

Perceptions of siblings of children hospitalized due to chronic disease

Percepções de irmãos de crianças hospitalizadas por doença crônica

Percepciones de los hermanos de niños hospitalizados por enfermedad crónica

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Abstract

Background: The daily family life of a child with chronic disease changes according to the illness's demands. The siblings of these children may receive less attention from both parents, as well as from the rest of the family, who may focus more on the sick child and not in a similar way on the healthy sibling.

Objectives: To compile perceptions of siblings of children hospitalized due to chronic disease.

Methodology: Siblings of children diagnosed with chronic diseases, aged between 8 and 16 years, participated in the study. We used open interviews, recording, transcribing, and submitting them to analysis.

Results: We were able to interview only four siblings. In the interviews' analysis, four categories of results (Coping with the sibling's disease; Family restructuring; Experiences resulting from the sibling's hospitalization; and Experiences of exclusion) emerged.

Conclusion: The siblings of children with chronic diseases live in a situation of vulnerability and exclusion, demonstrate difficulties in dealing with their perceptions and feelings, which proves it is essential to involve the sibling in the nursing process.

Keywords: chronic disease; siblings; pediatric nursing; family; perception; health vulnerability

Resumo

Enquadramento: O quotidiano familiar de uma criança com doença crônica é modificado decorrente das exigências recorrentes da doença. Os irmãos destas crianças podem receber menos atenção, tanto dos pais, quanto da restante família, que podem interessar-se mais pela criança doente e não da mesma forma pelo irmão considerado saudável.

Objetivos: Compilar percepções de irmãos de crianças hospitalizadas por doença crônica.

Metodologia: Participaram do estudo irmãos de crianças diagnosticadas com doenças crônicas, com idades entre os 8 e os 16 anos. Utilizaram-se entrevistas abertas, que foram gravadas, transcritas e submetidas à análise.

Resultados: Apenas 4 irmãos puderam ser entrevistados. Na análise das entrevistas, emergiram 4 categorias de resultados (Enfrentamento da doença do irmão; Reestruturação familiar; Experiências a partir da hospitalização do irmão; e Experiências de exclusão).

Conclusão: Os irmãos das crianças com doenças crônicas estão em situação de vulnerabilidade e exclusão, demonstram dificuldades em lidar com as suas percepções e sentimentos, o que mostra a importância de integrar o irmão no processo de enfermagem.

Palavras-chave: doença crônica; irmãos; enfermagem pediátrica; família; percepção; vulnerabilidade em saúde

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Resumen

Marco contextual: La vida diaria familiar de un niño con enfermedad crónica se modifica de acuerdo con las necesidades recurrentes de la enfermedad. Los hermanos de dichos niños pueden recibir menos atención, tanto por parte de los padres como del resto de la familia, quien puede mostrar más interés por el menor enfermo y no tanto por el hermano considerado sano.

Objetivos: Recopilar las percepciones de los hermanos de niños hospitalizados por enfermedad crónica.

Metodología: Participaron en el estudio hermanos de niños diagnosticados con una enfermedad crónica, con edades comprendidas entre los 8 y los 16 años. Se utilizaron entrevistas abiertas, que se grabaron, transcribieron y sometieron a análisis.

Resultados: Solo se pudo entrevistar a 4 hermanos. En el análisis de las entrevistas, surgieron 4 categorías de resultados (Afrontamiento de la enfermedad del hermano; Reestructuración familiar; Experiencias a partir de la hospitalización del hermano; y Experiencias de exclusión).

Conclusión: Los hermanos de los niños con enfermedades crónicas están en una situación de vulnerabilidad y exclusión, y demostraron dificultades al lidiar con sus percepciones y sentimientos, lo que muestra la importancia de integrar al hermano en el proceso de enfermería.

