Parental information and presence in a pediatric critical care unit

L. Ennazk, Y. Mouaffak, G. El Adib, S. Younous

Department of pediatric intensive care unit. King Mohamed VI University Hospital, Marrakesh, Morocco

Corresponding author: L. Ennazk, Department of pediatric intensive care unit, King Mohamed VI University Hospital, Marrakesh, Morocco. Email: lennazk@gmail.com

Abstract

Background
Information given to families in an intensive care unit (ICU) is an ethical requirement and a medical necessity. In a pediatric area, the relationship between the physician and the patient is transformed into a triangular relationship which comprises "medical team - patient and parents. Indeed, family satisfaction is a goal that fits into the overall improvement of quality of care in a medical department in general and in a pediatric intensive care unit (PICU) in particular. On the other hand, parents are allowed in several structures of the northern countries, to attend and participate in cares, which is still not allowed in our context.

Objectives
To measure the satisfaction of caregivers and parents about the information given to them and to meet the current role of parents in the care given to their children in our PICU.

Materials and Methods
A transversal survey with a descriptive and analytic vision was conducted in the PICU of a teaching hospital in Marrakesh-Morocco. Two questionnaires were administered: one to the health care providers of the PICU and the other one to 50 parents.

Results
More than half of parents believe that the reception in the PICU is satisfying when all the caregivers and the staff want to improve it. 91.6% of the nurses and 60% of the doctors affirm that the restriction of visits in the ICU is often well-founded and justified. The majority of caregivers express their unwillingness to the presence of parents during the medical round

Conclusions
There is a general willingness of the team to improve practices but the concept of open-rea does not seem to be easily accepted yet.

Keywords: intensive care unit (ICU); information-parents; opinion-care givers opinion.

Introduction
Patient satisfaction is recognized as an important marker of quality care in a medical department in general and in ICU in particular [1]. In pediatrics, the patient is represented by his parents because of his disability and its lack of autonomy. The child admission in a PICU is an emergency situation that constitutes a physical and
psychological aggression during which contact with the parents is unavoidable. Improving communication and considering the family satisfaction is interesting for practices assessment. On the other hand, the restriction of visits in duration and number in intensive care unit has no supporting evidence. Even more, it has been shown that free access considering the state of health of the patient and care requirements are beneficial both for patients, parents and caregivers [2]. However, the open rea concept is not easily and universally accepted especially in a developed country where the sake of medicalization and proximity health care is still persistant.

In Morocco, few studies have focused on measuring the satisfaction of families in intensive care unit patients [3, 4]. To our knowledge, this is the first study evaluating the presence and the information given to the parents of a Moroccan PICU patient. This work came from a will to assess practices, when we know that it is the only third level PICU unit throughout the hole south of Morocco.

The aim of this study is to measure the satisfaction of the health care providers and the parents about the information given to families in the PICU.

**Methods**

We conducted a transversal survey with a descriptive and analytic vision. Two questionnaires were administered: one to the health care providers, the other one to 50 parents who have been interviewed by the same interviewer.

Inclusion criteria were as followed :

- All health care providers at Mohamed VI Marrakesh teaching hospital’s pediatric intensive care unit (PICU).
- Relative of a patient who have stayed at the unit at least 48 hours.
- Patient’s relative who have visited the unit at least twice and has had a discussion with one of the physicians of the unit.
- Patient’s relative who clearly accepts to participate in the survey.

Exclusion criteria :

- Patient’s relative under age of 18
- Relative of a patient for whom a stopping of medication has been considered.

The random sampling of 50 parents has been made in the department after patients have been discharged. The survey conducted with health care professionals aimed to shed light on their knowledge, attitudes and practices toward the quality of information that is provided to parents, as well as their opinions about their presence during rounds and nursing. The survey was distributed to all the unit health professionals including doctors and nursing staff. The data was collected anonymously through a questionnaire that the health care professional were invited to complete.

The survey administered to patient’s relatives was designed to help us gain insight in their opinion about the information they are provided with, as well as their position toward the concept of open-rea. The questionnaire was answered anonymously and was based on 20 items that are focused on measuring the satisfaction of patient’s relatives about the information given to them by the PICU staff and 14 items that addressed the concept of open-rea.

All relatives were informed about the purpose of the study. Only consentent members were recruited. Data collection was carried out with respect for the anonymity of individuals and the confidentiality of their reponses.

