

# COMMUNICATING WITH PARENTS OF AN ILL CHILD – A CONTINUOUS CHALLENGE FOR A MODERN PEDIATRIC NURSE

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## ABSTRACT

Interpersonal communication is the basis of activities undertaken by the nurse on behalf of the patient. Communication by the nurse while caring for the hospitalized child is continuously becoming more important. The pediatric nurse gains data necessary for planning and performing nursing care chiefly from the parents of the ill child. Bilateral, appropriate communication between the nurse and the parents of the pediatric patient helps both the parents and the child to get adjusted to the disease and to combat it. The continuous presence of the parents at the bedside of the child-patient is necessary, but at the same time presents the contemporary pediatric nurse with new challenges. The objective of the paper is drawing attention to the role that is fulfilled by the parent-nurse communication in the therapeutic process and to the associated challenges faced by the contemporary pediatric nurse.

The paper reviews medical literature addressing the effect of the parental presence with the child in a pediatric ward. The analysis has been performed of the expectations of the parents of the hospitalized children with respect to the medical staff, as well as of the benefits and difficulties associated with the constant presence of the parents in the ward as evaluated by the pediatric nurses.

Constant parental presence in pediatric hospitals seems to continue to be a novelty that is not fully accepted by the nurses. Nevertheless, a change in forming the collaboration between the parents and medical staff of pediatric wards becomes visible. Of significance is the participation of the parents in nursing and diagnostic procedures that would be adjusted to their expectations and abilities. One may note that the process of including the parents in active participation in the care of their child evolves in the right direction; nevertheless, both the parents and the staff need to learn various forms of collaboration. There is a need of improving interpersonal communication in the parents-nurse relationship, since respectfulness and personal culture in their mutual relations leave much to be desired. The prerequisite of developing the appropriate parents-nurse relation is continuous education of the nursing staff and the entire medical personnel, formulation of clear and unambiguous rules governing the parental presence in the hospital, developing appropriate standards of care that would take into consideration the role of the parent in the therapeutic team, as well as preparing appropriate hospital infrastructure.

**Key words:** parents, child, pediatric nurse.

## INTRODUCTION

Hospitalization is a strenuous experience for a child as it is associated with a considerable physical and mental burden. The necessity to stay in hospital requires the child to adapt to a new environment that – contrary to the domestic setting – is unnatural and strange. In view of the immature psyche, the child cannot cope with new, difficult situations and use effective adaptative mechanisms. The child is not self-reliant, rather he is helpless, dependent on adults. He requires his basic needs to be met, such

as the emotional relationship with his parents, love, a sense of safety, cognitive and motor activity, playing and learning [1, 2]. It is the duty of the nurses who are the closest to the patient to fulfil the psychosocial needs of the children hospitalized in pediatric wards; however, only the constant presence of the mother or father does provide the child with true mental comfort and a sense of safety. Allowing the child for maintaining a constant contact with the parents – in keeping with the provisions of the Chart of the Rights of the Child-Patient – is necessary to make the stay in hospital an event that leaves as few unpleasant

memories as possible. Proper communication between the nursing staff and the patient and his family favors effective therapy and meeting the natural developmental needs of the child.

