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BIOETHICAL PRINCIPLES IN THE COMMUNICATION OF BAD MEDICAL NEWS IN PEDIATRICS

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Abstract: Revealing bad news to patients and family members is recognized as one of the most difficult medical tasks, which has special characteristics in Pediatrics, related above all to the bioethical principles of Autonomy and Non-maleficence. This research investigated how pediatricians at the Pablo Arturo Suárez General Hospital in Quito (HPAS) carry it out, through a semi-structured interview applied to 13 doctors, the results of which were analyzed using qualitative methodologies. It was found that pediatricians applied several strategies for communication with their patients, that the best performance in that function was directly related to greater professional experience and that the principle of Autonomy was partially respected.
Keywords: Bad medical news, Communication in Pediatrics, Autonomy, Non-maleficence

INTRODUCTION

Bad news is defined as that which involves death in the short or medium term, a catastrophic illness or one perceived as such by the patient's environment, or apparently minor illnesses that affect the life plans, mediate or immediate, of the patient or his or her context. (Rodríguez-Salvador, 2002) (Artús et al., 2012). There is unanimous agreement that the doctor must tell the truth to his patients; However, experts emphasize that such disclosure must be careful, adapted to the language and time of each patient, allowing them to somehow reach the truth for themselves and maintain some degree of hope (Nie & Walker, 2016). The lack of training in this type of communication can influence the development of psychological morbidity (Payán, 2012) and burnout in the professional (Fallowfield & Jenkins, 2004).

Effective communication between adults and children/adolescents requires sufficient time, attentive listening, eye contact, agreement between body language and what is said, and responding to their concerns as many times as necessary. The health professional, and in particular the pediatrician, must adapt their language to the maturity and development of each minor (Pérez-Pedraza & Salmerón-López, 2006), respecting their social, cultural (Cruz-Hernández, 2004) and family characteristics (Burbinski & Naser, 1999), in addition to not lying to him or overwhelming him with technical words; Adolescent patients also need to guarantee the confidentiality of their medical problems (Araneda, 2011) and progressively greater respect for their autonomy (Lorente, 2015) (Gamboa-Bernal, 2006).

In the final decades of the 20th century in developed countries, and within the framework of the paradigm shift from medical paternalism to increasing patient autonomy, serious shortcomings were detected in this communication, as a result of which many medical schools included the theme in their programs. In developing countries the process has been slower. Among the strategies proposed, the most used is the SPIKES protocol (Baile et al., 2000), which includes six steps: 1. Location, 2. Perception, 3. Invitation, 4. Knowledge, 5. Empathy, 6. Summary and strategy.

Adequate communication of bad news has been associated with greater patient well-being, greater adherence to treatment, more control of symptoms, better final results (Payán et al., 2009) (Hilkert et al., 2016) and fewer legal claims (Bragard et al., 2018). The communication of bad news in Pediatrics has not been exhaustively studied, but some specific characteristics have been identified (Mateos, 2013) that entail bioethical problems, especially referring to autonomy (Arroba & Serrano, 2007) and the need to explain medical problems. both to responsible adults and to the sick child or adolescent. There are key factors that facilitate this interaction:

maintaining bidirectional, collaborative and family-centered communication between the pediatric team, children and their responsible adults; remember that what is said - and how it is said - will have a decisive effect on family well-being; avoid paternalism to cultivate a relationship of trust between healthcare personnel, patients and family members. A fundamental aspect when speaking with minors is that the doctor knows the process of cognitive and emotional development, especially that related to the acquisition of the notions of illness and death and the change in the minor's central needs (Martino-Alba & Del Rincón -Fernández, 2012).

The doctor-patient relationship is based on the minimum bioethical principles of Non-maleficence and Justice, as well as the maximums of Beneficence and Autonomy; This relationship, asymmetrical by nature, requires from the healthcare provider the cultivation of multiple virtues and full respect for the intrinsic dignity of patients as human beings (Gracia, 1998). The ethical imperative to reveal the truth to patients, relatively recent in Western medicine, is based on the one hand on respect for their autonomy and rights, and on the other on universal values such as honesty (Nie & Walker, 2016).

METHODOLOGY

It was a qualitative and epistemologically subjective study, which was carried out through semi-structured interviews, in the HPAS of the Ministry of Health, in Quito. The interviews were applied, after obtaining Informed Consent, virtually or in person to 13 treating physicians from the Pediatric Service; were recorded on audio recording and transcribed for analysis. The SPIKES Protocol (Baile et al., 2000) was used as a model of excellence in medical communication of bad news. The qualitative analysis was manual and supported by the ATLAS.ti program.

