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FAMILY INVOLVEMENT IN THE CARE OF HOSPITALIZED CHILD

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ABSTRACT

Background: United Nations Children's Fund (UNICEF) states that children have the right to remain close and stay in contact with their parents. Parents should always consider what is best and share responsibility for bringing up their children. In Malaysia the research about the involvement of the family towards children's care is very rare. Therefore, this research is very important in order to improve family care in Malaysia.

Objectives: This study is

i. To identify family caregiver's involvement during care of children admitted in hospital,
ii. To identify family's experiences when they encounter healthcare provider's behaviour
iii. To determine the relationship between family involvement during care and family's experience when they encounter healthcare provider's behaviour towards the child care.

Method: A cross sectional study was conducted, using a questionnaire among 300 parents, who accompanied, stayed and was involved in the care of their children who were admitted in paediatric ward at Hospital Sungai Buloh, Hospital Selayang and Hospital Tengku Ampuan Rahimah.

Results: This study found that family involvement during care does not relate with family's experience when encountered with healthcare provider's behaviour towards the child care. Moreover, this study also shows that family are involved in the care of their hospitalized child. Besides that, caregivers are usually experienced indivisuals with good behaviour.

Conclusion: Families experience during the stay at the hospital will influence their assessment of the health care system, their expectation and the ability to face the same situation in the future.

Keywords: *Paediatric care; Family involvement; Family caregiver; Hospitalized child.*

INTRODUCTION

Participation of parents in care of children admitted in hospital has been driven by evidence covering a period of 50 years, which emphasizes the adverse effects of hospitalization for both children and their parents (Coyne and Cowley, 2007). Parents will act as a bridge between child and healthcare provider to ensure their children's needs are met. Integral to this, needs of parents also reflect the needs of their children (Foster *et al.*, 2010).

In addition, Coyne and Cowley (2007) found that the contribution of parents in the care of children admitted in hospital has been increasingly emphasized in paediatric nursing practice, since many issues of harmful effects of hospitalization towards children has already raised 60 years ago. Though children have a right to get the care from parents or family, families that are separated from the children due danger to their health, right of alternatives has been developed for them (UNICEF, 2006). For that reason, it is now well accepted that the participation of parents benefit children and families. As a result anxiety can be reduced for both parents and children if parent or guardian accompany the child into the hospital (Coyne and Cowley, 2007). In Malaysia the research about the involvement of the family towards children's care is very rare. Therefore, this research is very important to improve family care in Malaysia.

LITERATURE REVIEW

Family as a whole can provide a safe keystone for its members. The definitions of a safe basic family is a family that provide a relationship that can be embraced among all family members regardless of age and they feel really feel comfortable with each other and between people from outside the family. Moreover one vital feature in achieving this state is the ability to cooperate which is shown to be higher in secured families (Byng Hall, 2008).

Family centred care concept was used to describe about

the importance of the involvement of the family for the care of hospitalized children. The wards that implement family centred care were recognized parents as central for the well being of their children and hence, it is important in decision making for care of their children. Nurses confessed that parents know their children better that anyone, but in practice, nurses are better than them in taking care of the children admitted to hospital especially in the technique of complicated procedure. But, apparently the involvement of the parents or the caregivers is not present in every situation. So in order to implement it, current clinical practice guidelines should be based on current evidence of the clinical environment (Network *et al.*, 2005).

Family is always affected when the child is admitted in hospital (Shields *et al.*, 2003). Parent also known as primary caregivers usually participate and try to accompany their children in hospital (Foster *et al.*, 2010). Parental involvements in the care of hospitalized child are influence by responsibility for the treatment of their sick child, professionalism, support and work environment (Pergert *et al.*, 2012). It has been reported that separation between the family and children admitted in hospital can affect physical, emotional and psychological well-being of children and family (Grantham-McGregor *et al.*, 2007). Children without parental care are at risk for discrimination, inadequate care, abuse and exploitation, and their well being is often affected (UNICEF, 2006). The adverse effects of hospitalization like anxiety, unfamiliar environment and the stress of the disease exerts the need of parent's care for the children (Roberts and Messmer, 2011).

To create an effective partnership between healthcare provider and the family, the healthcare provider should have good understanding of family needs (Garrouste-Orgeas *et al.*, 2010). Moreover, the most important factor of overall patient satisfaction with hospital care is the parent's satisfaction with nursing care (Kawar *et al.*, 2011). The parents believe that most of the nurses are hard-working and they are concerned about the patient and their relatives. However, the parents want nurses to take initiative regarding care giving by staying alert always during their busy schedule (Lam *et al.*, 2006).

