PSYCHOLOGICAL AND ETHICAL ASPECTS OF THE PRESENCE OF FAMILY MEMBERS DURING CARDIAC RESUSCITATION IN CHILDREN

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ABSTRACT

The presence of family members during medical investigations has given rise to intense debates. These disputes had at their center ethical, psychological and political issues. The authors approach, from a theoretical perspective, aspects related to the presence of family during medical interventions in children with cardiac problems, especially during cardiac resuscitation procedures. This field has accumulated the pros and cons generated by health policies in various countries, the level of collaboration of the family, the special training of doctors and of the whole cardiac resuscitation team, the participation of the family in work protocols and the creation of conditions for conducting cardiac resuscitation in this manner.

Keywords: child, cardiac deficiencies, malformations, cardiac resuscitation, family, psychological distress, therapy

INTRODUCTION

The presence of family members during medical investigations is a topic which has been intensely debated and which has given rise to opinions for and against it. The latter referred to the state of public opinion, patients, their families, as well as medical staff and researchers. The research directions of this problematics have tackled ethical aspects (related to patient autonomy, the patient's right to have his entire biopsychomedical context built in order to regain his health, the right of the family to get involved in the patient's recovery), psychological aspects (decreasing the patient's level of psychophysical distress through the presence of someone close or of the family, by the adequate understanding of the situation), as well as political aspects (reducing litigious problems by eliminating the family's doubt regarding the efforts of the medical staff or decisions made in difficult situations).

In pediatric hospitals, including family members in the multidisciplinary team caring for the child has gained ground in many countries and has become a quality marker for services rendered to children especially in emergency units (1). Creating spaces specifically for parents, setting up rooms for them to rest and accepting them during medical maneuvers like cardiac resuscitation (CR) have been criteria imposed by health policy-makers around the world.

It should be noted that not all European countries are in favor of the presence of parents or family members during CR procedures. Among the main causes we mention the hyper-protective model or the cultural or religious context. Some countries encourage the integration of cultural or religious aspects, including the spiritual counseling of patients and their families, as well as respect for customs throughout critical moments (prayer, incantations, verses or rituals). Thus, the integration of the critical moment in the flow of events of the family is facilitated along with overcoming the time of death with fewer psycho-emotional consequences. Beliefs regarding difficult moments and death have strong cultural influences and they can haunt the witness to the critical event throughout his entire life. For this reason, integrating family members during CR procedures must be the result

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of a good situation management process, where the hospital protocol, the fears of the medical staff and the wishes of family members and of the patient should blend in harmony, to everyone's benefit.

The presence of family during CR – the pros and cons

The perspective of health policies

The participation of family members in CR maneuvers has been proposed since 1987, being a relatively new concept in patient care. In 2010, the *American Heart Association* turned the proposal into a recommendation for the presence of family members during CR, but without enough statistical evidence of the benefits or negative consequences of this step (2).

A common position on the participation of family members in patients' cardiac resuscitation has been jointly drafted and ratified by the *European federation of Critical Care Nursing associations* (EfCCNa, ratified on 28 April 2007), the *European Society of Paediatric and Neonatal Intensive Care* (ESPNIC, ratified on 10 February 2007) and the *European Society of Cardiology Council on Cardiovascular Nursing and Allied Professions* (CCNAP, on 16 June 2007) and published in the European Journal of Cardiovascular Nursing (3).

In 2012, the *American Academy of Pediatrics* gave a new direction to medical services for children, recommending the movement towards patient-centered and family-centered care. This directive, proposed as health policy, brings to the fore the positive consequences of childcare in these circumstances. The focus is on the importance of involving family members, the child and the young adult in the decision-making process regarding the patient's and family's quality of life and biopsychosocial well-being. The proposed recommendations are specifically for pediatricians to integrate patient-centered and family-centered therapy in medical practice within hospitals, clinics and community care centers (4). The AAP recommendations refer to accepting parents as partners in patient care, regardless of race, ethnicity, culture or socioeconomic situation. The AAP recommends providing formal and informal support to family members, within an ethical and legal framework.

The studies conducted in pediatric hospitals in the USA have proved that openness towards a family-centered and patient-centered care system has brought financial benefits to hospitals. Parents' participation in their children's hospitalization and treatment has led to increased satisfaction for parents, a decreased number of hospitalization days for children and lower frequency of appeals to emergency services (5). The associated hospitalization costs and the decrease in litigious events have resulted in decreased investments in these directions and investments, instead, for the benefit of the patients and their families (treatments, residential spaces for accompanying parents, medical services etc.).

The patient's perspective

Care for the patient, both at the hospital and at home, as well as the emergency intervention when it comes to critical situations, represent a process with a considerable psychoemotional charge, throughout which the patient, especially the pediatric patient, needs support from the loved ones. The level of physical and mental distress caused by the event in itself can be mitigated by the presence of relatives. The family is a unique source of information on the small patient's personality, behavior, expectations, beliefs and picture of the disease for the medical staff.

