

THE PERSPECTIVE OF AN IDEAL PEDIATRIC INTENSIVE CARE UNIT FROM THE POINT OF VIEW OF HOSPITALIZED CHILDREN

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ABSTRACT: Pediatric Intensive Care Units are set up in stressful, isolation, anxiety and sensory hyperstimulation environments. This qualitative study aims to know the perspective of an ideal Pediatric ICU from the perspective of hospitalized children. Seven children aged 7 to 12 years participated. Data collection occurred through individual semi-structured interviews, associated with the drawing request made by the children. The statements were analyzed through the Content Analysis Technique that allowed the emergence of the following categories of analysis: the increase of playful activities and the family full time in the ICU. The "ideal" ICU was shown by children as a happy, fun, colorful and lively environment. A place where, in addition to taking care of their illness, the child could simply be a child, play and have fun as they usually do every day of their lives.

KEY WORDS: Child; Hospitalization; Pediatric Intensive Care Unit.

A PERSPECTIVA DE UMA UNIDADE DE TERAPIA INTENSIVA PEDIÁTRICA IDEAL A PARTIR DO OLHAR DAS CRIANÇAS INTERNADAS

RESUMO: As Unidades de Terapia Intensiva Pediátricas configuram-se em ambientes estressantes, de isolamento, ansiedade e de hiperestimulação sensorial. O presente estudo, de natureza qualitativa, tem como objetivo conhecer a perspectiva de uma UTI Pediátrica ideal a partir do olhar das crianças hospitalizadas. Participaram sete crianças com idades entre sete a 12 anos. A coleta de dados ocorreu por meio de entrevista semiestruturada individual, associada à solicitação de desenho realizado pelas crianças. Os depoimentos foram analisados pela Técnica de Análise de Conteúdo que possibilitou que emergissem as seguintes categorias de análise: ao aumento de atividades lúdicas e à família em tempo integral na UTI. A UTI denominada de "ideal" foi mostrada pelas crianças como um ambiente alegre, divertido, colorido e cheio de vida. Um local onde, além de cuidar de sua enfermidade, a criança possa simplesmente ser criança, brincar e se divertir como costuma fazer todos os dias de sua vida.

PALAVRAS-CHAVE: Criança; Hospitalização; Unidade de Terapia Intensiva Pediátrica.

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INTRODUCTION

The experience of falling ill and hospitalization requires that the person concerned copes with demands that exceed his own capacity of adaptation. This is most evident during childhood since it is an unexpected experience surrounded by phantasies and fear, especially when it occurs for the first time¹.

In the case of children, hospitalization interferes directly on their development and exposes them to invasive medical procedures, far away from home, school, friends and kin. In fact, children are greatly sensitive to the hospitalization process and they need to adapt themselves fast to changes in their daily lives. They have to cope with strange people with whom they have had no intimacy, within a hostile environment, featured by strict routine².

Serious illnesses in children trigger contradictory feelings, such as fear, anger and loss which disrupt the family socially, financially and emotionally. Children's hospitalization breaks down family sentiments and perspectives where they were inserted and where they were synonymous to the future, the fulfillment of dreams and parental expectations³.

Children's imaginary on health and disease affects their attitudes to the diagnosis, health promotion, coping with the disease itself, and the process of treatment and rehabilitation⁴.

Frequently, hospitalization produces a double trauma in children. Besides their removal from the family, a cozy and protecting environment, they are taken to a cold, impersonal and hostile place. The presence of the family is therefore mandatory, accompanying hospitalization, as much as possible, to contribute towards a better coping with the disease and encouraging the children to support suffering and anxiety during the painful process⁵.

It is a common belief in pediatric institutions that children do not have sufficient maturity to understand the process of the disease and hospitalization. Treatments are frequently performed with parents and children grudging. Several families try to avoid giving information to children on hospitalization, procedures and treatment since they think that it will cause undesirable effects. The emotional component that determines differences

between children of the same age group and development should be underscored, but also differences in meaning levels expressed by children in different situations should be taken into account^{4,6}.

Humanized assistance to hospitalized children should include three integrated aims, namely recreational, educational and therapeutic. Through play, learning, reflection on children's feeling and psychosocial support, the work must promote development, learning, psychosocial adaptation of sick and hospitalized children⁷.

The manner humans relate themselves to disease and hospitalization has recently undergone great changes due to the exponential progress in health technology. The process involving one's disease and hospitalization or of other members of the family produces adaptations and changes. Feelings are at a stretch when one deals with children's hospitalization in a pediatric intensive care unit (PICU)⁸.

Current paper analyzes the ideal PICU from the point of view of hospitalized children and discusses the possibilities to comply with such demands and needs so that the hospitalization period becomes nicer and more comfortable for children.

