced the hospitalization of a grandchild in intensive care units, which significantly shakes them. However, when they realize that they can provide their family with support in the middle of a crisis, they fight for the family, at the expense of their own suffering. They considered this role to be costly and stressful and pointed to lack of support and specific resources for grandparents during the hospitalization of grandchildren, especially regarding their need to be included and informed by the care team.

The main researcher is a member of the healthcare team of the unit where data collection was carried out and thus presents a limitation of the present study. This can lead to a biased approach during the interviews, considering her prior relationship with the families.

However, the need to develop evaluation strategies and family interventions with all family members is of utmost importance, and further studies should be carried out in this direction, including third and fourth family generations. Based on the results of this study, nursing practice must find ways to increase its understanding and inclusion of families when caring for children hospitalized in intensive care units, both for parents and grandparents.

RESUMO

Objetivo: Compreender a experiência dos avós de ter um neto hospitalizado em Unidade de Terapia Intensiva Pediátrica. **Método:** Estudo qualitativo, que utilizou o referencial teórico do Interacionismo Simbólico e, como referencial metodológico, os pressupostos da Teoria Fundamentada nos Dados, realizado com avós de crianças hospitalizadas em Unidade de Terapia Intensiva Pediátrica de um hospital-escola de uma universidade do interior de São Paulo. Os dados foram coletados por meio de observação participante e entrevistas semiestruturadas e analisados seguindo as etapas de codificação aberta e axial da Teoria Fundamentada. **Resultados:** Foram entrevistados nove avós. Identificaram-se dois fenômenos: “Percebendo-se envoltos em uma tempestade” e “Lutando para ser a âncora da família”, que compreendem o sofrimento vivenciado e o papel de suporte desenvolvido pelos avós durante a hospitalização. **Conclusão:** Os avós desenvolvem um importante papel de sustentação familiar durante a crise, portanto é essencial que se pense em estratégias de cuidado da família que envolvam também essa geração familiar, cada vez mais presente e participativa nos diferentes cenários de atenção à saúde.

DESCRIPTORIOS

Criança Hospitalizada; Avós; Relações Familiares; Enfermagem Pediátrica; Unidades de Terapia Intensiva Pediátrica.

RESUMEN

Objetivo: Comprender la experiencia de los abuelos que tienen un nieto hospitalizado en Unidad de Terapia Intensiva Pediátrica. **Método:** Estudio cualitativo, que utilizó el referencial teórico del Interacionismo Simbólico y, como referencial metodológico, los presupuestos de la Teoría Fundamentada en los Datos, realizada con abuelos de niños hospitalizados en Unidad de Terapia Intensiva Pediátrica de un hospital-escola de una universidad del interior de Sao Paulo. Los datos fueron recolectados por medio de observación participante y entrevistas semiestructuradas y analizados siguiendo las etapas de codificación abierta y axial de la Teoría Fundamentada. **Resultados:** Fueron entrevistados nueve abuelos. Se identificaron dos fenómenos: “Percibiéndose envueltos en una tempestad” y “Luchando para ser el ancla de la familia”, que resumen el sufrimiento vivido y el papel de soporte desarrollado por los abuelos durante la hospitalización. **Conclusión:** Los abuelos desarrollan un importante papel de sustentación familiar durante la crisis, por lo que es esencial que se piense en estrategias de cuidado de la familia que involucren también a esta generación familiar, cada vez más presente y participativa en los diferentes escenarios de atención a la salud.

DESCRIPTORES

Niño Hospitalizado; Abuelos; Relaciones Familiares; Enfermería Pediátrica; Unidades de Cuidado Intensivo Pediátrico.

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