Easily accessibility towards health care providers is one of the important criteria for patient care. In building trust and long term relationship, attention, mode of treatment and the personal care offered are very important factors. The interaction with the doctor is vital so that it will provide right diagnosis and lead to a successful outcome. In order to understand patient's condition correctly, a doctor needs to spend sufficient and effective time with them (WHO, 2011). Moreover, health services research about health care and patient relationship has become one of the vital areas that benefits for both medical researcher and administrators (Wong and Lee, 2006).

Parents are ready to assist their children in daily life activity but they are not willing to get involved in the nursing responsibility based on clinical skills such as identifying their child vital sign and care for the child's intravenous infusion (Shields *et al.*, 2006). In addition, parent's participation and involvement in the care of their child in the ward make parents know and understand about their child condition clearly and make parents feel more secure (Lam *et al.*, 2006).

Browne and Talmi (2005) suggested that intervention that occur during hospitalization impact on the cognitive development and perceptions of parental pressure. Moreover, they also reported that in this way the physiological response (such as temperature, heart rate and respiration rate), behavioral, social and emotional reactions and needs of nutrition of the child will be regulated properly. Besides, this relationship also provides the keystone for development of self regulation capacity and helps to foster child's mental health.

The presence of family in caring for children in the ward can reduce distress, medicine, restlessness followed by earlier discharge (Kawar *et al.*, 2011). However, the lack of knowledge in child care may affect the treatment but quality of care can be improved if parents participate in decision about their child's care (Ygge *et al.*, 2006). According to Pergert *et al.* (2012) reported that in the paediatric oncology unit the involvement of parent in the care of sick child was beneficial in the children's hospital at Sweden.

But sometime parental involvement may cause stress to the children regardless of the mode of treatment they received (Söderbäck and Christensson, 2007) and may cause inconvenience to both parents and nurses if they

cultural influence are consudered (Davies, 2010; Söderbäck and Christensson, 2007).

METHODOLOGY

i) Study Design

A cross sectional study was conducted among parents, who accompanied, stayed and was involved in the care of their children admitted in paediatric ward at Hospital Sungai Buloh, Hospital Selayang and Hospital Tengku Ampuan Rahimah. A sampling was done on about three hundreds (300) families and their participation were on voluntary basis.

ii) Instrument

The self administered questionnaire was based on the Need of Parents of hospitalized children Questionnaire (NPQ) developed by Kristjansdóttir (1991, 1995). A modification was made for this study to cater for the Malaysian cultural environment. However, some concepts were taken from study by Söderbäck and Christensson (2008) where a questionnaire based on NPQ, was used in Mozambique. The researcher already sent an email to an author to get permission to use the questionnaire. Validity of the questionnaire has been evaluated using pilot study.

In this research, pilot study was done on 20 parents who accompany, stay and were involved in the care of their child at Hospital Tengku Ampuan Rahimah. Based on studies of Söderbäck and Christensson (2008), the reliability analysis of the inner consistency of the Need of Parents of hospitalized children Questionnaire (NPQ) had a Cronbachs range in prior studies of Alpha (á) = 0.91-0.92.

The questionnaires consist of three parts,
Part A: Demographic data (child and parents),
Part B: Caregivers' involvement in the care of a hospitalized child, and
Part C: Family caregivers' experiences on behaviour of health care provider.
The statement of part B was examined with a four-point Likert scale ranging from 'yes, always', 'yes, sometimes', 'no, never', and 'I do not know'. On the other hand, part C was examined with a five-point Likert scale which are 'very good', 'good', and 'quite well', 'bad', and 'very bad'.

iii) Ethical Approval

This research had been approved by research community ethic from Universiti Teknologi MARA (UiTM) and it also has been approved by National Medical Research Register (NMRR) with register ID number NMRR-11-1060-10671. To show their permission to involve in this study, the researcher asked the respondents to fill up and sign the consent form.

iv) Data Analysis

All the data recorded were subjected to computer software, Statistical Package for the Social Sciences (SPSS version 20.0). In order to measure the frequency and percentage, descriptive analysis was done based on the data regarding the parent's involvement in the care of children admitted to hospitals. The numerical data is measured by mean and standard deviation (SD). While categorical data were explained by frequency (n) and percentage (%). Pearson Correlation is used to analyze the hypothesis testing of the relationship of two categorical variables which are family involvement and their experience towards behaviour of the health care providers.

