FAMILY-CENTRED CARE IN A PAEDIATRIC HOSPITAL AS SEEN FROM THE PERSPECTIVE OF A NURSE AND A PARENT

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A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

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ABSTRACT

Introduction: The study evaluated the involvement of parents in the care of hospitalized children from the perspective of nurses and parents.

Material and methods: The research was based on an original questionnaire conducted with 289 nurses and 271 parents of hospitalized children.

Results: Hospital regulations are available for the parents according to 95.2% of the nurses and 76.7% of the parents. The older the hospitalized child, the more significant observing the hospital regulations was to the parents ($p < 0.02$). Also, complying with the epidemiological principles was dependent upon the age of the child ($p < 0.0001$). In total, 97.4% of the parents and 95.2% of the nurses, regardless of education level, specialization, or duration of employment, described the presence of the parents with their children in the hospital as necessary, and 46.4% of the nurses and 70.8% of the parents reported the presence of the parents at night as important. The necessity for a 24-hour stay with their child was greatest for parents with primary education, and the least was for university-educated parents ($p < 0.02$). The nurses reported that the constant presence of the parents seldom reduced their responsibilities. The nurses with specialization more often reported an increased workload as compared to non-specialized nurses ($p < 0.02$). Also, the assessment of the parent's involvement in caregiving activities was dependent on the nurses' specialization ($p < 0.02$) and length of employment ($p < 0.05$). Declared readiness to perform care-associated activities involving their child increased with the increasing age of the parent ($p < 0.05$) and was also dependent on the profile of the ward ($p < 0.005$).

Conclusions: According to nurses' and parents' opinions, the presence of the parents with their child in hospital during the day is necessary, but not always during the night. Despite the engagement of the parents in care-associated activities, their presence causes an increased workload for the nurses.

Key words: paediatric nurse, parents of hospitalized child, therapeutic team, family-centred care (FCC).

INTRODUCTION

In world literature, much attention is devoted to family-centred care (FCC) [1-7]. In paediatric hospitals in developed countries FCC is considered "best practice" in caring for sick children. The needs of a sick child are best understood in the context of their family, culture, and upheld basic values, while the knowledge of the constraints of the environment allows for planning the best medical care that would provide a sense of safety and satisfaction for the patient [5, 6]. However, making joint therapeutic decision requires appropriate, trust-based communication between healthcare professionals and parents of the sick child; such communication should be based on the exchange of information and mutual respect [1, 4, 6, 7]. The idea of FCC is difficult to implement in everyday practice. Discrepancies between the nurses and parents in perceiving their roles, unwillingness of the medical staff to share with the parents potentially negative or fast-changing information, restrictive rules, the permanent presence of the parents at the bedsides, as well as insufficient understanding of the needs of the family have proven to be the key problems [1]. The idea of FCC is universally accepted by nurses, but a significant workload resulting from the shortage of well-qualified staff, not always satisfactory social conditions prepared for parents in paediatric hospitals, and a generally observed decrease of empathy levels in society lead to questions about the level of implementation of FCC in everyday practice.

Children's rights

Powerful negative emotions associated with illness and separation from family members used to

negatively affect the process of young patients regaining their health [8]. Implementation of the FCC into paediatric hospital is the best way to counteract the negative feelings of both children and their parents. Changes in the organization of health care in Poland in the 1990s have also concerned FCC. Since that time the rights of hospitalized children and their parents have been guaranteed by the Patients' Rights Act, the European Charter of Patient's Rights, and the European Charter of Children's Rights. These legal acts determined the rights of children to be visited and/or stay with the parent around the clock. The parents are a source of information about the young patient, her/his habits, eating preferences, and associated behaviours, the way of communicating her/his needs, etc. [9]. The presence of the parents by the bedside not only strongly affects the basic emotional needs of the child, helping them to cope with anxiety and stress, but also has a considerable impact on the therapeutic process.

