Parents’ participation in taking care of hospitalized children: A concept analysis with hybrid model

Parvaneh Vasli1, Mahvash Salsali1

ABSTRACT

Background: Although today parents’ participation in taking care of hospitalized children is considered as an indispensable principle, it is still among the concepts with no consensus about. The main objective of this study is to define parents’ participation in taking care of hospitalized children.

Materials and Methods: The concept of “parents’ participation in taking care of hospitalized children” was analyzed using a hybrid model in three phases: Literature review (theoretical phase), fieldwork, and combination of literature review and fieldwork (analytical phase).

Results: Based on the results of the theoretical (literature review), fieldwork, and analytical phases, the best definitions for the concept of “parents’ participation in taking care of hospitalized children” are mutual relationship and gaining parents’ trust toward nurses, giving the required information and education to the parents about care and treatment process, assigning the needed home care to the parents, involving the parents in caregiving process, and finally, defining their participation in decision making (clarifying the parents’ role) in order to improve the quality of care given to the children.

Conclusions: The findings of this study showed that the dimensions of parents’ participation can be applied in pediatric wards, and nurses can improve the quality of care through application of the obtained findings.

Key words: Children, concept analysis, hospital, Iran, nursing, parents’ participation

INTRODUCTION

 Nowadays, health care has been transformed to a patient-centered model, so that the patient plays a more active role in care.1 In this model, the patients and their relatives attend caregiving process as the main partners and are involved in health providers’ decision making, treatment, and administration of procedures.2 In pediatric nursing, family-centered care is also a basic element, which emphasizes on dynamic relationship between the family members and treatment and care providing team, as well as involves the family in care.3 Parents’ participation in taking care of hospitalized children seems to be the basic foundation.4 Parents should be clearly active in decision-making process in relation to taking care of children and participation in care.3 Some terms used to describe the concept of participation of the parents are parents’ participation, involvement of parents in care,5 participation in care,6,7 caring partners, being involved in mutual participation of care,6 family-centered care,7 and family participation.6,7 Application of synonyms for this term has confused the nurses, revealing the lack of a consensus on the concept of parents’ participation, so that nurses have no clear definition about parents’ participation.6,7 Coyne, quoting from Darbyshie, states that the concept of parents’ participation is one of the most controversial issues which should be clarified, as its clarification leads to more efficient application and evaluation of its weak and strong points.6 Finally, it should be mentioned that understanding of this important concept increases its application in action and ultimately improves the quality of pediatric care in hospitals. Family unit has a great value in Iranian traditions,8 and strong ties of family members and parents’ responsibility are highly valuable.9 In other words, parents’ participation in taking care of a hospitalized child is the symbol of families’ power,8 but despite the importance of this issue, limited research has been conducted on the concept of parents and health providers taking care of hospitalized children in developing countries.10 Nurses also seem to have a different definition for this concept. Clarification of this concept can absolutely help its definition and promotion of nursing care in pediatric wards. Therefore, the researcher decided to analyze the concept of parents’ participation in taking care of hospitalized children.

1Faculty of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

Address for correspondence: Parvaneh Vasli,
Faculty of Nursing and Midwifery,
Tehran University of Medical Sciences, Tohid Square, Iran
E-mail:parvanehvasli@yahoo.com

www.SID.ir
**Materials and Methods**

Linguistic concepts are the presentation or mental images of phenomena, and are essential for occupational relationship.\(^{[11]}\)

One of the approaches in concept analysis and development is hybrid model. It is one of the conceptualization, concept invocation, and theory development methods, which is used to modify the abstract concept and ambiguity in nursing.\(^{[12]}\) This model is generally applicable in all disciplines and practical sciences, especially in nursing. In fact, as hybrid model reveals the general insights and attitudes in a clinical setting, it is specifically used in studying the important nursing phenomena.\(^{[13]}\) One of the concepts that has a high application in clinical setting but lacks a clear definition in nursing in Iran is the concept of parents' participation in taking care of hospitalized children. This issue reveals the necessity of clarification of meaning and dimensions of the above-mentioned concept through hybrid model as the best content analysis method. This content analysis is conducted in three phases: Theoretical, fieldwork, and analytical phases. In the theoretical phase, the theory maker vastly and structurally seeks for the study-related issues and application of the concept.\(^{[12]}\) The data related to fieldwork are collected through interviews with participants and then analyzed to extract and confirm the concept. This phase is actually a literature review phase. Comparison and giving a semantic meaning to the results and reviewing the practical and theoretical phases result in the ultimate phase, which is the final analysis.\(^{[14]}\)

