

# COMPANIONS' PERCEPTIONS REGARDING THE INTUBATED CHILD IN PEDIATRIC ICU

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**ABSTRACT:** Intubation brings meanings for companions in the Pediatric Intensive Care Unit, as it causes change of the child's body image, interferes in communication, and suggests severity in the clinical picture. This study aimed to analyze the companion's perception regarding the intubated child, and was undertaken between July and October 2011, in a hospital in Campo Largo, in the Brazilian state of Paraná. A study with a qualitative approach was undertaken, using semi-structured interviews, held with eight participants. The categories, based on the content analysis, were: 'Impact caused by the severity of the illness and the intubation'; 'Intubation as a channel for life' and 'The companion's attitudes and behaviors'. It is concluded that the intubation is initially perceived as a period of commotion and shock caused by the unit's environment and resources. Some companions transpose to themselves the child's possible feelings. Also, it is understood as a means of survival, and the companions develop coping strategies, showing themselves to be resilient, and viewing it as learning for life.

**DESCRIPTORS:** Child; Pediatrics; Intubation.

## PERCEÇÃO DE ACOMPANHANTES SOBRE A CRIANÇA INTUBADA EM UTI PEDIÁTRICA

**RESUMO:** A intubação traz significados para acompanhantes em Unidade de Terapia Intensiva Pediátrica, pois ocasiona alteração da imagem corporal da criança, interfere na comunicação, sugestionando gravidade no quadro clínico. O objetivo foi analisar a percepção do acompanhante sobre a criança intubada, entre julho e outubro de 2011, em um hospital de Campo Largo/Paraná-Brasil. Foi realizada pesquisa de abordagem qualitativa, por meio de entrevista semiestruturadas, com oito acompanhantes. As categorias, a partir da análise de conteúdo, foram: Impacto com a gravidade da doença e a intubação; A intubação como canal de vida e Atitudes e comportamentos do acompanhante. Conclui-se que a intubação é percebida inicialmente como momento de comoção e abalo com o ambiente e recursos da unidade. Alguns acompanhantes transpõem para si possíveis sensações da criança. Também, é entendida como meio de sobrevivência e os acompanhantes desenvolvem estratégias de enfrentamento, mostrando-se resilientes e encarando como aprendizagem para vida.

**DESCRIPTORIOS:** Criança; Pediatria; Intubação.

## PERCEPCIÓN DE ACOMPAÑANTES SOBRE EL NIÑO INTUBADO EN UTI PEDIÁTRICA

**RESUMEN:** La intubación trae significados para acompañantes en Unidad de Terapia Intensiva Pediátrica, pues ocasiona alteración de la imagen corporal del niño, interfiere en la comunicación, sugestionando gravedad en el cuadro clínico. El objetivo Del estudio fue analizar la percepción del acompañante sobre el niño intubado, entre julio y octubre de 2011, en un hospital de Campo Largo/Paraná, Brasil. Fue realizada investigación de abordaje cualitativo, por medio de entrevista semiestructurada, con ocho acompañantes. Las categorías, con base en el análisis de contenido, fueron: Impacto con la gravedad de la enfermedad y la intubación; La intubación como canal de vida y Actitudes y comportamientos del acompañante. Se concluye que la intubación es percebida inicialmente como momento de comoción y shock con el ambiente y recursos de la unidad. Algunos acompañantes transponen para sí posibles sensaciones del niño. También es entendida como medio de sobrevivencia y los acompañantes desarrollan estrategias de afrontamiento, revelando resiliencia y mirando como aprendizaje para vida.

**DESCRIPTORIOS:** Niño; Pediatría; Intubación.

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## INTRODUCTION

In recent decades, an exponential advance in health technology has been observed, which impacts on how the human being relates to disease and hospitalization. Humans are bio-psycho-social-spiritual beings and any alteration in one of these dimensions has repercussions on the other three. The process of illness and hospitalization in oneself or in a close person causes adaptations, changes and mobilization of subjective contents. When it is a child, hospitalized in the Pediatric Intensive Care Unit (PICU), the emotions may be more intense.