Palabras clave: enfermedad crónica; hermanos; enfermería pediátrica; familia; percepción; vulnerabilidad en salud

Received for publication: 08.10.18

Accepted for publication: 27.01.19

Introduction

Chronic diseases in childhood are long-lasting, cause sequelae, and impose limitations on the child, subjecting him/her to invasive procedures and long periods of hospitalization. The family accompanies the child during this period, facing a situation of unknown outcomes, with the feeling of imminent loss (Ichikawa et al., 2014). The everyday life of a chronically ill child changes according to the requirements resulting from the disease, such as interruption of daily activities, prolonged hospitalization, medical examinations, therapy adherence, coping with undesirable effects of medication, limited understanding of the diagnosis, financial maladjustment, anguish, sorrow, pain, and constant fear of possible death. As a result, subject to tension, the family functioning is disorganized, as each member needs to readjust their behavior (Araújo, Reichert, Vasconcelos, & Collet, 2013; Misko, Santos, Ichikawa, Lima, & Bouso, 2015).

Consequently, the siblings of these children may receive less attention of both parents, as well as of the rest of the family, teachers, and friends, since everybody worries about the well-being of the sick child, and not about the healthy brother. Furthermore, the siblings struggle with coping with their parents' suffering and the uncertainty of the sick sibling's treatment, prognosis, and survival (Lovgren, Bylund-Grenklo, Jalmsell, Wallin, & Kreicbergs, 2015).

Considering that children are the best sources of information about themselves (Vasques, Mendes-Castillo, Bouso, Borghi, & Sampaio, 2014), the objective of this study was to gather perceptions of siblings of children hospitalized for chronic disease.

Background

The siblings of children with chronic diseases face changes in emotional health because they have a higher risk of developing depression, anxiety, post-traumatic stress, poorer quality of life, behavioral difficulties, guilt, and social isolation (Haukeland, Fjermestad, Mossige, & Vatne, 2015).

Some of the experiences lived by the healthy siblings trigger emotional changes, such as the attendance of traumatic procedures, alterations in the health status of the sibling, unfamiliarity with the distressing disease, and in particular changes in the relationship with the parents (Humphrey et al., 2015).

The difficulty of the siblings of sick children in expressing feelings such as fear and unhappiness, associated with emotional instability caused by parental alienation, can worsen the experience of stress (Haukeland et al., 2015). The life changes experienced by the sibling of a hospitalized patient with chronic disease are an exciting area for nursing practice, namely from the perspective of family-centered care (Shields, 2015).

The family-centered care is understood as an approach to planning; providing assistance and assessing healthcare; generating mutual benefits for all actors involved in the care, that is, benefits for the healthcare team, for patients, and their families (Johnson et al., 2008).

Thus, from this perspective, one cannot require that parents take care only of the hospitalized sick child, but negotiation is vital to ensure that the other healthy or sick children at home also receive affection and care from parents (Shields, 2015).

The family is the main actor in coping with the disease, both in the healing process and the dying process, so its inclusion in the care is essential (Misko et al., 2015; Humphrey et al., 2015; Santos et al., 2013).

Regarding inclusive care, the siblings of children in pediatric palliative care who received support during the sibling's disease had higher scores of quality of life and lower incidence of depression, anxiety, or behavioral problems, when compared with the siblings who did not receive the same support (Humphrey et al., 2015).

Currently, there is greater scientific production focused on chronic patients and their parents. Studies on the experience of the siblings of children hospitalized for chronic disease can justify the raising of subsidies to assist families better, thereby contributing to a better quality of life for these children and adolescents.

Research Question

Which perceptions have arisen in the siblings of chronic patients as a result of changes in their lives after their siblings became sick?

Methodology

This study used a qualitative design with narrative research, involving individual narrative reports and the interpretation of their meanings. We emphasized the experiences of siblings of children with chronic diseases, who were encouraged to tell about their experiences so they

could find meaning or interpret phenomena based on each meaning (Driessnack, Sousa, & Mendes, 2007).

The study took place in the pediatrics infirmary and the nephrological care center of the pediatrics unit of a Hospital University of Education in the countryside of São Paulo State. The pediatric ward includes a teaching and research field; whose assistance is admittedly a regional reference service of the Single Health System (SUS). With 48 beds, the hospital admits around 1500 children per year, who remain in the unit for 8.6 days on average. The leading causes of hospitalization include surgical procedures, infectious diseases, and diagnostic procedures. Respiratory failure, diagnostic research, and intensive treatment are also factors that can lead to hospitalization. We did not establish the number of interviewees previously and determined the number of participants during the interviews. The participants were selected based on the contents of the interviews, using the theoretical saturation method, occurring when the interaction between the research field and the researcher does not generate elements that define or deepen the theorizing. The qualitative researches in the health area have applied this concept widely (Fontanella, Ricas, & Turato, 2008).

