Perception of family members and caregivers regarding patient safety in pediatric inpatient units

ABSTRACT
Objective: To understand the perception of family members and caregivers regarding Patient Safety in a pediatric inpatient unit.
Method: Qualitative study with exploratory-descriptive design. Twenty-four semi-structured interviews with caregivers were carried out in three pediatric inpatient units of a university hospital in the south region of Brazil between June and August. The thematic content analysis was supported by the QSR NVivo software version 11.0.
Results: Nine themes were identified, and grouped in two categories: "Patient safety assumptions" , describing knowledge that caregivers related to patient safety and the need of family inclusion and partnership; and "Patient safety protocols implemented on the institution" , highlighting coherent lines with protocols already established in the hospital that promote safety.
Conclusions: Caregivers’ perceptions about Patient Safety in a pediatric inpatient unit prove that they assimilate orientations that support the safe care, although they do not have solid knowledge on the topic.
Keywords: Patient safety. Caregivers. Family. Child, hospitalized.
INTRODUCTION

Looking forward to improving the quality of care, the topic of patient safety is gaining increasing prominence in the world scenario. In addition to being a patient’s right, it is an ethical commitment of the health professional(3), being defined as the reduction of avoidable harm to the patient during the process of health care(2). Suitably, the definition points to avoidable harm, since the risk of adverse consequences to the patient is inherent to the complexity of the health care.

Thus, the patient safety depends on the adoption of strategies aimed at avoiding the occurrence of preventable adverse events and, when this is not possible, minimizing its consequences for the patient(3). This approach proposes the adoption of a safety culture, in which errors can be recognized and avoided, encouraging a safer care practice. Thus, safety has become an essential component of quality of care(3).

In this perspective, error is the failure to execute a planned action according to what was desired or the incorrect development of a plan. Incident is the event or circumstance that could have resulted, or has resulted, in unnecessary harm to the patient. Incidents can still be classified into: reportable circumstance, where there is significant potential for damage, but the incident does not occur; near miss, which is the incident that does not reach the patient; incident without harm, the one that affects the patient, but does not cause harm; and Adverse Event, presented as the one that results in harm to the patient(3).

Actions aimed at safe care become even more relevant in pediatrics, since children have specific physical and psychological characteristics, which condition them to a higher probability of occurrence of safety incidents. Among these characteristics, it should be highlighted the accelerated metabolism and greater variation of body weight when compared to the adults, which makes necessary the frequent adjustment of doses and drug concentrations; immaturity in the development of organs and systems; curiosity and unpredictability of the movements, characteristic of the child’s own development, lacking constant monitoring and vigilance; among others.

Researches show us the importance of including family members in the care of patients, especially in pediatrics. Encouraging the presence and participation of family members in the childcare promotes education, responsibility and a safety culture. It allows the approach of health professionals, favoring adherence to the treatments, the process of coping with the disease and the autonomy of the parents(4-6).

In addition, the WHO encourages, through the Patient Safety Program, that patients are placed at the center of care and included as partners, thus contributing to greater safety of care(5). In relation to this, it is necessary to investigate the patient’s perception of patient safety and safety of family members and/or caregivers, aiming at the development of actions that promote their involvement in the safety of the hospitalized child.

In pediatrics, the inclusion of family members or caregivers is essential, as children do not have sufficient maturity or insight to understand what is happening, making them dependent on the decisions made by their parents(6). With regards to that, family members and/or caregivers of hospitalized children should be considered as essential barriers that help prevent adverse events, and including them in child care reduces the chance of errors during care(3).

In addition, their role goes beyond providing care and support, since they can contribute as team partners in child care and as important barriers to prevent the occurrence of adverse events. Thus, it is relevant to know what the family members and companions understand about the Patient Safety theme and how they recognize in the actions of the professionals initiatives to promote the safe care of hospitalized children.

The effective participation of the family and/or caregivers in the child’s healthcare assists in reducing the occurrence of adverse events. Through observation and questioning, caregivers develop a monitoring role that contributes to the development of a patient safety culture(6). Despite this, the literature on this subject is still very scarce, motivating the elaboration of this study and looking for the answer to the following question: what are the perceptions of family members and caregivers regarding patient safety in pediatric inpatient units?

