A Comparison between Actual and Preferred Participation In the Care among Parents of Hospitalized Children in Vietnam

นิพนธ์ต้นฉบับ

Original Article

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วารสารไทยเภสัชศาสตร์และวิทยาการสุขภาพ2559;11(4):137-143.

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Thai Pharmaceutical and Health Science Journal 2016;11(4):137-143.

บทคัดย่อ

วัตถุประสงค์: เพื่อเปรียบเทียบการมีส่วนร่วมกับความต้องการมีส่วนร่วมของบิดามารดาในการดูแลเด็กที่เข้ารับการรักษาในโรงพยาบาล และเปรียบเทียบแต่ละค่าว่ามีความต่างอย่างไรตามเพศของเด็กและคุณลักษณะของบิดามารดาในการดูแลเด็กเวียดนามที่เข้ารับการรักษาในโรงพยาบาล **วิธีการศึกษา:** กลุ่มตัวอย่างเลือกแบบสะดวก เป็นบิดามารดาของเด็กชาวเวียดนามที่เข้ารับการรักษาในหอผู้ป่วยระบบทางเดินหายใจ โรงพยาบาลเด็กแห่งหนึ่งในประเทศเวียดนาม จำนวน 63 ราย สอบถามข้อมูลทั่วไป และใช้แบบสอบถามการมีส่วนร่วม แบบสอบถามความต้องการมีส่วนร่วม และแบบสอบถามการรับรู้ความรุนแรงการเจ็บป่วยของบุตร ค่าสัมประสิทธิ์ความเชื่อมั่นของ 3 แบบสอบถามเท่ากับ 0.81, 0.88 และ 0.81 ตามลำดับ รวบรวมข้อมูลระหว่างกุมภาพันธ์ถึงเมษายน 2559 ทดสอบความต่างของค่าเฉลี่ย **ผลการศึกษา:** ค่าเฉลี่ยของคะแนนการมีส่วนร่วมของบิดามารดาในการดูแล เท่ากับ 72.02 และความต้องการมีส่วนร่วมเท่ากับ 77.75 ซึ่งกิจกรรมที่ความต้องการมีส่วนร่วมกับการมีส่วนร่วมแตกต่างกันอย่างมีนัยสำคัญทางสถิติ ได้แก่ กิจกรรมที่ทำประจำ กิจกรรมทางการพยาบาล การแลกเปลี่ยนข้อมูลข่าวสาร และการตัดสินใจในการดูแล **สรุป:** พบว่าบิดามารดาของเด็กชาวเวียดนามที่เข้ารับรักษาในโรงพยาบาลมีความต้องการมีส่วนร่วมมากกว่าที่พบการมีส่วนร่วมจริง แสดงถึงความต้องการที่สามารถเอื้อให้บิดามารดาเหล่านี้พยายามได้อีก ดังนั้นพยาบาลเด็กควรสนับสนุนบทบาทของบิดามารดาในการดูแลเด็กป่วย และส่งเสริมการมีส่วนร่วมให้สอดคล้องกับความต้องการของบิดามารดา โดยอาจพัฒนาโปรแกรมช่วยส่งเสริมการมีส่วนร่วมของบิดามารดาดังกล่า

คำสำคัญ: การมีส่วนร่วมของบิดามารดา, การมีส่วนร่วม, ความต้องการมีส่วนร่วม, เด็กป่วยที่เข้ารับการรักษาในโรงพยาบาล

Abstract

Objective: To compare differences between actual and preferred parent participation among Vietnamese parents in the care of their hospitalized children and related factors including the child's gender and parents' characteristics. **Methods:** A convenience sample of 63 parents of the children hospitalized in the respiratory ward of a children hospital in Vietnam. In addition to demographic data collection form, three questionnaires consisting of actual parent participation, preferred parent participation, and perceived illness severity were used. Reliability coefficients of the three questionnaires were 0.81, 0.88 and 0.81, respectively. The survey was conducted from February to April, 2016. Mean score differences were tested. **Results:** The mean score of the actual parent participation was 72.02 while that of the preferred parent participation was 77.75. Activities with significant higher mean scores in the preferred participant than the actual participation included routine care, nursing care, information sharing, and decision making. **Conclusion:** Vietnamese parents of the hospitalized children had a preferred participation high than the actual participation. This indicates a possibility to enhance their participation in the care for their own hospitalized child. Pediatric nurses should encourage the parents for care participation. A program to promote such participation should be developed.

