## Mothers' Experience of Caring For Their Hospitalized Child in Jordan's Hospitals

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Abstract: Background: Parents' presence near their hospitalized child has been recognized to be important for both child and parents. Aim: The aim of this study was to describe mothers' experiences when their child was admitted to the hospital and to capture the mothers' perspective of their participation. Material and Method: A phenomenological hermeneutic design was adapted to capture mothers' experiences of her child's hospitalization and her participation. Conversational style interviews were conducted with mothers of 8 children at the pediatric ward of a tertiary metropolitan hospital in Amman. Results: The major categories that illustrated the mothers' experiences of participation in their childcare included reasons for staying with the child, impact on family's routine, expectations of nurses, and comments on facility provisions. Discussion: Our findings highlight high needs among mothers for participation in caring of their hospitalized children, in addition to their needs for communication. Mothers in this study believed that accompanying their hospitalized child is an unconditional aspect of being a parent and hold a strong desire for participation. Overall, these findings showed diminishing levels of emotional and practical support to the mothers at a time when the need for support and communication was likely greater; therefore, nurses should take the initiative in assessing these needs and in supporting them accordingly.

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## Introduction

Parent participation in their child's care during hospitalization has become the foundation stone of modern pediatric nursing. A variety of ways exist for parents participation, ranging from assisting with activities of daily living to being directly involved in important health care decisions. Shields, Pratt & Hunter (2006) argued that it is the parent, not the health care provider, who is continuously present in their children's life and will be ultimately responsible for their wellbeing. Therefore, it is the responsibility of nurses to support and encourage parents in continuing this vital role. Overall, research in the last decade indicates that parents generally desire and expect to be involved in caring of their hospitalized child; however the ways in which they want to be involved may differ. Participation in care can range from passive presence to total care by parent (Power & Frank 2008). Hopia et al. (2005) argued that parents needed and expected to be involved in basic child care activities normally performed at home. Yet, there are discrepancies between what parents want to do and what they actually do for their hospitalized child for example: mothers prefer to do breast feeding through ling on the bed at home while applying this procedure in setting position on chair near small child bed at hospital. This may increase the risk of parental dissatisfaction and potential for conflict between parents and health care professionals (Ygge, et al., 2006).

Positive and negative parents' attitudes towards parents' participation in caring for hospitalized children were described in several studies. In general, most parents felt that their participation in their child's care was very important and beneficial to their child, to nurses and to themselves (Hughes 2007, Rotegard 2007, Shields, Young & McCann 2008). Parents view themselves as making an important contribution to their child's care in hospital because of their unique knowledge of their child and their ability to reassure and provide comfort to their child. Hopia et al (2005) and Abdelkader, et al, 2012) asserted that negative parent attitudes included feeling incompetent or overwhelmed because they lacked knowledge or skill to participate effectively in their child's care. Therefore, it can be argued that parents need for information and detailed instruction is a recurrent theme in all family studies (Tourigny, Pineault, 2005). Chapados, and Without information about the child's illness and medical needs, parents felt they were unable to be involved or in control. Precisely in Jordan, parents plead the health care professionals, specifically nurses- for emotional support, individualized treatment and respect. (Abdelkader, et al, 2012)

## The study Aim

This study aimed to explore Jordanian mothers' experiences of their participation in taking care of their hospitalized children

## Method

A qualitative hermeneutic approach built on Heideggerian philosophy (Laverty, 2003, Speziale & Carpenter, 2007) which interprets the personal meaning of individual experiences was adapted to capture and understand the meaning behind mothers' experiences of participation in their children's care during hospitalization. Hermeneutic phenomenology isfocused on subjective experience of individuals and groups (Laverty, 2003, Speziale & Carpenter, 2007). It isan attempt to reveal the world as experienced by the subjectthrough their life world stories (Speziale & Carpenter, 2007). This school believes that interpretations are all we have and description itself is aninterpretive process (Kafle, Hermeneutic phenomenology is interdisciplinary approach that takes from across the disciplines and has a very considerable yet distinct setof principles that are essentially targeted to uncovering thebetter understanding of a phenomenon (Kafle, 2011). As a method within theinterpretive research paradigm, it shares quite a manysimilarities with other research designs yet it has its ownpremises and differs from many of them on different stabilities 2003. do a hermeneutic (Laverty, To phenomenological research is an engagingprocess where the orientation towards the phenomenon is thematter of central concern and its reporting fustian demands for unique richness (Neergaard, Olesen, Andersen, and Sondergaard, 2009).