Nurse-parent relationship in family-centred care

Building a good nurse-parent relationship is one of the most challenging tasks faced by the contemporary paediatric nurse. In a hospital where FCC has been introduced, the relationship between medical staff, especially nurses, and the parents of hospitalized children is not always simple. First of all, no clear tasks of paediatric nurses regarding their role in patient care that would take into account the age-dependent individualized needs of a sick child, as well as the needs of parents staying with their child, have been defined [10-12]. Second, both nurses and parents frequently do not have a good level of communication. Appropriate exchange of information between the parents and medical staff together with a skilful guidance of parental behaviour exercised mainly by nurses may positively affect both the emotions of the child and the parental emotions [13].

Parents' expectations

Hospitalization of child is always associated with a fear and anxiety among the family members. Very often it triggers an inappropriate attitude of distrust towards medical staff (doctors, nurses, etc.) [14]. They expect the nurse to manifest knowledge, competence, manual skills, quick reaction to the needs of the child and the parents themselves, as well as kindness, compassion, understanding, emotional- and information-related support, and good communication skills [15-20]. The parents are of the opinion that their duties include staying with their children in hospital and providing basic care, i.e. feeding, changing diapers, bathing, and providing young patients with clean clothing. Unfortunately, sometimes parents react badly and negatively to indifference, haste, or discourtesy from the nurse, but at the same time they rate well the performance of the nurses in the wards. These factors are not conducive to building a good mutual relationship between medical staff and parents.

Nurses' expectations

The paediatric nurse has to deal with excessive expectations of the parents and with the real needs of a sick, helpless child. Nurses expect the parents to stay by the bedside of their children, appropriately participate in their care, and meet their parental care-associated needs. Nurses perceive administrative and technical duties or supervision of medical equipment as a part of their duties. Rarely they do realize that one of the most essential duties of paediatric nurses is to assist parents in taking care of their children [21]. Parents are expected to be present with their children, to be engaged in proper parental care of the sick child, and to provide basic care, like feeding, changing the baby's diaper, and child care activities. However, parents, particularly those with children with special needs, frequently possess numerous concerns and doubts about carrying out caregiving duties properly. They require assurance that, in an emergency, they can rely on nursing assistance [7, 21]. Effective functioning of FCC depends on the whole therapeutic team, but as the first line it depends on the nurses and on the parents. It also depends on the hospital policies. For FCC to be truly beneficial in the care of a sick child it is necessary to continuously analyse the nurses' and parents' opinions in this field. Experiences gained in different hospitals will be helpful to establish the procedure on FCC in Polish paediatric hospitals.

The aim of the study was evaluation of the involvement of parents in the care of a hospitalized child as seen from the perspective of nurses and parents of paediatric patients.

MATERIAL AND METHODS

The study was based on original questionnaires developed by the author with separate versions for paediatric nurses and parents of hospitalized children. The *action research* strategy was employed to recognize the competence superiority of a given group of subjects to define the real problem. The research tool was validated based on the relevance and reliability coefficient. The evaluation addressed the factual relevance, face validity, and construct validity. Reliability was evaluated based on the Kappa coefficient, the value of which for the 2 afore-mentioned questionnaires was on the acceptance level, in keep-

ing with the criteria formulated by Landis and Koch [22, 23]. The study received a positive opinion from the Ethics Committee of the Jagiellonian University (approval no. 1072.6120.330.2018, dated 20 December 2018). The questionnaire-based study was carried out in the University Children's Hospital in Krakow. The questionnaires were anonymous, the participation in the study was voluntary, and no activities were performed that might have affected the results presented in the questionnaires.

The analysis included 289 questionnaires completed by the nurses (285 women, 4 men) and 271 questionnaires completed by the parents (227 women, 44 men). All the nurses were full-time employed and provided care to patients hospitalized in medical treatment or surgical wards, or in intensive care units. The parents of children hospitalized in the University Children's Hospital of Krakow had stayed with their offspring for at least 2 days and nights. The parents were informed that completing the questionnaire would not affect the care and treatment of their hospitalized children.