We included siblings between 7 and 17 years of age who lived with their chronically ill siblings. We chose to interview 7-year old and older children because we find that at this age the child is in the concrete operational stage, can answer questions and provide information about his/her experiences (Vasques et al., 2014). Another inclusion criterion in the study for interviewing the sibling was the minimum time of treatment of 1 year, because the child or adolescent has, in principle, already dealt with possible limitations and changes in everyday life and family relations (Vieira & Lima, 2002). We used the open interview using a guiding question: "Tell me your history and your family's after your sibling got sick". Throughout the interview, according to the proposed objectives, we asked questions and made requests such as: "Tell me a little more about it"; "You told me that . . . what else would you like to tell me about it?"; "What do you mean by that?"; "What more do you have to say about it?"; "Can you explain it better?"; "How was it for you?". The interview was of semi-structured design and took place in a single moment, individually, in a closed room. The script for the interviews began with questions about the siblings' socio-demographic characteristics.

The interviews were audio-recorded and identified with fictitious names, a fact only known to the researchers to ensure the confidentiality and anonymity of their testimonies. Immediately after data collection, we fully transcribed the interviews, preserving the ideas, the sequence, and the language used by the subjects for later analysis.

We recorded all the interviews with the device *Sony Corp* (after the participants' consent) and manually transcribed them soon after, for a better analysis of the data. The most extended interview lasted 53 minutes and 37 seconds, while the shortest lasted 17 minutes and 47 seconds.

We carried out the content analysis in three phases: material pre-exposure or fluctuating readings of the corpus of interviews; selection of units of meanings; and, finally, the process of categorization and subcategorization (Campos, 2004).

The methodological framework adopted for the content analysis was that of Bardin (2011). During the pre-analysis, two authors carried out the fluctuating reading of the transcribed material several times. Then, when establishing the data corpus, we conducted an in-depth reading to identify the categories of participants' perceptions related to the sibling's chronic illness; hence, we underlined the transcribed material in different colors, according to context and registration units. In the process of categorization of the results, the researchers grouped the reports' fragments according to the colors assigned to the repeating reports and, consequently, have nominated in consensus the categories of perceptions resulting from the interviews.

This method consists of a set of techniques used in qualitative researches that aim to ascertain the meaning of the transcribed interviews (Bardin, 2011).

The project was registered in Plataforma Brasil and approved by the Research Ethics Committee of the Institution (Parecer nº 1,867,236). We collected the data in a tertiary teaching University Hospital, in the countryside of São Paulo State, from December 2016 to May 2017.

We interviewed the participants after the parents of the children hospitalized due to chronic illness had signed the Free and Informed Consent Form and the subjects (the patients' siblings) understood and signed the Informed Consent Form.

We used a standardized checklist - COREQ (Consolidated criteria for REporting Qualitative research).

Results

We identified 37 potential siblings, but during the six months of data collection, we were able to interview only four siblings: Snow White (16 years old), Timon (8 years old), Jimmy Five (8 years old), and Mickey (13 years old). Of those 37 possible interviewees, nine did not return when the researcher contacted them to schedule the interview; one did not appear

for the interview on the scheduled day, and it was not possible to reschedule it; three visited their siblings when the researcher was not in the unit; two patients were discharged before it was possible to schedule the interview with their siblings; the remaining 18 siblings lived in distant cities with commuting difficulties and, consequently, did not visit their siblings in the hospital during the data collection. Table 1 shows the characterization of the sample.