Keywords: parent participation, participation, preferred participation, hospitalized child

Introduction

Hospitalization of a child is a stressful situation for the child and their family.[1-3] In fact that tension causes a change in a young child's health condition and environmental routine.[4] Parents feel a lack of position because they are in an unfamiliar environment leading to their experience of a loss of control and independence.[5] However, effects of hospitalization on young children are more or less dependent with their parents, which make the situation difficult when the parents' role changes after the children are hospitalized. Therefore, parent participation has many benefits for both the children and their family as it helps reduce stress and anxiety, maintain family relationships, prevent behavioral deviations, improve coping with illness in hospitalization, and an increase in sense of security.[2]

Parent participation in the care of their hospitalized children is multiple actions of parents engaging in specific levels of care based on children's status, negotiation, agreement, and communication with nurses by means of exchanging information pertaining to the hospitalized children. In addition to the communication between parents and nurses, this communication could also involve nurses educating and providing information about the process of

treatment and care for parents to achieve a proper parental participation in care process and an acceptable children's health outcome.[6] According to the concept of Schepp[7], parent participation is divided into four specific areas of care for their hospitalized children, including participation in routine care, technical care, information sharing and decision making. One of the most crucial attributes of parent participation is that both the actual and preferred parent participation could be more or less since both are influenced by the child and parent characteristics.[7,8] The discrepancy between the actual and preferred participation could result in a conflict and frustration.

In Vietnam, parental involvement in taking care of hospitalized children is very common nowadays. However, there has been a lack of data about actual and preferred parent participation in their childcare at the hospital. Therefore, it is necessary to identify the level of actual and preferred parent participation in their childcare in hospital in order to support appropriate parental participation in their hospitalized children. Moreover, there has been a limited understanding about factors relating to parent participation in caring for their young hospitalized children. Therefore, this study aimed to compare differences between actual and preferred parent participation among Vietnamese parents in the care of their hospitalized children and related factors including the child's gender and parents' characteristics consisting of age, prior experience, educational level, employment status, number of dependent children in the family, and perceived severity of illness.

Materials and Methods

A comparative descriptive design was employed in this study. Data collection was performed in the respiratory ward at Hai Duong Children's Hospital, Hai Duong province, Vietnam from February to April, 2016. Based on Polit and Back[9], sample size in this study was 63 parents. This sample size was based on the fact that the population effect size was not known, therefore a medium effect size of 0.5 was assumed, with a desired standard power of 0.80, a two-sided type I error of 5%. The participants were selected by a convenience sampling method. The inclusion criteria for these participants included 1) being able to speak and understand Vietnamese, 2) age of 18 years or older, and 3) providing care for their young children (under 5 years old) in the pediatric wards for more than 48 hours.

Instruments

Four-part self-report questionnaires were used to collect the data from the participant parents. The first part was a ***demographic questionnaire*** which was developed by the researchers. The questionnaire asked the participant about the age and gender of the child, and the participant parent's characteristics including age, relationship with the child, educational level, employment status, number of dependent children in the family and prior experience in hospitalized child care.