Although the decisions belong to the doctor, they are made in agreement with the family and communicated to the patient in a way that makes them understood and assimilated as correctly as possible. Compliance also depends on the way the parents participate, as information offered by them regarding the child's psychological profile and behavior is an important factor for establishing intervention strategies.

Previous restrictions regarding family members' access inside clinics have caused the child's separation from the family environment (parents, siblings, other relatives) and from school to be an important factor of an increased level of distress, especially in emergency intervention clinics. Here, the quick succession of events gives the family the impression that it is not keeping pace with the stages of the interventions, that the patient lacks an environment close to his usual one (6). But the patient and the family must understand that some restrictions are determined by the interest in the patient's post-intervention health, in that he must be protected against additional factors of physical and mental distress, such as infections, the emotional state of visiting relatives etc. The positive effect of family support has been proved by numerous studies.

The medical staff's moments of reluctance must be justified (presented and explained) to the family. Presenting the patient's situation step by step will determine expectations consistent with the following stages and parent participation ensures the patient's higher level of trust, diminishing his

angst and suspicion. The patient will not be regarded as an object, but as a person who is dependent on and integrated in the family.

From a psychological point of view, Bowlby's Attachment Theory (7) may explain the reasons why it was necessary to impose this change. Studies conducted on hospitalized children have shown that the effects of a separation from the family deepen suffering, reflecting negatively on their ability to recover. Psychologists claim that the presence of parents (especially of the mother or the carer) ensures the psychoemotional balance of the child, which is an important factor of quality of life and the recovery process.

The child's perception of his own family is profoundly connected to cultural, ethnic and religious issues. For these reasons, the presence of the family near the child or teenager must be carried out with great skill and openness, because the parent represents a binding factor between the patient and the medical team (8). But the achievement of this objective can be strongly influenced by the beliefs of the family. For instance, Bowmen and Zinger have emphasized that the members of the Chinese community in Toronto rejected the directive in advance, arguing that: "negative outcomes can result from negative thoughts" (9).

The perspective of family members

A number of studies conducted by Jabre et al. have focused on benefits on the state of psychological well-being in relatives who witnessed CR maneuvers. The studies assessed the short-term and long-term positive effects on the psychological state of family members and the level of post-traumatic stress associated to the critical event they participated in (10). The results presented by the 2014 research highlight the positive consequences of assisting a family member during CR on the experience of mourning subsequent to the patient's death. The usual state following an event with a major impact on the person (death, traumatic event etc.) is not considered a mental disorder. Unlike it, the state of pathological mourning (complicated or traumatic) appears in the manual for the classification of mental disorders and represents the premise for the development of psychological disorders – traumatic stress and separation stress (11). The results of research have emphasized the fact that the participation of family members in CR diminishes long-term negative psychological effects, decreasing the level of depression, anxiety and post-traumatic stress and making relatives get over the unhappy event with fewer psychoemotional consequences.

These results, also presented by other studies, are related to the family's wish to have an active role in the decision-making process during CR (12). Involvement creates the feeling that they have actively participated and have done everything in their power to save their child, thus adapting to their stressful situation easier and accepting its consequences. On the other hand, in certain situations, even suspicions about the resuscitation efforts beyond the closed doors of CR rooms are discarded; realistic expectations are created in correlation with the patient's state, because relatives have had the possibility to see his step-by-step development from a medical point of view. In terminal stages, the relative is given the opportunity to say goodbye and be with the patient until the end of his life, which gives family members the feeling that they have cared for and been with him until the end (10,11).

In the case of children in critical states, the family's feelings of guilt and helplessness instill a stronger wish to participate in CR, compared to relatives who assist adults. Even for simpler medical maneuvers, though the mothers' level of anxiety is high and it is suspected that this state is transmitted to children, it has been noticed that the small patients are more collaborative and exhibit lower levels of anxiety than those who are not assisted (13). Though worried about the child's state and aware of his situation, the mother finds the necessary resources and tools to lower the patient's level of distress (she knows what he likes, she uses the right method to pacify him, she encourages him, she projects future situations with a positive impact on the child, she practices methods of relaxation appropriate for him – touching, words, music etc.). Young patients' family members prefer to participate in CR maneuvers up to approximately 75%, compared to adult patients' family members, for whom the percentage of desirability is approximately 55% (14).

Psychologically, the possibility given to parents to participate in medical maneuvers in difficult situations instills in them the feeling of regaining their parental role, so affected during hospitalizations, when responsibility is taken over by medical staff. Research on the level of distress of parents whose children are ill indicates the alteration of the parental model as an important issue, as well as the idea that they cannot have control and intervene to help their children (15).

As active participants in the intervention team, parents have minor interference in procedures; in a behavioral assessment, they have all offered support to their children: 91% have talked and 73% have

caressed or kissed them (16). Participating relatives very rarely obstruct medical maneuvers. Parents' distress after participating in invasive and painful interventions on their children is lasting; it has been estimated as 6 months for the mothers of small children and up to 2 years for the mothers of newborns at risk (17).