There are studies focusing on the experience and the feelings created in the families which have children hospitalized in PICU<sup>(1)</sup>. In this regard, we highlight the procedure of intubation and the family members' perception regarding the same. We have noted, in our practice, from companions' accounts, that this is a procedure which creates anxiety, uncertainties, and the actual possibility of coming face-to-face with death.

As it is a complex department, ICU mobilizes all the hospital infrastructure and support services<sup>(2)</sup>, has its own routine, and various stressors – physical, environmental, psychological and social. Among the resources utilized, there is mechanical ventilation, which can be defined, in accordance with the III Brazilian Consensus on Mechanical Ventilation, as ventilatory support for the treatment of patients with acute respiratory insufficiency or chronic acute respiratory insufficiency. It aims to maintain gaseous exchange and the correction of hypoxemia and respiratory acidosis. Invasive ventilation (the process of intubation) uses an orotracheal or nasotracheal prosthesis – also known as a cannula or tube – or tracheostomy cannula<sup>(3)</sup>.

In the light of this, the PICU can appear as a frightening space, principally due to the quantity of equipment. The fear and the threat of death are emotional reactions present in the parents of children hospitalized in PICU<sup>(1,4-5)</sup>. Since ancient times this issue has been surrounded by imagination, uncertainties, fear and repulsion; it mobilizes feelings of despair, sadness, indignation, rage, guilt, and difficulty in acceptance<sup>(6)</sup>.

During their lifecycles, human beings experience stressors which require solutions to be sought if difficulties are to be faced, illness

being one such aspect. People who pass through adverse situations may face them with success and emerge strengthened, while for others, this experience of confrontation and strengthening does not occur. This human capacity for confronting, overcoming, and being strengthened or transformed by adverse experiences and/or situations is termed resilience<sup>(7)</sup>. There are also other forms of coping, such as the belief in the spiritual dimension. As a result, illness may mobilize faith in human beings, as a means for a cure or for coping with a situation of difficulty<sup>(8)</sup>.

In the light of the above, this article aims to describe the perception of the companion regarding the intubated child in PICU.

## METHOD

The present study was developed based on research with a qualitative approach undertaken with companions of intubated children, hospitalized in the Pediatric Intensive Care Unit of a public hospital in the state of Paraná. The sample was random, the inclusion criteria being: companions of children aged between 28 days and 14 years old being mechanically ventilated in the PICU in the data collection period, and who were willing to answer a semi-structured questionnaire. Data collection was undertaken between July – October 2011, following approval of the project by the Committee for Ethics in Research in Human Beings of the State Health Department of Paraná/Worker's Hospital, under N. 344/2011, of 30th June 2011. The participants were informed about the study's objectives and the ethical aspects, and following that signed the terms of consent.

The data collection instrument contained data for identifying the interviewee and the question "What does it mean to you to see the child intubated?". The data were collected by two researchers: one undertook the interview, and the other recorded it. The records were analyzed using content analysis, based in the phenomenological perspective. The phenomenological method is concerned with the meaning of the experiences from the viewpoint of the subjects who experienced them. Some stages were followed in this study, namely: the meaning of the whole; distinguishing the units of meaning;

transformation of the routine expressions of the subject into psychological language; and, finally, the stage of summarizing the units of meaning, transformed into proposals<sup>(9)</sup>.

Based on the data analysis, some data regarding the profile of the companions interviewed were raised, as well as the composition of categories and subcategories for analysis. The interviewees were identified by the letter "I", followed by the sequential number of the interview.

## RESULTS

A total of eight companions participated in the study, all of whom were female, adults, with an average of three children, and different educational levels, ranging from incomplete primary school education through to Higher Education at the postgraduate level. Six companions were the mothers of the children, and two were grandmothers. Through the data for identification of the interviewees, it is observed that only one mother comments that she "is not working", and another reports that she is a housewife; the other companions refer to their jobs: teacher, supermarket self-stacker and production assistant. All mentioned that they were off work because of the child's period of hospitalization in PICU. There were different socio-economic levels, with a mean income of 2.8 minimum salaries. They also stated that they were from different regions of the State of Paraná.