Almost 60% of the surveyed nurses were university graduates, and more than half of the group had a nursing specialization (paediatric, surgical, anaesthesiology). Close to 70% of the nurses had practised the profession for more than 15 years. The caregivers of the hospitalized children were mostly female (more than 80%), predominantly living in Malopolska Province, aged above 36 years, and having completed secondary or university education. More than half of the parents had previously stayed with their child in another hospital. The caregivers defined the clinical status of their child as suffering from a life-threatening (32.5%) or a terminal condition (14%). In 25.8% of the parents, the admissions of their children were elective. The characteristics of the nurses and parents participating in the study are presented in Table 1.

Analysis of questionnaire results

The responses provided by the nurses were analysed depending on the duration of their employment, education level, and specialty; each possible response was taken into consideration, as well as combined positive or negative response. The responses given by the parents were analysed depending on the parental age, gender, place of residence, and education, as well as taking into consideration such factors as the age of the child and the state of their health, the consecutive number of hospitalizations, and the profile of the ward on which the patient was hospitalized. The statistical analysis was performed taking into consideration each possible response and by combining positive responses (yes, I guess so, rarely) and negative responses (no, I guess not, never).

Table 1. Characteristics of nurses and parents participating in the study

Parameter	Nurses		Parents	
	n	%	*n*	%
Gender				
Female	284	98.3	225	83.1
Male	4	1.4	44	16.2
No response	1	0.3	2	0.7
Education				
Secondary	94	32.5	139	51.3
University	173	59.9	130	48
No response	22	7.6	2	0.7
Specialization				
Yes	164	56.7	–	–
No	119	41.2	–	–
No response	6	2.1	–	–
Years of employment				
Up to 5 years	39	13.5	–	–
5-10 years	28	9.7	–	–
11-15 years	21	7.3	–	–
More than 15 years	201	69.5	–	–
Parent age				
20-25 years	–	–	5	1.9
26-30 years	–	–	45	16.6
31-35 years	–	–	94	34.7
Above 35 years	–	–	125	46.1
No response	–	–	2	0.7
Place of residence				
Lesser Poland – city	–	–	100	36.9
Lesser Poland – village	–	–	129	47.6
Another province – city	–	–	24	8.9
Another province – village	–	–	18	6.6
Child's age category				
Newborn < 1 month	–	–	14	5.2
Infant 2-12 months	–	–	43	15.8
Children > 12 months	–	–	214	79
The child's health condition (assessed by the parent)				
Life-threatening/fatal	–	–	88	32.5
Terminal illness	–	–	38	14
Scheduled hospitalization	–	–	70	25.8
Others	–	–	56	20.7
No response	–	–	19	7
Child's hospitalization in USDK				
First	–	–	124	45.8
Next	–	–	144	53.1
No response	–	–	3	1.1

Statistical analysis

Irrespective of the surveyed group, the calculations included the percentage of answers to close-ended questions and multiple-choice questions. The close-ended questions were analysed grouping similar responses. The statistical analysis employed the chi-square test to determine the relationship between 2 nominal variables. The analysis was performed using SPSS Statistics software and contingency tables. Statistical inference was based on percentage values. A probability level of $p < 0.05$ was adopted as being statistically significant.

RESULTS

Compliance with the hospital regulation

As many as 95.2% of the nurses (more often with university education as compared to individuals with secondary schooling) declared that they always or often introduced the parent to the hospital regulation chart; this was confirmed by 76.7% of the parents, but, regardless the age, gender, place of residence, and education level, 18.5% of them found the regulations to be incomprehensible. Although 64.2% of the parents declared that observing the hospital regulation was highly important, in the opinion of the nurses, only 46% of the parents followed the hospital rules. Observing the hospital regulations was related to the child's age: the older the hospitalized child, the more significant was observation of the hospital regulations to their parents ($p < 0.02$). Also, complying with the epidemiological principles, declared by 75.3% of the parents, was dependent upon the age of the child ($p < 0.0001$). For 18.2% of parents of newborns, observing the rules defined by the hospital staff was of no importance whatsoever.