### **THE ILL CHILD – THE SPECIAL ROLE OF THE NURSE**

Interpersonal communication is the foundation of activities undertaken by the nurse on behalf of the patient. Communication of the nurse caring for the hospitalized child is particularly significant, since it refers to proper interpersonal communication between the nurse and the hospitalized patient, as well as with his parents [3]. The necessity of the child to be hospitalized is associated with the need for professional nursing care, the important element of which is introducing the child to the role of the patient, minimizing his anxiety and fear and entering into and maintaining a contact with his parents [4]. The approach to the ill child, the ability to communicate with him require the pediatric nurse to have not only extensive medical knowledge, but also special personality traits. The child goes through various stages of development and his reaction to the disease and hospitalization differs at each stage. Proper communication between the medical staff and the patient is a factor that shapes his positive attitude towards the therapeutic process. One of the more important steps in nursing care is winning the trust of the ill child; he very promptly senses whether the staff has taken a liking to him and understands his problems. It is important for the child to be treated by the medical staff with full respect for his dignity and privacy. Numerous authors emphasize the high significance of such personality traits of the pediatric nurse as calmness, friendliness, kindness, amenity, understanding or even a sense of humor [1, 5]. While talking with the child, the nurse should use a simple, easy to understand language. The patient should have an opportunity to ask questions related to his stay in hospital and diagnostic and therapeutic procedures. The level of information conveyed to the child must, however, be adjusted to his age, mental abilities and present needs [2]. Based on the obtained information, the child forms the picture of his disease. A sufficient amount of necessary information pertaining to the character, symptoms and effects of the disease and the desired modes of behavior exerts a motivational effect upon the active participation of the child in the therapeutic process. The nurse may help the child prepare for surgery and other procedures, telling him in an easily understandable manner what is going to happen. Fear of the unknown may be also considerably alleviated by getting the child acquainted with medical equipment. It allows for a better understanding of the conveyed information; the child begins to experience a sense of being treated with respect and sympathy. It is un-

ceptable to scare the child with medical procedures, make him ashamed, humiliate him or address him with malicious remarks. The child may not be promised he will feel no pain if the statement is not true. Informing the child in an incompetent way about his disease or the future medical procedures, concentrating solely on problems associated with the disease, disregarding the patient's mental anguish or his sensitivity represent well-known factors that adversely affect the healing and recovery processes. Effective interpersonal communication between the nurse and the child is a highly important tool providing the patient with the knowledge regarding the state of his health and the employed therapy and thus increasing the chance of the child's confirming to the plan of treatment [6, 7]. It is necessary to maintain the balance between providing the child with information and careful listening to what his answers are and how he responds, as well as to carefully observe his reactions.

### **CO-PARTICIPATION OF THE PARENTS OF THE ILL CHILD IN TREATMENT**

A significant element building the quality of nursing care is the ability to cooperate with the parents in hospital care of their children. Changes in the health care environment have resulted in the nurses being confronted with numerous challenges, including meeting the care-associated expectations and involving the parents in the therapeutic process. An inseparable element of hospitalizing the child is the constant presence of his parents at the bedside. The patient has every right to have them present in hospital as per the provisions of the Chart of the Rights of the Child-Patient. Parental presence is necessary to minimize negative experiences of the child that are associated with his stay in hospital. It should be remembered that the child's reaction to separation from his mother depends on the developmental stage. Children up to 3 months of life react to a change in their environment exhibiting changes in the rhythm of sleep, appetite urination and defecation. When 4-6 months old, the child reacts to sudden disorientation with violent crying, the 7-18-month-old child treats every instance of his mother walking away as a loss: anything the child cannot see does not exist. The most difficult situation is that of the child hospitalized when 1.5 to 4 years old. In this period, the child's attachment to his mother is very strong and his trust absolute. Children above 4 years of age are susceptible to persuasion and capable of waiting for their mothers returning. Older children are more independent of their parents. In this group, reactions to hospitalization are usually manifested by moodiness and at times aggressive behavior [2]. For many years, hospitalization of the child used to be associated with separation from the parents and entrusting the care