Even if the positive effects have been emphasized by many studies, others also point out the negative aspects of witnessing medical maneuvers performed on patients in critical situations (18); the brutality of resuscitation maneuvers, the treatment of the patient as an object, nakedness, the lack of defense and response, invasive explorations and treatments, grabbing and the speed of the actions may create a situation of major psychoemotional distress in the participating relatives.

The medical staff's perspective

The percentage of doctors who agree to the participation of family members close to the patient does not go above 50% (19).

According to nurses, the presence of family members during CR maneuvers is inappropriate, due to the uneasiness they experience while being watched working (47.6%), the difficulty of focusing on their language and the terms they use throughout the intervention, because some remarks might be misinterpreted by patients' caregivers (75%). 48.4% of nurses have not agreed to the presence of a family member during their activity and 52.8% have declared that they are not professionally trained to deal with family members, to offer them psychological and emotional support (20). Other results highlight the fact that the medical staff is disturbed by the level of stress. The anxiety of the medical team working under the family's pressure, sometimes forced to continue CR maneuvers at the latter's insistence, is amplified by the fear of being accused in relation to their professionalism (21).

More recent studies remark upon the stronger adherence of medical staff to the idea that family members participate in medical maneuvers, the acceptance of psychological benefits for caregivers. Medical staff acknowledge the need for specific training to adequately face the family's behavior and difficulties caused by the presence of an emotionally involved person, who has high expectations; they need to be trained to cope with both the patient's situation and the parents' anxious behavior (22). The following behaviors are desirable and expected of nurses by the families of patients in critical situations: maintaining eye contact during communication with them, not avoiding the family when it requests additional information on the condition of the patient, answering questions about the prognosis promptly and honestly (23).

The differences regarding acceptance of the family in the child's critical moments have been explained by ethical particularities and by the health policy implemented in various countries. For example, questioning nurses in Sweden has highlighted a reluctance in accepting the family, compared to nurses in the UK. It is possible that countries with a more paternalistic care model exclude the participation of family in critical events, while countries which have adopted a holistic care behavior might be more receptive to the integration of relatives in maneuvers during intervention in crisis situations. However, without a doubt, the orientation towards family-centered care determines an approach with positive effects both on the patient and on family members.

There are differences between the various categories of medical staff regarding the level of acceptance of the presence of the family in critical situations like CR. Doctors, nurses, critical care techs or priests in hospitals are less disturbed by the presence of the family than technicians who manipulate patients' medical devices, security personnel, pharmacists or resuscitation personnel (24).

In order to effectively integrate family members during medical maneuvers, medical staff must be trained regarding: the way to approach the family, their assistance throughout critical moments, the use of communication skills, providing information about maneuvers and the prognosis, as well as counseling relatives in case of an unfortunate ending.

The perspective of hospital managers

Many of the emergency intervention departments within university hospitals in the USA and Western Europe feature protocols and specialized staff to integrate patients' relatives who are present during CR. A few studies have identified that the family's degree of satisfaction also depends on the permissiveness of the hospital, the additional conditions created to facilitate visits, arrangements for meetings destined for family members, the training of secondary personnel to communicate with the family and the adoption of a family-centered care model for patients in critical states (25). Medical staff, although open to allowing the family to be present during medical maneuvers, remain reluctant, which makes the management of the medical unit avoid the imposition of measures.

Research focused on the opinion of medical institution management has found that respondents are aware of the fact that family members can emotionally tolerate CR situations (59%), they do not interfere with care maneuvers and the medical team is not affected by the presence of the family (88%). In addition, the family facilitator, who is specially trained to communicate with the family and provide counseling in CR situations, is usually a nurse who participates in all special cases (70%) (26).

Imposing protocols to guide the family's integration and participation in the decision-making process has been the result of identifying the positive consequences for hospital management: the increased satisfaction of relatives with the services provided, the lower number of conflicts between family and medical staff, the decreased number of unrealistic expectations of relatives, the improved relationship between medical staff and family members and the decreased number of litigations. Moreover, the presence of family helps parents understand and accept the medical condition of their children easier (27).

CONCLUSIONS

Patient-centered and family-centered care throughout treatment, hospitalizations, medical interventions or critical situations is increasingly widespread and implemented in hospitals, clinics and care centers. Intervention protocols and the training of medical staff to effectively communicate with family members guide the assimilation of relatives into the intervention team and make it possible for them to actively participate in and sometimes decide on the care of the patient. The acceptance of family members during medical maneuvers brings benefits in what concerns the subsequent development of psychological problems like post-traumatic stress, depression or anxiety. The readiness of medical staff to accept relatives during CR depends on the common intervention model in that country and it is influenced by various factors, such as culture, the professional training of support people or health policies. Nonetheless, family participation during medical maneuvers remains a recommendation, not an obligation.

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