Three domains were explored in the conducted interviews including mother's perspective of their participation; discrepancies between mothers and nurses' participation in care; and mothers' attitudes towards participation in their children's care.

#### **Participants**

Semi-structured conversational style interviews were conducted with mothers of 8 children at the pediatric ward of a tertiary metropolitan hospital in Amman. Three of children were admitted for surgical intervention and the other five for medical treatment mainly renal system defect. One child was the first baby of the family, the other children have sibling were staying at homes, either with father or family relatives. All of children were admitted for more than 72 hours to the pediatric ward and their age ranged from five months to nine years, mothers were invited to participate in this study. Mothers' ages ranged between 23-42 with mean 32 years. Two mothers have works while the rest did not have any work outside the home.

## Interviews

A semi-structured interview started by asking the mothers a broad question about their experience in the participation of their children's care. The introductory question was: would you please describe

your experiences when your children was cared for in the hospital? Probing questions were used to detail these experiences, such as: would you please give me an example of that? Can you remember a specific incident that illustrates this? Can you tell me more about that experience? What effect does that have on you? Those probing questions were used to steer the conversation and to direct meaningful data disclosure (Polit & Beck, 2012). Interviews were terminated after saturation of meaning conveyed by participants was achieved (Polit & Beck, 2012). Tape-recorded interviews were conducted in the patients' rooms by two of the authors. The interviewed mothers were encouraged to describe their experience as sincerely as possible. Notes about the impression of the interview process, the parent's nonverbal responses, and the environmental factors that have influenced the interview process were also taken into consideration. The duration of the interviews varied between 60 and 90 minutes. The tape-recorded narrative interviews were transcribed verbatim to text by the researchers.

### **Ethical considerations**

Ethical approval was obtained from the relevant research ethics committee at the faculty of Nursing at the University of Jordan. All interviews were voluntary and based on informed consent. Confidentiality of interview data and personal identity was assured; the mother informed that she was given a false name attached to the data from the point of collection and that audio tapes will be erased on completion of the study. There was no financial reward for participation, and participant's right to withdraw from the study at any time was also explained.

### Interpretation of the data

Interviews were initially transcribed verbatim in Arabic and then translated into English. Expressions, such as exclamations, laughter, and expletives were included in the text and separated from the verbal text with square brackets, where as pauses were indicated by using dashes (Morse and Field, 1995). The transcript was checked against the audio taped data for accuracy by one of the authors and thus the original meaning and intent of the data were preserved. The interviews were analyzed in several steps, beginning with reading the transcript several times as to acquire a sense of the general meaning; then interpretations and understanding of the meaning of the parts of the text; finally, significant statements were extracted and formulated into meaningful units (Polit, & Beck, 2012). The research context was organized into clusters of themes. All meaningful units were described in details and an interpreted whole of the phenomenon was formulated by examining them earning conveyed in the interview

narratives. After data analysis was completed, final themes were returned to mothers to credit the captured meaning behind their personal experiences in caring for their hospitalized children. Credibility the member checking is one process that contributes to the rigor of qualitative research (Speziale & Carpenter, 2007).

### **Findings**

Findings indicated that the narratives dealt with experiences of emotional tension among all of the mothers. Every mother participated in this study portrayed the situation when her child was hospitalized. The narratives described the mothers' experiences when they had to stay with their children and the impact it had on their life. The essence of mothers' experience based on the stated domains during their children's hospitalization was expressed in four themes: reasons for staying with the children, impact on family's routine, expectations of nurses, and perceptions of facility provisions.

# Reasons for staying with the child

Regardless of child's age and severity of illness, mothers believed that their sick children were too young to look after themselves. Therefore, mothers in this study were eager to stay with their hospitalized child. When the mothers were asked about how they spent their time in the hospital, they mentioned a list of activities they performed for their children.

First, mothers in this study stayed at the bedside of their sick children as to provide individualized care. When a child was hospitalized, his/her usual day-to-day care needed to be readjusted so as to fit into the hospital routine, such as the feeding schedule, the time for changing clothes, and bathing.