of the young patient to the nurses and physicians. Strong, negative emotions associated with the disease and separation from the dearest family members did not positively affect the process of recovery. Regardless of age, the child experienced fear of pain and suffering, insecurity and isolation. Any hospital was associated with facilities in dull, monotonous colors, anonymity, scenes of diseases and suffering. Starting from the nineties of the 20th century, the parents of the ill children have been given a chance of caring for their offspring and the 24-hour presence in hospital as per the provisions of the Chart of the Rights of the Child-Patient. In the course of hospitalization, the children are provided with the best condition for regaining health and for playing, learning and recreation, while the duration of hospital stay is reduced to a necessary minimum. Since the afore-mentioned time, there has occurred a considerable development of pediatric nursing and employment of new solutions in nursing care that would match the expectations of the children and their parents [4]. Active participation of the parents in the therapeutic process is necessary and provides a source of knowledge of the patient, his habits, ways of signaling his needs, disliked foods, etc. However, what is the most important is the fact that the parents involved in caring for their child considerably neutralize their child's negative experiences. During their entire stay in hospital, the parents should be informed in a clear and understandable manner about the performed procedures. An appropriate exchange of information between the parents and the nurse and guiding the parental behavior effected by the nurse may exert a direct consequence on the emotions of both the child and his parents. The parents are often exhausted and in despair, demonstrate anger, helplessness or even aggression. The manner in which the nurse behaves in such a situation is an issue involving sensitivity, composure and understanding [8]. Building a good "nurse-parents" interpersonal relationship is among the most difficult challenges that are faced by the contemporary pediatric nurses. The parents want to actively participate in the process of treating their children, they have become members of the therapeutic staff, yet it seems that both the parents and the staffers have not been sufficiently prepared for this process. Twenty-four-hour presence of the parents in pediatric hospitals is an obvious fact, nevertheless, it still appears to be a novelty that is not fully accepted by the staff. On the other hand, one can observe efforts on behalf of introducing changes in building the cooperation between the parents and staff of pediatric wards.

Studies on communication between the pediatric nurse and the parents of the ill child are scarce, but the subject is addressed increasingly more often as it is both difficult and interesting. As it undeniably follows from the available studies carried out among

nurses, one can list numerous advantages and also multiple problems associated with the constant presence of the parents at the bedside of the hospitalized ill child. According to Łukasik *et al.* [9], the positive factors include openness of the medical staff towards the parents and parental adherence to hospital regulations governing their stay at the bedside. The negative factors are associated with lack of space in pediatric wards and lack of understanding between the staff and the parents of the hospitalized children. Undoubtedly, the 24-hour-long presence of the parent at the bedside is important, especially in case of hospitalizing newborns, children up to 4 years of age and chronic and terminal pediatric patients. Studies carried out among nurses by Marć [3] demonstrate that only 25% of the investigated nurses always enter into a contact with the parents, more than 45% does it often and more than 28% from time to time. For the majority of the nurses, the most important objective of entering into a contact with the parents is obtaining detailed information on the health status of the patient, almost 75% of the nurses establish an interpersonal contact with the parents to clear their doubts and answer questions associated with hospitalization, and more than one half of nursing staff want to raise parental spirits. In the opinion of the majority of the studied nurses, the principal subject of the conversations is broadly understood nursing care, followed by exchange of information on the current health status of the child and subsequently by getting to know the ways to spend parental leisure, organization of care for the patient and the parents in the ward, parental fears and expectations and the topography of the ward. Łukasik *et al.* [10] indicate the need of improving interpersonal communication in the "parents-medical staff" relations since respect and personal culture in mutual contacts leave a lot to be desired. Of significance is also making it possible for the parents to participate in care procedures and diagnostic tests. Yet the participation should be adjusted to the expectations and abilities of the care-givers. The parents in hospital constitute a versatile group of individuals with various levels of general and medical knowledge, discipline, personal culture, nutritional and personal hygiene-associated habits. They want to be useful in hospital but they do not know what, how and where they can do. They expect an interest and assistance from the nurses. They want to feel that no member of the medical staff shrugs off their comments on disturbing symptoms of the disease and the needs of their child, they expect the certainty that all the procedures are performed for the good of their child, even if they are unpleasant and painful.

