

Parents Involvement in Child's Care in an Arab Pediatric Setting

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Abstract

Background: Parents' participation in their child's care has been recognized as a key component to develop a satisfying experience for parents of a hospitalized child. However, studies suggested that parents' participation in care is under searched for nonwestern societies.

Objective: The purpose of this study was to measure activities performed by parents in caring for their hospitalized child, as well as to evaluate parents' actual participation level at the pediatric settings in Jordan.

Method: A descriptive study with a convenient sample of 294 parents, most of whom were mothers, completed the Arabic version of the Index of Parent Participation/Hospitalized Child and a socio-demographic form at four major hospitals in Amman. Results: Results revealed that parents have moderate mean score of actual participation in their child's care. Domains of participation were limited to activities of daily living and providing comfort, and less for activities related with advocating and providing technical care. While parents were willing to participate in care, some parents felt they had to perform some aspects of care. These activities are described and discussed within the context of Jordan's health care system.

Conclusion and implication for nursing and health policy: New approaches to promote a partnership between parents and other health care professionals are needed. Nurses need to better understand parents' expectation or desired level of participation and support them at the level they are most comfortable with.

Keywords: Parent's participation; Child's care; Jordan; Arab; Pediatric settings

of PP is an important element of family centered care (FCC) and presents a partnership between child's parents and other health care professionals. This partnership is reflected in the standards of pediatric nursing practice. According to this group, children's health care should be built within the concept of FCC for optimal health and well-being [2]. However, it is argued that while parents' participation is an important element of FCC, it presents particular challenges at the bedside [3]. One aspect of the challenges it provides is the fact that parents' expectations of participation in their child's care differ between them. Secondly, parents' views about participation may be altering if they were informed of all participation opportunities [3].

Literature Review

Based on previous reports, parents generally desire and expect to be involved in caring for their hospitalized child, but the ways in which they want to be involved may differ [3,4]. The extent of PP in care of a hospitalized child can be mostly influenced by parent's perceptions of what is expected of them [5,6], competency to perform technical aspects of care [6] and confidence to ask nurses for help with technical aspect of child's care [7]. Activities involved in PP were comprehensively reviewed by Power and Franck [1], and showed that the main activities involved in PP were related to basic child care and parenting roles. Recent research in PP has extended into more advanced role such as monitoring, medication administration, and care coordination. Power and Frank [1] retrieved nine studies related to parent's participation with care. An extensive search of literature failed to find any studies on parents' participation in care at any Middle Eastern country. In Jordan, while PP concept has been applied for over a decade, research in this area is still under-searched. Preliminary research in pediatric nursing showed that parents of hospitalized children in Jordan are in need of further support and empowerment to enable them to participate in providing care for their hospitalized children [8]. Accordingly, the purpose of this study is to highlights the role of parents in pediatric nursing practice by measuring parents' actual participation in the care of their hospitalized children at the pediatric settings in Jordan.

Introduction

Parents' participation (PP) has been defined as the physical, psychological or social activities performed by parents for a child in the hospital setting where they take part in the care of their child across the entire hospital episode [1]. The concept

Research question: What is the level of parents' actual participation in the care of their hospitalized children at the pediatric settings in Jordan?

Methods

Design

A descriptive, cross-sectional design was used in this study. This is an efficient mean for collecting a large amount of data and discovering a large number of interrelationships in a relatively short period of time [9].

Sample and settings

A convenience sample approach was utilized to select participants who were eligible for this study. Parents were eligible to participate in this study if they were the main caregiver at the bedside of the child for at least 24 hours. Parents of adolescent patients were excluded from the study. Data were gathered between February 2014 and June 2014. The settings were selected by simple random sampling techniques and consisted of one public hospital, one university affiliated hospital, and two private hospitals. The inpatients units in those hospitals included both medical and surgical cases.

Procedure

The principle investigator (R.A) explained the study to potential participants and invited them to participate. Parents were assured that their decision regarding taking part in this study would not affect their child's care and that they could withdraw at any time. If parents agreed to participate, they were asked to sign a consent form and to complete two sets of questionnaires. Parents who consented to participate in this study were asked to complete two separate parts of a self-report questionnaire: a socio-demographic form and the Index of Parent Participation/ Hospitalized Child (IPP/HC) [10].

Ethical consideration

Ethical approval from the Institutional Review Board (IRB) was obtained from each hospital setting, as well as the Research Ethics Committee of the Faculty of Nursing at the University of Jordan. Permission for using of Parent Participation/ Hospitalized Child (IPP/HC) [10] was obtained from the author prior to data collection. The completed questionnaires were coded for analysis and kept in a double locked office.