The three categories extracted from the content analysis are described in table 1, with their respective subcategories.

Category 1, "Impact caused by the severity of the illness and the intubation", refers to the shock felt by

the companion due to the seriousness of the illness and the intubation. In the subcategory "Fright resulting from the PICU's environment and resources", the companions' accounts provide examples of aspects of despair, not only due to the ICU environment, but due to the intubation in itself, which is a technological resource used in these environments:

*I was frightened, because anybody would be. Ah, it has an impact on you. (I1)*

*I have never seen this! It was a shock for me! I remember him all purple in the hospital, and afterwards this device was put in place. (I4)*

*Nervousness, despair, suffering, panic. (I8)*

In the subcategory "Transposition to the companion of feelings of the intubation", it was observed through the companions' accounts that some of them transpose to themselves the feelings of the intubation, that is, they indicate feelings which are they imagine or perceive to be experienced by the child, and feel them themselves. The accounts below provide examples of this aspect:

*We know it is a way for her to breathe, but we feel suffocated, thinking how it must be to breathe through it. (I1)*

*And seeing him with the apparatus makes you feel bad. (I4)*

*The tube must be uncomfortable. (I5)*

Quadro 1 - Categorias e subcategorias advindas da análise de conteúdo. Campo Largo-PR-Brasil, 2013

CATEGORIES	SUBCATEGORIES
1. Impact caused by the severity of the illness and the intubation	Fright resulting from the unit's environment and resources
	Transposition to the companion of feelings of the intubation
	Imminence of death
2. The intubation as a channel for life	The tube as a means of survival
	Prior experiences
	Obtaining information about the intubation
3. Attitudes and behaviors of the companion	Resilience
	Spirituality
	Learning

*I think it is not comfortable at all, and for the person using it, it is worse. It is hard for me to stay here in ICU, when I reach my limit I have to get out. (17)*

*It is difficult to express it, we feel it more. (18)*

In accordance with the subcategory "Imminence of death", it was ascertained that when the companions experience illness and hospitalization at the child's side, principally in a space which requires specialized care, such as ICU, it is common for feelings of loss and of the presence of fear of death to arise. The accounts below demonstrate this:

*He looks like he's dead. (14)*

*In the same way that he is okay, it might be that he is not. (15)*

*[...] and there is the fear of death, as happened with my daughter. (17)*

*It really seems as if our daughter is dying. The thought that your daughter is going to die, that's all. (18)*

In relation to category two, through the interviews held, it was perceived that six of the eight companions related intubation to the child's salvation and survival, as shown in the category "Intubation as a channel for life". In the subcategory "The tube as a means of survival", the following accounts exemplify this fact:

*It is to save her [...]. If this tube were not there, they might not have saved her. (13)*

*Without the tube, there's no way to live. If it were not for the tube, she might have already drowned in her own secretions. (17)*

*Now, I am getting used to it, I know it is so that she can breathe. Without it there is no way for her to breathe, it is what is best for her. (18)*

Previous experience of having a family member

intubated were reported in four interviews, as shown in the subcategory "Previous experiences". Some examples:

*I wasn't so worried, because my father was intubated. (12)*

*Nothing is new in this. I've seen it lots of times, it becomes routine. It is not a problem anymore. My uncles and my children have already had [the tube] due to breathing problems, you know? (17)*

*I have already seen my mother intubated, but it is different with your child. (11)*

The information obtained regarding the process of intubation was mentioned by three companions, as shown in the subcategory "Obtaining information on intubation". Two of these three companions produced comments related to the lack of information, and in one interview, the information offered was shown to be important for calming the family member, respectively:

*I didn't know why they put that tube in. (13)*

*We hear a lot of things, such as the risk of dying. (15)*

*I became calmer after the information given by the doctor and the psychologist. (12)*

Category three is made up of "The companion's attitudes and behaviors", and refers to the attitudes and behaviors reported in the interviews regarding the intubated child. The subcategories analyzed were "Resilience", "Spirituality" and "Learning".