The literature emphasizes the importance of care that is concentrated on the family (Family Centered Care – FCC) as the basic concept within the "medical staff-pediatric patient" relation, although it may

be difficult to introduce and maintain [11–14]. Family centered care is the basic principle of caring for the child; it requires the process of negotiations between the health care staff members and the parents, what in consequence results in collaborative decision making with respect to the care of the child. The principles and philosophy underlying FCC should be employed as the "best practice" in pediatric hospitals in developed countries. Such an assumption has originated from the recognition that the emotional needs of the hospitalized children were in the majority of cases not met, there were parents not involved in direct care of their children, the children themselves were unprepared for hospital procedures, while visiting pediatric patients in hospitals was controlled. The patient is best understood in the context of his family, culture and values. The knowledge of society-related determinants allows for planning the best health care, safety and satisfaction of the patient [15]. Meisenhelder and Gibson [11] in their study performed in the Children's Hospital of Philadelphia (CHOP) demonstrate in what ways partnership is cultivated in improving patient care, the said partnership being an important element in improving caring for the patients, leading to increasing satisfaction levels in all the participants in the process and being a source of positive experiences. The authors show that the implemented and continuously updated behavioral model KIDS CARE is helpful in building cooperation between the staff and the child and his family, provides guidelines allowing for developing respectful partnership with the patients and their families. Family centered care (FCC) is also recognized to be fundamental in case of supporting the parents of neonates and premature newborns [16, 17]. As it follows from studies carried out in Denmark, where standard care and family centered care were compared, GFCC (Guided Family Centered Care) is the model that provides a systematized structure of the afore-mentioned communication between the nurses and the parents of premature babies. Guided activities of the nurses and parents are to minimize parental stress and encourage objectification of care through building a dialogue. A good cooperation between the parents and the nurse is believed to be the most important factor in shaping parental positive experiences in the Neonatal Intensive Care Unit (NICU). Family centered care promotes recognizing and expressing emotions that allow for reaching a deeper level of communication and also slowly builds mutual understanding between the nurses and the parents. The studies carried out by Weis *et al.* [18] demonstrate GFCC to be a model supporting the communication between the nurses and parents in the neonatal intensive care unit. This kind of intervention increases the sensitivity of the staff members and the nurses are prepared to lead the parents through their difficult personal experiences associated with caring

for the premature infant. Neonatal care is based on a participative approach to all activities in order to introduce the changes into practice, but it also requires advanced professional training of the nurses, an appropriate model of employment, providing the parents with tools allowing for constantly caring for their children and recognition of parental abilities in caring for the newborn. Family centered care is individualized and it takes into consideration the effect of physical and cultural environment. Initially, the model was underestimated, but training courses for nurses have been upgraded and have resulted in a noticeable interventive progress [17–20]. As it is demonstrated by the studies, the Western concepts of family centered care are also accepted by pediatric nurses from Arab or African countries [21, 22]. Nevertheless, full acceptance of family centered care following and based on the Western values will most likely be unsuccessful. The Western model requires cultural modification and further development of the nursing staff. As it follows from the review of the literature on the subject [23], there are discrepancies between the parental expectations and the degree to which the nurses are willing to allow the parents to participate in the care of their children. The parents want to be involved in the care of their children, but they are confronted with lack of communication with the nurses and the fact that parental activities are limited. It appears that the nurses have a highly clear idea of the activities in which the parents may be involved and do not negotiate with the care-givers in this matter. For family centered care to become real, the nurses have to effectively communicate with the children and their families. The parents need to have a chance for negotiating with the medical staff matters pertaining to their involvement in the new roles and the decision process in the care of their children. Although the importance of the model of family centered care is well grounded, the nurses are of the opinion that employing all its aspects in daily practice is not important [23, 24].

While we emphasize the significance of good interpersonal communication, we cannot disregard the parental expectations in this area. Bednarek *et al.* [25] demonstrate that the parents expect the nursing staff to provide various forms of care – in the first place they put care directed at implementation of therapeutic tasks, followed by protective and educational aspects. More than one-half of the parents who completed the questionnaire report that they expect informational support and – to a slightly lower degree – emotional support. The parents expect to gain a sense of safety and to hold conversations addressing alarming health- and care-related symptoms and signs. Almost  $\frac{3}{4}$  of the questioned subjects are of the opinion that the nursing staff prepares the parents predominantly for performing activities associated

