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« Experiences of Parents and Caregivers in Pediatric Intensive Care Unit: A Qualitative Study »

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Authors' contributions

Each author made substantial contributions to several of the following steps: conception, design of the work, acquisition, analysis, and interpretation of data.

Each author approved the submitted version and agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Abstract

[Background] In pediatric intensive care units, parents and healthcare professionals attend to children who verbally and non-verbally express their pain and suffering, fears, anxieties, desires and wishes in complex intensive care situations. What can we learn from these experiences to improve the way we can take care of and support children?

[Objectives]: The main objective of this clinical ethics study is to focus on the experience stories of parents during their child's hospitalization in a Pediatric Intensive Care Unit, to analyze their discourse and to propose an ethical perspective.

[Method] The current research collects the experience reports of parents during their child's hospitalization in a Pediatric Intensive Care Unit (PICU), and those of the caregivers who treated them. Seventeen semi-directive interviews were conducted in the PICU of the Nantes University Hospital from November 2017 to June 2019. Each interview lasted around one hour. The main results of our study are analyzed and informed by the four ethical principles of T. Beauchamp and J. Childress: autonomy, beneficence, non-maleficence, and justice.

[Results] The interviews highlighted the difficulties encountered by parents during the hospitalization of their children, such as the distance between their home and the hospital, the technicality of PICU's environment, and the difficulty in finding their place as parents. For medical and paramedical teams, their main concerns are undoubtedly to improve the coherence and continuity of their posture towards parents, to promote parental autonomy, and to stay fully aware of the profound existential changes that the child's illness brings about for parents: it is the caregivers' duty to take this into account and to respect the parent's rhythm as much as possible.

[Conclusions] The main disagreements between healthcare teams and parents, where they exist, are communication problems that are easily controlled, for the most part, by caregivers.

Keywords

Clinical Ethics, intensive care unit, pediatrics, care, parents

1-Introduction

Every year, the PICU of the University Hospital Center of Nantes (France) admits around 600 children and their parents. Being announced that their child is ill and at risk of dying is probably the most difficult experience for parents. Thus, we can wonder about the care they receive at the hospital. Is it up to the challenge? Caregivers may not always be sufficiently available and approachable to enable parents to understand and participate in their child's care. Parenting may be difficult to maintain when a child is hospitalized. Parents' feelings about this experience can be a source of information for improving the way caregivers take care of (information, involvement of parents in the care of their child...) and support their child. [1] These experiences can lead to more tailored information for parents, better communication with parents, and more parental involvement in the care that is personalized to each child and parent.

The main objective of this clinical ethics study is to collect the experiences of parents during the hospitalization of their child in PICU, to analyze their discourse and to propose an ethical perspective using the four principles of T. Beauchamp and J. Childress (2013) : autonomy, beneficence, non-maleficence and justice [2]. The interviews conducted as part of this clinical ethics research revealed several aspects that we believe are essential to improving quality of care in pediatric intensive care units and more generally in hospitals.

1-Materials and methods

This research was part of an observational, single-center and prospective study in the 12-bed PICU of the University Hospital Center of Nantes (France). The regulatory qualification in Non-Interventional Research was submitted and validated by the Research Ethics Committee of the University of Paris Descartes on September 13 2016 (n° 2016-53). The study was divided into two parts: an ethological observation of children admitted to the PICU for more

than one week (unpublished data to date) and interviews with the parents and caregivers of these children (subject of the present article). Participants included in the study were expected to be children between one month and 18 years old admitted in our PICU for more than one week.

Although admission to intensive care was a distressing event for every parent, we chose to interview only parents whose children had been in hospital for more than a week to make their view of intensive care more "chronic". Parents had to give their consents for both their child participation and their own to be included to the current study. Semi-directive interviews were conducted by a pair of investigators including one clinician and one humanities specialist (philosopher or sociologist), independent from the PICU team. Caregivers of included children were also interviewed.

After obtaining consent of the parents, the semi-directive interviews took place in the intensive care unit in a dedicated room. The two researchers met with parents and caregivers, if possible during the care phase, or otherwise later, within a maximum time span of one month. Based on a standardized questionnaire, the interviews covered the following 10 points (in the order below):

1) Presentation of the research and investigators

2) Identification details of the parents (age, gender, profession, place of residence)

Elements on the history and health status of their child:

3) The child's history: pathology(ies) involved, treatment since the beginning of the disease, current medical devices (probes, intubation, etc.) and ongoing drugs

4) Child health conditions (on PICU admission, during PICU stay, at the time of the interview)

5) The child's expression and communication (with parents/with caregivers)

6) Signs of participation and opposition to care and their variations depending on the medical acts performed, time, people, etc.