**Results**

*Questionnaire for caregivers* - The 23 members of the PICU team responded to the questionnaire. The sex ratio was of 0.55. The average age was 25.47+/-2.34 years. 71%of participants were nurses and 29% were physicians. The analysis shows that 11.8% of staff thinks that ensuring a warm welcome in the PICU is not
required (Fig. 1). 5.9% of staff say they are not required to respond to parents questions. 64.7% of staff believes that information should be given to parents by the same person (Fig. 2). 59% of staff believes that information should be given in a room designed for this purpose (Fig. 3). 64.7% of the nursing staff believes that an information book for parents will improve the quality of the messages. 100% of caregivers surveyed want to improve the information given to patient’s relatives. 82.4% of caregivers surveyed did not keep written traces of the information given to patient’s relatives (Fig. 4).

94.1% of caregivers have already prevented a parent to see their child when they wanted to. 82.4% say they are disturbed by the presence of parents during rounds. 70, 6% find it useful to explain to parents the materiel and equipment used for their child’s care. 100% of respondents did not agree with the extension of visits’ timeframe to 24 hours a day.

Patients questionnaire - A total of 50 people responded to the questions. The ages were between 20 and 70 years with an average age of 31.64.

86.0% found that the person who received them were welcoming. 46% of parents report that caregivers do not introduce themselves to them before addressing them. Only 39% think the waiting area is not comfortable.

86% say they have received information about the health of their child. Only 71% understood the information. 84% and 79% respectively do not recognize the doctor and IDE taking care of their child. 64% would like to have the information delivered to them by a single person.

54% have been prevented from seeing their children while they wanted to see him. 72% reported being bothered by limited visiting hours. 88% would like to visit their children at any time of day. 84% would like to spend the night with their child. Only 32% have attended care given to their children. 54% would like to participate in the care provided to their children. 60% believe their participation in the care provided to their children could have a positive impact.
The relationship between the physician and patient has undergone a significant change over centuries. It was once based on a purely hierarchical framework, where one protagonist (the doctor) had the superiority by his knowledge and power, while the second, (the patient) was held in a situation of weakness. Today, medical paternalism has gone and the patient is both empowered and active toward his support.

In a PICU, this binary doctor-patient relationship is expanded into a triangular relationship: patient - doctor - parents. Indeed, providing information to families of patients in pediatrics is based on ethical principles. The Code of Medical Ethics emphasizes the need for fair and accurate information to hospitalized children’s parents [5]. In PICU, law has placed family as an essential partner especially when the patient is incompetent. Furthermore, the inclusion of family members in a family-centered care approach is increasingly recognized as a criteria of quality care. It is therefore an essential concern.

This study showed that the reception room was perceived as "very good" by the majority of surveyed parents (48%), whereas the caregivers who wish to improve it. Many surveys made in intensive care units note a high satisfaction rate among families. N. Soumagne et al. noted high levels of satisfaction regarding structure and organizational indicators in a surgical and medical ICU [6]. Satisfaction expressed by families must not omit to consider the bias of the interviewer since our questionnaire was not auto-administered. On the other hand, the desire to improve the quality of hospitality expressed by caregivers shows the level of awareness among the team mostly composed of young people.

The family information is not limited to the transmission of data related to the health status of the patient. It is a communicative approach in which the two poles recognize and understand each other. Parents who do not recognize the doctor and nurse in charge of
their child are respectively of 84 % and 79 %. We think that this is due to duty system used in PICU. In addition, 64% families would like to have the information issued by the same person. For that we believe that communication tools must be integrated in teaching programs for all health care providers [7] which is a lacking point in the current medical teaching programs.

Recent data from the literature support the continuous accessibility of PICU for family [8]. Visit restriction in time and number of visitors is still largely applied in the world without any well-founded justifications. Several satisfaction surveys advocate a liberalization of visits and emphasize their beneficial effect on both families and caregivers. Families see their stress and anxieties reduced and thus, are more receptive to information. [9] On the other hand, the presence of families facilitates communication with caregivers, encourages them to take part in the therapeutical education and improves caregiver – patient’s family relationship [10-11].

In our study, we found a stand-off between the caregivers and families opinion concerning the open area. Similar studies observed that parents and caregivers agreed with parental presence in pediatric intensive care, and that it decreased confusion and anxious anticipation among parents [12]. For us, the statement pushes us to ask questions: is it early for integrating this new concept or is it an anxiety of judgment from the medical staff?

Conclusions

This first study to measure satisfaction of patient’s families in a pediatric resuscitation in Morocco shows a wide margin between the opinion of families and caregivers. The need to improve information for patient’s families is felt. The establishment of an open area system in the current time should be preceded by a study of the reasons that can be behind this reluctance.

References

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