Instruments

The Socio-demographic form

The demographic questionnaire included 24 items regarding parent's socio-demographics, such as their relationship to child, age, level of education, employment status, marital status, size of family. The demographic characteristics related to the hospitalized child included age, gender, date of

admission, length of hospitalization, and number of admissions.

The Index of Parent Participation/Hospitalized Child – Actual Activities (IPP/HC-AA)

The IPP/HC is a 36 items that measures parents' actual participation of care. The 36 activities listed in this tool are grouped under four categories:

- Providing comfort: includes eight items (1, 2, 3, 4,21, 24, 25, 26)
- Activities related to daily living ADL: includes eight items (8, 9, 10, 11, 12, 19, 20, 34)
- Advocating for their child measured by 16 items: (13, 14, 15, 16, 17, 18, , 22, 23, 28, 29,30, 31, 32, 33, 35,36)
- Technical task measured by 4 items (5,6,7,27).

Parents checked the activities they participated in during the last 24 hours in a two-point scale (Zero if absent and one if present) using the IPP/HC. A space was also provided at the end of the tool for parents to identify activities that they participated in but that were not included in the checklist. The score for the checklist is determined by counting the number of total activities checked by the parents as present; the higher the number, the higher the parental participation score, with possible scores ranging from 0 to 36 [10].

Parents' participation levels are categorized as minimum, moderate, and maximum level of participation [3,10]. Parent participation level is suggested to be negative (minimum) if the range of percentage was 0 to 44.4%, or a total item score of 1-16. This suggests that parents' participation included providing minimum activities of care for their child such as comforting the child and providing activities of daily living (ADL) [10-12] A neutral (moderate) level, defined by a range of percentage from 47.2 to 88.8% or a total item score of 17-32, indicated that parents' advocated for their child in addition to providing the minimum activities of care [13]. Positive (maximum) level of participation defined as a range of percentage from 91.6-100% and item scores of 33-36, includes providing activities related to comfort, ADLs, advocating for their child, in addition providing technical care [14].

Psychometric properties of the IPP/HC tool is presented in a different study, it's valid and reliable in several studies such as [3,4,8,15-17]. In this study, cross-cultural validation was performed to develop a valid and reliable version to the IPP/HC in Arabic language. The internal consistency for the translated IPP/HC yielded a Cronbach's alpha of 0.91.

Results

Characteristics of the sample

A total 320 parents were invited to participate in this study. However, only 294 completed the study, providing a response rate of 91.8%. The majority of the sample were mothers (270, 91.8%), 31 years old and above (174, 59.2%). The number of participants in the private, public and university affiliated hospital were equally distributed (34.0%, n= 100, 32.3%, n= 95,

33.7%, n= 99). The demographic characteristics of the parents and their hospitalized child are presented in **Table 1**.

Table 1 Demographic characteristics of the participants (N=294).

		Frequency	(%)
Parent's Demographics			
Relationship to the child	Mother	270	91.8
	Father	24	8.2
Age	18-25	47	16
	26-30	73	24.8
	31 and more	174	59.2
Educational level	Illiterate	4	1.4
	Elementary school	24	8.2
	Secondary school	102	34.7
	Diploma	100	34
	University	52	17.7
	Higher education	12	4.1
Type of hospital	Private	100	34
	Public	95	32.3
	University (teaching)	99	33.7
Child's Demographics			
Child's Sex	Male	158	53.7
	Female	136	46.3
Child's Age	Infant (1-12 month)	85	28.9
	Toddler (> 1 - to 3 years)	74	25.2
	Preschool (> 3 - to 6 years)	65	22.1
	School (> 6 - to 12 years)	70	23.8
Number of previous admissions	None	102	34.7
	One time	57	19.4
	Two times	26	8.8
	Three times and more	109	37.1
Admission Route	OPD (planned)	127	43.2
	ER (not planned)	167	56.8
Type of case	Medical	218	74.1
	Surgical	76	25.9
Severity of child's disease	Acute	183	62.2
	Chronic	111	37.8
Length of hospital stay (in days)	1-3	118	40.1
	4-7	58	19.8

	> 7	118	40.1
Child's diagnosis	Respiratory	83	28.3
	Cancer	64	21.8
	Renal	44	15
	Neurological	27	9.2
	investigation of symptoms	54	18.4
	GE	14	4.8
	cardiac	3	1
	other	4	1.4
Insurance	Yes	232	78.9
	No	62	21.1

Descriptive statistics of parents actual participation in care

The 36 activities listed in the IPP/HC are divided under four categories. **Table 2** provides the particular frequencies distribution and percentage of activities of parents by item. The mean score of parents' actual participation was 74.7 (SD = 14.3) and ranged from 30.6-100. This represents a high moderate level (47.2-88.8%) as suggested by Romaniuk [3].