The most important elements of this study that inform us about the parents' autonomy as well as their well-being and possible suffering:

- 7) Parents' interactions with the healthcare teams (physicians/nurses/caregivers): communication, organization of care, relationships with the child, etc.
- 8) Remarks on the child's current environment (lighting of the room, acoustics, etc.)
- 9) Information on any religious belief of the parents.

Population description relied on quantitative (means \pm standard deviation) and qualitative (percentages) data.

The study did not pretend to reach an exhaustive knowledge but intended to rely on a certain number of cases beyond which new cases would not add anything to the knowledge already acquired. This study therefore aimed to achieve the "saturation effect" with regard to the arguments identified in the interviews. It strived to achieve its objective by relying on a multidisciplinary team composed of caregivers and non-clinicians, specialists in the human and social sciences. A plurality of views and points of view was therefore involved in this study and as such, it brought to light more elements than a single view would.

2-Results

Description of population

Thirty-three children were eligible in the period between November 2017 and June 2019 (20 months in total). Out of these, 17 children were included because of their length of stay, and with the agreement of the parents for the interviews. The differences between included and non-included children were mainly the length of stay (longer for included children, with 46 days versus 21 days), and the shorter distance in kilometers to Nantes University Hospital (69 km for included children versus 129 km). The average distance that parents had to travel to see their child was $69 \text{ km} \pm 75$ (1 km - 253 km), or about 1 hour to 1 h 30 min by car to come

to Nantes University Hospital (a few minutes to almost 3 hours by car). Children disease were classified into chronic or acute conditions regarding the cause of their PICU admission. The child population is described in Table 1.

Invasive supportive techniques consisted of tracheal intubation, invasive or non-invasive ventilation, peripheral or central, venous or arterial catheters, urinary catheters, and general sedation. More specific medical acts included cardiopulmonary bypass for heart disease, gastrostomy and ileostomy for digestive surgery, and two extracorporeal membrane oxygenations (ECMO), as well as hemodialysis. Infections during the stay were observed, some with sepsis. One child died after 12 days in hospital.

The average delay between the child's admission in the PICU and the parents' interview was 32 days \pm 20 (9 days - 71 days).

Main results of the interviews

Seventeen semi-directive interviews for seventeen children (two interviews for one child, considered as one interview for the results) were conducted. Each interview lasted around one hour. Of the 17 interviews, we met with 28 parents: 6 interviews were with a single parent (5 were with the mother alone; 1 with the father alone). For each child, we met with a nurse involved in the care of the patient.

The average distance between home and hospital is an important point established in our study, because this distance can cause anxiety – especially during the car ride in shock, sometimes at night, after the admission ("We leave for 2 months", a mother had told her husband) – organizational difficulties (housing, siblings, work) but also potential relationship difficulties.

However, there is a strong and continuous presence of parents during the day (several hours) with their child, with an impact that is most often positively assessed by caregivers. A strong

presence (most of the day or even night), particularly of the mother, is to be noted in 6 cases, but in more than a majority of cases (11 interviews/17) it is both parents who are present with the child.

Parents are also often included in their children's care (help with the bath, with dressing for example), and the perception of this parental involvement by the various actors is positive in half of the cases. However, despite the described benefits of the parents' involvement, another important point highlighted in our study is the existence of discrepancies regarding the place given to parents by caregivers in care: these discrepancies can lead to disagreements or even conflicts. We met Mrs. X., the mother of 3-month old T., hospitalized for correcting surgery of her congenital heart disease. An event turned Mrs. X.'s confidence in the team upside down. Until it occurred, "most of the time", she was asked if she wanted to be present during care. One day when T. was "unwell", a physician she had "never seen" asked her to leave because he was going to intubate T. She explained: "I came back, he had intubated her, T's eyes were empty, puffy, bulging". She told the physician that her daughter was not well. He answered her: "Ha? Do you think so?". She exploded with anger and then asked for an external opinion that proved to be consistent with that of the healthcare team.

