

# Jordanian Parents' Needs While Their Child is Hospitalized

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## Abstract

**Objective:** To explore the needs of Jordanian parents in relation to their participation in the care during the hospitalization of their child.

**Method:** A descriptive cross-sectional study where a questionnaire was administered to parents of hospitalized child, aged one month to thirteen year olds. Pearson correlation coefficient was performed to examine the relationships of parents' needs and their participation.

**Results:** The superior needs among 192 parents (90%) were that mothers were concerned about trusting in staff, trusting of staff and acquiring information. The high significant correlation ( $r = 0.80$ ) emphasizes the relationship between parents' participation in the care of their hospitalized child and parents' need especially for support and guidance ( $P < 0.01$ ).

**Conclusions:** The findings confirmed that parents have a desire to participate in the care of their hospitalized child after fulfillment of their needs, similar to studies in Western and Eastern countries. Jordanian parents had no choice in child care participation; their basic needs were not met such as trust of staff, and support and guidance to parents and other family members.

**Keywords:** Hospitalized child, Jordanian parents, Parents' needs, Parents' participation.

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## Introduction

The presence of parents near their child in the hospital and their participation in the care given has been recognized to be important and necessary for the child and for the parents themselves.<sup>1</sup> All that encompass parental rights must be taken seriously into account by health professionals and included in the planning of nursing care, especially parents' participation in the care of their child.<sup>2</sup>

There is a literature about the care of hospitalized children in developed countries, but little from developing countries.<sup>3</sup> Most of the work reviewed was sourced from the nursing literature, while in developing countries; the available literature was largely from medicine. Shield's review was aimed at Sweden to critically examine the effect of hospitalization on children and their parents.<sup>3</sup> Lam, et al. found that most parents perceived that they needed help from hospital staff in order to meet their needs to empower them for participating in the care.<sup>2</sup>

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Parents have different needs and different ways of ensuring those needs are fulfilled. Hallström and Runeson identified five different strategies parents used to ensure their needs were satisfied: avoiding being a bother, having a positive attitude towards the staff, asking questions, preparing themselves, and informing the staff about how they wanted things to be arranged.<sup>4</sup> It is important for professionals to identify these differences among parents, otherwise a risk exists that the needs of quiet and undemanding parents will not be met, and this may affect the care their child receives.

Other studies conducted in developed countries compared the perceptions of needs held by parents of hospitalized children with those held by the staff caring for them; the English and Swedish arms of those studies by Shields, et al. indicated that parents did not need as much help as the staff supposed.<sup>5, 6</sup> Those parents of hospitalized children are more independent than staff perceived them to be. However, parents have complained that health care professionals provide too little information about their child's condition and treatment, which lead to a negative attitude of parent towards participation in the care of their child at hospital.<sup>7</sup>

The studies from developed countries recommended that parents should be allowed to stay in the hospital with their child and that parents' participation must be appropriate. Furthermore, hospital staff needs to be educated about the special needs for parents and their children. Children should be prepared for hospital admission, if possible, and parents' needs should be met. While in developing countries, the insufficient literature suggested that the importance of parents' participation in the care of a hospitalized child is starting to become recognized.<sup>6</sup> In Jordan there has been inadequate attention given to the above needs in pediatric practices, and most of the time the needs of the parents are not sufficiently evaluated by health care professionals, who frequently neglect to stress on the parents' participation or include them in the health care plan.

Parents' participation in the care of patients is supposed to be based on their needs. The concept of need, however, is difficult to define because parents and caregivers may have different opinions. According to Orem's self-care theory, it suggests the need for the examination of the independence of people and the ability of them to meet their needs themselves. Orem's model of self-care mentioned that humans have an innate ability to care for themselves, and the role of nursing is to ensure that this is maximized in their time of need.<sup>8</sup> Three constituents comprise Orem's theory: 1) self-care, 2) self-care deficit and 3) nursing systems.<sup>9</sup> Taylor has described family as an important part of the application of Orem's self-care theory: first, a conditioning factor which influences individual self-care systems as parents' need when being at the hospital with their sick child; second, it is the setting for dependent-care which becomes relevant when self-care is not possible, for example, with children and infants; and third, it is a unit with certain functions in relation to both self- and dependent-care. Dependent-care is a consequence of self-care; parenting is described as dependent-care, and not all dependent-care is done as part of parenting especially for a hospitalized child.<sup>10</sup>

Parents in this context were considered as the child's natural or adoptive parents, in other words, the primary care-giver to the child.