The actual parental participation scale (APPS) and the preferred parental participation scale (PPPS)

The APPS and the PPPS were developed by Schepp.[8] They were used to measure the APP and the PPP, respectively, in the hospitalized children. Each of the APPS and PPPS comprised 24 items with 4 subscales namely routine care (10 items), technical care (4 items), information sharing (4 items) and decision making (6 items). For example, question number 24 of the APPS is "I comfort my child during painful procedures," while the PPPS counterpart is "I prefer to comfort my child during painful procedures." Identically, the two questionnaires employed the Likert-type rating response scale ranging from 1-none of the time to 4-all of the time. The total scores ranges from 24 to 96, where lower score indicating less and higher score suggesting more parent participation in the care of their hospitalized children. In this study, the two scales had a high internal consistency reliability with the Cronbach's alpha coefficients of the APPS and PPPS of 0.81 and 0.88, respectively.

The perceived severity of illness's scale

The perceived severity of illness's scale was a visual analogue scale. We used it to measure perceived severity of illness by the parents of the hospitalized children. It was developed and used in a previous study by Wongcheree and colleagues.[10] This instrument measured the perceived severity on a 0-to-10 scale where 0 indicating no severity and 10 a very severe illness. This analog scale was further classified as mild (0 - 3), moderate (4 - 6) and severe (7 - 10). In this study, the perceived severity of illness's scale was found to have a high test-retest reliability with a Pearson's correlation coefficient of 0.81.

All questionnaires were translated from English into Vietnamese language by the back-translation technique. Firstly, two translators, who were fluent both in English and Vietnamese, independently translated the original English version into Vietnamese. A single Vietnamese version of the instrument was then made by unifying of the two translated versions with sound agreements from both translators and the researchers. The Vietnamese version was then back translated into English by the third translator who was fluent with Vietnamese and English. Lastly, the original English version and the back translated version were compared by the researchers to validate the accuracy of the translation process and comparability of the meaning and content.

Data collection procedure

A human subject's approval was obtained from the Ethical Approval Committee, Faculty of Nursing, Burapha University, Thailand (IRB No. 01-02-2559). Data collection process was begun after the permission was granted by the director and head nurse at a respiratory medicine ward of Hai Duong Children's Hospital, Vietnam. Parents who met the study criteria and agreed to participate in the study were asked to sign a consent form. The researcher (Phuong DT) then gave the questionnaire to the participant. It took about 25 - 30 minutes to complete the entire questionnaire. Once completed, the questionnaire was checked for completeness and accuracy.

Data analysis

Descriptive statistics including frequency with percentage, mean with standard deviation and range were used to describe all variables including demographic characteristics of the child and parent. Paired t-test was used to compare mean of the total scores of APP and PPP and their comparable subscales, including routine care, technical care, information sharing and decision making. Independent t-test and one-way analysis of variance (ANOVA) were used, when applicable, to compare means of APP and PPP regarding difference of the child's gender and the parents' characteristics including age, educational level, employment status, number of dependent children in the family, prior experience of taking care of hospitalized child and perceived severity of illness in caring of their hospitalized child. All of the statistical assumptions for each of these tests were met. Statistical significance level for all tests was set at a type I error of 5%.

Results

Demographic characteristics of the children

Of the 63 children, about two-thirds were male (69.8%). The majority were one year old or younger (52.4%), followed by one to three years old (27.0%), and three to five years old (20.6%). Their age ranged from 2 to 58 months, with a mean of 19.65 ± 17.11 months.

Demographic characteristics of the parents

Of the 63 parents, more than half were younger than 30 years old (58.7%). Their age ranged from 22 to 43 years, with a mean of 29.05 ± 4.33 years (Table 1). The majority were mother (85.7%). About half had a high school education (50.8%), while 22.2% were with secondary school degree and 27% had a college/university degree. In terms of employment status, the most found were general workers (28.6%), followed by office workers (23.8%), farmers (20.6%). About half reported having one dependent child in their family (50.8%), while having two children was found in 41.3%. More than half of the parents had prior experience of taking care of hospitalized child (57.1%). In addition, the majority of the parents perceived their child's illness as moderate (54.0%), followed by severe (41.3%), with a mean score of 6.30 ± 1.57 and a range of 2 – 9 (Table 1).