We also analyzed the impact on the actors (parents and caregivers) of the highly technical environment of the rooms in the pediatric intensive care unit. Technical installations have negative consequences for parents. Sensory stimuli can be intense and frequent (noise and light in particular). Thus, parents (and caregivers) underline the discomfort of this environment for them and for the child (6/17). Parents point to the "infernal noise", the "chaos", the "lack of privacy" of the hospital room and complained: "it's almost torture. There are too many beeps. Why don't they use bird songs instead? When you hear the caregivers laughing, it's fine, there are positive noises! Since connected objects are developing, we don't understand the use of "beeps" when nurses could wear connected watches or bracelets for

monitoring, couldn't they ?". Kaur's study about noise pollution in PICU underlines the involvement of beeps and alarms in noise pollution, leading to sleep disturbance, negative impact on patients' recovery and raising tensions between caregivers and families. They promote the use of technological progress to reduce the sound discomfort[3].

In addition, rare parents (2/17) underlined that the caregivers did not respect the day/night rhythm.

In some interviews, another element that appears is the parents' sense of guilt towards their child. In case of genetically transmitted disease, guilty may be so heavy that it leads to tensions with the grandparents (2/17).

Even if they are not predominant in our interviews, our study reveals the existence of communication problems, disagreements and even conflicts between the different actors [4], in particular between parents and caregivers.

Some parents point out problems of access to information: one couple reports that when they arrived at the hospital, they stayed "4 hours without information, waiting". Others say that important medical acts, such as extubation, took place without their knowledge and in their absence. Parents also report discrepancies in the information provided by caregivers: "Is there a physician in charge? Who decides?" "It's never the same".

Parents sometimes express frustration due to the uncertainty in outcome, changes in the medical team's decisions (especially concerning the date of discharge of their child), lack of information about the medication administered (which explains in their eyes the desperate use of the Internet) but also about the precautionary measures to be taken when returning home or to nursery. One parent reported : "if we don't ask anything, we are not informed of anything...I had the impression that they had more time for me after my fit of anger". Another told us : "Physicians always ask to take time: "We have to give ourselves time". I'm not heard by the physician." Some parents distinguish the posture of nurses ("listening") from that of

physicians ("focused on the medical") and said us : "The nurses' approach is fine. With the physicians, you feel there is a "court" (Judgement) behind it. They talk to us about probabilities, statistics". Other reported : "We don't dare to talk to the physicians, we don't dare to disturb them, we tell ourselves that they are busy looking after the children".

Real conflicts, i.e. deep disagreements between the actors leading to a real breakdown in communication between the caregivers and the parents, are rare: in only 1 case, following a major misunderstanding regarding the patient's care (a physician unknown to the parents demands that they leave the room at a difficult time for the child), an external opinion from the team was requested by the parents.

In our interviews, the parents' religious beliefs does not appear to be an obstacle to understanding and decision-making. When it is present, it seems to be a comfort to parents.

Finally, our study reveals differences in the perceptions the various actors have of the children in almost half of the cases (7/17):

- caregivers sometimes refer to parental "denial" and also to the "gap" between the position of caregivers, especially when they are wondering about withholding or withdrawing treatment, and that of parents who have not yet reached that point.

- some parents think they know their child better, perceive their suffering or, on the contrary, their state of well-being and told us : "We could have told them"; "The physicians see M. five minutes a day and we see him all day"; "We know our child better than they do".

- Parents can also feel that their child is "manipulating" caregivers – a rare occurrence, and reported : "A. is not very patient and controls caregivers well, she complains about a boo-boo."

- Finally, there are disagreements about the impact of certain acts on children. For example, one mother stated that she preferred artificial breastfeeding over maternal breastfeeding because she perceived it as "too tiring" for her child. The nurse thought otherwise.

3- Discussion and Interpretation

The main results of our study are analyzed and informed by the four ethical principles of T. Beauchamp and J. Childress [1]: autonomy, beneficence, non-maleficence, and justice.

(i) Respect for Parents' Autonomy

Parents express the difficulty of exercising their parental function in the context of their child's illness. The announcement of the diagnosis, the hospital setting and the need to adapt the family's organization are all factors that they are confronted to and that force them to draw on their financial resources in order to be able to be present for their child and their family. Caregivers acknowledge this effort and legitimize it by underlining the positive impact of the parents' presence with their child. Indeed, they are points of reference for their child in this brand-new environment that is the hospital. In order to facilitate this adaptation, the provision of information on the organization and functioning of the unit makes it easier for parents to understand the hospital environment: "the distribution of a welcome booklet significantly improved understanding" [5].