All mothers participated in this study believed that her own child was different from other children, therefore her child will not be able to fit into the hospital routine. Moreover, mother viewed herselfe as the only one who knew her child's emotion, character and behavior. Mothers feared that health care providers might not understand child's need. One worked mother of medical case child stated:

"....my child cannot be far away from me, I cannot be in place and my child in other place as hospital.,.. I prefer to be with him each moment.....he refused to let his aunt to stay with him, and me too, because no one can understand my child's needs as I, my child has special style and routine to do his daily activities as bathing, dressing...

Second, the mothers commented on the shortage in nurses and their heavy workload. They felt that although nurses had been working very hard, some children were not receiving the necessary attention. But they also felt that nurses should not be blamed. In case there was any sudden change of condition, the mother could report to the nurses promptly so that

immediate action could be taken. The mothers stated that they were always the first person to find out her children's problems, such as fever ordislodgement of intravenous cannula, and report to the nurses. Even though the children's conditions were stable, mothers felt that they had to ensure their children's safety. One mother of medical case child remarked:

".... Nurses have work load, most the times I told the nurse about the intravenous cannula if dislodge out, and the nebulizer finished to my child to stop the oxygen...,"

Third, mothers' presence was to meet the children's and their own emotional needs. According to the mothers, their children were very afraid of health care professionals and regarded them as a symbol of "giving injections". Mothers also wanted to provide a sense of security for their children, especially when undergoing some invasive procedures such as taking blood samples or insertion of intravenous cannula. According to the mothers, individual physicians and nurses determined whether they were allowed to stay during distressing procedures. Moreover, the mothers explained that if they did stay with their children they would have missed her children and kept thinking and worrving about them. Mothers appreciated the opportunity to stay with their children and verbalized the inability to leave their children alone in the hospital. One mother of surgical case child stated:

"..... nurses not informed me about my child's health progress unless I asked"......."Just a few comforting words from the nurses would brighten my day"....My child sometimes has fear of nurses ,and called them as "giving injection".....so I prefer to be with my child for Intravenous cannula or any invasive procedures, some health team members refused to let me to be with my child but mu child refused and me too..."

#### Rescheduling of family's routine

Once the children were hospitalized, mothers had to rearrange their daily living schedule in order to stay with the children. Moreover, relatives such as grandmothers and aunts were called upon to look after the other children remaining at home. Sometimes school-age children assumed the responsibilities of looking after their younger siblings. One unworked mother stated:

"... My big son has a heavy responsibilities of the homecare he is in sixth grade, started to take care for his little brother who is in the first grade by assisting him to do his homework, and dress him to school daily, clean the house, and do his homework...sometimes my mother and my sister who live near my home visit my family and they are cleaning the house and clothes of my kids, also prepare foods for few days...also there is burden on

my husband, in addition to his job outside the house, at evening sometimes he prepare his food and his dressing for the next day. While when I was at home, I do that and he did not do any things for himself....

## **Expectations of nurses**

According to the mothers' perceptions, the most nurses were very professional and worked very hard. Most nurses showed concern about patients and their parents. Mothers also emphasized that nurses should take more initiative in reporting the children's conditions to them, although nurses perceived that explaining the children's condition, treatment plan and prognosis was the responsibility of the physicians. One mother of surgical case child remarked:

"A nurse who is willing to communicate with children and parents is a caring nurse...just a few comforting words from the nurses would brighten patients' day."

# Perceptions of hospital facilities

Mothers prefer to stay with their children in order to provide them emotional support even mostly there are uncomfortable hospital facilities. Mothers commented that the hospital facilities seemed inadequate to enable parents to stay for 24 hours with their children, despite favorable hospital policies. The mothers had the following comments on three aspects of facility provisions: First, she commented on the sleeping facilities. There was no provision for parents's leeping in. Mothers had to sit on a plastic chair by the bed side and lean forward to rest her heads on the children's bed for the whole night. Mother of surgical case child complained of glutealpain and numbness of the arms after sleeping for a period of time. She described the situation:

"My child has been staying here for 16 days. I am 20 weeks pregnant and I should stay sitting on this plastic chair for 15 nights. With this type of plastic chair, if you hold your child and sit on it for a while, you will definitely have buttock pain. I had pain over here (pointing to the sacral spine) for several days. I am not expecting a very comfortable sleeping environment, but at least not a chair that adds to my hardship. Besides, parents frequently woke up due to the performance of routine care to their children and the crying of other children in the unit."