The companions' reactions and attitudes, when they were confronted by the reality of the intubated child, gave rise to demonstrations of adaptive and super-active behaviors. In the subcategory "Resilience", this aspect supports this construct, which is the individual's capacity to face unfavorable situations, and to develop the ability to face them positively. The accounts below demonstrate this issue:

*You have to have control, you have to reason, to be calm, to keep control. It's necessary to know, to discern and understand.* (11)

*We have to try to improve.* (17)

A further two reports show that optimism can be an artifact for behavior which is not necessarily resilient, but as a possible denial relating to the adverse context. In the examples below, the companions speak briefly about their feelings of sadness and worry, but then indicate their expectation that everything will work out:

*There is a feeling of sadness to see him with all this equipment, but I know that he'll get out of this. I remember him laughing.* (14)

*We do worry, but I think nothing will happen.* (16)

The search for meaning, which encompasses the subcategory of "spirituality", may be clearly noted in the following account:

*You need to have a spiritual understanding. Our faith, our religion, helped a lot. If the spirit is weak, the flesh does not understand. The word says that we have to be prepared for death. And this just goes to show that we really do have to be prepared.* (11)

In the subcategory "Learning", the accounts show varying feelings of the companions, including the capacity to adapt to situations, as in the following account:

*As time passes, you get used to it, you have to live with it.* (17)

However, what is emphasized here is the capacity for learning within the diversity, and the suffering resulting from this seems to induce the construction of a reflexive awareness regarding questions of life, health and illness:

*This [the intubation] was a lesson for me, so that I could grow. A learning. In practice, everything is different.* (11)

## DISCUSSION

All the companions of children hospitalized in PICU were female, corroborating the data found in the literature regarding the female in the role of caregiver.

The female role, as a part of female nature associated with the representation of self-denial and lovingness, is a determinant for the responsibility for care to be delegated to the woman<sup>(10:293)</sup>.

Regarding the care for the child and work, the companions mentioned changes; this evidences that when a member of the family is hospitalized, the family system as a whole is shaken in its homeostasis, with an exchange of roles occurring. The companions referred to come to accumulate functions, between the caregiver for the hospitalized child, and the person who maintains the home (employment link). As a result, the family – representing a social group which maintains its own routines and relational patterns – is broken when one of its members is hospitalized; in the case of children, one can observe changes in the family dynamic and different emotional reactions<sup>(4)</sup>.

When hospitalization occurs unexpectedly, the stress is even greater, as there is an association with loss and death. ICU is generally a place with technological apparatus designed to benefit the child, but these can also make the environment frightening due to the equipment, the noise, and the impersonality<sup>(4-5)</sup>.

After all, the situation of hospitalization is something unique which is not part of a person's life projects. This being the case,

all and any invasions in the vital space are something aversive which, besides their abusive character, also present components of pain and disheartenment<sup>(11:68)</sup>.

Being a companion in ICU can be experienced through feelings of isolation and privation, not only because of the distancing from the social and family routine, but because of the physical and functional structure of the service itself<sup>(1)</sup>.

In the same sense, the companions of children hospitalized in ICU can feel distress, discouragement, worry and uncertainty related

to the illness and, in addition to this, the fear of losing the child becomes a genuine threat<sup>(12)</sup>. Furthermore, a large proportion of the companions believes ICU to be a hostile, negative place, which does not produce health, in which there is pain, suffering and death, due to this being an environment in which seriousness of the condition, the invasiveness of the equipment and the risk of death are present<sup>(13)</sup>.