Table 1

Characterization of the interviewees and hospitalized siblings

Interviewed sibling Codename, age, and education level	Hospitalized patient Codename, age, and diagnosis
Snow White, 16 years old, sophomore year of secondary school	Dopey, 11 years old, Bilateral adrenal tumor
Timon, 8 years old, 2 nd grade of elementary school	Pumba, 2 years old, Refractory epilepsy
Jimmy Five, 8 years old, 3 rd grade of elementary school	Smudge, 11 years old, Nephrotic syndrome
Mickey, 13 years old, 5 th grade of elementary school	Minnie, 7 years, Cushing's syndrome

The chronically ill siblings are between 2 and 11 years old, three of them male and one female. The chronic disease diagnoses of the siblings were: refractory epilepsy, nephrotic syndrome, Cushing's syndrome, and bilateral adrenal tumor, according to the colors assigned to repeating reports.

The researchers carried out the content analysis, reading exhaustively each interview, then organized them using a color code, focusing on similar reports of the participants, and, finally, defined four categories of results of the participants' perceptions: Coping with the sibling's disease; Family restructuring; Experiences resulting from the sibling's hospitalization; and Exclusion experiences.

In the category of Coping with the sibling's disease, we observed demonstrations of feelings triggered by the diagnosis and hospitalization of the chronically ill children, as well as learnings resulting from coping.

The siblings were able to name different feelings in different moments during the illness. All reports referred sadness, particularly in the moment of discovering the disease or of the sibling's hospitalization: "I understood that Smudge would be hospitalized here at the hospital for a long time, so I felt sad" (Jimmy Five, 8 years old, Brother of Smudge, June 2017). Concerning the hospitalization, they usually report missing their siblings: "Smudge says he

misses me, and I miss him too" (Jimmy Five, 8 years old, brother of Smudge, June 2017). They identified and described the anguish they feel for witnessing the disease and its resulting limitations: "Sometimes I feel distressed (cries) because she is in this situation and I would like to help her" (Mickey, 13 years old, brother of Minnie, April 2017).

The concern about the fluctuating clinical parameters, even though they are not identified, means constant monitoring in the face of uncertainty:

Well, we worry more when there are these changes, but the last time the change was huge! He gets examined every 6 months, and this time the results were altered. Now we are worried about it. (Snow White, 16 years old, sister of Dopey, May 2017)

The siblings also reported the fear of getting sick the same way as the chronically ill patient: "But you have to be more careful so that Smudge does not return to the hospital, because nobody knows how he got that bacteria . . . I was afraid to stay at home and get the bacteria" (Jimmy Five, eight years old, brother of Smudge, June 2017). In the interviews, the sister considers her brother's disease to be the cause of their family's union but understands she learned this after she grew older and more mature and the child's clinical status improved.

So, I thought . . . it was all his fault (low voice/pause). But, nowadays, I believe that it was not . . . I believe that things happened . . . until he had this problem, I believe it was to unite my parents. They fought a lot. Then, the brother's problem forced them to be more together to be able to deal with it. So. . . it was also after my brother's problem that I started living with my parents. So. . . it was wrong, right? This thought. . . (Snow White, 16 years old, sister of Dopey, May 2017)

In the category of Family restructuring, the siblings report changes in daily routine and family structure, as a result of the frequent appointments or repeated episodes of hospitalization of the sick siblings. Consequently, caregivers become absent in the routine of their healthy children, who need to deal with their sibling's and caregivers' absence: "I feel sad, because I love Mommy and Pumba, and they are both away. They cannot come home now because Pumba is in Tauranga" (Timon, 8 years old, brother of Pumba, May 2017); "I never slept in my grandmother's house. It was . . . I was not very happy, so I did not even say goodnight to Mommy, nor hug and kiss her because she was not home (speaks quietly, crying voice)" (Jimmy Five, 8 years old, brother of Smudge, July 2017); "my aunts were always at the hospital. They were allowed in, so one of them took turns with my mother, she stayed while my mother went home to shower" (Snow White, 16 years old, sister of Dopey, May 2017).