Table 1 Demographic characteristics of the parents (*N* = 63)

Characteristics	N	%
Age (years) *M* = 29.05 , *SD* = 4.33, range = 22-43		
- < 30	37	58.7
- ≥ 30	26	41.3
Relationship with child		
- Mother	54	85.7
- Father	9	14.3
Education level		
- Secondary school	14	22.2
- High school	32	50.8
- College/university degree or more	17	27.0
Employment status		
- General worker	6	28.6
- Office worker	13	23.8
- Famer	15	20.6
- Business owner	11	17.5
- Housewife	18	9.5
The number of dependent children in the family		
- 1	32	50.8
- 2	26	41.3
- 3 or more	5	7.9
Prior experience of taking care of hospitalized child		
- Yes	36	57.1
- No	27	42.9
Perceived severity of illness *M* = 6.30 , *SD* = 1.57, range = 2 - 9		
- Mild	3	4.8
- Moderate	34	54.0
- Severe	26	41.3

Scores of the APP and PPP

The mean total score of the APP (72.02 ± 5.28) was lower than that of the PPP (77.75 ± 6.20), with a statistical significance (P < 0.001) (Table 2). In terms of subscales, all mean scores of the APP subscales were lower than that of the PPP subscales with a statistical significance. Specifically mean scores the subscale of participation in routine care were 32.33 ± 3.28 and 33.14 ± 3.48, respectively (P < 0.05), of participation in technical care were 12.67 ± 1.76 and 13.17 ± 1.52, respectively (P < 0.05), of participation in information sharing were 11.67 ± 1.64 and 13.16 ± 1.64, respectively (P < 0.001), and of participation in decision making were 15.35 ± 3.03 and 18.27 ± 2.87, respectively (P < 0.001).

Table 2 Scores of the actual parent participation (APP) and the preferred parent participation (PPP) (N = 63)

Variable	*M*	*SD*	Range	t-test†
Actual parent participation				
Total score	72.02	5.28	61-86	
Subscale scores				
- Routine care	32.33	3.28	25-40	
- Technical care	12.67	1.76	9-16	
- Information sharing	11.67	1.64	8-15	
- Decision making	15.35	3.03	8-22	
Preferred parent participation				
Total score	77.75	6.20	62-90	-7.27#
Subscale scores				
- Routine care	33.14	3.48	27-40	-2.17*
- Technical care	13.17	1.52	10-16	-2.16*
- Information sharing	13.16	1.64	10-16	-5.95#
- Decision making	18.27	2.87	11-24	-7.74#

† t-test comparing mean score of APP with PPP, on the total mean score and each of the subscale scores

* *P* < 0.05, # *P* < 0.001

Scores of the actual parent participation (APP) by child's gender and parents' characteristics

Once differences in the child and patent's demographic characteristics were taken into account, it was found that the mean total scores of the APP mostly were not statistically different (Table 3). Except for the education level, we found that parents with lower education seemed to have higher mean score of the APP (P < 0.05). There was a trend that parents perceiving their child's illness as more severe were more likely to report a higher APP score. However, such trend was not statistically significant.

Table 3 Scores of the actual parent participation (APP) by child's gender and parents' characteristics (N = 63).

Variable	*M*	*t*	F
Child gender			
- Boy	72.20	0.43ns	
- Girl	71.58		
Age (years)			
- < 30	71.65	-0.66ns	
- ≥ 30	72.54		
Prior experience of taking care of hospitalized child			
- Yes	71.75	-0.46ns	
- No	72.37		
Education Level			
- Secondary school	74.79		3.42*
- High school	71.88		
- College/university degree or more	70.00		
Employment status			
- Business owner	73.55		1.01ns
- Famer	73.15		
- General worker	72.33		
- Housewife	70.67		
- Office worker	70.07		
The number of dependent children in the family			
- 1	71.28		.72ns
- 2	72.96		
- 3 or more	71.80		
Perceived severity of illness			
- Mild	68.33		1.61ns
- Moderate	71.44		
- Severe	73.19		