Table 2 Frequencies distribution of IPP/HC in parents by items (descending order).

IPP/HC	Parents (N=294)			
	No		Yes	
	F	%	F	%
Activities of Daily Living(ADL)				
Fed child or set up his/her food tray	11	3.7	283	96.3
Changed clothes or pajamas	14	4.8	280	95.2
Helped with elimination	18	6.1	276	93.9
Settled for sleep or nap	22	7.5	272	92.5
Bathed child/sponged with a washcloth	69	23	225	76.5
Brush teeth/performed mouth care	141	46	153	53.1
Providing Comfort				
Comforted child when upset (does not include comforting during a painful procedure)	17	5.8	277	94.2
Spent quiet time interacting with child	27	9.2	267	90.8
Took child to playroom if allowed	121	41	173	58.8
Comforted child during a painful procedure	14	4.8	280	95.2
Actively played with child in room (games, blocks, etc.)	127	43	167	56.8
Stroked child/rubbed back	43	14	251	85.4
Took child for a walk, if allowed	175	59	119	40.5

Advocating for their child				
Asked physician for information about child's condition	15	5.1	279	94.9
Told nurse about something your child needed	41	13	253	86.1
Asked the nurse or doctor to explain something that you did not understand	29	9.9	265	90.1
Played with child for the purpose of getting him/her to talk or used role play	146	49	148	50.3
Told nurse about child's daily routines or his/her like or dislikes without being asked to do so	143	48.6	151	51.4
Talked with child about child about why he/she needs a test or treatment	131	44.6	163	55.4
Suggested to a nurse or doctor a different way time of doing something that you think would be better for your child	121	41.2	173	58.8
Asked nurse for information about child's care.	63	21	231	78.6
Asked nurse for information about child's condition	29	9.9	265	90.1
Providing Technical Care				
Helped nurse give medication (would including getting child to cooperate).	26	8.8	268	91.2
Kept track of how much child eats or drinks and tell nurse or recorded the amount on an intake and output sheet	86	29.3	208	70.7
Kept track of how much or how often child urinates and tell nurse or recorded it on an intake and output sheet	94	32	200	68
Kept track of when child had a bowel movement and tell nurse or recorded it on an intake and output sheet	118	40.1	176	59.9

Table 3 Parents' mean scores and standard deviation of the parents' participation.

Group	N	Mean	SD*	Range
Parents	294	74.7	14	30.6 _ 100

Table 4 Frequency distribution of parents' participation level.

Parents' participation level	Minimum (f) %	Moderate (f) %	Maximum(f) %
Parents (N=294)	(4) 1.4%	(237) 80.6%	(53) 18.0%

The majority of parents (80.6%, n=237) had a neutral (moderate) parents' participation level. A neutral (moderate) participation indicates that parents provided care for their child in hospitals through activities of daily living, comforting, and advocating, with no interest in providing technical task for children. Only (18.0%, n=53) of parents had a positive (maximum) level of participation, indicating the inclusion of technical aspects of care. Four parents (1.4%) had minimum level of participation, indicating the provision of a minimum amount of participation in the care of the child (**Table 3 and 4**).

Added activities done by parents at the end of the tool

Out of 294 parents participated in this study, 56 parents provided further activities to the open ended question, "Are there any other activities that you (as parents) performed for your children that are not in this list?" Parents' listed 38 activities that they actually did for their child. The listed activities were mainly redundant, and included activities listed under ADLs, such as bringing the child's favorite food and cleaning his clothes, or activities related to comfort such as reciting versus of Qur'an (the Muslims' holy book). However, some parents' added activities related with technical care such as taking the child's vital signs (particularly the temperature) and administering cold compresses to their child. A significant percent of parents cited that they helped with their child's nebulizer and in securing the oxygen mask for their child. A limited number of parents commented that they performed suctioning and tracheostomies care for their child, despite nurses' disapproval.

Discussion

As recorded in previous studies [3,10], the majority of parents at the pediatric setting of Jordan's hospitals reported a moderate participation level in the care of their child. This suggests that parents are involved in their child's care through providing activities of daily living, comfort, and advocating for the child, but not involving activities related to technical care.

