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RESEARCH ARTICLE

Factors Predicting Parent Participation in Caring for Hospitalized Children with Chronic Diseases

Vatinee Sanyod¹, Linchong Pothiban^{1*}, Jutarat Mesukko¹ and Srimana Niyomkar¹

¹Faculty of Nursing, Chiang Mai University, 110/406 Intawaroros Road, Sripum District, Chiang Mai, Thailand.

Abstract:

Background:

Being hospitalized with chronic disease is a stressful situation for most children that can affect their well-being. Parent participation in child care is required for getting a better outcome.

Objective:

The objective of this study was to identify factors predicting parent participation in caring for hospitalized children with chronic diseases.

Methods:

In this study, the participants consisted of 234 parents of hospitalized children with chronic diseases and 125 nurses who cared for the children in four tertiary hospitals in central Thailand. Self-reported questionnaires were used in data collection. Data were analyzed using a descriptive statistic, Spearman's correlation coefficient, and ordinal regression.

Results:

The results revealed that parent participation in caring for hospitalized children with chronic diseases had a statistically significant positive relationship with perceived self-efficacy in caring for hospitalized child, information support from health care providers, and communication between parents and nurse ($r = .39, .34, \text{ and } .39$ $p < .01$, respectively). Using ordinal regression analysis, the parents' perceived self-efficacy in caring for their child was the only predictor of parent participation in caring for hospitalized children with chronic diseases, accounting for 72.65%.

Conclusion:

Parents' perceived self-efficacy in child care was the only predictor with a strong influence on parent participation in child care. This can be used as preliminary data for developing an effective intervention program for enhancing parent participation that would result in better health and quality of life for those children.

Keywords: Parent participation, Hospitalized children, Children with chronic diseases, Chronic diseases, Child care, Stress.

Article History

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1. INTRODUCTION

Chronic diseases are the major health problems among children worldwide. The most evident adverse consequences include the associated exacerbations, hospital admissions, and school absences [1,2]. Chronic diseases in children are considered as a stressful experience that negatively affects both children and their parents psychologically [3]. Although children with chronic diseases are usually given care at home by family, especially the parents, hospitalization may be re-

quired when there is exacerbation or complication. During hospitalization, family care for the child is not only provided by health care providers but also by the parents who help taking care of the child in daily living tasks. In Thailand, nurses provide the principal care to hospitalized children, so parents cannot play a role in the care of their child. Most parents report a feeling of anxiety, stress, uneasiness to ask for help from a nurse, being out of control because of the disease and/or treatment. In addition, parents felt that home care was better than hospital care because of the lack of privacy and unfamiliarity with the place.

Empirical evidence on chronic care consistently support

* Address correspondence to this author at the Faculty of Nursing, Chiang Mai University, 110/406 Intrawaroros Road, Sripum District, Chiang Mai Province, 50200, Thailand; Tel: +66896147591; E-mail: vatinee@webmail.npru.ac.th

Family Centered-Care (FCC) that highlights the importance of family as a primary source of support and takes into account the involvement of family members in all dimensions of patient care [4, 5]. Based on the FCC principle in which family is central to child's health, FCC encourages true collaboration, partnership development, and information sharing between patients, families, and members of the health care team [6 - 9]. FCC has been applied in different settings of pediatric care in Western and Eastern cultures [10 - 12], including Thailand, where parents generally have access to their hospitalized children 24 hours a day and are primarily involved in caring for these children.

Parent participation could be seen as a concept confined in FCC [13]. Parent participation plays the most important role in the child's life, both in wellness and illness. In this study, the emphasis is on the role of participation of parents in caring for children with chronic diseases in the hospital. According to Schepp [14], parents should be involved in providing care because hospitalization cannot be managed only by health professionals in the hospital. Toddler and pre-school children are not able to take care of themselves and communicate their needs to others, especially their blood relations such as father or mother [15 - 17]. Multidisciplinary studies have affirmed the benefits of the important role of parents in both physiological and psychosocial health outcomes for children [11, 18, 19]. However, parent participation in care is found not to be sufficient as needed. A parent may feel uncertain that they can do the caregiving tasks. Moreover, they may not be allowed to involve in technical care for the child. Therefore, exploration of factors affecting parent participation is needed.