How can we maintain the role of parents as the child's referents, knowing that they cannot choose their future on their own? The hospitalization of a child is akin to a decrease in their parental autonomy. This situation poses a problem for parents: during an interview, one mother relates that she "does not know what it is to be a mother in hospital", another that she has "lost her role as a mother for a medical vision". Healthcare was not part of their vision of

parenthood, so they find themselves confronted with a redefinition of their role that requires them to integrate the child's illness into it.

Some studies [6-7] have investigated parents' perceptions of their parenting role in pediatrics and neonatology. They showed that the main reason for their disruption is related to the inability to protect their child from pain. Moreover, parents' estimation of the impact of hospitalization on their parental role depends mainly on their subjective view of their child's illness and not on medical assessment alone. The "role restriction" described in these studies is also emphasized by the parents we interviewed.

At birth, the woman becomes a mother, the man becomes a father and the fetus becomes a child. This stage has many impacts on the rest of the newborn's life, hence the development of practices, such as skin-to-skin, aimed at strengthening the parent-child bond and improving the newborn's health status from the very first moments of life [8-9]. Childhood illness, when present from birth, disrupts this process by limiting the time the newborn spends with his or her parents and adding physical and psychological hardships. The presence of parents and their participation in care allows them to take on the role of "caregiver", and thus to become, in spite of everything, attachment figures for the child [10]. Medical interventions often involve a mother-child separation. During this separation, the mother experiences a feeling of emptiness and guilt, some parents question the place they have in their child's world, and one couple tells us of their concern about "whether (their) child loves them". These hospitalizations from birth complicate the appropriation of the family circle and the construction of the parental relationship, which may explain the difficulty parents have in finding their place in these situations.

Also, in the light of our interviews, it appears that parents' confidence in the healthcare team depends in particular on the coherence and continuity of the team's posture (information,

decisions...), which recalls in particular the conclusions of S. Milgram's experience on obedience to authority: when authority shows contradictions, disagreements and inconsistencies, individuals oppose authority [11]. Explanations about the organization of the unit and care, as soon as the child is admitted in PICU, could then allow for the initiation of a trusting relationship. Communication within the nursing staff and the appointment of a referring physician are all elements that ensure the consistency of the information given to parents. Guidelines from American Association of Pediatrics recommend that information concerning child's illness, condition, treatment and prognostic should be given within 24 hours of admission. (ref: Davidson JE, Alakson RA, Long AC et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, And Adult ICU. Crit Care Med 2017;45:103-28)

Concerning their involvement in care, the parents interviewed would like the teams to leave them free to choose when and how they want to participate in care (some acts, such as injections, are judged by some parents as "too difficult", they also want to "protect themselves"). Nurses are in the best position to regularly seek out the different possibilities of involving and giving parents a place in their child's care (taking the child's temperature, helping her/him with the bath or with dressing, taking their child in their arms as soon as possible, etc.) that meet both their request and the objectives of care [5]. One physician emphasized that parents choose their level of involvement in decision-making processes and that it is important that caregivers respect their choice.

Parental autonomy is only possible if parents are properly informed. As legal guardians of the child, they give their consent for the care to be carried out. Thus, this consent is only viable after parents have been given explanations regarding their child's condition, the benefits, the risks and the place of the medical acts in the child's care. Parents qualify this information on their own initiative. Indeed, the technical aspects of pediatric intensive care, as well as the many uncertainties about the prognosis, make it difficult to give a clear picture of the

situation. Prognosis uncertainty that is usually presented as probabilities can blur the status report and leave room for confusion. This underlines, in keeping with numerous studies on the subject [12] the importance of the words used by caregivers. However, it is reported in our interviews that a clear and adapted explanation allowing parents to understand the problem makes it easier to appropriate it and thus to face it more calmly: in the case of a heart problem explained by a diagram, a mother tells us that "it is reassuring to understand and to be able to explain [the problem] to others".