RESULTS AND DATA ANALYSIS

Part A: Demographic data

A total of 300 of children respondents are collected in this research. In terms of gender 51.3% were male and 48.7% were female.

Table 3.1: Demographic data (Child)

Demographic data (Child)	n(%)
Age:	
Below 1 year	61 (20.3)
1 year – 3 years	104 (34.7)
4 years to 5 years	41 (13.7)
6 years and above	94 (31.3)
Gender:	
Male	254 (51.3)
Female	146 (48.7)

A total of 300 of respondents participated in this research. In terms of gender 18% (n=54) were male and 82% (n=246) were female. The range of respondents is between 19 to 54 years old (mean age=34.31, SD=6.907).

Other demographic data included the number of household members that respondent live with. 50% (n=150) of the respondent are living with 5-7 members in the household and only 2% (n=6) from the respondent are living with more than 10 members in their household.

For children in the household, 22.3% (n= 67) of the respondent were having 1 child in their household, followed by 22% (n=66) of respondent have 3 children in

their household. In addition to that, only 5% (n=15) of the respondent were having children more than 7.

Table 3.2: Demographic data (Parents or guardians)

Demographic data (Parents or guardians)	n(%)
Respondent age range between 19 to 54 years old	**34.31±6.907**
Race:	
Malay	234 (78)
Chinese	37 (12.3)
Indian	21 (7)
Others	8 (2.7)
Gender:	
Male	54 (18)
Female	246 (82)
Household Members:	
2-4 Members	115 (38.3)
5-7 Members	150 (50)
8-10 Members	29 (9.7) >
10 Members	6 (2)
Children in the Household:	
1 Child	67 (22.3)
2 Children	60 (20)
3 Children 66 (22)	
4 Children	59 (19.7)
5 Children	22 (7.3)
6 Children	11 (3.7)
7 Children or more	15 (5)

Part B: Caregivers' involvement in the care of hospitalized child

From the findings of this study it was evident that the entire respondents are providing basic care to their child such as feeding, bathing, comforting and more. But, only 92.7% (n= 278) always do these jobs diligently and 7.3% (n=22) will do it occasionally. When it comes to receiving information on the condition of the child, 88.3% (n=265) are always ready to receive it but, only 0.7% (n=2) are never ready to receive information from health care providers. Besides that, majority of the respondent (67.3%, n=202) seek religious support and only 12% (n = 36) who does not receive any religious support from any organization or health care provider.

Meanwhile, 70.7% (n=212) participated in decision making towards child's treatment and only 8% (n=24) who never participated in the child's treatment. In addition to that, 46.3% (n=139) are not trained to give more complicated care such as dealing with wounds or giving injections to the child. When it comes to participation in painful or frightening situations of the child, only 49% (n=147) ready participate and 20.7% (n=62) never participated with the child care.

Based on the result, total mean of family involvement are 1.54. Therefore, it shows that though families are involves in the care of their hospitalized child but seldom participate completely in this process.

Table 3.3: Caregivers' involvement in the care of a hospitalized child

Answers n (%)	Yes, always	Yes, sometimes	No, never	I do not know
To provide basic care (such as feeding, bathing, comforting) Mean±SD (1.07±0.26)	278 (92.7)	22 (7.3)	-	-
To receive information on the condition of the child Mean±SD (1.15±0.47)	265 (88.3)	29 (9.7)	2 (0.7)	4 (1.3)
To receive religious support Mean±SD (1.5±0.81)	202 (67.3)	54 (18)	36 (12)	8 (2.7)
To participate in decisions concerning the child's treatment Mean±SD (1.39±0.66)	212 (70.7)	62 (20.7)	24 (8)	2 (0.7)
To be taught to give more complicated care (dealing with wounds, giving injections) Mean±SD (2.29±0.92)	81 (27)	66 (22)	139 (46.3)	14 (4.7)
To participate in painful or frightening situations for the child Mean±SD (1.81±0.92)	147 (49)	77 (25.7)	62 (20.7)	14 (4.7)
Total mean of family involvement:		**1.54**		

(n = 300) Scores from 1 to 4 (4 = I do not know, 3 = No, never, 2 = Yes, sometimes, 1 = Yes, always, %)

Part C: Family caregivers' experiences of encounters with behaviour of health care provider

Based on these results, the respondent rated their experience regarding the behaviour of doctors and nurses as highly appreciable with a mean of 'good'. From the total mean of experience, family rated with highest value (mean = 4.32) when encountered with doctor's behaviour. Meanwhile, there were only 0.08 difference of mean from the total mean of experience when encountered with nurses (mean = 4.24).