**Theoretical phase**

In this phase, for literature review of the articles published until August 2011 in relation with parents' participation in taking care of hospitalized children, databases such as PubMed and ProQuest were searched using the key words, parental partnership, parental participation, family-centered care, parental involvement, hospital, child, and nurse. For literature review, manual article search and the references of the articles were also used in addition to the two above-mentioned databases. Finally, 37 articles were found. The articles with no access to full text were excluded and the rest indicating a definition or concept were selected and similar or opposite cases were reviewed.

**Fieldwork**

This phase was conducted through semi-structured interviews with 11 nurses working in two educational pediatric centers affiliated to Tehran University of Medical Sciences. Participants’ selection was non-random and through snowball method. Inclusion criteria were being interested in attending the study and sharing the experience and working in pediatric ward with at least 1 year of work experience. All participants were nurses with over 3 years of work experience in pediatric wards. One of the interviewers was a supervisor and the other was a head nurse. Some interview guide questions were: What is your perception on parents’ participation? How do you involve the parents in taking care of their children? What does parents’ participation need? How can parents’ participation be developed? Data analysis was conducted by content analysis. It has been used in numerous nursing researches and is applied as a systematic objective research method to explain qualitative phenomena.\(^{[15]}\) Its qualitative approach is a flexible method for text data analysis,\(^{[16]}\) and is used when there is no adequate knowledge about a phenomenon.\(^{[15]}\)

The interviews were recorded and transcribed by jet audio software. The mean length of each interview was 50 min. The transcriptions were reviewed several times line by line and the coded categories and subcategories were revealed by reduction process. After ending the content analysis, the themes related to various dimensions of the concept (parents’ participation in taking care of a hospitalized child) emerged. For rigor of the data, the researchers returned the transcriptions and extracted codes to the participants and colleagues, and based on their indications, the needed modifications were done. Prolonged engagement in interviews transcripts was noticed in data analysis.

It was tried to increase rigor of the data through sampling with the upmost variance by conducting interviews with nurses in different wards, with different work experiences, and working in various shifts.

**Ethical considerations**

This study was approved by the ethics committee of Tehran University of Medical Sciences. Related permissions were obtained from the heads of related hospitals. All participants gave oral informed consent to attend the study and for their voices to be recorded. They were explained about the confidentiality of their information and their option to leave the study whenever they liked, as well as their right to receive the results in case of their request.

**Results**

The concept of parents’ participation is not clearly defined in literature and texts, and has been mentioned by different terms such as involvement of the parents, participation in care, mutual participation, parental caregiving, and involving the parents as caregivers,\(^{[4]}\) but the simplest definition is parental participation, which means parents’ participation in taking care of a hospitalized child.\(^{[7]}\) This refers to the activities that are done by the parents for their child in hospital, so that they either conduct or share a part of caregiving. Parents’ participation can be in the form of giving physical, psychological, or social care.\(^{[17]}\) Literature
review of the articles in relation with participation can help clarifying the dimensions and characteristics of this concept. Table 1 briefly represents the various dimensions of parents’ participation in taking care of a hospitalized child.

The characteristics, defined in Table 1 for the concept “parents’ participation in taking care of a hospitalized child” can lead to a theoretical definition, i.e. parents’ active involvement in specific levels of care based on negotiation, agreement, and mutual open interactive relationship with nurses through exchange of information and increase in parents’ level of awareness and skills.