Presence of the parents with their children in hospital

In total, 95.2% of the nurses were in favour of the necessary presence of the parents with their children in hospital (responses of "absolutely yes" and "I think so" comprised 61.7% and 33.5% of the nurses, respectively). The responses were independent on the nurses' education level, specialization, or duration of employment. Also, 97.4% of the surveyed parents were of the opinion that their presence at the bedside of their hospitalized child was necessary. Contrary opinions addressed the presence of the parent during the night: 46.4% of the nurses considered the parental presence to be necessary 24 hours a day, while 39.4% claimed a parent staying at the bedside at night was necessary only when there were special reasons, e.g. breastfeeding; 18.7% of the nurses pointed to a severe condition of the child as the only reason for the parents to stay with the young patient at night (Fig. 1).

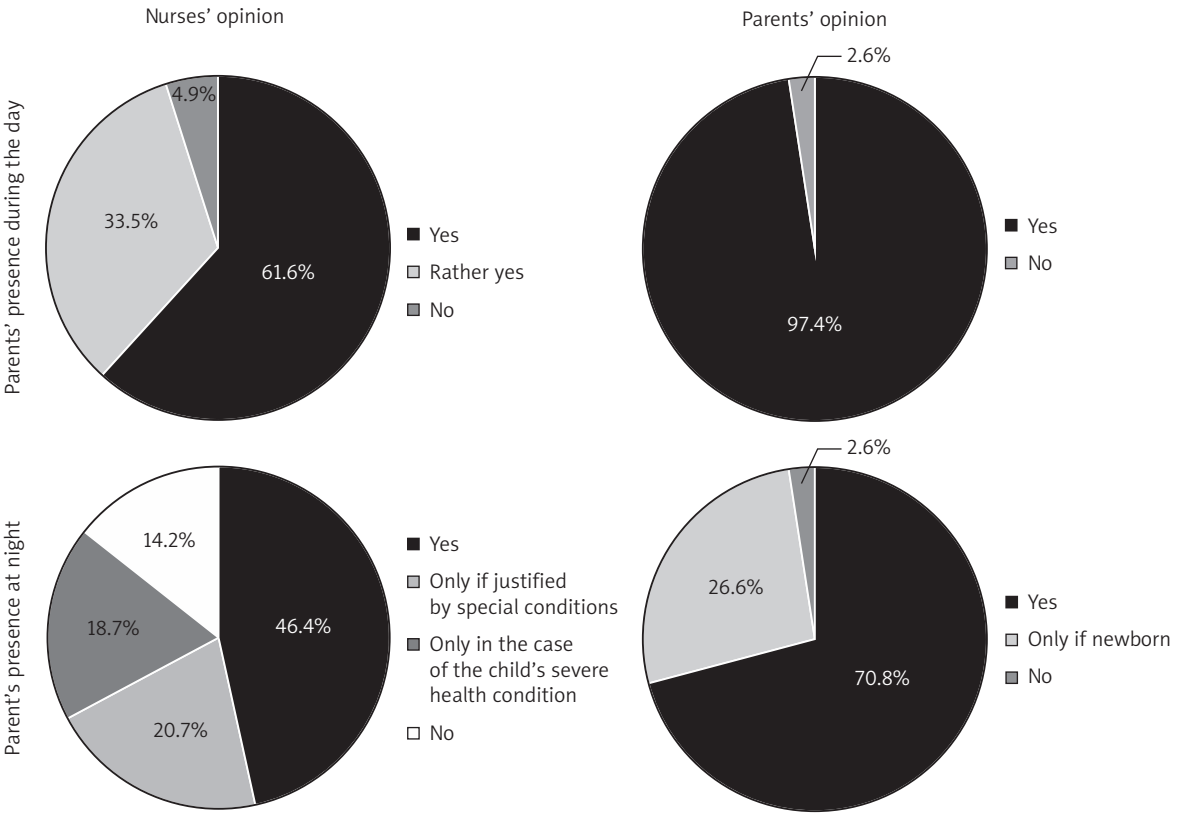

Figure 1. Necessity of presence of parents with their child in the hospital in the parents' and nurses' opinion

A total of 70.8% of the parents indicated their 24-hour presence with the child to be necessary, while 26.6% of the subjects believed their presence was necessary only when the child was young. The necessity for a 24-hour stay with their child was highest for parents with primary education, and the lowest need was seen in the university-educated parents ($p < 0.02$) (Fig. 2).

