Defending the rights of children in a hospital setting: nurses’ advocacy in health

Em defesa dos direitos da criança no ambiente hospitalar: o exercício da advocacia em saúde pelos enfermeiros

En defensa de los derechos del niño en el ambiente hospitalario: el ejercicio de la abogacía en salud por las enfermeras

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ABSTRACT

Objective: To identify the actions of nurses in defending the rights of hospitalized children. Methods: Qualitative research conducted in two hospitals in southern Brazil, with twelve nurses, using semi-structured interviews in June 2014. Results: Nurses advocate for the rights of hospitalized children by performing actions intended to ensure the right to life, dignity and health. Conclusions: The actions of nurses defending the rights of hospitalized children were mainly performed by providing guidance that enabled the participation of children in their own care and promoting the autonomy of parents or legal guardians to make decisions concerning the care provided to their children. Implications for practice: Acknowledging health advocacy actions represents advancement in the practice of nursing, as it provides nurses opportunities to cope with future experiences in the pediatric context.

Keywords: Nursing; Health Advocacy; Child Advocacy; Hospitalization.

RESUMO

Objetivo: Conhecer as ações dos enfermeiros na defesa dos direitos das crianças hospitalizadas. Métodos: Pesquisa qualitativa, desenvolvida em duas instituições hospitalares do Sul do Brasil, com doze enfermeiros, - por meio de entrevistas semiestruturadas, em junho de 2014. Resultados: Foi possível perceber que os enfermeiros exercem a defesa dos direitos das crianças hospitalizadas através de ações que visam garantir o direito à vida, à dignidade e à saúde. Conclusões: As ações dos enfermeiros na defesa dos direitos das crianças hospitalizadas, foram realizadas, principalmente, por meio de orientações que possibilitam a participação da criança nos seus cuidados e a promoção da autonomia dos pais ou responsáveis para a tomada de decisões quanto aos cuidados com a saúde da criança. Implicações para a prática: O reconhecimento das ações de advocacia em saúde constitui um avanço para a prática da enfermagem, pois oportuniza aos enfermeiros subsídios para o enfrentamento de futuras vivências no contexto pediátrico.

Palavras-chave: Enfermagem; Advocacia em saúde; Defesa da Criança e do Adolescente; Hospitalização.

RESUMEN

Objetivo: Conocer las acciones de las enfermeras en la defensa de los derechos de niños hospitalizados. Métodos: Investigación cualitativa, desarrollada en junio de 2014 en dos hospitales en el sur de Brasil con doce enfermeras, a través de entrevistas semiestructuradas. Resultados: Las enfermeras ejercen la defensa de los derechos de los niños hospitalizados a través de acciones que garantizan el derecho a la vida, la dignidad y la salud. Conclusiones: Las acciones de las enfermeras se producen principalmente a través de directrices que permitan la participación de los niños a su cuidado y la promoción de la autonomía de los padres o responsables sobre el cuidado del niño. Implicaciones para la práctica: El reconocimiento de las acciones de defensa de la salud es un paso adelante para la práctica de la enfermería, puesto que garantiza a las enfermeras los subsidios para el enfrentamiento de futuras experiencias en el ámbito pediátrico.

Palabras clave: Enfermería; Abogacía en la Salud; Defensa del Niño; Hospitalización.
INTRODUCTION

In the health field, a human being, previously the object of intervention and primarily clinical practice, currently requires being perceived as an individual included in social, physical, and cultural contexts. Hence, health workers, and among them nurses, need to work on the promotion and protection of the health of individuals, considering their wholeness, honoring ethical and legal precepts to respect and ensure the rights of people.1 The fight for individuals’ rights began with the Universal Declaration of Human Rights, a historical landmark in the search for and defense of the rights of human beings, which acknowledges the fundamental rights of all people. In the context of children, however, the need for specific laws to ensure their proper growth and healthy development emerged, which culminated in the Declaration of the Rights of the Child, a landmark for the promotion and protection of rights of individuals during childhood.2,3

In Brazil, child and adolescent rights are grounded on the Brazilian Constitution; however, only the Statute for Child and Adolescent (in Portuguese, Estatuto da Criança e do Adolescente/ECA) has consolidated these rights.4 The ECA provides that hospitalized children have the right to integral care provided by the Brazilian Public Health System (in Portuguese, Sistema Único de Saúde/SUS), ensuring children’s universal and equal access to actions and services intended to promote, protect and recover health.