* *P* < 0.05; ns = non-significant

Scores of the preferred parent participation (PPP) by child's gender and parents' characteristics

We found no differences in the PPP total scores in most of the child and patent's demographic characteristics (Table 4). However, we found that those working as the office workers had a PPP total score higher than those with other employment status (P < 0.05). It was worth noting that general workers expressed the lowest PPP score. In addition, there was no clear pattern of the PPP total scores among parents with different perceived severity of their child's illness. Furthermore, while those perceiving their child illness as more severe had a high APP total score (Table 3), the PPP total score was found highest in those perceiving a mild illness.

Table 4 Scores of the preferred parent participation (PPP) by child's gender and parents' characteristics (N = 63).

Variables	M	t	F
Child gender			
- Boy	78.11	0.72^{ns}	
- Girl	76.89		
Age (years)			
- < 30	77.35	-.60^{ns}	
- ≥ 30	78.31		
Prior experience of taking care of hospitalized child			
- Yes	77.61	-.20^{ns}	
- No	77.93		
Education Level			
- Secondary school	79.79		1.13^{ns}
- High school	76.81		
- College/university degree or more	77.82		
Employment status			
- Office worker	81.60		2.89*
- Housewife	77.83		
- Famer	77.54		
- Business owner	77.00		
- General worker	74.77		
Number of dependent children in the family			
- 1	77.81		.11^{ns}
- 2	77.61		
- 3 or more	78.00		
Perceived severity of illness			
- Mild	80.33		.64^{ns}
- Moderate	77.06		
- Severe	78.31		

* $P < 0.05$; ns = non-significant

Discussions and Conclusion

In our study, parents of the Vietnamese hospitalized children showed their preference to participate in their child care (72.02 points) than their actual participation (77.75 points) ($P < 0.001$). According to the concept of Schepp,[7] the parents' preference to participate in their child care indicated the benefits of decreasing parental anxiety and stress levels. Therefore, parents desired to involve in their hospitalized child's care. In addition, the result showed that over 50% of the parents perceived their child's severity of illness as mild to moderate. Therefore they could have felt more comfortable in taking care of their child. In addition, this preference suggested that parents needed to maintain their roles and responsibility of taking care of their hospitalized child. Parents' desire to participate in their child's care could help them reduce stress and anxiety, and maintain family relationships.[2,6] This finding was supported by the previous literature showing that parents preferred to participate in their child's care even though the actual participation was lower.[11-14]

For each of the subscales, the score of the preferred parent participation was significantly higher than that of the actual participation. This finding was similar to the previous studies that they revealed that parents reported an elevated desire to participate in their hospitalized child's care.[7, 8,15,16] A high preferred participation in routine care could be due to the fact that Vietnamese parents were able to perform routine care as activities of their child's care at home and maintain parental roles for the hospitalized child. This finding was consistent with the previous studies showing that parents wanted to engage in giving their child basic care.[11,17-19]

In addition to routine care, Vietnamese parents also showed that they preferred more participation in technical care. This could be explained that the prior experience might influence parent participation in technical care for activities of their child care. Moreover, as Vietnamese parents stayed longer with their hospitalized child, they would have more experience and confidence to participate in the technical care. This finding was similar to the previous studies.[12,14] It also has been known that parents wanted to participate in technical care because they wanted to learn more skills and gain more experience. Such improvement could allow them to provide a better child care at home after discharge from the hospital.[20]

In terms of information sharing, Vietnamese parents preferred more participation than the actual participation. The finding was similar to the results of previous studies.[13,15, 21] These authors identified that the parents preferred to increase communication both with the child and nurses to share information relating to their child's illness and activities of the caring process in the hospital. Most of the parents reported that they searched for information about their child's illness, prognoses, treatment, side-effects and care giving issues for their child.[22] The parents expressed their desire and value in receiving information from nurses, voicing their preferences and choosing how treatments were administered to their child in the hospital.[23] Vietnamese parents also wanted healthcare providers to share information to help them take better care for their child.