Thus, the present proposal is relevant for the health area and, particularly, for nursing, because in carrying out a study from the perspective of the companions of hospitalized children makes it possible to strengthen and promote the culture of patient safety in institutions. The objective of the study was to know the perceptions of family members and caregivers regarding patient safety in pediatric inpatient units.

METHOD

This is a qualitative study, using an exploratory-descriptive design, carried out as part of the matrix project entitled “Patient Safety in Hospital Care Services for Children in the City of Porto Alegre/RS”. The qualitative approach was chosen by the flexibility in the apprehension of the experiences...
of the individuals participating in the process. Additionally, when delineating by the exploratory-descriptive scope, it is possible to emphasize the description of human experiences, making it possible to understand how the users see the proposals referring to patient safety.

The information was collected between June and August 2016 in three pediatric admission areas of a reference educational institution, located in Porto Alegre, Rio Grande do Sul, Brazil, with 24 hospitalized children’s companions/caregivers, based on the data saturation criterion, according to which the sample size is related to the information redundancy range.

Legal guardians or primary caregivers of hospitalized children in the period of data collection for at least one week were included. Occasional and underage caregivers were excluded. The participants’ selection was intentional, assisted by the nurses of the units that indicated possible participants according to the criteria.

The companions/family members were approached by a researcher, previously trained to perform the interviews, who was not part of the unit's functional body, on the patient’s bedside, where a brief explanation was given on the subject of the research and the invitation to participate was made. By accepting, they were individually taken to a reserved space inside the unit of hospitalization, with the intention of preserving their privacy and ensuring the free expression of opinions. During the interview, the children were accompanied by a nurse technician or a visitor of the child who was present at the time.

Individual interviews were carried out through a semi-structured script elaborated in the matrix research project, which contained questions about the characterization of the companions/caregivers; the perceptions of major patient safety incidents; types of adverse events; and the referrals that happen in the daily care of children hospitalized from the perspective of caregivers.

Each interview lasted about 30 minutes; they were recorded in digital audio. Afterwards, they were transcribed in full in the Microsoft Word text software version 2012, and sequentially organized. During the typing, the name of the participant was replaced by the letter “P” plus number according to the order of the interview. The speeches were adjusted from the point of view of spelling to facilitate the reader’s understanding, but without changing the sense given by the interviewee.

For the analysis of the information obtained in the previous stage, the content analysis of the thematic type was used. As a tool for the organization of this information, the QSR software Nvivo version 11.0 was used.

The ethical aspects of the project to which this study is linked have complied with the Resolution 466/12 of the National Health Council regarding the submission and approval by the Institution’s Ethics and Research Committee and signature of the Free and Informed Consent Term.

RESULTS AND DISCUSSION

From the information collected from the interviews with the companions and caregivers of hospitalized children, nine themes that were grouped into two categories emerged, presented in chart 1.

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Chart 1 - Thematic categories obtained after the information analysis process. Porto Alegre, RS, 2016.

Patient Safety Assumptions

The Knowledge about patient safety and error recognition was the topic mentioned in the first question addressed to the companions of the hospitalized children. When questioned about what they had heard about patient safety, several respondents claimed to be hearing the term for the first time.
The first time I heard it was with you now, I have never heard of it, I do not know what it is all about. (P24)

[...]not in the patient safety, I did not hear it, I knew about work safety, but not the patient. (P18)

Through the interviews conducted, it was possible to observe that the participants did not have a formal knowledge or a concrete definition of the concept of patient safety. The guidelines are passed on to the relatives in an automatic way, without contextualization or explanation about their justifications. Thus, they are understood as individual rules and not as part of a process aimed at ensuring patient safety. However, compared to a similar study published in 2012, it is possible to highlight advances in the approach of the professional with the family member to the development of a culture of patient safety.