Note that after the ECA, the National Council for the Rights of the Child and Adolescent - CONANDA was established. This council, a permanent collegiate body of a deliberative nature, provided for in the Statute for Child and Adolescent,5 is intended to enable greater deliberation and have greater control over policies intended to promote and defend the rights of children and adolescents at the federal level.6 CONANDA’s current primary legal authority includes establishing standards for the national policy regarding how to address the rights of children and adolescents and also to enforce proper implementation of the Statute of the Child and Adolescent.7

In the context of health services, considering the constant presence of nurses, the good relationship these professionals establish with patients and families, and their broad knowledge concerning how the health system functions, it is justifiable that nurses advocate for patients in their practice, and actually likely that they will do so.8

Nurses play an important role in the defense of child rights, ensuring rights are respected, especially during hospitalization. Hospitalization is a stressful event in the life of a child and family, with the potential even to impede a child’s healthy growth and development. Hence, ensuring the rights of a hospitalized child is intended to enable better treatment and care conditions, as well as to minimize the stress arising from hospitalization.2,5,6

It is extremely important that the families of hospitalized children acknowledge themselves as entitled to rights, exert their autonomy toward the health staff, and help by searching for, demanding and fighting for the rights of their hospitalized children.9 Nurses need to exercise advocacy in health, orienting families concerning their children’s rights so that, with such knowledge in hand, these families can demand their rights and avoid harm with the potential to impact the growth and development of their children.10

Health advocacy is an important concept when discussing the defense of the rights of hospitalized children.2 There are three widely disseminated definitions in the literature regarding advocacy in nursing, namely: protect patients against undesired medical interventions; free patients from discomfort of unnecessary treatment; and educate patients so they become active subjects making choices and decisions regarding care and treatments.7

One integrative review addressing advocacy in child health reports that the use of the term advocacy in the health field is directly associated with the field of care provided to children, encompassing actions performed by health workers with the potential ability to advocate for children, defending their rights, especially in the community health sphere.11

The first experiences of advocacy in child health took place in 1975, when a group of American pediatricians started claiming the rights of children and included health workers as important actors in the fight to ensure such rights. Nonetheless, even though the first discussion regarding advocacy for pediatric patients emerged in 1975, research involving this topic is still incipient,1 showing there is an important gap to be explored, a fact that justifies the implementation of this study.

Given the previous discussion, the following guiding question was established: What are nurses’ actions in the context of promoting the defense of the rights of hospitalized children? In order to answer this question, this study's objective was to identify the actions of nurses in defending the rights of hospitalized children.

To verify what actions nurses perform to defend the rights of hospitalized children and help them recognize such actions, can strengthen the ethical dimension of nursing practice, which is where the relevance of this study lies.

METHODS

This descriptive-exploratory study with a qualitative approach was part of a larger project entitled: "Patient advocacy and coping in nursing: possibilities to exercise power in the face of moral distress experiences," approved in the call for
research projects 14/2012 (process 474761/2012-6). The study was conducted in three units, two pediatric hospitalization wards and a neonatal intensive care unit (NICU), from two hospitals, one public and one private facility, located in a city in the extreme south of Brazil.