Findings of fieldwork
After analysis of the main content, the dimensions of parents’ participation were obtained in four themes of parents – nurses’ cooperation (with two subthemes of open communication and trust), education and increase of parents’ awareness and skill in care, assigning home cares to the parents (with three subthemes of physical, emotional, and safety), and finally, the range of participation and decision making (with two subthemes of domain and time of participation). The first important characteristic of the concept of parents’ participation in taking care of a hospitalized child is cooperation (with two subthemes of open communication and trust). In this regard, nurse no. 6 stated:

“… They rely on us through a mutual communication which is made, then, they believe that we are suffering from their pain too. If someone is going to participate in care, he/ she should be explained, to be explained means to spend time on him/her, so that the other side can trust on and cooperate with us….”

To achieve trust and finally patients’ cooperation, there should be a mutual communication between parents and nurses. Having a hospitalized child is a great source of anxiety and stress for the parents as they face a role change. This is when they need help to overcome their role in taking care of their hospitalized child. This open and efficient communication can absolutely help the parents reach peace. Mutual exchange of information occurs through this very communication.

Participation is impossible without exchange of information and parents’ education. In this regard, one of the nurses said:

“… Participation is possible when there is a purposive system with an appropriate and complete planning and education…” (Nurse no. 5)

Access to current information about the child’s disease, diagnosis, and treatment helps the parents feel having control and security and adapt with their child’s hospitalization and have a greater share in care, as one of the patients explained:

“… If we can educate the mother well, we are relaxed as we have told her what to do….” (Nurse no. 3)

This is so that the parents, based on their ability, can have a part of care while the child is under supervision of treatment and nursing team. In this concern, one of the participants stated:

“… I think giving care, personal hygiene and nutritional issues can be assigned to the mothers. They are capable of these duties. The given care should also help us somehow; and the

Table 1: Characteristics of the concept “parents’ participation in taking care of a hospitalized child” and the samples selected by literature review

<table>
<thead>
<tr>
<th>Concept characteristics</th>
<th>Items selected by literature review</th>
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<tbody>
<tr>
<td>Negotiation and mutual interaction of nurses and parents</td>
<td>Support and open communication is essential for parents’ participation[18]</td>
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<tr>
<td>An agreement to clarify the parents’ roles and to state their level of participation</td>
<td>For parents’ participation, communication should be made with them[19]</td>
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<td>Clarification of the roles is a principle of participation and its responsibility is for the nurses[19]</td>
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<td>Parents need adequate knowledge about the roles; otherwise, they are confused[21]</td>
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<td></td>
<td>Appropriate parents’ participation needs negotiation and clarification of their expectations. Negotiation means mutual continuous agreement in relation with planning child care based on resources, requests, and needs of parents and the child[9]</td>
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<tr>
<td>Increase of parents’ awareness and skill in care</td>
<td>Encouraging the parents to participate, educating the parents, explaining about the cares the parents should give, and supervision of parents’ function are among the activities of nurses in participation[20]</td>
</tr>
<tr>
<td>Involving the parents in caregiving</td>
<td>To involve the parents in care, it is essential to give them identical and homogenous information[19]</td>
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<td>Nurses should educate the parents about the manner of care[20]</td>
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<td>Parents often participate in basic cares such as changing clothes, feeding, health, and preparation of the tools for the child, doing things that the children need in their natural life like supervising children’s general condition and pain[20]</td>
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<tr>
<td></td>
<td>Parents’ participation is the care given by the parents and involving the families in taking care of the child[9]</td>
</tr>
<tr>
<td></td>
<td>Parents participate in usual cares and, if they like, perform nursing cares[20]</td>
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mother should be permitted to take care of her child when there are signs and symptoms of the disease. For example, when the child has a fever, the mother should not lose her heart. They learn the cares in this way.…” (Nurse no. 8)

Assigning a part of care to the mothers decreases their anxiety and frequent and disturbing questions that negatively affect the quality of given care and increases the feeling of independency. The results obtained in the present study, of which some have been presented above, showed that nurses like to assign some of the cares to the parents. This issue requires spending time and supporting the mother. For education, based on mothers’ and children’s personal needs, care systems should be switched to patient-centered mode instead of duty-centered mode. Table 2 presents the list of cares, which the parents can undertake, and are classified into three groups of physical, emotional, and safety cares.