A study carried out in the United Kingdom with the aim of exploring patients’ perceptions and experiences regarding patient safety found similar results. It is observed that people do not have a well-defined concept about what is patient safety, having partial and multidimensional ideas regarding the subject. In some cases, the respondents linked patient safety to specific aspects such as medical records or medication errors. In others, they led to a larger dimension, mentioning the patient well-being and the technical quality of care.

When questioned about the errors, the participants related to medication administration, communication, patient identification, procedures and diet. In some cases, they have stated that they do not believe that it could be considered an error if it did not harm the child.

Regarding the bracelet, if he is not wearing a bracelet for those who have allergy, being that he had allergy. (P8)

It just happened to change the schedule, to reach, like, a medicine that was for 8 and another one for 9 and they give you both together [...] but changing the patient’s name is not going to affect him. (P7)

[...]his Omeprazole is oral. And the technician did not make sure that it was oral and put through the tube, and it was not well diluted, and then it ended up blocking, and then it was necessary to repass the tube. (P17)

The errors identified by the participants permeate the different areas of care. Although the adverse events related to medication and procedures are the ones that most concern relatives, the speeches also show a concern about the lack of communication. Failure to include companions in the care process and ineffective communication causes them to feel excluded from the treatment, becoming anxious and insecure, and giving them the impression of lack of transparency.

The questions regarding the Companion Role were the ones that obtained the most immediate and objective answers during the interviews. The family members stated that their functions as companions permeate the care of the child, providing support and comfort at the difficult time of illness and hospitalization. In addition, many statements show that caregivers are convinced that they are responsible for monitoring the care provided to their children.

It is the care, right, because in fact in the ward there is a technician for five children, so, as much as she wants, she cannot manage five children, right. (P1)

When the nurse comes, I always confirm with her what she is giving. Before she even speaks, I ask her what it is, then she picks it up and I always try to confirm it to see if she is giving the right one. (P12)

The role of the companion is very important for the affection, so that he knows that I am here, that I am with him at that moment and feel safe [...] (P16)

The family members act as the spokesperson for the child, and feel the need to provide accurate and correct information about the child’s health conditions.

If we are not around, [...] sometimes the nurse does not know what happened [...]. If you do not tell anyone, nobody will know. (P10)

I am his voice, right. I see myself like that. You have to be present to take care of, give all the support, all the support, everything they need, to inspect, right. (P11)

The interviewees acknowledge that the primary role of the companion is related to the emotional scope of the child, worrying about their protection, shelter and well-being. In addition, they observe that because they are focused only on their child, they can contribute in ways that could not be realized by the professionals who take care of several children during their workday. Such information is corroborated by a study carried out in Portugal, in which family members were interviewed regarding their involvement in the care provided to hospitalized children. Although some perceive their role as co-adjuvant, serving...
only as a companion for the child, many emphasize their importance in the supervision of professionals and in the benefits related to safety(5).

The participants themselves recognize that they play an important role as Barriers that favor a safe care. They report that when they are included in the care provided, receiving guidelines that are pertinent to the treatment of the child, they feel more confident to be active in the safety of the patient.

[...it is a permission that comes, right, so you feel better to do this inspection. Because there are many mothers that sometimes do not want to talk much, do not want to bother because “oh, then she/he will be alone with my son, who knows what will happen...” [...] then, at the moment it is authorized, encouraged, we feel better. (P11)

How am I going to question you if I do not know what is going on? I think the family has to understand what is going on with the patient. (P2)

Including the companion in the care of the hospitalized child is a way to make the environment less hostile, facilitating their adaptation and making the experience less traumatic. The partnership developed between the professional and the companion generates confidence on both sides, which favors the provision of safe care for the child.

This research you are doing is good, [...] it is important to know what is good, what is bad, just to see if it improves what is bad, right? [...] And prevent it from keep on happening. (P10)

I think that frequent training, right [...] I found it really cool, these recycling courses that the hospital offers. (P16)

The professional qualification through continuing education and the encouragement of research in the field of patient safety are other barriers to the occurrence of safety incidents mentioned by the participants. These actions should be prioritized by the hospital management, demonstrating the value of the team of professionals working in the institution, recognizing the importance of dialogue and recognition, thus ensuring ways to achieve a patient safety culture(11).