METHODOLOGY

Current exploratory, descriptive and qualitative research was performed in clinical and surgical units after children have been discharged from PICU of a university hospital in a town in south Brazil. Seven children of both genders, between 7 and 12 years old, participated in current research. They had been kept at least for 24 h and for a maximum of 5 days in an intensive unit. Patients who were kept anesthetized after discharge from PICU, patients with previous neurological conditions or following hospitalization, patients without the least physical and mental conditions to answer a questionnaire for data collection were excluded. Sampling was intentional and number of participants occurred by theoretical saturation.

The patients' medical charts in the clinical and surgical PICUs which revealed criteria of eligibility for participation in the survey were first consulted. Patients

who fulfilled the inclusion criteria were identified by electronic charts, featuring name, age, gender, schooling, period in PICU and the time between discharge from PICU and data collection.

Patients featuring inclusion criteria for current study were selected and, together with parents, were personally invited to participate in the research. The researcher demonstrated the aims, risks and benefits of the study and provided the Term of Free Consent to the adult in charge of the child in two forms.

Data were retrieved after soliciting a thematic drawing followed by an interview with a semi-structured script. Approach was individualized and undertaken near the hospital bed of the child in a ward or in a reserved place close to the nursing facility of the clinical and surgical PICU.

Drawing was a strategy to access children, to help communication between researcher and children, and the child's narrative helped in the analysis of categories. Children are stimulated to think on changes that may be undertaken so that PICUs may be friendlier to them. In fact, researchers who work with children employ play resources, such as drawings, as a communication strategy for the interview aimed at data collection⁹.

Participating children received a color label to maintain anonymity. Reports on the theme drawing and interviews were recorded in audio and wholly transcribed. After data collection, they were processed by Bardin's thematic contents (2011).

Since research involved human beings, Resolution 466/12 of the National Health Council was complied with. Current study was authorized by the Committee of Ethics in Research of the Universidade do Vale do Itajaí (n. 2.118.123).

RESULTS AND DISCUSSION

During the data collection period, nine children complied with inclusion criteria, but only seven agreed to participate in the study. Table 1 shows the main characteristics of the participants.

Categories were constructed after analyzing material collected in drawing, reports and interviews, taking

into account theoretical guidelines and research aims. According to Bardin (2011), they are categories a posteriori. The main themes identified from the data analysis are related to an increase in play activities and to the family during the entire period in PICU.

As a rule, children revealed that they liked the PICU environment where they were hospitalized. When asked what may be changed in PICU, some replied that they would change nothing and that everything was alright. However, stimulating their imagination, there is always something that may change.

Several children would bring toys to the PICU and try to make the environment nicer with recreation activities. Others would modify what was not agreeable in PICU, such as the presence of parents.

Child with Code name Green would make a more agreeable PICU through the presence of clowns and playing. Further, Green would remove the patient from the bed and take her to the toilette. Her drawing showed precisely the changes indicated.

Table 1. Characterization of the agents in current research

Code name	Age	Gender	Period in PICU	Motive of hospitalization in PICU	Interview after discharge from PICU
Purple	9y 1m	Female	4 days	Diabetic Ketoacidosis	1 day
Rose	8y 4m	Female	2 days	Closed abdominal trauma	2 days
Red	11y 3m	Male	3 days	Closed abdominal trauma	3 days
Yellow	12y 2 m	Male	1 day	Asthma with severe respiratory insufficiency	2 days
Green	10y 2m	Female	1 day	Convulsive crisis	1 day
Blue	11y 2m	Male	2 days	Post-operative period from lung decortication	2 days
Water green	10y11m	Female	2 days	Post-operative period from laparotomy and direct hemicolectomy	2 days

I would call people to put on clown's clothes to play with the children. I would take the person to the toilette. (Green)



Figure 1. I drew a clown juggling, juggling balls and juggling one, a pot with a flower on his head. There is also another clown juggling on a ball and balancing three vases, one in each hand and one on his head. She's a doctor taking a child to the toilette. (Green)

Another child, code name Purple, at first did not think that anything would change in the PICU. Afterwards, she suggested several plays that would entertain children during hospitalization. She drew precisely what she described, or rather, play things that may be done within the PICU.

I wouldn't change anything. I don't know. Well, rope jumping, running, hide and seek, play with a ball, yes, play with a doll. (Purple)



Figure 1. I drew people in a garden, playing with a ball, a girl and a boy and three girls playing and pushing a rope and a doll near the girl who is playing with a ball with the boy. (Lilás)

Participant code name Yellow identified the need to place more TV channels for the entertainment of children during hospitalization in PICUs and desired that children would be free to choose the channel they liked best. Drawing replicated what he said and included the logo of the TV that would be available to children.