Finally, once their child is discharged from hospital, the gap between being partially involved in the child's care during the hospital stay and being totally in charge at home seems huge for some parents. Seeking autonomy and some form of control when surrounded by medical staff is far from having to cope with any situation "alone" at home. This is especially true in the case of malformations, heart disease and genetic diseases: how to reconcile education and the child's illness? How to let your child grow up without falling into the trap of overprotection? For several types of illnesses requiring long-term medical care, parents and caregivers will have to form an alliance around the child. Caregivers can help answer these questions, particularly by communicating the precautions to be taken when leaving the hospital beforehand. Parents also find support among their peers in the "parents' house" across the street from the Hospital. The pediatric intensive care team notes that requests for information from parents are often made too early to be answered. In this case, the professionals ask for "time" so that they can have the elements they need to provide an answer. This situation is often unbearable for parents who have to make do with an indeterminate near future that is rarely reassuring.

(ii) Beneficence

Hospitalization in PICU is a real ordeal for families. Each parent develops different strategies to cope with these events. It is the caregivers' duty to take this into account and to respect parents' rhythm as much as possible, especially when the illness is announced, which is the moment the caregiver upsets the parents' representations, then bursts into their fantasy world: this announcement can have a traumatic effect leading to physical, emotional, psychological and cognitive shock, which is frequently followed by a moment of astonishment. This can then result in an impossibility to think, an inability to realize and elaborate this event that freezes their imagination. This is particularly the case when the illness is announced during pregnancy: in this context, can the parents imagine the baby as the professionals tell them he/she will be after birth[13]?

In complex cases, including withholding or withdrawing treatment, religious and spiritual beliefs appear to be a source of support for parents and patients. One American study suggests that these beliefs may have more impact on how decisions are made than on the decisions themselves [14]. One mother refers to groups of people praying for her child: E., an 11-year-old boy waiting for a heart transplant, asks, "Why did Allah decide on this issue?" "Allah gives hardships to those he loves," his mother replies.

During our interviews, the strong involvement of professionals was also underlined. Most parents feel well supported in PICU and appreciate the proximity of the nursing staff: in this unit, there is one nurse for every two children. The parents call the nurses by their first names, which breaks the barrier of the white coat. This proximity allows for the establishment of a bond of trust, the parents feel reassured and know that their child is well looked after. One mother, whose child has been cared for from birth, is extremely grateful to the team: "They are the mother when I'm not there". This benefit is even more obvious when the parents have experienced another pediatric unit where the health care teams are smaller, and therefore the professionals have less time to spend with them and their child. Parents emphasize the lack of

communication during transfers from one unit to another that led to disagreements with the new teams who were not informed of certain precautions to take.

(iii) Non-maleficence

The dehumanizing nature of the technical environment of pediatric intensive care is highlighted in our interviews in that it distances the main actors from what the child's social environment should be. How can we restore meaning to the parental relationship, maintain the links between the actors and not lose the very essence of care [15]? When the length of hospitalization is long, parents make it as comfortable as they can for the child (music, drawings, toys, transitional objects) but some say they don't dare to do so and would like to be clearly told that they have the right to. Some parents are marked by the disproportion between the size of their child and the amount of machinery needed for care. However, this negative perception of the environment by parents must be qualified: for some, hyper-technicality can also be reassuring, synonymous with supervision and care. Some noises in particular can be perceived positively, while others are irritating.

In case of genetic pathologies, the guilt of the parents noted in our study may impact their position in their child's care. This guilt reinforces the need for empathy and understanding from caregivers to enable effective and appropriate communication with parents, and a correct choice of words appears to be essential to their well-being. For example, one mother tells us about an antenatal consultation: "The pediatricians had some harsh words: 'The advantage to your term is that you will be able to say goodbye'. 'This is not unreasonable obstinacy', one doctor told us, but we came back home with 'unreasonable obstinacy' in mind."; "When the shock is there, you can hear the complete opposite," confides another mother, herself a doctor. Finally, parents' understanding of "seriousness" is not always the same as that of physicians: for some parents, having an interventricular communication operation, for example,

corresponds to "open-heart" surgery and is therefore a source of major concern, whereas for surgeons it is a simple operation in the majority of cases. Three couples, whose infant's pathology was discovered during pregnancy, refused the proposal for medical termination of pregnancy because the information given by the doctors was not alarming: a surgeon had said that "it's operable", without specifying the gravity, a father recounted "the 'teddy bear' information from the cardio-pediatrician... a little too optimistic". Those parents regret they had not been given enough information to measure the importance of the pathology; in one case, the mother even asks "why did they tell us to continue?"