Participants were invited to reflect on their Posture in the face of error during the hospitalization of the child. The error intolerance was the emerging theme in the speeches, and the severity of the error was taken as a key point in the reaction to the event.

If it did not harm him, fine; but if it harmed, we would have a very big conflict right, because it is a child, right? (P15)

First, I would beat the nurse who let her fall. Second, I would sue the hospital [...] I would call the reporters to come, to see, you know. Because they are trained for it. To take care of the children. There is no way for an error to occur. (P5)

Still, some statements have highlighted the error as inherent in human beings.

Look, you have to pay a little more attention because, you see on television fatalities that happened due to negligence, by mistake, we’re all... to err is human [...] (P12)

They are here working, I know that many times they are under pressure, they are here a bit with a very serious patient [...] then, I have this understanding [...] But of course, if it had not happened, the better, right? (P17)

When faced with an adverse event that they consider to be serious in their care process, patients and their families tend to ignore all the correct procedures that have been performed, especially remembering the situation in which the error occurred. An error experience can lead to the loss of trust in the institution and in the health team, both for the current hospitalization and for the next ones that may occur(9).

Within the context of patient safety assumptions, it is important to highlight that the family members are aware of their responsibilities as companions of the child, participating in care and acting in the prevention of errors. They are willing to help the health team and mobilized to find the best care for their children. It was possible to understand that they act for the safety of the child, even if they do not relate their actions to the specific guidelines provided by the health team.

Patient safety protocols implemented at the institution

According to the participants’ statements, the Communication was identified as a fragility in the care process. Failure to obtain satisfactory information about treatments and behaviors adopted, as well as not having their own observations regarding the condition of the child considered
were recurring issues. In addition to perceiving obstacles in the communication between professionals and companions, the statements show the difficulty of communication among the professionals themselves during the sharing of information about the patients:

Because you stay here, you have a lot of doubts, right [...] until the teacher comes, three doctors come, four doctors, and each one says something different, (P9)

I want to be aware of my daughter’s treatment, but they were kind of blurring it, they were not giving me the information I wanted to know, there are mothers who like it, but I like to know everything that happens to my daughter, it is my right, her right, (P24)

Despite the flaws identified in this process, some statements highlight the importance of communication for patient safety:

If you had no guidance, you would not know what to do, if you were really doing what they told you or not. (P14)

[...] the dialogue between the team and the family is essential for the child’s safety during hospitalization; because it is there that you will expose what you want and receive what your child will need. (P2)

Effective communication is a fundamental work tool for humanized care aimed at patient safety. It becomes even more important in the hospitalization area because it involves planning that is tailored to the needs of each individual. Thus, in addition to dedicating themselves to communicating with other professionals, the professional must be willing to communicate with the patient at all times, including during procedures, clarifying doubts and receiving the information they are passing on to them(12).

The link between the patient and/or the family member and the professional providing care is decisive in reestablishing the health of the one receiving the care, being created basically by the way in which the communication between individuals happens(13). The family members interviewed openly convey the need to be informed and heard so that they can understand what is happening to their children and deal with the difficulties imposed by the illness and hospitalization situation. Thus, they convey the calm and confidence acquired to the child, enhancing the family engagement and the safe care.

As for the Identification of the patient, some of the companions interviewed pointed out that the professionals of the institution confer the identification bracelet at all times of care. They reported that they check the patient’s name when medicating and performing procedures, and also verify the integrity of the identification bracelet:

When they usually come in, when they change their shift, the one who leaves is always checking, right, if it is on the arm, on the hand, on the foot, something like that [...] if it is wasted, they go there and get it right, they put it, right [...] (P10)

The care with the bracelet also, of identification, to see if the person has the bracelet, if the name is visible (P17)

However, a recurring observation made by the companions is that the professional stops performing the patient identification checking in the recommended way when the hospitalization becomes prolonged.