I would put Sky to change channels. Supply more cartoons children want. That's it. (Yellow).

The girl with code name Rose also would like to bring clowns and balloons into the PICU. She said that friendlier nurses would be introduced to deal with hospitalized children and improve the PICU environment. She would put more TV sets, remove injectable medicine which really disturb children and change the bed for a more comfortable one. When the girl was drawing, she exhibited weariness and impatience. Therefore, she drew only a part of what she intended, drawing only the balloons. She asked my name and wanted to put it in the drawing.

Yes, I would place a lot of balloons. Clowns. I would place more agreeable doctors. I would place forty TVs and I would remove all injections. And a better, better bed! (Rose).

In the case of privacy, the boy with code name Blue suggested changes for PICU that would make it more comfortable for children. He suggested division boards between the beds to favor the patients' privacy and avoid cross contamination. Further, he said that parents may have more time in PICU since they would have a proper place to accommodate themselves in. His drawing was an exact replica of the proposed PICU.

I know! I would draw a room side by side since there was only a room where I was staying; the remaining section was free, it was not so, it was not so closed up. Each must have a room. Yes, so that no danger exists and also so that the visit would be prolonged (Blue).

The boy with code name Red suggested that the main change should be the permanence of parents with the children during the whole hospitalization period in the PICU. Besides, he would place a TV for all the children in PICU. He drew the drawing accordingly.

That's it, let parents stay here at all times, place a TV for all the children. (Red)



Figure 3. I drew myself, my father and a TV. (Red)

The last child interviewed, code name Water Green, insisted on the importance of parents during hospitalization in PICU and suggested that they should remain during all the time they deemed proper and necessary. The drawing included her mother to represent parents and care givers at PICU.

I would allow parents to stay as long as they wished. (Water Green)



Figure 4. I drew my mother. (Water Green)

The PICU under analysis comprised eight paediatric beds, including two isolation beds and six in the ward. Four TV sets are available for all the children: one in each isolation section and two in the ward with the six beds. TV sets in the isolation sector has access to cable children's programs and the child may ask for a

change in the channels according to preference. The two TV sets in the ward lack cable. Instead, a data stick with children cartoons and music are available. Other options are recorded and the children may select what to assist even though they should agree with the other patients that will assist the same program.

The presence of mothers or kin in the PICU is a complicated issue since it implies the reorganization of labor at theoretical and practical levels. For instance, the PICU under analysis does not allow parents of the children at all times since there is no available space. They may remain with the children for four hours in the afternoon and for 30 minutes in the evening. No visits are allowed in the morning.

Due to its characteristics with strict and inflexible routines, hospitalization during childhood may cause negative feelings and may affect significantly children's emotional state, triggering fear and high stress rates. This is due to the fact that at that very moment the separation from objects representing safety and affection occurs, coupled to the absence of parents and kin which is perceived by children as a sort of abandonment by their most cherished people¹¹.

Admission to the hospital is experienced by children as an anxiety source. Integrated activities between health professionals, family and children should be developed to avoid stress situations and hinder them from equating disease and feelings of fear and unhappiness with regard to hospitalization and treatments by the health team¹².

The discussion on the humanization of PICUs currently ranges from the physical environs to the relationship between health professional and patients/parents. The philosophy of humanization is gaining ground in the perception of PICU: the site makes possible the recovery of patients and not a place for patients with only a small chance of survival¹³.

The hospital under analysis already has several features that classify it as child-friendly. Corridor walls are colorful; a toy room is available for children hospitalized in the wards (excepting children hospitalized in the PICU); volunteers visit the hospital frequently to play and socialize with the children, bringing presents and affection. During commemoration dates, especially

during Christmas, Easter and Children's Day, servants deck the hospital with festive displays.

The hospital environment is comprehended by children as a menacing and dangerous place due to invasive and painful procedures. Hospitalization during childhood may be highly traumatic since it causes a distance between loved ones, toys and playthings, coupled to children's isolation and their separation from their normal environment. Consequently, children, depressed by disease, should have some means to externalize their feelings and minimize their fears and anxieties¹⁴.

Hospitals should focus on the environment they provide and how to adapt it children's life style, such as cozier decorations, a homely aspect with common dress and beds, objects proper to childhood, lively colors in the halls. Further, children should have a place, close to their bed, to put their personal objects such as drawings, photos, letters from their friends or from their family¹⁵.

Few occasions are available for children's play when they are hospitalized. Children are not allowed to have direct contact with others, mainly because of cross infection. Parents are allowed to bring toys so that the children would not feel themselves alone in the PICU. It should not be made of cloth so that it would be cleaned easily. Children may play but alone and in their beds. Besides playing is an activity inherent to children's behavior and basic for their welfare, it may be pinpointed as the most important activity during childhood for their motor, emotional, mental and social development. It is a form of communication with the environment in which they live and express their feelings, anxiety and frustration. Playing may be considered a source of adaptation and a tool for their health's formation, maintenance and recovery. The need for playing, similar to other needs for physical and emotional development, does not cease when they are sick or hospitalized¹⁶.