The literature review has shown that many factors are related to parent participation in caring for hospitalized children with chronic diseases. Among those factors, the most frequently reported factors were parent-related and nurse-related. Parents' perceived self-efficacy in caring for hospitalized children, defined as the judgment of parents on how effectively they can perform the tasks associated with providing care for the children with chronic diseases, was found to be positively related to parent participation in caring for hospitalized children [20 - 22]. Perceived information support from health care providers, defined as the parents' perception of receiving information and advice regarding child's illness, treatment, complication, nursing care from health providers, was also found to be associated positively with parent participation in child care during hospitalization [23]. Communication between parents and nurses, defined as the parents' perception of quality communication between parents and nurses, was also found to be positively related to parent participation in the care of hospitalized children [20, 24]. Regarding nurses related factors, nurses' attitude towards parent participation showed a positive relationship with parent participation in caring for children in hospitalization [24 - 28]. Nurses' knowledge of parent participation and its benefits is also positively related to parent participation in caring for hospitalized children [23, 29].

As most previous studies examine only bivariate correlation between a selected variable and parent participation in caring for hospitalized children with chronic diseases, little

is known about factors influencing parent participation in caring for the child, particularly parent participation in the care of the child with chronic disease whose condition is more deteriorated. Therefore, the objectives of this study were to identify and access the factors that correlated with parent participation in caring for hospitalized children with chronic diseases.

2. MATERIALS AND METHODS

2.1. Study Design and Sample Population

A predictive correlation design was used to identify and explain predicting factors of parent participation in caring for hospitalized children with chronic diseases. The factors being investigated consisted of the parents' perceived self-efficacy in caring for hospitalized children, information support from health care providers, communication between parents and nurses, nurse's attitude of parent participation, and nurse's knowledge of parent participation. A multi-stage sampling procedure was used to determine a representative sample of the research participants in order to obtain a total of four hospitals as follows: Nakhon Pathom Hospital, Ratchaburi Hospital, ChaophrayaYommarat Hospital, and PhahonPhonPhayuhaSena Hospital. The sample size of parents and nurses was estimated using G*Power Program version 3.1.9. In this study, using F test (multiple linear regression: fixed model, R² deviation from zero), the effect size was calculated from R²1-R²2, $\alpha=.05$, $\beta=.80$. The purposive sampling consisted of 234 parents of hospitalized children with chronic diseases aged 1-5 years and 125 pediatric nurses caring for those children in four hospitals in central Thailand province between February-May 2017. The sample of parents was selected based on the characteristics meeting the following inclusion criteria: 1) being the primary caregiver of the hospitalized child, 2) age 15 years or older, 3) being able to verbally communicate, read and write in Thai, and 4) willing to participate in the study. The sample of nurses was selected based on the following inclusion criteria: 1) graduated with a bachelor's degree in nursing, 2) licensed for professional nursing and midwifery, 3) working in the pediatric unit, and 4) willing to participate in the study. The samples were purposively selected based on the inclusive criteria; four hospitals were purposively selected based on the number of children patients being hospitalized annually.

2.2. Data Collection and Instrument

The researcher and well-trained research assistants (RAs) approached potential participants. The researcher selected two research assistants who were registered nurses and experienced in conducting research to help collect data. They were informed about the study objectives, the inclusion criteria of the potential subjects, consent forms, and the important roles of the research assistant. Finally, the researcher formally trained them on sample recruitment and administration and the collection of questionnaires. The research assistants reviewed the medical records of all hospitalized children with chronic diseases to recruit potential respondents who met the inclusion criteria. The parents were informed about the study and procedures and asked to participate. Those who agreed to participate were asked to sign the consent form and completed

the questionnaires in a private area in the pediatric unit by themselves. The research assistants checked the completion of the questionnaires. After the participants agreed to take part in the study, they were asked to sign a consent form. In this study, the participants' names and information were treated confidentially. No individual identity was detectable in written reports. Data were not shared with other people.