with feeding and administration of supplementary foods. As it follows from the studies carried out by Marć [2], the parents most often expect the nurse to offer assistance in caring for their children. The parents enter into a contact with the nurse to be provided with detailed information on the child's health, they expect explanations addressing all their doubts associated with the therapeutic and nursing process as well as formal issues emerging during hospitalization. Studies confirm [26] that the parents receive from the nurses predominantly instrumental, evaluative and informational support, with emotional support being offered only at times [26]. Waksmańska *et al.* [27] asked the parents about their expectations addressing the traits that should be possessed by the pediatric nurse. The parents indicate such traits as professional knowledge, kindness, patience, gentility, good verbal communication skills, determination, manual dexterity, ability to work as a part of a team and empathy. In the opinion of the parents, the most strongly anticipated behavior of the nurse is her involvement and her ability to answer any question in a satisfactory and comprehensive manner. Almost 95% of the studied parents emphasize such traits of the nurse as attentiveness and competences [25].

The parents see the advantages of their staying at the bedside of their child in hospital. When asked about this issue as an element of the studies performed in a pediatric hospital by Łukasik *et al.* [9], they list active participation in the therapeutic and nursing care processes, a close contact with the medical staff, acquisition of a part of caring procedures, a higher degree of cooperation of the child with the medical staff, organization of the leisure time of the child in hospital, an increasing sense of safety of the child, easier establishment of contacts with the child by the medical staff. Nevertheless, in the opinions of the parents, their interactions with the nurses do not constitute a cooperation-based relationship. The in-depth knowledge of such interactions will allow for promoting and introducing the philosophy of life that is based on complete cooperation in the name of the good of the patient [27].

## SUMMARY

In the last years, we have been observing changes occurring in pediatric hospitals in Poland. Along with such changes, the demands addressed to the staff employed in pediatric wards are changing. The above presented data confirm that the demands addressing the nurses have been considerably increased with respect to their ability to communicate with the ill child and his care-givers. This is a relatively new issue. On the one hand, it has resulted from the development of the knowledge on the psychological needs of the child, whereas on the other – from a higher aware-

ness of the parents of their right to fully participate in the therapeutic process of their child.

In the literature on the subject, the opinion predominates that the participation of the parents in the therapeutic process involving their child in hospital is an advantageous phenomenon. The nurses see the positive role of the parental presence in hospital, especially when hospitalization of the youngest children, chronic and terminal patients is concerned. The “nurse-parents of the ill child” relation is not simple, as from the parental side, it is to a great measure based on emotions. The parental demands addressing the nurses are exorbitant, what very often breeds conflicts and is a source of stress both for the parents and the staff. Nevertheless, as it follows from all the publications, there is no turning back from parental participation in the therapeutic process involving their child. Thus, the communication between the pediatric nurse, the ill child and his parents is currently a great challenge, the more so that there are no ideal solutions in building the “nurse-parents of the ill child” relation. However, as it can be seen, the process of including the parents in active participation in the care of their children evolves in the right direction. Nevertheless, both the parents and the staff need to learn various forms of cooperation. In this process, proper information on the principles of such cooperation must necessarily be provided by the nurses, while the parents must demonstrate openness and readiness to listen. The nurses must realize that the parents are an important element of good quality care of their children. On the other hand, the parents should know that they can obtain every kind of assistance from the nurse. Bilateral, good communication of the nurse with the parents of the pediatric patient helps both the child and his parents in adjusting to the disease and combating it.

## CONCLUSIONS

1. Pediatric hospitals in developed countries employ family centered care as the “best practice”.
2. Building the program of caring for the hospitalized child with the family as the strong basis of the therapeutic team should be commenced in Polish pediatric wards.
3. It is necessary to provide continuous education of the nursing and the entire medical staff in the field of interpersonal communication aiming at cooperation with the family in the therapeutic process.
4. Standards of care of the ill child should be developed, the said standards taking into consideration the role of the parents in the therapeutic team.
5. Clear and unambiguous rules governing the parents staying with their child in hospital should be developed.
6. It is necessary to prepare optimal hospital infrastructure to meet the needs of family centered care.

## Disclosure

The author declares no conflict of interest.

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