The purpose of the present study is to explore the specific needs for Jordanian parents in relation to their participation in the care of their child during hospitalization. This study answers two main questions:

1. What is the degree of importance to parents for the following specific parents' needs?
  - a. The need for trust in the staff,
  - b. The need for the trust of the staff,
  - c. The need for information,
  - d. The need for support and guidance,
  - e. The need for the fulfillment of their physical and emotional needs, and
  - f. The need relating to the hospitalized child together with the other members of the family.

2. Are there effects from those needs for parents' participation in the care of hospitalized children?

## **Methods**

The design of this study was a descriptive cross-sectional. Data was collected by using self-report questionnaires from parents in pediatric wards.

## **Sample**

This study used a convenient sample of 200 parents who had children one month to thirteen years, hospitalized in pediatric wards for at least three days staying over three months.

## **Setting**

The target hospital was one of the university hospitals in Jordan with 522 beds and 12 wards. The two pediatric ward capacities are 58 medical and 40 surgical beds distributed in three different class rooms related to the health insurance degree of the patients; these classes are different in physical room facilities and resources but health care services are the same. Pediatric intensive care units were excluded, because no parents are allowed to stay there.

## **Data collection**

In order to carry out the study, approval was granted by the Scientific Research Committee at the University of Jordan/Faculty of Nursing and the target hospital. The parents were invited to participate at the day of the child's discharge, by a research assistant in each ward. The packages for each participant contained the Needs Parents Questionnaire (NPQ) with a cover letter that includes information about the purpose of the study, what was expected from participants, where to return the packages, and that the study was anonymous. Participants were told that the information given would be treated anonymously. Ethical issues were followed throughout the study to ensure the protection of the human rights of the participants.

## **Variables and Instrument**

The tool was based on the Needs of Parents of hospitalized children Questionnaire (NPQ) developed by Kristjansdottir<sup>11-13</sup> where the questions and statements comprise a scene of physical and emotional needs which parents might experience during a child's admission, including support, information and participation in the child's care. The NPQ was further developed and modified when used in several western countries, with the aim of cross-cultural comparisons, as in the United States and Iceland,<sup>12-14</sup> Sweden<sup>5</sup> and the United Kingdom.<sup>15</sup> Reliability analysis of the inner consistency of the NPQ had a Cronbachs range in prior studies of  $\alpha = 0.91-0.92$ <sup>13-15</sup> The NPQ contained 43 statements that had been derived through expert consultation; piloting and reliability testing with parents provided evidence that this tool is valid and reliable to measure parents' needs.

The questionnaire was translated from English language to Arabic language and back translation was done and checked by another English-speaking lecturer nurse. The questionnaire contained 43 statements of possible needs of parents during their child's hospitalization. The items in the questionnaire were divided by its authors into seven groups according to their content: a) The need for trust in the staff, b) the need for the trust of the staff, c) the need for information, d) the need for support and guidance, e) the need for the fulfillment of their physical and emotional needs, f) the needs relating to the hospitalized child together with the other members of the family, and g) The effects of the previous needs on parents' participation with their hospitalized children. Parents responded to the statements on a Likert scale. Data analysis assessed the level of importance of each item of need as perceived by parents to ascertain their priority.

The Arabic version questionnaire was pre-tested on twenty parents prior to data collection to know any comment about the structure, difficulty, clarity of items and the time needs of filling out the questionnaire. These pilot respondents were not included in the sample.

## Statistical Analysis

The data was analyzed by the Statistical Package for the Social Sciences (SPSS for Windows Release 16). Data was entered for each of the items that make up the Needs of Parents for hospitalized child Questionnaire (NPQ). Once the data had been entered, screening for missing data was done. Descriptive analyses of all the variables were performed to check for normalcy. An NPQ score was calculated for each variable. The descriptive statistical analysis began with a frequency analysis to identify the distribution of socio-demographic characteristics among the family caregivers and details of admission to the hospital wards. This descriptive data was presented in percentages. Further descriptive analysis explored how parents valued their needs and their expectations to participate in the care on the wards. The independent variable *t*-test and one-way ANOVA were done to differentiate the means scores of variables, and a Pearson correlation with stepwise linear regression to infer the relation between variables was carried out. Backup copies of the data file and all the data were stored for safekeeping.