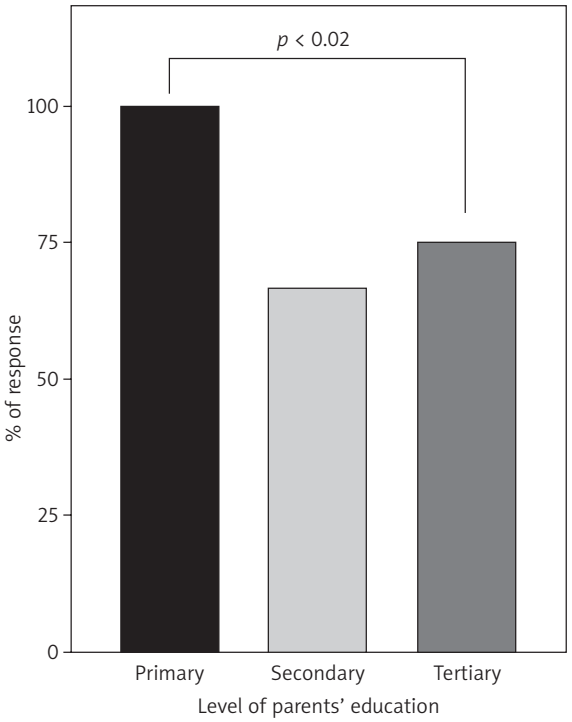

Figure 2. Necessity of the presence of parents with their child in hospital in relation to parents' education

Workload due to the presence of parents by the bedside

In the opinion of 50.5% of the nurses, the presence of a parent in the ward contributed to increasing their workload. Such an opinion was independent of the nurse's education level and length of employment, but it was dependent on the specialization of the nurse. The nurses with specialization more often reported an increased workload (59.1%) as compared to non-specialized nurses (41.3%) ($p < 0.02$). A total of 77.1% of nurses confirmed the parental participation in caring and performing hygiene-related activities for their children, but the differences in the evaluation were dependent on specialization (positive responses were more often offered by non-specialized as opposed to specialized nurses [$p < 0.02$]) and job seniority (the nurses with an employment history of less than 5 years and more than 15 years more rarely confirmed the participation of the parent in care and hygiene-associated activities as compared to the nurses with the employment history of 5-15 years [$p < 0.05$]).

More than half (64.6%) of the parents confirmed performing care-associated activities for their child, but 25.5% did so in situations when the nurses were busy with other duties. Declared readiness to perform care-associated activities involving their child increased with the increasing age of the parent ($p < 0.05$) and was also dependent on the profile of the ward: in the medical care wards, 60.1% of the parents expressed their willingness to help the nurses in performing activities involving their children, while the percentage was 41.3% in the surgical wards ($p < 0.005$). In the opinion of 86.9% the surveyed nurses, the parents gladly participated in educational activities teaching them hitherto unknown care and hygiene-associated activities to be performed in their children. As many as 63% of the nurses stated that the parents did not perform easy care-associated activities for their child and very often or often asked nurses to do so.

DISCUSSION

A child's stay in a hospital ward is a source of stress both for the young patient and for their parents. The paediatric nurse is the first person with whom they have contact, and their appropriate attitude dramatically affects the sense of safety in the child and the parent. Admission of the child to a hospital ward is also the beginning of building a relationship between the parents and medical staff.