Although the nurses pointed to assigning cares to mothers, they also emphasized on the fact that the level of parents’ participation must be determined and they should not handle all professional tasks, as nurse no. 5 indicated:

“… They should do primary care and just in general wards as this does not decrease the load of work for the system (health system)… the jobs they are aware of should be assigned to them which means primary care like cleaning the baby.”

On the whole, the ambiguous level and margin of parents’ participation and their involvement in all cares not only cannot solve any problems but also may lead to malpractice and increased load of nurses’ work and physicians’ distrust toward nurses. Assignment of the care to mothers should be limited to primary and basic care and what they may need in future. For instance, nurse no. 4 stated:

“… Mothers should not be allowed to do the jobs which are not related to them, for example, suctioning (procedure), but what you know they can do, and the things not related to child’s recovery.”

Final analysis

In this phase, the findings of both theoretical and fieldwork phases were compared with each other and their results have been presented in two sections of outcomes and results and concept characteristics subsequently.

Outcomes and results were obtained in theoretical and fieldwork phases, of which one of the most basic prerequisites of parents’ participation in taking care of a hospitalized child is attendance of the parents by the child. In numerous studies, it has been emphasized that the parents should attend to their child to participate in care.[8,20] The other prerequisite for parents’ participation is parents’ interest and positivity, as well as the attitude of the staffs to work with them.[20] If parents are not aware of the importance and effects of their participation in

<table>
<thead>
<tr>
<th>Physical care</th>
<th>Psychological care</th>
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<tr>
<td>Primary health care</td>
<td>Hugging the child</td>
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<td>Breast feeding, feeding, and intake/output control</td>
<td>Relaxing the child</td>
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<td>Giving oral medications</td>
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<tr>
<td>Position change</td>
<td>Prevention of child from falling off the bed</td>
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<td>Skin care</td>
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<tr>
<td>Phototherapy-related cares in pediatric and NICU wards</td>
<td>Prevention of child from falling down to ground</td>
</tr>
<tr>
<td>Temperature control and bathing child’s feet with lukewarm water</td>
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<tr>
<td>Blood sugar control and diabetes injection in diabetic patients</td>
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<tr>
<td>Preservation of urine catheter and angiocatheters in surgical ward</td>
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<tr>
<td>Bleeding control and dressing in surgical ward</td>
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<tr>
<td>Presentation of health history to treatment team</td>
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<tr>
<td>Administration of suction, physiotherapy, occupational therapy, and gavages in PICU</td>
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<tr>
<td>Taking the child or his/her laboratory sample out of hospital</td>
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<tr>
<td>Collection of urine and stool</td>
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<td>Giving help in height and weight control and physical examination</td>
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Table 2: List of cares undertaken by mothers in physical, psychological care, and safety of their children in hospitals
care, nurses’ struggle to involve them in care is useless. On the other hand, if nurses do not agree with parents’ participation, the expected outcomes never occur. The results and effects of parents’ participation obtained in both phases showed that parents’ participation has numerous positive effects including their satisfaction, anxiety and pain reduction, children’s sleep recovery, parents’ peace and encouragement, and appropriate communication with the staffs, feeling of capability in parents, more adaptation of parents with the child’s conditions, promotion of quality of care, and finally reduction of nurses’ work load. But in some cases, inappropriate results including parents’ feeling of incapability and stress in doing some of the cares, distance of mothers from family, and their job.

**Limitations of the study**

This study tried to analyze the concept of parents’ participation in taking care of a hospitalized child from the viewpoint of the nurses, but as the parents also have a share in this issue, lack of parents’ experiences can be mentioned as a limitation of the present study. It is essential to conduct further studies on parents’ experiences concerning their participation.