The interviewed siblings report everyday family memories, which occurred when the chronically ill child was not hospitalized. They described moments when the family was together, and the sick sibling was able to enjoy the activities:

I remember one day! . . . Pumba fell off the bed! It happened at the other house. He got a bump on the head! . . . My aunt fed him! (excited). He liked to pull hair. He taps on the water! (makes hand gestures; silence). It was nice to bathe him. I helped dry him, scent him. I took him on my lap! Mom has a picture of me, Pumba, and Hawk holding him! (Timon, 8 years old, brother of Pumba, May 2017)

In the category of Experiences resulting from the sibling's hospitalization, the siblings recount their experiences in the hospital environment. Thus, they manifest the feeling of strangeness towards the devices their sibling uses and even physical symptoms due to lack of explanation of the meaning of inputs and objects at the bedside:

Smudge had much stuff stuck to him (pause), many devices. Three saline solutions stuck to him. Some big things with saline solution to give to Smudge. I was shocked because he had many things on him. Then I started to vomit. (Jimmy Five, 8 years old, brother of Smudge, July 2017)

One sibling mentioned calling to God, interceding for their mother's suffering, due to the risk of death of their sibling, during the hospitalization in intensive therapy: "I am going to see Pumba, did you know he woke up? He slept for a long time. And I asked Dad in Heaven to wake him because Mom was crying a lot!" (Timon, 8 years old, brother of Pumba, May 2017).

Two siblings also reported dependence on religion and the listening space provided by the Church:

Aham. I have nothing to say here, I already said everything at church. And I always forget what I say. I go with my friend who lives close to me (silence). He is really tiny. And there is also popcorn. Popcorn and soda . . . We take photos, laugh, talk, make popcorn . . . The music is beautiful there! And then we leave. Then I come back home. (Timon, 8 years old, brother of Pumba, May 2017)

"Today, at 6:30 pm, I will go to church, I will pray for Smudge to get better soon because Mommy and I are sad. This way, I think he will return home sooner" (Jimmy Five, 8 years old, brother of Smudge, July 2017).

The siblings' involvement in care was considered beneficial for all the family and a preventive measure to deal with potential loss experiences:

Everyone, right. From the beginning, everyone was well aware of the situation. I think that is good. Because if something happens, we will not know it immediately. It is something we al-

ready know for quite some time. So, if something happens, we will be already kind of prepared. If I may say so. (Snow White, 16 years old, sister of Dopey, May 2017)

Also, they state they feel genuine joy for being included and affection for perceiving they are wanted and welcomed by the sibling: “Ah, I feel happy! Because I am participating in her treatment, and she is happy when I come. Today she was very happy! (smiles)” (Mickey, 13 years old, brother of Minnie, April 2017).

In the category of Exclusion experiences, we identified everyday situations of siblings’ invisibility within the family and amongst individuals who orbit the assistance to the sick sibling:

Sometimes I would go with my grandmother to the hospital’s entrance, and she would go up to be with my brother, and my mother came down to see me, have lunch with me . . . or something like that (pause). And at that time I still had no relationship with my brother. (Snow White, 16 years old. Sister of Dopey, May 2017)

I do not really understand much of her treatment. So, sometimes I have doubts, you know. I ask my mother, but she also does not know how to explain it to me! So, sometimes I end up asking the doctors here (pause). That is it. I cannot come here a lot, because it depends on the city hall’s car, the driver does not want to bring me sometimes (crying voice). (Mickey, 13 years old, brother of Minnie, April 2017)

“We – Snow White and Dopey – did not have a relationship. I did not see my brother; it took a while to meet him; it took a while to see him. And I had a relationship via telephone with my mother” (Snow White, 16 years old, sister of Dopey, May 2017).

The standardization, which is inconsistent with the involvement of siblings in relevant social events to promote family experiences, highlights the exclusion experiences of siblings or their fragmented inclusion:

“I was able to attend some parties, but only when they were for me. In Easter, in the children’s day I would go, but on mothers’ day I could not go” (Snow White, 16 years old, sister of Dopey, May 2017).

The interviewees regard the exclusion of siblings with some naturalness because they were surprised when contacted for the interviews: “I thought it was different because they have talked with my mother, but never asked to talk with me” (Mickey, 13 years old, brother of Minnie, April 2017).

Discussion

Giving voice in this study to the siblings of chronically ill children allowed a more profound contemplation of the universe of their experiences, perceptions, and feelings during the path taken by the family, which could never be summarized by objective variables (Vasques et al., 2014).