The mothers in this study expressed concern about the hygiene facilities. There were hygiene facilities, such as toilet and bathroom for pediatric patients but not parents. Some parents would take a shower cautiously in the pediatrics bathroom and not secured well. One mother of medical case child remarked:

".... The hospital facilities are in general good like toilet cleaning is done every 6-8 hours, but I cannot

take shower unless if there is trusted person standing in front of the unlooked by key bathroom door..."

In addition, food preparation was also mentioned. The mothers appreciated the hospital staff to provide them with meals as the patients so that they did not need to leave the hospital for buying meal. One mother of medical case child remarked ".... meals three times per day are offered to me and my child which are mostly delicious but sometimes

".... meals three times per day are offered to me and my child which are mostly delicious but sometimes not as my child's prefer, so I am calling for delivery meal from the nearest restaurant..."

### 4. Discussion

Parents viewed their children's hospitalization is the most critical event in their lives regardless of the children's health condition and the length of children's hospitalization. Staying with the hospitalized children was an unconditional aspect of being a parent for those mothers. Mothers in this study put aside their personal commitment, their family needs and their basic physiologic needs in order to accompany their sick children 24 hours per day.

Mothers' need for constantly being at the bedside of their children in this study had seldom been reported in Western studies (Shields et al, 2006). However, the low level of fathers' participation reflects that mothers remain as the primary caregivers of their children like any western and eastern communities, especially when their children are sick. Those parents often provided the usual day-to-day care to their children (Roden, 2005, Falk von Wendt, Klang, 2007, Tourigny, et al, 2005).

Mothers' description of their experiences in caring for their hospitalized children showed that mothers had a strong desire for participation, which was in line with previous studies (Ygge et al., 2004). Findings also confirmed that mothers' participation in their children's care was done with the intention to provide individualized care to their sick children, to ensure adequate children monitoring, as well as to meet both children's and mother's own emotional needs.

Mothers' comments that their children had always faced problems fitting into the unit routine were interesting as it can be argued that the daily unit routine could not meet those children's needs (Shields et al. 2008). Children in this study were expected to cooperate with standardized treatments and received no individualized treatment. Findings in this study showed that instead of demanding the hospital to modify the pediatric unit to meet those children's needs, mothers altered their own living schedule to stay with their sick children so they could

provide flexible and individualized care for their children.

The majority of mothers in this study showed their understanding that nurses were very busy and therefore should not be expected to monitor every child closely.

As a result, mothers expressed their concerns that their children may not be well looked after. The greater the hours that parents stayed with their children, the higher the chance that they might identify their children's problems; and thus the stronger the belief that their presence at their children's bedside was essential..

Children in this study viewed the health care professionals as a symbol of

"giving injections". Mothers expressed the idea that their children were afraid of nurses and doctors presence in the room. Mothers believed that their presence would be the most appropriate mediators to assist in providing care and emotional support for their children. Shields et al. (2008) suggested that parents could serve as a link between their children and the staff; in addition it can assist in relieving the children's anxiety and providing a sense of security. The mothers' presence with their children can also alleviate their stress as they can witness their children's progress and current condition thus reduces their fear of the unknown.

While some mothers stated that they were satisfied with the nurses' performance in taking care of their children, some mothers expressed their expectations that nurses should take more initiative to offer help and to report children's progress to their parents despite parent's presence at their children' bedside. Similar toFalk et al, (2007) finding that parents of children with head injuries prefer to stay and share the care with nurse.

Mothers in this study felt that the provision of information was particularly important during times of stress. However, some mother did not express explicitly their personal need for communication or emotional support from the nurses. This can be related to mother's perspective that the nurses' primary focus was the sick children in the wardsimilar to study finding of Kyritsi, Matziou, Perdikatis, Evagelou (2005). Parents' needs for communication and emotional support during children's hospitalization are essential for better partnership in children's care (Lam et al , 2006 & Abdelkader et al , 2012). In view of mothers' passiveness in seeking help or emotional support, nurses should take an active role by starting asking about parents' need for assistance in their children's information, Providing demonstrating recognition of parents' great efforts in children's care and showing concern about parents' wellbeing can

help both parents and their children to feel cared forsimilar to **Sarajarvi**, **Haapamaki**, **Paavilaines** (2006) findings. Parents' recognition of nurses' support is likely to make them more willing to collaborate with nurses to provide bedside care for their childcare.