In regard to the characterization of these facilities, the NICU is from a university hospital with 14 nurses and is divided into three hospitalization sectors: intermediate (five beds), intensive (10 beds) and kangaroo with two beds, in addition to three beds reserved for isolation. The Pediatric Unit, which belongs to this same university hospital, has 17 hospitalization beds and its staff is composed of six RNs. Finally, the pediatric unit belonging to the philanthropic hospital has three nurses and 20 beds: three cribs for SUS patients and 12 cribs for patients from the private sector, i.e. patients with a health insurance plan.

Inclusion criteria were: being a nurse working in one of the pediatric hospitalization units selected; having worked for at least three months in one of the units selected; and signing free and informed consent forms. Exclusion criteria were: not being present at the time and place of data collection due to vacation or leave. Twelve nurses working in the three pediatric units from the aforementioned facilities were selected according to the non-probabilistic convenience method, according to their interest, presence at the study setting, and availability to participate in the study at the time of data collection.

Data were collected in June 2014, at different times and places arranged according to the participants’ convenience. Semi-structure interviews containing closed questions (to characterize the participants) and open questions addressing aspects related to the nurses’ actions to advocate in the defense of the rights of children in a hospital setting, were recorded and lasted 30 minutes, on average.

Analysis of data collected in the interviews was based on discursive textual analysis, which is a method of qualitative data analysis, the purpose of which is to produce new understanding regarding discourses and phenomena through a self-organized process that encompasses a sequence of three steps; deconstruction, categorization, and capturing the new emerging element or communication.12

In the deconstruction step, the interviews were examined in detail and deconstructed until they reached units of meaning, which are statements concerning the phenomenon under study. Relationships among units of meaning were established in the categorization step, in which four categories based on the Statute of the Child and the Adolescent were established. The last step, intended to communicate or capture the new emergent element, sought to explain the understanding of the investigated phenomenon, which is the product of a new combination of elements constructed over the previous steps.12

Ethical aspects were complied with according to Resolution 466/12, National Council of Health. The study was approved by the Institutional Review Board (Process No. 97/2013). The nurses’ reports are identified by the letter E, following by a sequential number (E1 to E12).

RESULTS

Based on the answers provided to the open questions, four categories were established (Figure 1), namely: 1) Nurses’ actions to ensure the right to life and dignity; 2) Nurses’ actions when facing suspicions of mistreatment or confirmed instances; 3) Nurses’ actions to ensure a parent stays full-time with the child, the right to leisure and food; 4) Nurses’ actions when facing suspicions of mistreatment or confirmed instances.

Nurses’ actions to ensure the right to life and dignity

This category shows that nurses take actions to defend the rights of hospitalized children to ensure their right to life and dignity. Such guidance is provided to parents or legal guardians and to the children themselves, according to their level of understanding, ensuring that child and family take part in the child’s care and exercise their autonomy in decision-making.

[...] I see it as a professional relationship where the nurse has to provide the family members with all information regarding nursing care. Here, we take care of the child and the child often lacks understanding so we have to talk to the parents about all that happens with the child, every care procedure, all the work we do. What we do is clearly and coherently transmitted at a level the family is able to understand. Whatever right the family doesn’t know about, we explain to them that they have rights [...] (E7).

Other actions performed by nurses in order to ensure the right to life and dignity involve demanding improved infrastructure and safety conditions in the health environment. Such actions are intended to provide safe and high quality health environments, improving comfort and providing appropriate conditions to protect, promote and recover the health of children, as well as avoiding any harm, especially with the potential to impede healthy growth and development.

[...] We try to focus on the child’s safety. We often get to the room and the crib’s bars are not raised and sometimes there’re unfamiliar people in the corridor. We try to identify
who these people are, but no one outside this unit is allowed to stay […] (E4).

[…] We are concerned with patient safety and we often are not in a position to ensure safety because it does not depend on us going there and building a fence and setting it up in front of the elevator. We’ve sent a lot of requests to several managers […] (E1).