Although the data collection lasted 6 months, recruiting approximately 118 chronically ill patients based on the inclusion and exclusion criteria, we could have interviewed 37 siblings. However, the conduction of only four interviews becomes an exclusion practice of the healthy sibling.

Hospital absence justifications of siblings, due to distance or unawareness of flexible and authorized visitations for children under 12 years old, mean there is no policy of sibling’s inclusion in care.

Therefore, the four interviewed siblings contributed to achieving the objective of this study, providing substantial and complex reports. They shared their perceptions, sorrows, fears, worries, memories, and feelings in coping with the disease of their chronically ill sibling.

One participant considered the family restructuring, resented by the children and perceived by the researchers, due to mother and sibling separation, a positive consequence, as the parents rebuilt their family to overcome the difficulties. Consistent with the experience’s heterogeneity in different life stages, the literature shows that, although the well-being of siblings of chronically ill children is increasingly compromised, there is also evidence of several possibilities such as increased maturity, sensitivity, and greater family cohesion (Humphrey et al., 2015).

In the experiences resulting from the sibling’s hospitalization, the feeling of strangeness towards the displayed therapy devices suggests

that there was no prior preparation, which their visitation required. The literature indicates that the siblings should be prepared for the visitation to the hospitalized child, especially when it is a first-time visitation (Humphrey et al., 2015; Lovgren et al., 2015; Paiva, Carvalho, Lucchetti, Barroso, & Paiva, 2015).

Thus, the siblings of chronically ill children should have the right to choose when to visit them and for how long. They should be warned that they may feel nervous or scared and that those feelings are natural. Furthermore, the devices and equipment used by the patient should be described to the siblings. Before the visitation, it is also necessary to describe how the hospitalized child looks like and behaves (Lash, 2013).

Concerning the learnings resulting from coping with their sibling's chronic disease, they report different ways to cope with this reality and to express their feelings. So, they presented the faith in God as a coping mechanism for the experience of almost imminent loss of their sibling. Although there is a service of hospital chaplaincy, no participants asked for spiritual care to the patient and their family, which we consider unfortunate because of the possible experience of spirituality that transcends loss experiences, as well as serving as a support tool to face difficulties, to personal empowerment, to reflect on values and the meaning of life (Paiva et al., 2015; Sav et al., 2015).

Snow White manifested the desire to be included in care to the sick child in her interview, as shown by the literature, which presents the inclusion of siblings as a way for them to feel supported and aware of their sibling's diagnosis and prognosis, during the whole course of the disease, in a path to healing or death (Lovgren et al., 2015).

The complexity of care integrity requires a unique disposition of the patient and his/her family for the treatment. This care focuses not only on the treatment results but also on the professionals' conduct, requiring that they share responsibility in the treatment because they need to continuously adapt care over time, due to the constant technological updates and the progression of the disease (Sav et al., 2015).

As experiences of exclusion from care, the reports of the participants infer the difficulty in obtaining transportation for their trip to the

hospital as the main reason for their exclusion. Furthermore, the participants also mentioned their exclusion from parties like *mothers' day*, as if the role of their mothers was exclusively to be the *mother of the chronically ill patient*.

The siblings of chronically ill children define participating in family activities as not just doing something, but also as being involved in an activity, as feeling part of a group. Not participating in these activities can cause feelings of exclusion and adjustment difficulties to the sibling (Woodgate, Edwards, Ripat, Rempel, & Johnson, 2016).

Taking into account the astonishment of Mickey, who considers the experience of talking with one of the researchers *different*, we note that the other family members, not the mother, are not included in the routine care of professionals who attend to the chronically ill patients.

The siblings play a unique role in the growth and development of a child. They share family secrets, and nobody else in the life of a child can share this experience. The loss of this special relationship causes suffering and deep sadness, thus being beneficial to talk about these aspects (Wender, 2012).