[...] as she is well known, so most people do not look at the bracelet, who knows. (P1)

They do not [look at the bracelet]. They just ask. Just ask the name, right. (P3)

Patient identification is an important step that must precede each of the care provided. One of the most effective and least expensive ways to carry it out is the use of the identification bracelet. However, the routine of checking the bracelet before any procedure that is performed is not strongly instituted, especially in pediatrics, where difficulties in verbal communication, the patient’s restlessness to remain restricted to the bed and the frequent bed rest due to isolation precautions pose an even greater challenge in this action(6,14).

Failure to check the identification bracelet when the patient is hospitalized for an extended period, expressed by the professionals, can lead to mistakes, which may lead to errors. It should also be highlighted that hospitalized patients are attended by several teams, composed of many different professionals, with the care also fragmented by turns, making it imperative the use of the identification bracelet(15).

Many interviewees recognized that issues relating to the administration of Medications are directly related to patient safety, and stressed the importance of being included at that time. They related the occurrence of errors involving medications to the amount of prescribed medications and to the automation of the procedure. They reported that most of the time, what is being given to the child is most often reported, and they have observed the use of medication identification tags as a safe way to do this.
I worry more about the wrong medication […] that is what I care about the most. (P7)

The medication gets in that very automatic thing, they know they have to give it […] because we know that most mistakes are because of so much medication, […] other more complex procedures, require more attention than a simple medication. (P8)

The medication process is complex and involves many steps. An error in this process can severely compromise the patient safety. It demands precision and responsibility from professionals, from the medical prescription to administration to the patient, and it should not become an automatic activity, performed without concentration. Among the predisposing factors to the error in this process are the lack of accuracy in dosages, unreadable prescriptions, and failures in communication between health team members(9).

An integrative review of 40 articles published in 2016 on medication errors demonstrates that this event raises concern not only for family members and companions, but also for managers, professionals and researchers. In addition, by bringing the medication dosage error as the most recurrent in the studies, followed by the exchange of patients and wrong time, it should be highlighted the importance of professional qualification regarding the drug process(16).

When mentioning the measures taken to the fall prevention in the units, the participants were unanimous in saying that this is one of the care measures prioritized by the professionals of the institution. They emphasized that most professionals leave the side rails of the beds always raised, and that they guide the parents and companions to follow the same procedures. Safety measures are also taken to avoid falls during patient transport. The use of the bracelet for identification of the risk of falls is mentioned as a good practice that helps in the prevention of falls.

I see people take great care, respect a lot, this matter of making a safe transportation, right? We already do the transportation, both me in the wheelchair with him, both him on the bed, on the stretcher, in the crib, and every time it was safe and careful, right. (P17)

[…] the staff is very careful, the beds have the protections on the side, if we leave the room a little and there is a nurse, he already raises the bars of the bed, there is the bracelet with the risk of fall […] ] (P18)

Fall is a frequent occurrence of pediatric patient safety(10), making it necessary to invest in prevention strategies, and especially in the orientation of the family members. In many situations, the fall is responsible for worsening the patient’s state of health and prolonging his or her stay in the hospital, which can lead to trauma, unplanned withdrawal of catheters and drains, emotional changes and fear of falling again, clinical worsening, and even death(17).

In addition, the pediatric patient is not aware of the risk and is subject to accidents that are typical of their age group. The prevention of falls is initially due to the detection of the risks present in the environment, through the use of pre-established organizational tools for the analysis of the theme, such as risk scales for fall. The use of identification bracelets of risk for falls, determining increased attention, and the participation of family members in the daily activities of care and recreation within the hospital, play a key role in preventing this event(18).

Hand hygiene, by means of washing with soap and water or the use of alcohol gel, was the measure of Infections prevention most mentioned by study participants. They reported receiving guidance on the correct way of hand hygiene and the reasons for performing this action. However, they report difficulties in passing information to the child’s visitors, justifying the fear of embarrassing others.