Findings of this study are consistent with previous studies that identified parents as an active participant in their child's ADL care [3,6,18,19]. This study provides additional information on the level of Arab parent participation in the care of their child. More than 90% of parents in this study were responsible for feeding their hospitalized child, changing their clothes and assisting the child with elimination and sleeping. Fewer parents, however, were able to participate in the child's bathing or mouth care. Romaniuk [3] suggested that the presence of intravenous lines and lack of supplies required to perform both bathing and mouth care may hinder parent's abilities to perform such activities. It is suggested that nurses should empower parents to resume the child's routine care of bathing or oral hygiene by asking parents to bring supplies needed to perform child's bathing and mouth hygiene, by offering parents such supplies, and by providing assistance when needed.

Analysis of data related to types of activities parents provided to comfort their child show that the majority of parents in this study were able to comfort their child when upset (94.2%) and during painful procedure (95.2%). However, fewer parents were able to provide distraction activities to their children, such as taking their child for a walk (59%) or actively playing with their child in their room (43%) or at the playroom (41%). This can be explained in light of limited resources available to support parents at the Jordanian hospital, in the lack of playroom areas in the pediatric setting, and the absence of play therapy models in nursing practice. Given these deficiencies, it is imperative for nurses to

empower parents with supportive activities to foster their skills in meeting their child's other needs.

The current study showed that 86.1% of parents were able to communicate with the nurses regarding their child's need which is consistent with findings by Romaniuk [3]. Fewer parents were able to perform activities related with advocating for their child. Almost half of the parents were unlikely to suggest ways to individualize their child's care. Moreover, findings showed that 44.6% of parents were unable to communicate with their children regarding why he/she needed a test or treatment. Nurses should keep in mind that parents may not have an adequate level of information to tell their child about his/her treatment [20] this finding suggests that parents may lack information related to their child's condition and treatment. Therefore, it is argued that nurses should pay more effort in establishing better communication approaches with parents in a manner that insure transparency and simplicity of information [21].

With regard to activities related to providing technical care, the majority of parents reported assisting with medication administration. However, parents' maximum participation level was achieved only by 18% (53) of the total participants. This participation level included the activities related to providing for the child's health-deviation requisites that need technical skills, in addition to activities for providing child's universal and developmental requisite. The low percentage of frequency in the maximum level of participation might be due to the fact that more than one third of parents (102, 34.7%) had no experience of previous hospitalization and lacked knowledge or skill to participate effectively in their child's care. This lack of experience might lead to feelings of incompetence or being overwhelmed. This is congruent with previous studies [3,6,22,23] which suggested that parents who had no previous experience of hospitalization found it difficult to participate in the technical care of their child.

The written comments provided at the end of the questionnaire showed that some parents provided technical care such as suction and tracheostomy care despite nurses' disapproval. The most frequently cited activity by the parents were holding the oxygen mask for the child or assisting with their child's nebulizer treatments. Although parents were willing to participate in these activities, parent felt they had no choice but to participate in these activities. This supports previous studies suggesting that parent's participation in care of their hospitalized child may stem from parents desire of ensuring a good care for their child and/or parents fear that if they don't do these activities the care would otherwise not be done [3,6].

Limitations and strengths of the study

Our study has several limitations, including the use of a convenience sampling to recruit participants, and the use of cross-sectional design with a one-time data collection which may give indefinite results about parental actual participation. Additionally, the small proportion of fathers responding to the study may limit generalizability of findings. Finally, the risk of social desirability bias when using self-reported measures,

especially related to a parent's response to present oneself as a good parent and their beliefs about how good parents should participate in their child's care.

In the other hand, this study provides information about parent's actual participation level in care where no prior studies have been conducted. An important strength of this study is the high response rate and the relatively large sample size obtained in this study. The heterogeneity of the participants who represent a wide variety of ages, medical diagnoses, and hospitals sectors allows generalizability of results. Finally, the use of IPP/HC instrument, a valid and reliable tool for evaluating parent participation in both English and Arabic, was used. The wide variations of activities provided within the IPP/HC as well as the use of open ended question at the end of the tool provided a supplementary context for data analysis.

Conclusion

The findings of this study suggest an urgent need for a strategic plan to promote parental participation in the care of hospitalized children. Parents need to be able to negotiate the nature of their participation, as well as being empowered to negotiate new roles for themselves in sharing care. Health care managers and policy makers in Jordan need to play a more visible and instrumental role in developing policies related to parents' participation in the care at pediatric setting. In recognition of parents' participation value within a family-centered care model, further studies are needed to determine the differences between parents actual and desired participation in care. Using qualitative research may provide better insight into parent's perspectives regarding their participation in care, as well as nurses' ability to meet parents' desired participation.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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