Mothers in this study expressed their discontent toward the facilities provided at the hospital, specifically regarding the inadequate sleeping and hygiene facilities at the children's bedside. This inadequate facility support has been found in diverse pediatric care settings as reported by Ygge et al, 2006 & Shields et al, 2008 Regardless of mothers' discontent with the facility provisions at the hospital, mothers placed their personal physical and psychological needs in a lower priority compared to their children's needs.

### Rigor of the study

For the purpose to build the confident of the reader in this study, the researcher highly ensured that the text is credible. One way to establish credibility member checking (Laverty, 2003, Speziale & Carpenter, 2007). Therefore, the finding of this study was reviewed by the mother and verified that it was clearly represented her thoughts, feelings. Dependability of the study included the aspects of consistency (Polit & Beck, 2012, Speziale & Carpenter, 2007). In this study having only one interviewer (the researcher) is one way to assure dependability.

Other process that contributes to the rigor of qualitative research is theconformability which concerns with the aspect of neutrality (Laverty, 2003, Speziale & Carpenter, 2007). This established by audit trial; which included a record of all decision rules used in data management and analysis processes. The researcher submitted the transcript of the finding to one qualitative researcher colleague who read them independently and saw that they followed from the data (raw data, analysis notes, coding) and confirmed most of the study categories, the differences were discussed between them after reread the data and some discrepancies were ignored. Then conformation about the final categories was made.

Assuring transferability of this study the researcher tried to give full description of the study (setting, sample, data collection and analysis procedures) in an attempt to enable the reader to make a transferable judgment. Finally, the reflexivity issue was insured in this study through detailed and contextual writing, and a reflexive account of the research process. Through journaling, the researcher separated her own preconceptions, experience and believes from the descriptive raw data during

analytical phase of the study to decrease as much as possible the potential bias and influence..

#### **Conclusions**

The approach used in this study has value in the understanding of parents' perceptions of their participation in children's care. The findings of this study supported those in international studies that mothers also had a strong desire for participation in order to provide individualized childcare, ensure adequate children monitoring and meet the children's as well as their own emotional needs. The mother in the current study viewed accompanying her hospitalized children as an unconditional aspect of being a parent and was very willing to put aside her personal commitment and various family roles to spend long hours in the hospital and provide pragmatic and psychological care to her children. Obviously, some of the care that mothers provided, especially the psychological support to their sick children, is irreplaceable as Viedma-Dodd (2007) described this status. Adequate facilities and support resources should also be provided to parents in order to facilitate parent participation. Parents are very influential in their children's lives and can affect the children's recovery. Thus their physiologic, emotional and social needs should also be carefully considered...

## Recommendation

The qualitative approach used in this study and in other similar western studies (Lam et al, 2006) has value in the exploration of parents' perceptions of their participation in childcare. The findings of this study supported those in western studies The mother in the current study viewed accompanying her hospitalized child as an unconditional aspect of being a parent and was very willing to put aside her personal commitment and various family roles to spend long hours in the hospital and provide pragmatic and psychological care to her child. Obviously, some of the care mother provided, especially the psychological support to her sick child, is unique. Mothers are the child's most influential people and can affect the child's quality of care, and thus their physiologic, emotional and social needs should also be carefully considered by health professions as nursing.

Mothers need to be concerned of their needs and provide information in order to help them to cope effectively in this period. Hospital manager should pay attention to allocate-as possible- the environmental facilities in the hospital such as a separate temporary bed and washing facilities for mothers and possibly food, as well as emotional reassurance from the nurses that help mothers to

carry out their role towered their sick children effectively

### Limitation

A limitation to our study was the use of a semistructured interview mothers recruited from only one hospital. Recommendations for future research include expanding parents to include both mothers and fathers and recruiting participants from different settings and different hospitals.

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