**Discussion**

When there is no unique perception for a concept, the application of that concept is under question, communication is disturbed, and individuals’ responses will be based on their personal temporary judgments.

Clarification of the concept of participation is a difficult task as it has various meanings among people. Although the concept of parents’ participation is clear for teachers and professionals in clinical setting, quality care necessitates its clarification as a basic issue.

The results of the present study on investigating and comparing various dimensions of parents’ participation in taking care of a hospitalized child in two phases of theoretical and fieldwork have been presented in Table 3. Comparison of the findings in the two above-mentioned phases shows that almost all components of theoretical phase and fieldwork phase coincide with each other. Finally, it can be noted that the concept of parents’ participation in taking care of a hospitalized child means an open and interactive communication between nurses and parents, educating the parents about the process of treatment and care, assigning child’s home needed cares to parents and involving them in caring process, and eventually, determination of the range of parents’ participation in order to promote the quality of cares.

In the investigation of the obtained components, the first important and notable element of this concept was open and interactive communication between two sides. This open communication absolutely can help concurrent usage of parents’ and nurses’ knowledge and their mutual cooperation. The more active this communication is at the beginning of staffs’ exposure to the family, the more the possibility of parents’ trust to negotiate and come on an agreement with nurses is. Weak communication between nurses and parents definitely limits the negotiation. Negotiation is especially valuable when the parents face problems and are disappointed. In such conditions, nurses can help the family resist against problems through an appropriate communication and timely intervention. The second component of this concept was increase of parents’ awareness and skill in caregiving. Nurses should be assured that they can accomplish these cares. Nurses determine the level and manner of parents’ participation through the information they pass on to them, their support toward them, and the method in which they communicate with the parents. Another component in the concept of parents’ participation in taking care of children is their involvement in care. In this regard, Coyne states that parental care refers to assignment of a part of cares to the parents based on their capability and with the permission of treatment and nursing team while the child is under their supervision.

The clear role of parents in taking care of a hospitalized child is one of the important components of parents’ participation in care. The difference between patients’ and nurses’ perceptions about the behaviors, which are considered as cares, causes conflicts between nurses and parents, lowers the quality of care, and increases dissatisfaction in both sides.

**Table 3: Characteristics of the concept of parents’ participation in taking care of a hospitalized child in theoretical and fieldwork phases**

<table>
<thead>
<tr>
<th>Theoretical</th>
<th>Fieldwork</th>
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<tr>
<td>Open interactive and mutual communication and negotiation</td>
<td>Cooperation (with two subthemes of open communication and trust)</td>
</tr>
<tr>
<td>Increase of parents’ awareness and skill in caregiving</td>
<td>Education, and increase of parents’ awareness and skill in caregiving</td>
</tr>
<tr>
<td>Involvement of the parents in care</td>
<td>Assigning the needed care to parents (with three subthemes of physical,</td>
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<td>emotional, and safety care</td>
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<tr>
<td>Agreement and clarification of parents’ role</td>
<td>Range of participation, decision making (with two subthemes of domain</td>
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<td>and time of participation)</td>
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Parents should be clearly active in decision-making process concerning their childcare, allocation of the person who takes care of their child, or the level of their own participation. Meanwhile, nurses should determine their clear expectations for the activities they like the parents to participate in.\[3\]

One of the points discussed in the investigation of the two above-mentioned phases was the difference in parents’ participation, which means despite identical conditions, the level of parents’ participation in taking care of children can be different. It can be possibly due to some factors such as parents’ age, level of education, and cultural backgrounds. The findings of other studies revealed that the parents with higher education as well as younger parents are more eager for participation, while elder parents prefer to leave the care for the staffs.\[24\]

**CONCLUSION**

It is concluded that preparation of executive backgrounds and encouraging parents to participate in taking care of a hospitalized child, as well as adequate nursing human resources, spending more time on patients by nurses, and existence of a legal background to support nurses are essential.

Therefore, conducting studies on the obstacles and facilitating elements for this concept, as well as a similar study on parents’ viewpoints can help its application.

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**REFERENCES**