Nurses’ actions to ensure health: defending integral care and equal access

This category refers to strategies used by nurses to ensure the right to health, advocating integral care and equal access to actions and services intended to promote, protect and recover the health of children. It reveals that the state does not provide proper conditions to provide care to children, that the actions performed by nurses are based on providing orientation and referring parents or guardians to agencies or government bodies that can meet demands, such as the Guardian Council, so that these parents seek their rights through administrative channels, through the Health Department, or through judicial means.

[…] We often have to orient mothers to go to the Guardian Council when they [children] need medication, or some type of food. They have to go to Social Security, so we inform them that the council can help, because sometimes it can take more than a month. We’ve had cases of children who were hospitalized only because they needed [a special] formula and the mother could not buy it. There was an ongoing process in the Public Ministry, but it didn’t produce results, so we told her to go to the Guardian Council because it was out of the hospital’s hands; it’s a public matter, being able to get that medication […] (E1).

[…] It happened to a patient who needed to be transferred and then we tried the service that manages beds in hospital facilities. We always contact the patient’s family and encourage them to seek other means, not only through the SUS. They pursued it until they found a private hospital” […] (E11).

Likewise, the nurses’ reports show that the way the units organize their routines and work processes helps to ensure the children have integral care and equal access to actions and services. Hence, nurses also organize their working processes seeking to ensure the rights of children and those of their parents or legal guardians or orient them to seek these rights by referring them to agencies or governmental bodies whenever rights are not being met due to institutional limitations.
Toys have been used in nursing care to relieve tension and also as a communication tool; that is, nursing workers can use toys to provide explanations and also receive information from the child about what s/he believes are her/his experiences during hospitalization, so that these workers can establish goals for nursing care.

The Federal Council of Nursing ensures nursing professionals employ the therapeutic toy technique to provide care to the child and family, however, there are some difficulties and limitations in regard to these actions, especially the lack of time, lack of knowledge or insecurity in how to use toys in care delivery.

The nurses’ actions are also intended to ensure that children requiring special food have their needs met. Some children are hospitalized because they lack appropriate food or because they are allergic to certain foods. In this sense, nurses seek to orient the parents or guardians and empower them by promoting their autonomy so that they seek their rights and those of their children either through administrative or judicial means.

Additionally, if there is a suspicion of abuse, nurses pay attention to the parents or guardians and observe whether there is inappropriate behavior, such as neglect or abandonment,
referring cases to social workers and psychological services. In these cases, all the hospital services need to work together to ensure the child is safe.

[...]

[...] If I notice the mother poses some risk, I pay attention, I orient, I keep an eye on her, but I won't judge if she can or can't stay. For this, there's a social worker to monitor, to visit the family's home, and the psychologist to follow-up, to see if there's any risk to the child [...]. (E7).

DISCUSSION

The analysis revealed that the advocacy for the rights of hospitalized children on the part of nurses include actions intended to ensure the right to life and dignity, to health, to have the full-time company of a parent, to leisure and food, and to have suspected or confirmed cases of mistreatment reported. Additionally, providing guidance was the action most frequently performed by nurses to ensure the rights of children, which is in agreement with studies addressing advocacy on the part of nurses in different health settings, showing that advocacy especially includes providing guidance and clarification to patients in order to promote their autonomy. 8,13

In regard to the first category, Nurses' actions to ensure the right to life and dignity, the main actions performed by nurses are based on providing guidance and promoting autonomy, demanding improved infrastructure conditions within the unit and also patient safety. It is worth noting that the establishment of the Universal Declaration of the Rights of the Child in 1959 significantly and profoundly impacted the attitudes of nations toward childhood, reaffirming the importance of ensuring universality, objectivity and equality when considering issues related to the rights of children. Similarly, it has emphasized the importance of intensifying efforts to promote and ensure the rights of children of survival, protection and development.14

In this sense, patient advocacy in the field of child health has been a subject of discussion, aggregating healing actions, health promotion and political defense, seeking to create conditions for autonomy, equality, and justice in social relations, equal access to opportunities, as well as to empower patients and families to claim their rights. Hence, nurses play a fundamental role in the care provided to children, establishing bonds with them, helping them make healthier choices and contributing to their growth and development.11