Based on the rank, the doctors have the highest 'very good' response from the respondent compared to nurses. In contrast, respondent reported of having very bad experience from the doctors and nurses when it comes to the behaviour towards the sick child (0.7%, n = 2). Moreover, when it comes to attentiveness, explanation and sympathy, the respondent experience bad behaviour from the doctors (0.7%, n = 2).

Furthermore, as referred to Table 3.4, the total mean of caregiver's experience towards doctor are 4.32 whereas for nurses it is 4.24. Therefore, it shows that the patient on an average experience good behaviour of the health care providers.

Table 3.4: Family caregivers' experiences of encounters with behavior of health care provider

Behavior n (%)	Doctors	Nurses
Attentiveness		
Mean±SD	**4.28±0.66**	
Very good	121 (40.3)	118 (39.3)
Good	155 (51.7)	148 (49.3)
Quite well	22 (7.3)	34 (11.3)
Bad	2 (0.7)	-
Very bad	-	-
Communication		
Mean±SD	**4.40±0.60**	**4.32±0.62**
Very good	137 (45.7)	120 (40)
Good	145 (48.3)	156 (52)
Quite well	18 (6)	24 (8)
Bad	-	-
Very bad	-	-
Explanation		
Mean±SD	**4.31±0.64**	**4.18±0.66**
Very good	121 (40.3)	96 (32)
Good	153 (51)	162 (54)
Quite well	24 (8)	42 (14)
Bad	2 (0.7)	-
Very bad	-	-
Kindness		
Mean±SD	4.36±0.60	4.27±0.60
Very good	129 (43)	106 (35.3)
Good	151 (50.3)	170 (56.7)
Quite well	20 (6.7)	24 (8)
Bad	-	-
Very bad	-	-
Sympathy		
Mean±SD	4.16±0.69	4.13±0.65
Very good	97 (32.3)	84 (28)
Good	155 (51.7)	170 (56.7)
Quite well	46 (15.3)	46 (15.3)
Bad	2 (0.7)	-
Very bad	-	-
Positive attitude		
Mean±SD	4.32±0.58	4.23±0.62
Very good	115 (38.3)	100 (33.3)
Good	167 (55.7)	170 (56.7)
Quite well	18 (6)	30 (10)
Bad	-	-
Very bad	-	-
Behavior towards the sick child		
Mean±SD	4.38±0.66	4.26±0.67
Very good	137 (45.7)	110 (36.7)
Good	143 (47.7)	162 (54)
Quite well	18 (6)	26 (8.7)
Bad	-	-
Very bad	2 (0.7)	2 (0.7)
Total mean of experiences	4.32	4.24

(n = 300) Scores from 1 to 5 (5 = very good, 4 = good, 3 = quite well, 2 = bad, 1 = very bad, %)

The relationship between family involvement during care and family's experience when encountered with healthcare provider's behaviour towards the child care

Before determining the relationship of both the variable of family involvement and family experience towards health care behaviour, the researcher have checked the normal distribution of these two variable by using normal probability plot (graphically), skewness and kurtosis (number of statistics). Both the variables are normally distributed.

Based on Table 3.5, the r value is -0.012 with negative or poor correlation between the family involvement and family experiences. From this finding, it is revealed that there is no relationship between family involvement during care and family's experience when encountered with healthcare provider's behaviour towards the child care.

Table 3.5: Correlation between family involvement during care and family's experience when encountered with healthcare provider's behaviour towards the child care.

	Family Involvement Pearson Correlation	Family Experience Sig. (2-tailed)
Family Involvement	1	0.830
Family Experience	-0.012	0

DISCUSSION

Caregiver's involvement in the care of hospitalized child.

The view of patients, parents and relatives is one of the key factors for success to become a "magnet hospital" by attracting both patients and hospital staff. While parents previously expected to remain separated from their children but now they want to remain with their child in the hospital and wants to get involved in the process of care giving (Ygge, 2004). Information from health care providers to the family regarding child's condition is really important as because reduces their anxiety and the family does not feel neglected (Söderbäck and Christensson, 2008).

Network *et al.*, (2005) stated that parents were expected to participate actively in health care and decision making regarding delivery of care. In addition to that, study done by Hoehn *et al.* (2005), also stated that parents were involved in decision making of their hospitalized child for societal benefit and for the improvement of the child's health. However, in contrast to a study conducted by Söderbäck and Christensson (2008), most of the family caregivers refuse to take part in decision making for their child's treatment. This is because parents are working and the guardian (child's sister or grandmother) taking care of the child are not competent enough (Aziz and Pubalan, 2008).