Playing is part and parcel with childhood and is a necessary tool for socialization, communication and development of abilities. Hospitalized children need playing since it helps them to talk on the singularity of the process of being ill and be hospitalized, their feelings and anxieties¹⁵.

One may underscore that when playing is adequate for the children's development phase, it

decreases suffering and enhances cooperation during the procedures required for their treatment and cure. Playing is a mediator within the process of children's development, transforming elementary psychological functions, such as reaction to pain and crying, into more developed functions, such as the development of abstract thought⁹.

Playing within a hospital milieu makes the place friendlier and provides several stimuli which lessen physical and psychological tension and discomfort, and, consequently, enhances the patients' treatment and cure. The act of playing involves a large amount of creative acts which help to recover self-esteem and improve life quality of the patient undergoing treatment¹⁷.

Children's hospitals should have a proper place and capacitated professional to maintain recreation and ludic activities and thus trigger sensations of happiness to hospitalized children. Such an approach should make up the routine of daily attendance, such as therapeutic intervention, within a systematic and continuous manner and should not be restricted to determined and disarticulated activities. One should always remember that playing is part of the care and provides the humanized approach¹⁵.

From the perspective of the children who participated in current analysis, the ideal PICU may help health professionals to be aware of certain aspects which frequently are placed second such as, happiness and diversion, which should be the children's day-to-day style, even for those hospitalized in a PICU.

In the case of humanization in children's assistance, Brazil experienced progress when the Statute for Children and Adolescents (Law 8,069) was published on the 13th July 1990. Allowing parents or care givers to accompany children during the whole hospitalization period became a right and hospitals should provide conditions for the permanence of parents during all the time of children's and adolescents' hospitalization¹⁸.

Several health professional are always close to the PICU to provide quality assistance to the pediatric patients. They frequently need monitoring, infusion of medicine, ventilation support and the use of several technological apparatuses. It is highly important to underscore that the presence of an accompanying person goes beyond

legal issues. One believes in the benefits of recovery of children when parents or kin are present, giving support not merely in direct care but also emotionally¹⁹.

Since PICUs are seen as cold, weird and hostile sites, the mother's presence and the care given by her are highly relevant within the context of children's hospitalization in this environment. She decreases fear and anxiety with regard to procedures during hospitalization²⁰.

Hospitalization in PICU is not an easy thing for children and for their parents. The child's serious illness disrupts the family's dynamics and triggers a series of contradictory feelings such as fear, anger and loss which disrupt the social, financial and emotional structure of the entire family³.

When the family's or the care giver's company is not possible, illness conditions and hospitalization become a source of stress for children who are separated from their parents and left alone in a hospital environment. The latter, coupled to pain, fear of death and the perception of the family's anxiety, is not a nice place for children²¹.

However, during hospitalization, most PICUs do not allow the presence of care givers, due to intensive care and constant procedures administered to the patients. Parent, in fact, give great importance to technology and to professionals but, above all, they consider respect and sympathy indispensable. They perceive their child's hospitalization through the care given and their interaction with health professionals. In the case of care in PICUs, parents reveal that, in spite of being an intensive care unit, where work stress is high, they expect that professionals act by humanistic principles, give affection, respect and understand the child's condition, making possible the coupling of technological resources and humanized assistance¹³.

When the results of current study are analyzed, one perceives the need to make children active agents within the illness and hospitalization process, making them participate in therapeutic decisions and encouraging them to feel safe and comfortable during the whole hospitalization process

CONCLUSION

The ideal PICU is revealed by hospitalized children as a happy environment, full of fun, colors and bubbling with life. In other words, a place where, besides being treated of their illness, children may be simple be children and play as they have always done at home.

One may expect that these reports change one's perception on the environment of PICUs which should never be as impersonal and insensitive as adult ICUs. One must deal with children as a unique being, with proper needs, even during hospitalization in a PICU and they should not be dealt with as if they were miniature adults. Children dream and desire to be attended to during their stay in a PICU, respecting their limitations in that determined place and moment.

Few published studies are extant which feature children as an object of research. Consequently, few things are known on what children of all age brackets think about health, illness and hospitalization. Most publications use parents or care givers as research objects and forget the true individual who should be analyzed when one is dealing with hospitalization within the pediatric age bracket. Research work with children demands patience and empathy, both of which may be limiting factors. Research works on PICUs are also rare and further in-depth research should be undertaken within such non-explored conditions.

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