## Results

In total, 200 questionnaires were distributed to Jordanian parents of hospitalized children at the University of Jordan Hospital. One hundred seventy five completed the questionnaire with a response rate of 87.5 percent. Thirteen were excluded and 162 met the inclusion criteria. Data was entered into SPSS, coded, and organized.

Different items were clustered and calculated together to formulate the total scores of the following variables, parent's participation and parent's needs: trust in staff, trust of staff, need for information, need for support, need for physical and emotional needs, and needs related to hospitalized child together with other family members. Parent's participation was the principal dependent among different analytical procedures performed.

### 1. Characteristics of the sample

One hundred and sixty two parents participated in the current study. The majority of the hospitalized children were accompanied by their mothers (90%, n=145) who were aged thirty years and above (59%, n=95) and had a secondary school education (41%, n=67) rather than their fathers or someone else (Table 1). According to the results, mothers who accompanied their children through the hospitalization period were not working and had a monthly family income of 251 to 500 JD (360-800 USD). Among hospitalized children, the majority were males (61%, n=98), aged 4 to 9 years (30%, n=49), had acute surgical health problems (57%, n=92) and were care giver dependent (46%, n=74). Concerning parents' participation and their needs, results show a relatively reasonable mean of overall participation (4.19±0.70). Descriptively, parents' need to trust in staff, need the trust of staff, and need for information (4.67±0.6, 4.50±1.2, and 4.4±0.8, respectively) were relatively superior to their needs for support and guidance (3.80±0.7), need for fulfillment of physical and emotional needs (3.9±0.7) and needs related to a hospitalized child together with other family members (3.8±0.7) (Table 2).

**Table (1): Sample Characteristics, N= 162**

	<u>Variables</u>	<u>n (%)</u>	<u>Median</u>
<b>Care giver</b>	Mother	145 (90%)	Mother
	Father	13 (9%)	
<b>Parent's age</b>	18-25 years	20 (12%)	> 30 years
	26-30 years	46 (28%)	
	> 30 years	95 (59%)	
<b>Mother's education</b>	Secondary school	67 (41%)	Secondary school
	Diploma	35 (22%)	
	University degree	34 (21%)	
	Higher studies	5 (3%)	

<b>Care giver's work</b>	Yes	52 (32%)	Not working
	No	104 (64%)	
<b>Family Income</b>	≤ 250 JD	51 (32%)	251-500 JD
	251-500 JD	75 (46%)	
	> 500 JD	21 (13%)	
<b>Child's gender</b>	Male	98 (61%)	Male child
	Female	57 (35%)	
<b>Child's age</b>	1-11 months	40 (25%)	4-9 years
	1-3 years	33 (20%)	
	4-9 years	49 (30%)	
	10-14 years	34 (21%)	
<b>Child's health status at arrival</b>	Acute/ Emergency	92 (57%)	Acute/ Emergency
	Chronic	57 (35%)	
<b>Child's main complaint</b>	Surgical	106 (65%)	Surgical
	Medical	48 (30%)	
<b>Child's dependency</b>	Independent	32 (20%)	Dependent
	Needs assistance	56 (35%)	
	Dependent	74 (46%)	
<b>Child's length of stay</b>	1-3 days	57 (32%)	4-7 days
	4-7 days	60 (37%)	
	> 7 days	43 (27%)	
<b>Health problems at birth</b>	Yes	46 (28%)	No health problems at birth
	No	113 (70%)	

**Table (2): Description of Specific Parents' Needs of the Sample N= 162**

<b>Parents' needs</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>
<b>Trust in staff</b>	4.67	0.6	1-5
<b>Trust of staff</b>	4.50	1.21	1-5
<b>Need for information</b>	4.43	0.81	1-5
<b>Need for support and guidance</b>	3.80	0.75	1-5
<b>Need for fulfillment of physical and emotional needs</b>	3.92	0.72	1-5
<b>Needs related to hospitalized child together with other family members</b>	3.88	0.77	1-5
<b>Overall parents' participation</b>	4.19	0.70	1-5