Children are citizens in a particular condition of development, a condition that requires care to satisfy basic needs, as children do not have full understanding of their rights or conditions to defend themselves or make themselves heard.15 Therefore, nurses play a key role advocating and seeking the rights of hospitalized children, ensuring they receive information that is appropriate to their age16 regarding their health condition and rights, as well as the parents or legal guardians also receiving such information, to strengthen their autonomy and empower them to claim their rights.17,18

Communication established with children should be simple, effective, and result in clarification, enabling them to expose their doubts and needs concerning the health-disease continuum, promoting a relationship of trust between nurse and patient. Therefore, communication is extremely important in the care provided to hospitalized children, considering that it favors their integral care and minimizes anxiety at the time of hospitalization, so children can become more confident and self-assured in regard care delivery.18

Another action nurses perform intending to ensure the right to life and dignity is by demanding improved infrastructure conditions, which can provide greater comfort and wellbeing for children and ensure their safety. It is worth noting that when nurses demand better conditions in the workplace, they are indirectly advocating for the patients, as improved working conditions ensure the quality of care delivery.19

In regard to the second category, Nurses' actions to ensure health, nurses work to defend the child by organizing the work process, by providing guidance and promoting autonomy and referring parents to agencies and governmental bodies when the hospital facility is unable to provide care to the child. Article 11 of the ECA provides that children are entitled to receive integral health care through the public health system, ensuring universal and equal access to actions and services that promote, protect and recover health.4 Additionally, the National Council for the Child’s and Adolescent’s Rights (CONANDA) was established after the ECA to regulate the rights of children within hospital settings, listing the right of children to be hospitalized whenever necessary for treatment.16

The organization of the work process emerged as an important action to ensure the rights of children. Hence, the establishment of protocols, standards and routines in health units, and specifically in pediatric units, can help to ensure the rights of children by organizing the nursing work process and by qualifying health settings.19

Note that the actions of nursing professionals intended to ensure the rights of hospitalized children should be implemented especially when patients and families are facing economic, cultural, instructional or even cognitive deficiencies, considering that the role of nursing workers is to intervene in these situations to ensure the rights of these patients. In regard to the rights of children in hospital settings, CONANDA lists specific items that address this issue, among which is the right of children to be hospitalized when it is necessary for treatment.
The third category of actions is to ensure that a parent stays full-time with the child, and also the right to leisure activities and proper food. This reveals that nurses seek to establish bonds and a relationship of trust with the parents or guardians to ensure such a right. Having one of the parents stay full-time with a hospitalized child, a right that is provided in the article 12 of the ECA, minimizes the effects of separation and benefits the patient's emotional state, considering that hospitalization can lead to fear and anxiety, as children are removed from their familiar environment.\(^4\)

The presence of parents and family members during hospitalization is necessary to preserve both familial and community bonds, which support the planning of care. Hence, toys are used both to create, optimize and encourage the use of leisure areas. The right of children to leisure is provided in article 4 of the ECA, so that the implementation of playrooms or recreational areas for hospitalized children are mandatory in health facilities to ensure children have a healthy childhood by stimulating and improving the child's cognitive, affective, motor and social aspects.\(^4\)

Likewise, CONANDA provides that children have the right to enjoy leisure activities during hospitalization.\(^16\)

In Brazil, in 2005, the implementation of playrooms became mandatory in all, public or private, health care units providing pediatric care in hospitalization regimen.\(^14\) The Federal Council of Nursing recommends addressing this topic in undergraduate nursing programs, ensuring that nursing workers are able to employ the therapeutic toy technique to provide care to children and their families.\(^21\)