RESULTS

A total of 13 treating pediatric physicians were interviewed, 11 women (84.6%) and 2 (15.3%), men, with an average age of 47 years (33-68). 4 (30%) worked in Neonatology-NICU, 6 (46%) in Pediatric Emergencies, and 3 (23%) in Hospitalization-Outpatient Consultation. 61.5% did not receive any academic training on the subject.

The items with the greatest adherence to the SPIKES protocol were the adjustment of communication to the cultural level and the reactions of the interlocutor, and those with the least observance were designing a joint action plan with family members, avoiding interruptions and identifying the cause of the emotions. of the interlocutor.

A total of 84.4% of pediatric doctors reported that they communicate directly with their minor patients. Her main strategies were: explaining clearly, respecting the child, finding out what she knows and expects, empowering the adolescent, answering her questions, and applying ludo and art therapy. The participants identified situations that involve bioethical principles in the adequate communication of bad medical news: Autonomy underlies the mention of the obligation to respect the decisions of mature minors and their parents even in extreme situations, of the right that supports confidentiality and privacy of the patient and his family, and tolerance due to religious or cultural beliefs foreign to official medical thought; However, none of the pediatricians formulated the action plan in consensus with the family and/or the patient. Beneficence and Non-maleficence are expressed through communication, which must modulate the emotions of patients and doctors through compassion and empathy.

The basic objective of the doctors was for the interlocutor to understand the diagnosis and to produce acceptance, and if possible, continence; When faced with an emotional

outburst from the patient or his or her loved ones, they would wait for it to go away on its own, since the doctor does not know how to act in that situation.

The interviewees highlighted that medical communication must be adapted to the circumstances, the interlocutor (their age, culture, mood, desire or refusal to know everything about their diagnosis and prognosis) and the specific moment, and they emphasized that communication barriers must identify and overcome, and avoid common mistakes such as disguising the truth, providing incomplete information assuming that patients or families will not understand it, and above all using technical medical language when addressing laymen in the field, which reinforces the supremacy of the physician. in a social context still very attached to medical paternalism.

During the very serious agony of the child, some professionals stressed the importance of giving the family the opportunity to say goodbye to the child, which will allow them to cope better with grief, and of relaxing the rigid hospital structure to include longer visits, recreational and educational activities, therapies. unconventional and fulfillment of "last wishes" for minor patients. All emergency room caregivers agreed that the death of infants that occurred at home, generally due to aspiration, was one of the most difficult circumstances to face, both because of the shock and the intense emotional response of family members and because of the impossibility of doing something. more than confirming the death.

DISCUSSION

The interviewees agreed in pointing out the communication of bad medical news as an especially arduous task of medical action (García Díaz, 2006) (Vellutini Setubal et al., 2017), but their university training did not include this topic (Downar, 2017). (Geeta & Krishnakumar, 2017); (García-Reyes et al., 2008); (Arteaga-Rosero, 2014).

The external circumstances that hinder optimal communication were the same as in other developing nations: high number of patients assigned per doctor; illiteracy or minimal educational level of users; prejudices and distrust in the health system and deep-rooted beliefs outside the scientific-medical paradigm. Local doctors also emphasized the lack of a space with minimal amenities to hold a private interview with family members, a factor related to the age of the hospital's infrastructure, the overdemand for services and the inadequate architectural planning of the pavilions.

The peculiarities of the dialogue with patients or relatives in Pediatric Emergencies included that the bad news must be given to people with whom there was no contact before, the diagnoses and medical actions must be summarized in a concise but not hasty manner, absolve all doubts and in case of unfortunate epilogues (death, amputations, serious consequences...) the expression of regret must be allowed, all in the midst of the chaos that is usually the tone of the emergency. Those who work in Neonatology emphasized the mix of emotions, joy and concern, that the newborn and its disorder arouse in the family, and added that to the paternal mourning for the illness or real condition of the child is added the loss of the ideal image that had on it during pregnancy, in addition to the maternal tendency to blame herself for the problem. The pediatricians dedicated to the Outpatient Clinic highlighted the difficulty of

adolescents in accepting a diagnosis of chronic disorders that require continuous treatments and become reasons for conflict with their parents, alleviated by mediation by the doctor and by the progressive empowerment of the young person themselves. Communicating bad news to sick children and adolescents was recognized as very difficult by the pediatricians interviewed in this trial; Some of the doctors had developed their own techniques for these circumstances: two-way communication, taking care of expression, using games and drawings, and conferring some decision-making power on the minor according to his or her development.

In the Ecuadorian context, where medical paternalism still prevails, the autonomy of the pediatric patient -subrogated to their responsible adult- still has little significance in decision-making. In this study, doctors only occasionally involved parents in defining the therapeutic plan.

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