In a study done by Söderbäck and Christensson (2008), it was revealed that most of the family refused to learn the complicated processes of care but leave it to the professionals. It is because the respondent does not have time to learn and they fear using the equipments due to fear of discomfort or pain to the child, anxiety and lack of knowledge. Health care provider should train the guardians so that they will become more confident, understanding the importance of care with full commitment towards their child's health (Molina and Marcon, 2009).

According to Network *et al.* (2005), hospitalization is considered to be traumatic especially for infants and children less than age of five because they does not have the coping skills to handle stress, pain, separation from family and living in an unknown environment. It is known that during the period of hospitalization, children in the presence of parents or guardian feel secured and this in turn improve child's health (Molina and Marcon, 2009).

Family caregivers' experiences regarding the behaviour of the health care provider

Both doctors (mean: 4.40) and nurses (mean: 4.32) maintained a good communication with the patient and their parents to augment quality treatment and quick recovery (Grünberg, 2010; Contro *et al.*, 2004). Furthermore, good communication between health care providers and parents can lead to their satisfaction with the mode of health care (Noreña Peña & Cibanal Juan, 2011). In addition, direct communication with the paediatrician can make them understand more about their children's health condition (Beresford & Sloper, 2003) and will decrease misunderstanding by improving coordination of daily plan (Lye, 2010). According to Blackstone and Pressman (2011) for children with traumatic brain injury and spinal cord injury, the effective communication is important for long-term recovery and positive outcomes.

In addition to that, the study done by Noreña Peña and Cibanal Juan (2011) showed that quality of nursing care can be determined by effective communication and by developing interpersonal relation with the paediatric patient by the nurses. Likewise, paediatric patient get happier and enhance psychosocial wellbeing during hospitalization if they perceive positive interaction between nurse and their family. Furthermore according to Brady (2009), a good nurse is one with a good communication skill that include body language, tone of voice, smile, facial expression and eye contact. When it comes to the health care provider's kindness towards hospitalized child, both doctors (mean: 4.36) and nurses (mean: 4.27) had a mean of 'good'. These findings are supported by the studies done by Wysong and Driver (2009) that showed that nurses who are kind, friendly, polite and caring can give rise to high quality patient care. Sympathy is such a caring approach by health care providers towards patients that increase parents' satisfaction to care (Aziz & Pubalan, 2008). Likewise, a nurse must show empathy for the paediatric patient by being kind during administration of unpleasant procedure or a distasteful medication (Brady, 2009).

Based on the result of the present study it can be said that the mean of positive attitude of family caregivers' regarding their experiences encountered regarding the behaviour of doctors are 4.32 which is higher than the nurses (mean: 4.23). These findings are contradictory to the work of Duran *et al.*, (2007) that showed nurses have more positive attitudes than doctors when dealing with patients. In addition, the majority of pediatric nurses had a positive attitude towards mothers' participation in children's basic care (Mohamed *et al.*, 2011). But, according to Espezel and Canam (2003), parents received a positive attitude and good rapport of nurses towards their child. For family members with a disabled child, bonding between health care providers is important in order to maintain a positive attitude towards their child (Barbosa *et al.*, 2008). Furthermore, sharing and support by parents towards their child are influence by rapport that they maintain with the health care provider (Pergert *et al.*, 2012).

CONCLUSION

Based on this study, the researcher recommends educational programmes for parents about the importance of family involvement in the care of hospitalized child. Moreover, in the forum for health care provider in the Continuous Medical or Nursing Education (CME or CNE) it was said that behaviour towards sick child have to be developed effectively in order to improve health care skills. For further studies, big samples are required to represent the overall population of hospital in Malaysia. In addition to that, hospitals have to stress more about family centred care in order to improve the care of the hospitalized child.

The biggest challenge during conducting this study is low response rate from different races present in Malaysia, as they are unable to read in Malay or English and are thus not capable of understanding the questionnaire. Besides that, the sample of this study was drawn from the population of three hospitals, and it does not represent the whole hospital population of Malaysia.

This study demonstrated that family caregivers are involved in the care of hospitalized child. Moreover, family also experience good behaviour from the health care providers. It shows that health care provider from this three hospitals has good attitude and soft skills towards the sick child and their parents. Likewise, this study also shows that family involvement in the care of hospitalized child does not influence their experience with health care provider and vice versa.

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