Lastly, Vietnamese parents desired to participate more in decision making in their hospitalized child's care. The finding of this study was consistent with the previous studies.[12,24] They indicated that the parents wanted to be involved in decision making for their hospitalized child's care. The parents reported that they were guided directly from healthcare providers in the decision-making process for their

child's care.[22] However, the present study was inconsistent with the study by Shield (as cited in Alsop-Shield[25]) stating that few parents wanted to be involved in making decision for their hospitalized child's care. They usually let healthcare providers make the decision.

We found that the total APP scores were significantly different by education levels where parents with secondary school education had more actual participation than those with university degree. This could be explained that parents with lower education could have worried more about their child's condition. Therefore, they got more involved in child's care than parents with higher education. This finding was similar to the study of Koller which found that there was a significant difference in APP by the education levels.[26]

Vietnamese parents were concerned about their child's illness regardless of the child's gender as we found no difference of the APP scores between boys and girls. It meant that Vietnamese parental participation in their hospitalized child's care in boys and girls was equal. The finding of this study was congruent with the result of previous studies.[27,28] They showed that child's gender was not significantly influencing APP in their hospitalized child's care.

There were non-significant differences of APP regarding differences in parents' age, employment status, number of dependent children in the family, prior experience, and perceived severity of illness. This could be explained that Vietnamese parents regardless of these differences were likely to perform caring for their hospitalized child's care because of the love and concern about their child. The findings of this study were consistent with previous studies of Pranee[29] and Schepp[30] who found that parents' characteristics were not significantly influencing the APP.

In terms of the preferred parental participation and differences in demographic characteristics, there was a significant difference of the PPP total scores regarding employment status. Vietnamese parents working as office workers preferred more participation in their hospitalized child's care than those general workers. It could be explained that Vietnamese office workers had more opportunities to find information relating to caring for their hospitalized child. It was consistent with Bernhardt and Felter[31] who revealed that parents, especially mothers used the internet to learn more about diagnosing, treating specific pediatric health conditions and finding experienced childcare. Such working environments could have increased their need to participate more. Gender of the child also did not result in different PPP. This was consistent with the work of Gyeltshen[27] which indicated that there were non-significant differences between child's gender and PPP in their hospitalized child's care.

The results also showed that there were non-significant differences between preferred parent participation and parents' characteristic, including age, educational level, the number of dependent children in the family, prior experience and perceived severity of illness. These were similar to the previous studies that found that parents desired to be involved in their child's care at the hospital regardless of their characteristics.[15,27,29] Kristensson-Hallstrom also found that there was no correlation between the parent's desired participation and demographics of the parents, such as education, prior experience in caring of their children, length of hospitalization and number of children in the family.[32]

Our study was with some limitations, Firstly, the sample was obtained from only one pediatric ward. Therefore the generalizability to other settings in Vietnam is limited. A larger study should be conducted in the near future. Secondly, with its cross-sectional design, only a snapshot, not a change, of participation could be captured. We proposed longitudinal studies in the future to better capture parental participation. Lastly, as our method of data collection was convenience sampling, a bias and hence limited representativeness to a broader population of children was inevitable. A more systematic sampling technique should be used in the future studies.

In conclusion, Vietnamese parents of the hospitalized young children preferred a high degree of participation in their child's care, including activities related to routine care, technical care, information sharing and decision making. There are also significant differences between preferred parental participation with different employment status. Moreover, the actual parental participation with different education levels was significant. From this finding, pediatric nurses should encourage parental role in their hospitalized child's care and support them to meet their desire.

Acknowledgements

The authors would like to gratefully acknowledge the director, the head nurse of the respiratory ward, Hai Duong Children's Hospital, Vietnam, for their kind assistance and

support. We would like to show a great appreciation to the parents of the patients for their kind assistance during the time of data collection.

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Editorial note
Manuscript received in original form on August 8, 2016;
accepted in final form on October 13, 2016