Hospital regulations

The present results addressing parental observance to hospital regulations are similar to the observations made by other authors [9]. Parental unwillingness to adhere to the rules in the hospital regulations may be a consequence of a general lack of acceptance of strict rules shown by Polish society. The present results combined with the results of similar studies carried out among nurses show that observation of the hospital regulations by the parents as well as a consistent enforcement of such observance by the medical staff might contribute to an improvement in the cooperation between the staff and guardians of young patients [24]. As follows from the long-term observations of the leading author of the present study, for the parents their small child is of the highest importance, which means that they frequently manifest their dissatisfaction with the obligation to adhere to any regulations. The present results pertaining to parental observance of hospital regulations may also provide a stimulus for reviewing hospital regulations with respect to their understandability for individuals who are not educated in the broadly understood field of medical professions.

Presence of the parent with their child in hospital

Since the time the Chart of the Rights of the Child in Hospital was introduced in Poland, parents have had a guaranteed opportunity to be constantly present at the bedside of their hospitalized child, and the present results fully confirm their taking advantage of the said opportunity. As demonstrated by the analysis of the present results, the desire to accompany their sick child in the hospital was declared by almost 97% of the surveyed parents; this finding is consistent with results presented in other studies [9, 16-18, 20]. Also, the opinions of the nurses participating in the present investigation concur with the opinions of nurses presented in another study [24]. Although almost all the parents expressed their willingness to stay in the hospital with their sick child, the evaluation of 24-hour presence was clearly dependent on the education level of the parent. No attention was previously paid to such a dependency in the literature on the subject. The relationship may be explained by the workload and professional responsibilities, which are proportional to the educational level, and thus the parents with university education have considerably less time to devote to accompanying their child in hospital. Another explanation may be the fact that individuals with university education show a better understanding of the organization of work in a hospital and are better at evaluating the real needs of the child. It cannot also be ruled out that numerous well-educated parents of the hospitalized children reside and are employed elsewhere, outside of their familial place of residence, and thus have fewer opportunities to include other family members in caring for the sick child when they are hospitalized. Although the surveyed nurses and parents were aware of the advantages of a parent staying in hospital with the sick child, the parental presence in the ward also has some negative aspects. As follows from the present results, approximately 40% of the surveyed nurses called into question the necessity of the parents staying with the child during night hours. They expressed the opinion that the parent should stay in the hospital at night solely in special situations (e.g. when the mother breastfeeds the infant-patient or the child is in a severe condition). Nevertheless, as many as 13% of the parents showed negative feelings towards a nurse entering the child's room at nighttime; this observation is in line with the results presented in other papers [24]. Parents staying at the bedside of the child at nighttime is not always necessary, but at times it may result from parental inability to daily travel to hospital, either for economic reasons or due to a large distance. To make it possible for the families to stay together when the child is hospitalized, on the initiative of the Ronald McDonald Foundation in Poland, special houses (hotels) are constructed in the close vicinity of paediatric hospitals, where the families of young patients may find a home-like atmosphere and conditions. Unfortunately – as follows from the experience of the leading author – the possibilities offered by such houses are not fully taken advantage of. Even if the parents have an opportunity to rest at night in a comfortable setting, they stay in the hospital with their child. Taking into account safety, and emotional and developmental needs of the child, the presence of a parent at the bedside not only during the day but also at night seems to have priority. By accompanying the child continuously, the parent can better understand the whole clinical decision-making processes.

Workload due to the presence of the parents by the bedside

In the opinion of almost 80% of the nurses, the parents participated in patient care-associated activities. The percentage is higher when compared to data originating from other studies [24]. The difference is not astonishing, because over the last 15 years, the perception of a beneficial effect of FCC on the therapeutic process in the child has changed. As can be seen from studies performed by other authors, the parents willingly participate in patient care activities, but the prerequisite is their obtaining necessary information in this field [25].

As reported by the nurses with specializations, the presence of parents/guardians resulted in increasing their workload. The phenomenon is understandable because even if the nurses perform patient-care associated activities less frequently, they devote more time to the parents, giving them instructions on how to attend to such tasks. The nurses with specialization are to a greater extent aware of the effect of education of the patient and their family on the therapeutic outcome.