## 2. The relationship of parents' needs and their participation in the care

This section examines whether a relationship between different parents' needs (parents' need to trust in staff, trust of staff, need for information, support and guidance, fulfillment of physical and emotional needs, needs related to hospitalized child together with other family members and parents' participation in caring their children) exists. Pearson correlation coefficient was performed to examine these relationships and results are shown in Table (3). Data revealed significant correlations between the aforementioned variables at different levels ( $P < 0.05$  and at  $P < 0.01$ ). A relatively high significant correlation emphasizes the relationships between parents' participation and parents' needs ( $P < 0.01$ ) except the relationship between parents' participation and the need to

trust in staff ( $r = 0.12$ ,  $P > 0.05$ ). Among those needs significantly correlated to parents' participation, the parents' need for support and guidance was superior ( $r = 0.80$ ) to other recorded needs such as trust of staff, need for information, need for fulfillment of physical and emotional needs and needs related to a hospitalized child together with other family members which were satisfactorily correlated ( $r = 0.64$ ,  $0.43$ ,  $0.63$ , and  $0.64$ , respectively) to parents' participation. On the other hand, parents' needs were significantly correlated to each other except in their relationships with trust in staff. Trust in staff recorded low correlations with trust of staff and need for information ( $r = 0.18$  at  $P < 0.05$  and  $0.20$  at  $P < 0.01$ , respectively). Additionally, a relatively higher correlation ( $r = 0.74$ ,  $P < 0.01$ ) was observed between parents' need for support and guidance and their need for fulfillment of physical and emotional needs.

**Table (3): Means, standard deviations and correlations of parents' needs and their participation during hospitalization. N= 162**

	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
1. Trust in staff	1.00						
2. Trust of staff	0.186*	1.00					
3. Need for information	0.208**	0.280**	1.00				
4. Need for support and guidance	0.095	0.302**	0.439**	1.00			
5. Need for fulfillment of physical and emotional needs	0.133	0.209**	0.260**	0.745**	1.00		
6. Needs related to a hospitalized child together with other family members	0.067	0.203**	0.381**	0.631**	0.610**	1.00	
7. Parents' participation	0.120	0.649**	0.430**	0.800**	0.631**	0.645**	1.00
Mean	4.67	4.50	4.43	3.80	3.92	3.88	4.20
SD	0.65	1.21	0.81	0.75	0.72	0.77	0.65

\* Correlation is significant at  $\alpha=0.05$  (2-tailed)

\*\* Correlation is significant at  $\alpha=0.01$  (2-tailed)

### 3. The effects of recorded demographic variables on parents' participation

The effects of recorded demographic variables were examined in relation to parents' participation scores using one way ANOVA and parents' needs *t* tests. The Mann-Whitney U test and Kruskal Wallis test were used as ANOVA and *t* test assumptions were violated in terms of significant Levene's test of Homogeneity of variance. Although parents' needs were correlated to parents' participation (Table 3), no one demographic recorded variable is correlated with parents' participation which signifies the homogeneity of the sample selected and addresses no confounding effects other than parents' need to participate in the care of their hospitalized children.

### 4. Predictors of parents' needs for parents' participation in the care while child's hospitalized

This section answers the core question of this study that is which specific needs are important related to parents' participation in the care of their child during their child's stay at the hospital and how important these needs are. A stepwise linear regression analysis was used to estimate the probability of significantly correlated variables including all parents' needs namely the

need to trust in staff, trust of staff, need for information, need for support and guidance, need for fulfillment of physical and emotional needs and needs related to a hospitalized child together with other family members. The six aforementioned variables were entered into a linear regression analysis. The analysis consisted of a 4 step model with no missing cases on an entry level of  $\alpha = 0.05$  and removal at 0.1 using parents' participation scores as the dependent variable. As shown in Table 4, the outcome showed a predictive model of three predictors which were significantly related to parents' participation: trust of staff, need for support and guidance, and needs related to a hospitalized child together with other family members. These factors have a comparable power in the prediction of parents' participation. Need for support and guidance had relatively higher prediction effects ( $B = 0.453, P < 0.001$ ) compared to the need for trust of staff and needs related to a child together with family members as the need for support and guidance reported higher relationship and less residue compared to other significant needs (Table 4). As a result, the need to trust in staff, need for information, and need to fulfill physical and emotional needs were not able to predict parents' participation and were close to being of almost no importance to those parents having a hospitalized child.