Based on the accounts of the children's companions, one can say that there is a relation between the technological investment in the family members' confidence. ICU is a high-technology environment, with various resources available for attending the patient better; it is a critical area for the hospitalization of seriously-ill patients who need continuous and specialized professional attention, specific materials, and necessary technology for undertaking the diagnosis, monitoring and therapy<sup>(2)</sup>. As this study was undertaken in a hospital which attends only the public health network, these results seem to show that the family members trust the technological resources made available to society through the Unified Health System.

There were discourses from the companions of children in PICU which showed that previous experience of having a family member intubated had the effect of mitigating the impact felt by the companion in relation to the intubation process. However, the meaning attributed depends on the intensity and on the context of the previous situation. If it was perceived as extremely traumatic, it will probably bring sequelae; if otherwise, the fact will contribute to mitigating the suffering<sup>(14)</sup>.

Studies show that the companions, in discussion circles with professionals, felt free to talk about the time that they were passing through with their children, and in this way raise their doubts regarding issues which worried them, such as, for example, in relation to their child's illness. In this way, it was perceived that the companions are interested in learning and, through this, allow the health professionals to offer these people advice. Furthermore, the companions wish to interact with the health team, making themselves available to help in the care for the child, providing information and exchanging experiences with the professionals<sup>(12,15)</sup>.

In ICU, the communication process is fundamental for promoting humanization in

the hospital environment. For this to occur satisfactorily, it is necessary for the information to be transmitted, and for the person it is meant for to receive and understand it<sup>(4,16)</sup>. The receiving of reliable information regarding the patient is a reason for satisfaction and security, and contributes to the family's feeling of calmness. One must be careful, however, with information overload, as this can impair the understanding of the facts and establishment of a bond with family members and companions<sup>(4)</sup>.

It is possible to note in this study's reports that there is an attempt to overcome the adversities, indicating a pattern of adaptation to the present adversity. Resilience can, therefore, be considered a protective factor for the adaptation of the individual to the demands of the day-to-day. The mechanism of denial (total or partial) is generally temporary and is used by nearly all the patients, in initial or later phases of illness; it is a healthy way of dealing with suffering, comparing denial with a car bumper, protecting the patient/family member and allowing recovery with time<sup>(17)</sup>.

The intensity of feelings caused by the situation of coming face-to-face with seeing an intubated child can arouse reactions of a spiritual nature. In the routine of work in PICU, various manifestations of this nature can be observed in the hospitalized children's companions. It is a system of beliefs focussing on intangible elements, which transmits vitality and meaning to life. Regarding this issue it is pointed out<sup>(18)</sup> that in seeking meaning for life, human beings may or may not include formal religious participation.

It is noted here that the liberty of the creative power arising from the companion's experiences, through coexisting with the dynamic of care for the child and gradually understanding and re-elaborating the occurrences; a fact that may have been facilitated by the relationship with the PICU professionals. This assertion is confirmed by the fact that situations of approximation with death stimulate new meanings and feelings of life, which may cause changes in the caregiver, such as developing and expressing new attitudes, values and habits<sup>(19)</sup>. As a result, it is important for the health professionals who work in PICU also to offer support to these hospitalized children's companions, as the family, when well supported, helps itself and can help in the children's recovery<sup>(15)</sup>.

## CONCLUSION

This work aims to identify the different perceptions which the companions had upon seeing their child intubated. The research revealed that the experience of intubation is initially perceived by the companions as a period which has an impact upon them, in which these show that they are frightened by the PICU environment and resources.

After this initial impact, the intubation is understood as a channel for life, as a means of survival for the child, which also depends on the meanings of previous family experiences and on the information provided by the team regarding the intubation process. Finally, the study indicated that the companions develop strategies for coping with the adverse situations (intubation), showing themselves to be resilient and making use of spirituality, facing the situation as learning for life.

The study's results indicate some guidelines for the team's work regarding intubation. It was evidenced that information/communication during the intubation process allows the companions to have a better understanding of what is happening with the child, and calmness regarding the situation. Finally, it is appropriate to note that coping strategies regarding stressful situations were evidenced, showing that the companions find healthy ways of dealing with intubation.

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