Despite declaring their willingness to perform care-associated activities in their children, one-fourth of the parents were engaged in such activities only when the nurses were busy with other duties. Hence, the parents perceived performing care-associated activities involving the sick child as belonging to the category of duties to be fulfilled by the staff. A higher percentage of parents ready to perform care-associated activities was observed in general medical as opposed to surgical wards; this phenomenon is a result of parental lack of experience and parental fears regarding handling the child soon after surgery. The observation indicates a need for a better education of parents in the field of caring for a child who has been subjected to surgical procedures. This finding is clearly confirmed by the opinions expressed by more than 60% of the nurses, who admitted that the parents asked the nurse to perform care-associated

activities involving their child even though they could have performed these activities themselves.

The readiness to perform care and hygiene-associated activities was significantly dependent upon the age of the parent: the older the parent, the more pronounced her/his readiness to perform such activities. The observed dependence may be explained by the parent having more than one child and therefore being more experienced in performing care-related activities. The readiness of the parents to carry out care and hygiene-associated activities in their children is confirmed by the findings in other studies [15, 18]. The results of investigations carried out in parents of children hospitalized in paediatric institutions in various countries worldwide are similar [26].

The parents eagerly help in caring for the hospitalized child, but they need the nurses to offer advice, guidance, and support [27]. The parents often treat the nurse as a teacher, guardian, and moderator [28]. As is clear from the present study, the parents obtain assistance and get necessary information pertaining to caring for a sick child from the nurses; this observation is in agreement with the findings presented in other studies [20]. Nevertheless, other authors point to the fact that the parents receive support in the field of providing information and instruments necessary in caring for their children, but the degree of such support is lower than they would expect [29]. Hence, the parents of hospitalized children are more willing to participate in caring for their offspring as long as they receive necessary information and practical assistance. Such support is predominantly needed by parents of premature infants, newborns, and children patients of intensive care units [30].

Parental participation in daily care and hygiene-associated activities was evaluated higher by the nurses without specialization, as well as by the nurses with the shortest and longest employment history. Nurses with little experience are probably of the opinion that the parents know best how to perform care-associated activities for their children. Such nurses are less professionally confident and do not evaluate whether the activities done by parents are performed in a correct manner. Nurses with the longest employment history express a similar opinion because they assume knowledge is acquired by young parents on internet. Nurses without specialization are probably characterized by a lower level of awareness of a negative effect of incorrectly performed care-associated activities on the therapeutic process in a child.

Room for improvement in family-centred care

The parents of hospitalized children and the nurses agree as to the necessity of the parents to be constantly in hospital and be engaged in performing some activities involving their sick child. Nevertheless, it seems that in practice there is still a clear lack of an appropriate environment and atmosphere that would favour the nurses and parents defining their respective roles. Poor interpersonal communication and the failure to provide information are barriers that prevent development of the division of roles in patient care. To implement the assumptions of FCC it seems necessary to take actions that aim at improving the cooperation of the parents and medical staff, such as developing behaviour patterns that facilitate negotiating the roles of nurse and parent in caring for the sick child, as well as improving interpersonal communication [7, 21]. Making therapeutic decisions in cooperation with the parents of the sick child may produce the best results of treatment, while at the same time minimizing negative hospitalization-related psychosocial consequences. Many studies from different countries have been synthesized in a recently published scoping review [31] from which 4 main themes emerge: respect and dignity, participation, communication, and collaboration. They can be considered as an open space for further research on FCC.

CONCLUSIONS

According to nurses and parents, the presence of the parents with their child in hospital during their day is necessary, but not always during the night.

Despite the engagement of the parents in care-associated activities, their presence causes an increase in the workload of nurses

Cooperation between the nurse and the parents of a hospitalized child requires an unequivocal definition of the tasks and specification of the roles that are to be undertaken by both the nurses and the parents in their mutual cooperation.

The nurses must learn to perceive the parents as equal partners in caring for the hospitalized child.

The analysis of the opinions of the parents and nurses addressing broadly understood FCC issues should be taken into consideration when determining the scope of training for nurses.

Disclosure

The authors declare no conflict of interest.

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