**Table (4): Stepwise Linear Regression Analysis of Predictors of Parents' Participation. N=162**

<i>Variables</i>	<i>B</i>	<i>SE</i>	<i>β</i>	<i>P value</i>
1. <i>Trust in staff</i>	- 0.069	---	-0.027	0.397
2. <i>Trust of staff</i>	0.236	0.018	0.443	< 0.001*
3. <i>Need for information</i>	-0.033	----	-0.014	0.687
4. <i>Need for support and guidance</i>	0.453	0.036	0.519	< 0.001*
5. <i>Need for fulfillment of physical and emotional needs</i>	0.052	---	0.031	0.052
6. <i>Needs related to a hospitalized child together with other family members</i>	0.191	0.034	0.227	< 0.001*

\* *Predictors of parents' participation final model produced at  $\alpha=0.05$ ,  $F=288.6$ ,  $P<0.001$ ,  $R^2 = 0.849$ .*

\* *Excluded variables are: trust in staff, need for information, and need for fulfillment of physical and emotional needs.*

## Discussion

The findings in this study demonstrate that Jordanian parents with a hospitalized child, like parents from all over the world, have the same goal of wanting to return ill children to health, although they do not share the same socio-demographic conditions or view the caregiving situation from the same frame of reference as Western families who have a higher standard of living.<sup>16</sup> This study explored the specific needs and their important related parents' participation. The study found that, to a larger degree, parents have the exclusive care of the children and it is interesting to note, that mothers consider all the groups of needs that were studied more important than the fathers. The difference of importance with regard to the gender can be explained by the fact that in western civilizations, the role of the mother is more related to childcare and family care as well as to the needs that arise from this care which can be physical, emotional and social.<sup>16</sup> The findings of our study agreed with those findings of Kristjandottir,<sup>13</sup> where it was found that fathers rated all groups of needs as less important. Tradition in Jordan sees the mother as being exclusively responsible for the upbringing of the child, both in health and sickness, with the result that the mother perceives the needs that branch from the hospitalization of the child as more important.

According to the results, Jordanian parents consider the need for trust in staff, trust of staff and need for information regarding the prognosis,

the condition of the child and whatever happens to the child as highly important, more than support and need for fulfillment of physical and emotional needs. That's mean they have concern about participating in the care of their child rather than fulfilling their personal needs even with very limited bedside facilities like seats to sleep overnight. These results are consistent with previous studies which have examined the parents' needs of hospitalized children<sup>11, 12, 17, 18</sup> where all parents thought these needs were important.

The study has correlated the relationship between parents' participation and parents' needs such as needs for information, fulfillment of physical and emotional needs and needs related to a hospitalized child together with other family members. The study findings are supported with many studies such as Dearmun,<sup>19</sup> Neill<sup>20</sup> and Hallstrom<sup>21</sup> where the health care professionals look towards the parents and the needs of parents for information and support in order to facilitate parents' participation to be included in the medical staffs' activities. The need of parents for information regarding the progression of the health status of the child is important as the results of the study have shown because it is known that a serious and chronic illness affects the normal processes of development.<sup>22</sup>

The desire for the trust of the staff, the need for support and guidance, needs related to a hospitalized child together with other family members, the need for information, and taking

responsibility for the basic care of their child also seem to be universal needs.<sup>18, 23- 25</sup> Also, this present study from a Jordanian context demonstrates a need of support and guidance from health staff during and after hospitalization, as well as during the care process. However, not knowing what will happen to their children in the hospital will make parents feel neglected and abandoned.<sup>16</sup> These needs when they are not met will affect negatively on parents' participation as shown by this study.