A fallacy experienced in developing countries considers as family-centered care the presence of family members 24 hours a day beside the hospitalized patient, when, in fact, the family members are who perform the hygiene and comfort care, because of an insufficient number of nursing professionals to provide this care (Shields, 2015). In this paper, this fallacy stands out in the reports of participants who only saw their mother for short periods, to ensure the care of the hospitalized sick child; other reports on coping with the sibling's disease include family restructuring, experiences resulting from the sibling's hospitalization; and, especially, the exclusion from healthy conviviality, adequate for a developing child.

Considering these results, we emphasize that, from a genuinely family-centered perspective, nursing must seek a better adjustment and flexible negotiation relating to family situations (Shields, 2015).

The study limitation as to the number of interviewed siblings may justify the existence of other categories of results. Considering the policies of inclusion of the siblings of hospitalized patients, it may be possible to interview

new participants, with new perspectives about *being in the hospital with your sibling*, and to compare different perceptions in different stages of development for different age groups.

Therefore, this study explored a poorly discussed perspective by highlighting previously invisible characters in the culture of the researched hospital in a developing country. The siblings and their experience of life are evident to nursing and the health professionals who care for pediatric patients, with the purpose of promoting care integrity and health promotion for individuals and the whole, of tracing new paths in the history of the life of these characters. The siblings are a care front that must be considered and reflected upon as characters in the genuinely family-centered care.

Conclusion

We noted that the siblings of chronically ill children live in a situation of vulnerability and exclusion from care.

Special and perceptual reports on the uncertainties of coping with the sibling's disease, on family restructuring due to needs that emerge from the care to the chronically ill patient, on experiences resulting from the sibling's hospitalization, and on the exclusion from commemorative dates instigate to rethink the work process claimed as family-centered.

We believe that family-centered care transcends the mother's legal inclusion, or a companion's for 24 hours, but it involves extending care to individuals bound by fraternal ties. Given the siblings' surprise when being invited for the interview, favorable conditions occurred for the development of new research and care routines. It is essential that professionals welcome siblings during visitations to hospitalized patients, especially when the children witness their sibling surrounded by multiple devices. Therefore, we recommend a previous dialogue as a coping mechanism, so children from each age group can understand the situation.

It is crucial to broaden the scope of the commemorative events to include siblings and family members in the celebrations like mother's day, father's day, children's day, Easter, Christmas, among other culturally valued events, as a means of fostering family memories in hospital-

ized patients. However, to achieve this goal, it is necessary to carry out transdisciplinary work with social service, psychology, and pedagogy professionals, in addition to nursing practice. Nursing has the potential to renew its pediatric care scenario to integrate the siblings in all the phases of the nursing process, which can support inclusion policies and support and assistance routines to the siblings of hospitalized pediatric patients.

In a new scenario of truly family-centered care, including sibling visitations of siblings, in a welcoming and inclusive nursing process, it will be possible to conduct new studies that compare their perceptions, feelings, and needs at different ages or stages of development, to promote health and coping possibilities in the vulnerable situation of a sibling's chronic disease.

References

- Araújo, Y., Reichert, A., Vasconcelos M., & Collet, N. (2013). Fragility of the social network of families of children with chronic disease. *Revista Brasileira de Enfermagem*, 66(5), 675-681. doi: 10.1590/S0034-71672013000500006
- Bardin, L. (2011). *Análise de conteúdo*. São Paulo, Brasil: Edições 70.
- Campos, C. (2004). Método de análise de conteúdo: Ferramenta para a análise de dados qualitativos no campo da saúde. *Revista Brasileira de Enfermagem*, 57(5), 611-614. doi: 10.1590/S0034-71672004000500019
- Driessnack, M., Sousa, V., & Mendes, I. (2007). An overview of research designs relevant to nursing: Part 2: Qualitative research designs. *Revista Latino-Americana de Enfermagem*, 15(4), 684-688. doi: 10.1590/S0104-11692007000400025
- Fontanella, B., Ricas, J., & Turato, E. (2008). Amostragem por saturação em pesquisas qualitativas em saúde: Contribuições teóricas. *Cadernos de Saúde Pública*, 24(1), 17-27. doi: 10.1590/S0102-311X2008000100003
- Haukeland, Y., Fjermestad, K., Mossige, S., & Vatne, T. (2015). Emotional experiences among siblings of children with rare disorders. *Journal of Pediatric Psychology*, 40(7), 712-720. doi: 10.1093/jpepsy/jsv022
- Humphrey, L., Hill, D., Carroll, K., Rourke, M., Kang, T., & Feudtner, C. (2015). Psychological well-being and family environment of siblings of children with life threatening illness. *Journal of Palliative Medicine*, 18(11), 981-984. doi: 10.1089/jpm.2015.0150