During our interviews, we noted differences in how the child was perceived. Parents (especially during late hospitalizations) consider that they know their child best and are thus hurt when staff members disagree with them about the child's condition or feelings. Challenging their views in these situations is seen as a challenge to their role as parental 'referees', based on their difficulty in exercising their parental role in hospital. However, in some cases, parents are guided by their emotions and apprehensions about their child's condition and this influences their assessment. In these cases, it is important for caregivers to identify what is in the best interests of the child in order to make their decisions.

(iv) Principle of Justice

The distance between the hospital and the family home, which is not always freely chosen by the parents themselves, can lead to inequalities in the treatment of parents by caregivers and can thus unintentionally have consequences for the patient : in two cases, caregivers declare regretting a "lack of parental organization" (concerning a lack of parental presence with the child) which is clearly correlated in one case with a significant distance from the family home. The impact of this factor on the patient remains difficult to assess. However, a less-than-wished parental presence, and the potential tensions it generates with the caregivers may

easily impact the patient's well-being. The benefit of the “parents’ house” located opposite the Nantes University Hospital is a recurrent element stressed by parents and caregivers in our interviews.

Some parents also experience a feeling of guilt towards the system. Some mothers are on maternity leave when their child is hospitalized, which therefore does not affect their professional life. But fathers and parents of older children need to take time off work to be present with the child. In these situations, they stress the importance of support from their colleagues and superiors. But here again, it is clear that there are inequalities between parents who can afford to put their working life on hold and those who are less fortunate or less surrounded. Collective solidarity should be strengthened in this context.

Our study has several limitations. Parents with strong alliances with the healthcare team may have had greater motivation to participate. Strengths of our study include the flexible and open-ended nature of qualitative methodology, and the composition of the research team. Few patients are concerned, and the population is heterogeneous.

4-Conclusions

The interviews conducted as part of this clinical ethics research revealed several aspects that we believe are essential to improve the care of children in pediatric intensive care units and more generally in hospitals. For medical and paramedical teams, it is undoubtedly a question of further working on the coherence and continuity of their posture towards parents (parental participation in care, information, etc.), of being fully aware of the profound existential changes that the child's illness brings about for the child him/herself, for the parents and beyond for the whole family. The main disagreements between teams and parents, where they exist, are communication problems that are easily improved, for the most part, by caregivers. Although there is still room for improvement, the negative points put forward by the various actors should not hide the many positive points highlighted by the majority of families and

caregivers: in intensive care units, particularly pediatrics, progress is spectacular not only in terms of available therapies and results (today we are saving children who would have had no chance only a few years ago), but also in terms of quality of support (centered on the child's best interest) as well as internal (doctor-nurses) and external (caregivers-parents) communication. The very existence of this study, the participation of medical and paramedical teams for more than 5 years now in the EICPICU study [1] but also the strong involvement of parents themselves in the research, similarly show to what extent the place of parents in hospital services has changed, placing the concern for parents and patients ever more clearly at the center of care [16-17].

List of abbreviations

PICU : Pediatric Intensive Care Unit

RSV : Respiratory syncytial virus

ECMO : Extracorporeal Membrane Oxygenation

EICPICU : Ethics of Invasive Care in Paediatric Intensive Care Unit

References

1. Durand G, Dabouis G, Liet JM, Gaillard-Leroux B. Une étude d'éthique clinique en réanimation pédiatrique : la place accordée au patient dans la prise de décision. *Journal de Médecine Légale, « Droit, Santé et société », SÉRIE E : DROIT, SANTÉ ET SOCIÉTÉ* 2015. 4 ; 2 : 30-37.
2. Beauchamp TL, Childress JF. 2013. *Principles of Biomedical Ethics*. Seventh ed. Oxford: Oxford University Press.