Note that toys have been used in nursing care provided to children to relieve tension and also to establish communication, through which nurses can orient and clarify potential doubts children may have, as well as receive information about what the child believes s/he is experiencing during his/her hospitalization, which supports the planning of care. Hence, toys are used both to satisfy the children's need for recreation and to enable their physical, mental, emotional and social development during hospitalization.\(^14,22,23\)

Diverse studies have shown that this technique enables children to become more cooperative with their treatment and able to express their feelings more effectively during hospitalization.\(^14\)

To this end, the Federal Council of Nursing ensures nursing workers use the therapeutic toy technique to provide care to children and their families.\(^21\) Hence, nurses seek to stimulate children and ensure their access to playrooms or recreational areas within the hospital environment, enabling improved quality of care and recovery of their health during hospitalization.

The actions performed by nurses to ensure the right of hospitalized children to have proper food specifically refer to children who are admitted to the hospital due to a lack of proper food or an allergy to certain foods. Nurses provide guidance to promote the autonomy of these families so they can have their rights ensured by the state. In this sense, one study addressing the perceptions of families of children and adolescents with food allergies reports that families found that dealing with the condition became easier after receiving clarification from health workers, which improved the search for and adherence to treatment.\(^24\)

Likewise, guidance has been shown by another study addressing patient advocacy in a burn center to be a way to promote social justice, as patients are often unaware of the support they can get from the SUS or the state. Hence, guidance promotes the autonomy of patients so they are able to make themselves heard when facing social injustices that prevent them from accessing and receiving the resources necessary for their treatment.\(^25\)

Finally, the category of actions in the face of suspected or identified mistreatment shows the actions of nurses to defend the rights of hospitalized children linked to the reporting of suspected or identified mistreatment to the Guardian council. Article 13 of the ECA states that it is the duty of health workers to observe suspected or confirmed mistreatment and the reporting of such cases to the Guardian Council is mandatory.\(^4\)

Therefore, it is essential that nurses be knowledgeable and prepared to identify child victims of abuse, looking after children avoiding the situation of them suffering neglect, abuse or violence.\(^16\) In recent years, ill treatment, especially when associated with violence, has been one of the primary causes of death among children and adolescents, which is a severe public health problem in Brazil.\(^25\)

Considering the complex nature of abuse against children and its close relationship with violence and public health, the involvement of health workers, among whom are nurses, is extremely important, because these professionals can both identify the needed care and provide it and also report abuse such as noted above. In this sense, reporting suspected or confirmed abuse to authorities is mandatory for health workers who are subject to penalties of three to 20 times the minimum wage, according to article 245 of ECA.\(^4,25\)

In this context, the role of social workers within hospital settings is also extremely relevant, as these workers are the link between nurses and the Guardian Council. They are also responsible for providing guidance and effectively to enable the access of patients to public policies, so the practice of social workers does not only have a welfare nature, rather their practice has a socio-educational nature and strengthens the critical awareness of citizens.\(^2\)
CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The defense of the rights of hospitalized children on the part of nurses comprises actions intended to ensure the right to life and dignity, to health, to ensure that a parent accompany the child during hospitalization, to leisure and proper food, and to report suspected or confirmed cases of abuse. Guidance was the action most frequently performed by nurses in defending the rights of children, enabling their participation in care and promoting the autonomy of parents or legal guardians to make decisions concerning the care provided to their children.

Acknowledging the actions of nurses in the defense of the rights of hospitalized children represents advancement in the nursing field, as such acknowledgment supports nurses in situations they may experience in the context of pediatric units. In this sense, it seems relevant to ask: would the results of this study be similar if it had been implemented in other pediatric hospitalization units?

In light of that question, it is necessary to conduct other studies to corroborate the dissemination of knowledge and to devise strategies that strengthen the actions of nurses when advocating in the context of health care, contributing to the autonomy of nurses in the defense of the rights of hospitalized children. This study’s limitation is the use of a specific sample of nurses working in pediatric units located in two hospital facilities in the southern of Brazil, such that the generalization of results is not possible.

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Advocating for the rights of the hospitalized child
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