They advise you not to take another child, not to touch another child’s cradle […] when you come in, wash your hands, spill an alcohol gel and before touching the child. (P10)

It is important to always sanitize your hands, either in the entrance or when leaving, or wherever you are going. Because of the several microbes that are around the hospital, diseases that are there and that are not transmitted, circulating and we do not even see it. (P3)

[…] I am from the countryside, right, so my dad was very upset when I asked him to clean his hands […] (P9)

The reports diverge when referring to the adherence to these procedures by the professionals. They observe that professionals do not always sanitize their hands at the recommended times, and they bring as a concern the frequent use of alcohol gel over hand washing in all procedures.

I only see them using the alcohol […] washing the hand is very difficult, you know […] (P11)

[…] you get into a room, and it is hard to see people get in and go straight to the alcohol gel. It is very rare. (P9)
They are no longer guiding people to sanitize their hands before the procedures, it is no use having the notices at the entrance and not having a reception for visitors […] (P24)

Although hand hygiene is the most recognized way to prevent and control infections, adherence to this practice is still insufficient. An observational study performed in an intensive care unit of a hospital in Paraná shows that the adherence rates to this practice were 13% before contact with patient/environment; 7.8% before aseptic procedure; 35% after risk/contact with biological fluids and 46% after contact with patient and/or environment. This result shows that while it is recognized that hand hygiene is effective, adherence to this action does not happen as it should.

It is important that the education of both professionals and companions and family members is carried out, referring to the hygiene of the hands, highlighting the moments in which it should be performed, the form of realization and the relevant aspects of the products used, be it soap or the alcoholic solution. The use of liquid soap is recommended when the hands are visibly dirty, when exposure to potential spore-forming organisms is strongly suspected or proven, or after using the toilet. In every other situations, the World Health Organization (WHO) recommendation is for the use of the alcoholic solution, due to its effectiveness, lower infrastructure requirements, on-site availability, short application time and better skin tolerance. Thus, the use of alcohol gel for hand hygiene can be encouraged, backed by the WHO guidelines.

Through the reports, it can be seen that caregivers are committed to implementing measures to improve patient safety. The actions taken to prevent falls and correct administration of medications were assessed as effective and well established. However, in the process of communication among professionals and between caregivers and professionals, the correct identification of the patient and the prevention of infections were identified as important points of improvement to promote the safety of hospitalized children.

**FINAL CONSIDERATIONS**

The perceptions of family members and caregivers regarding patient safety cover aspects of both the empirical knowledge of protection and duties associated with parenting, and the specific protocols implemented at the hospital for patient safety. From the guidelines received and the professionals’ attitudes, caregivers and family members can understand and adopt behaviors and measures that favor a safe care.

Participants were eager to receive guidance and be included in the care of their children, and willing to play their role as a barrier in the prevention of adverse events. However, despite this provision, the family members did not have the domain of patient safety, demonstrating the need to elaborate education strategies and their inclusion in the safety of hospitalized children.

The development of actions to include family members and caregivers in the hospitalized child’s healthcare should be more valued, especially by the managers and leaders of the hospital institutions. The existing patient risk and safety management policies are reaching the patient’s family, but greater partnership among those involved is still required to promote an effective safety culture. Shared care can strengthen good practices in pediatric inpatient units on issues involving the prevention of adverse events in the hospitalization of children.

The results of this study reinforce the importance of sensitizing professionals to include the family and developing a partnership for safe care. Furthermore, it subsidizes managers to promote the inclusion and visibility of companions and family members in safety promotion strategies.

It is possible to highlight as limitations of this study: the information collection technique, being pertinent to the performance of focus groups, which could enable discussions on the subject among the participants. The performance of studies with a similar objective in other areas such as emergency and intensive care is needed, given its peculiarities. In addition, further research is needed on the involvement of the hospitalized child’s relative in patient safety, both from the perspective of the patient, and from the health professionals.

The effort to disseminate a safety culture among professionals, through many published studies focusing on this dimension, is remarkable. However, such knowledge poorly reach one of the most important links in this chain that aims to ensure the best possible care: the family. Therefore, it is necessary to invest in actions whose focus is the engagement and empowerment of the family as active individuals in the process of strengthening the patient safety culture.
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