- Ichikawa, C., Bousso, R., Misko, M., Mendes-Castillo, A., Bianchi, E., & Damião, E. (2014). Cultural adaptation of the family management measure among families of children and adolescents with chronic diseases. *Revista Latino-Americana de Enfermagem*, 22(1), 115-122. doi: 10.1590/0104-1169.2978.2379
- Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P., . . . Ford, D. (2008). *Partnering with patients and families to design a patient- and family-centered health care system: Recommendations and promising practices*. Retrieved from http://www.hqontario.ca/Portals/0/modals/qi/en/processmap_pdfs/articles/partnering%20with%20patients%20and%20families%20to%20design%20a%20patient-%20and%20family-centered%20health%20care%20system.pdf
- Lash, M. (2013). Brain injury: Helping brothers and sisters. *Pediatric Nursing*, 39(6), 309-310.
- Lovgren, M., Bylund-Grenklo, T., Jalmell, L., Wallin, A., & Kreicbergs, U. (2015). Bereaved siblings' advice to healthcare professionals working with children with cancer and their families. *Journal of Pediatric Oncology Nursing*, 33(4), 297-305. doi: 10.1177/1043454215616605
- Misko, M. D., Santos, M. R., Ichikawa, C. R., Lima, R. A., & Bousso, R. S. (2015). A experiência da família e/ou adolescente em cuidados paliativos: Flutuando entre a esperança e a desesperança num mundo transformado pelas perdas. *Revista Latino-Americana de Enfermagem*, 23(3), 560-567. doi: 10.1590/0104-1169.0468.2588
- Paiva, B., Carvalho, A., Lucchetti, G., Barroso, E., & Paiva, C. (2015). "Oh, yeah, I'm getting closer to God": Spirituality and religiousness of family caregivers of cancer patients undergoing palliative care. *Support Care Cancer*, 23(1), 2383-2389. doi: 10.1007/s00520-015-2604-1
- Santos, L., Araújo, J., Lima Júnior, R., Sousa, R., Conceição, V., & Santana, M. (2013). Palliative care for children with cancer: Reflections on the health-disease process. *Revista Brasileira de Pesquisa em Saúde*, 15(3), 130-138. doi: 10.21722/rbps.v15i3.6335
- Sav, A., King, M. A., Whitty, J. A., Kendall, E., McMillan, S. S., Kelly, F., . . . Wheeler, A. J. (2015). Burden of treatment for chronic illness: A concept analysis and review of the literature. *Health Expectations*, 18(3), 312-324. doi: 10.1111/hex.12046
- Shields, L. (2015). What is "family-centered care"? [Guest editorial]. *European Journal for Person Centered Healthcare*, 3(2), 139-144. doi: 10.5750/ejpch.v3i2.993
- Vasques, R., Mendes-Castillo, A., Bousso, R., Borghi, C., & Sampaio, P. (2014). Giving voice to children: Considerations on qualitative interviews in pediatrics. *Revista Mineira de Enfermagem*, 18(4), 1016-1020. doi: 10.5935/1415-2762.20140075
- Vieira, A., & Lima, R. (2002). Children and adolescents with a chronic disease: Living with changes. *Revista Latino-Americana de Enfermagem*, 10(4), 552-560. doi: 10.1590/S0104-11692002000400013
- Wender, E. (2012). Supporting the family after the death of a child. *Pediatrics*, 130(6), 1164-1169. doi: 10.1542/peds.2012-2772
- Woodgate, R., Edwards, E., Ripat, J., Rempel, G., & Johnson, S. (2016). Siblings of children with complex care needs: Their perspectives and experiences of participating in everyday life. *Child Care Health and Development*, 42(4), 504-512. doi: 10.1111/cch.12345