3. Kaur H, Rohlik GM, Nemergut ME et al. Comparison of staff and family perceptions of causes of noise pollution in the Pediatric Intensive Care Unit and suggested intervention strategies. *Noise & health* 2016 ; 18: 78-84.
4. Dalichoux B. 2014. Désaccords et conflits entre famille et équipe soignante dans les décisions de limitation et arrêt de traitements en réanimation pédiatrique. *Medical Sciences thesis, Université Claude Bernard - Lyon I, Faculté de Médecine Lyon Est.*
5. Béranger A, Pierron C, de Saint Blanquat L, Jean S, Chappuy H. 2017. Communication, information, and roles of parents in the pediatric intensive care unit: A review Article. *Arch Pediatr* 2016 ;24:265-272.
6. Obeidat HM, Bond EA, Callister LC. The Parental Experience of Having an Infant in the Newborn Intensive Care Unit *J Perinat Educ* 2009;8:23-9
7. Wallander JL , Venters TL . Perceived Role Restriction and Adjustment of Mothers of Children with Chronic Physical Disability. *Journal of Pediatric Psychology* 1995;20: 619-32
8. Bystrova K, Ivanova V, Edhborg M, Matthiesen AS, Ransjö-Arvidson AB, Mukhamedrakhimov R, Uvnäs-Moberg K, Widström AM. Early Contact versus Separation: Effects on Mother-Infant Interaction One Year Later. *Birth* 2009;36: 97-109.
9. Chen EM, Gau ML, Liu CY, Lee TY. Effects of Father-Neonate Skin-to-Skin Contact on Attachment: A Randomized Controlled Trial. *Nursing Research and Practice* 2017;8612024
10. So S, Rogers A, Patterson C, Drew W, Maxwell J, Darch J, Hoyle C, Patterson S, Pollock-BarZiv S. Parental Experiences of a Developmentally Focused Care Program for Infants and Children during Prolonged Hospitalization. *Journal of Child Health Care* 2014;18: 156-167.

11. Brossard A. 2008. Peau à peau en salle de naissance observation des pratiques et opinion des professionnels. Mémoire Diplôme d'Etat de Sage-femme, Archives de l'Université de Nantes, 2008.
12. Tereno S., Soares I., Martins E., Sampaio D. et Carlson E. La théorie de l'attachement : son importance dans un contexte pédiatrique”, *Devenir* 2007/2 ; 19 : 151-88
13. Milgram S. 1994. La Soumission à l'autorité. 2nd ed. Paris : Calmann-Lévy.
14. Spranzi Zuber M. Interprétariat, droits du malade et éthique de la communication. In Byk CH, editor. La bioéthique : un langage pour mieux se comprendre ? Paris : Editions ESKA/ Editions LACASSAGNE ; 2000.
15. Ben Soussan P. 2005. Le bébé imaginaire. Paris : Erès.
16. Superdock, A.K., Barfield, R.C., Brandon, D.H. *et al.* . Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: a qualitative study. *BMC Palliat Care* **2018 ;17** : 107. <https://doi.org/10.1186/s12904-018-0360-y>
17. Abuqamar M, Arabiat DH, Holmes S. 2016. Parents' Perceived Satisfaction of Care, Communication and Environment of the Pediatric Intensive Care Units at a Tertiary Children's Hospital. *J Pediatr Nurs*2015;31:177-84.
18. Apter G, Leblanc A. 2015. L'enfant Malade dans son corps, Paris : Erès Editions
19. Haute Autorité de Santé. Annoncer une mauvaise nouvelle. 2008 feb. https://www.has-sante.fr/portail/upload/docs/application/pdf/2008-10/mauvaisenouvelle_vf.pdf

Table 1 : Description of population

Variables	N = 17 (%)
Parents'home	
- Loire-Atlantique department	10 (59)
- Nearby department	5 (29)
- Distant department	2 (12)

Age (years)	2.7 ± 3.8 (1 – 11)
Gender : Male/Female	9 (53)/8 (47)
Sex ratio	1.1
PICU length stay (days)	46 ± 32 (13 – 116)
Underlying chronic conditions	12 (70)
- Congenital Heart disease (1)	5
- Giant omphalocele	1
- Urogenital malformation	1
- Esophageal atresia	1
- Congenital diaphragmatic hernia	1
- Bronchopulmonary dysplasia	1
- Epilepsy	2
History of prematurity	4 (23)
Primary admission diagnosis	
Postsurgical	10 (59)
- Cardiac	5
- Digestive	4
- Urogenital	1
Medical diagnosis	7 (41)
- Respiratory illness	4
- Burn	1
- Myéлитis	1
- Hemolytic uremic syndrome	1
Extracorporeal membrane oxygenation (ECMO)	2 (12)