As in Pongjaturawit's study on Thai parents,<sup>26</sup> Jordanian parents had no choice of participation in the care because their basic needs were not met with the trust of staff and the support and guidance to parents and other family members although they wanted to participate. While in China, parents can participate voluntarily and leave the rest of the care to the nurses to carry it out. Furthermore, in China most of the parents did not want to take part in decisions about their child's treatment, but preferred to leave that to the professionals.<sup>2</sup>

This study is also similar to the research carried out by Kyritsi<sup>22</sup> where parents desire to be trusted and parents' need for support and guidance were the superior needs for their participation in the care of their child which contributes to the preservation of the parental role in the hospital environment and to the reduction of stress, especially when parents discuss their participation in the care of their child with the nursing staff. Furthermore, other research has shown that the important information is needed for parents to enable them to participate in the care of the hospitalized child.<sup>27, 28</sup>

### **Strengths and Limitations**

A relatively high response rate of 87.5% was achieved during this study, perhaps indicating that parents found the issues covered to be directly relevant to their needs. The sample was drawn from one hospital, which cannot be said to be representative of all health facilities in Jordan. The questionnaire may not have included all possible needs of parents and may not accurately

reflect the parents' participation in the care of their child, so further qualitative or triangular research is recommended for studying these perspectives.

Kristjansdottir's NPQ<sup>11- 13</sup> was found to be as useful in Jordan as it was in Australia, England and Sweden. However, the tool needs to be revised, as societies around the world have changed since it was last reviewed in 1995.

### **Conclusion**

This study and other non-western studies,<sup>15</sup> which added to the opportunity to make comments, also had the value of being able to describe needs and experiences among a bigger population and might well be used for further comparisons in other countries and contexts. The findings in this study, in an Arabic context, confirm that parents have a desire to participate in the care of their hospitalized child when their needs are fulfilled, similar to studies in western and eastern countries. It should, however, be noted that the Jordanian parents' expectations, needs, and experiences are rooted in the health system. As Grantham-McGregor<sup>29</sup> argue in low-income countries, facilitating and supporting family caregiver's social conditions and their engagement, involvement and participation in the care process are important not only for survival but also for the sick child's recovery and development. Parents' experiences related to their participation in the care during a hospital stay further influence their expectations, their assessment of the health care system, and their ability to cope with similar situations in the future. It is suggested that the nursing staff must include the evaluation and satisfaction of parental needs and parents' participation in the child care planning. This also should be emphasized in nurses' education.

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## احتياجات الاباء والامهات في الاردن الذين لديهم اطفال مرضى في المستشفيات

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### الملخص

ان لتلبية احتياجات الاباء والامهات الخاصة خلال فترة مكوثهم في المستشفى قرب الطفل المريض للأثر العظيم الذي يعود بالفائدة على الطفل من جانب والاسره والمجتمع من جانب آخر.

هدفت هذه الدراسة لاكتشاف احتياجات الاباء والامهات الذين لديهم اطفال مرضى في المستشفى، ومدى تأثير تلبية هذه الاحتياجات على مشاركتهم في الرعاية الصحية المقدمة لأطفالهم في رحلة العلاج في المستشفى، من خلال توزيع استبانته خاصة بالاحتياجات على الاباء والامهات الذين لديهم اطفال في المستشفى والذين تراوحت اعمارهم بين شهر واحد وثلاث عشرة سنة. تم تحليل المعلومات حول الاحتياجات بالاسلوب الوصفي، و تحليل علاقة هذه الاحتياجات وتأثيرها على مدى مشاركتهم في الرعاية باستخدام معامل ارتباط بيرسون وتحليل الانحدار الثنائي.

لقد دلت النتائج على أن 90% من العينة من الامهات، وكانت أعلى الاهتمامات تتمركز حول الحاجة للثقة بالطواقم الصحي وعمله، ومن ثم الحاجة الى الحصول على المعلومات عن حالة أطفالهن الصحية. كما أثبتت الدراسة أن هناك تأثيراً ذا مؤشر احصائي ملموس بين حاجة الامهات للدعم والارشاد من قبل الفريق الصحي ليتسنى لهن المشاركة في تقديم الرعاية لاطفالهن في المستشفى لما له من تأثير كبير على صحة الطفل .

أثبتت هذه الدراسة أن الاباء والامهات في الاردن لديهم الرغبة في المشاركة بالرعاية الصحية المقدمة لاطفالهم اثناء اقامتهم في المستشفى، والذي يشجع على ذلك تلبية الحاجات الخاصة لهم ولافراد العائلة.

الكلمات الدالة: الأطفال المرضى في المستشفى، الآباء والأمهات في الأردن، احتياجات الوالدين، مشاركة الوالدين.