Seven questionnaires were used in data collection, including, 1) demographic data, 2) parent participation scale, 3) parent perceived self-efficacy scale, 4) information support scale, 5) health communication assessment tool, 6) families' importance in nursing care-nurses attitudes scale, and 7) nurses' knowledge of parent participation scale. The researcher sought permission from the owners of five instruments and two instruments from the original English version translated into Thai using back-translation method by the researcher and expert panels. Content validity and reliability were acceptable prior to administration in this study.

The Demographic Data Form recorded each participant's demographic data consisting of two parts. Part I was the personal data of the mothers or fathers, including age, marital status, occupation, education background, family income, prior experience in caring for hospitalized children, and number of children. Part II was the personal data of nurses, including age, marital status, education background, and experience in caring for hospitalized children with chronic diseases.

The Parent Participation Scale (PPS). It was used to measure parent participation in caring for hospitalized children with chronic diseases. This questionnaire was originally developed by Schepp [14] to measure maternal participation and was translated into Thai and modified by Chaichana et al. [32]. The PPS is a 24-item instrument consisting of four dimensions, including participation in routine care (6 items), technical care (8 items), information sharing (4 items), and decision-making (6 items). This instrument is a four-point Likert rating scale, ranging from 1 (none of the time) to 4 (all of the time). The possible total scores ranged from 24 to 96 and the scores are classified into three levels: low (24-48), moderate (49-72), and high (73-96). The original PPS provided good validity; the reliability was .95 [14]. The PPS in the Thai version obtained good content validity, and the reliability using Cronbach's alpha was .87 [32]. In this study, Cronbach's alpha tested in 10 parents in a pretest study was 0.82.

The Parent Perceived Self-efficacy Scale (PPSS). This instrument was used to evaluate the perceived self-efficacy of parents in caring for hospitalized children with chronic diseases. This scale was developed by Chaisom [21] based on Bandura's self-efficacy theory and Orem's theory. The PPSS was a 38-item scale. Responses are rated on a five-point Likert scale, ranging from 1 (not at all confident, I can't do that) to 5 (extremely confident, I can do that). The possible scores ranged from 38 to 190 and the scores are classified into three levels: low (38.00-88.67), moderate (> 88.67-139.34), and high (> 139.34-190.00). The original version of the PPSS provided good content validity (CVI=1.0), and the reliability using Cronbach's alpha was 0.96. In the present study, the Cronbach's alpha tested in 10 parents in a pretest study was .96.

The Information Support Scale (ISS). This questionnaire was used to evaluate the perceived information support from health care providers. This measure was developed by Samit [20] based on the health information support concept of the Institute of Nursing Certificate, the Nursing Department of Medical. It consists of 20 items to address three main dimensions including information and protection of human rights (8 items), information of illness, treatment, nursing practice (8 items), and information for activities (4 items). Responses to each item are rated on a five-point Likert scale ranging from 0 (none received information) to 4 (too much). The possible total scores ranged from 0 to 80 and the scores are classified into four levels: none (0), low (1-26), moderate (27-53), and high (54-80). The originality of the ISS i.e, the content validity, was assessed by five experts (CVI = .95), and Cronbach's alpha was .83 [20]. A pilot testing on 10 parents was conducted before this study, and Cronbach's alpha reliability in this study was .89.

The Health Communication Assessment Tool (HCAT). This instrument was used to evaluate the perception of communication quality between parents and nurses. This questionnaire was developed by Campbell *et al.* [31] and was revised by Pagano *et al.* [33]. The original version of the HCAT provided good construct validity confirmed by an exploratory factor analysis, and Cronbach's alpha was 0.89 [33]. After receiving permission from the owner, the original version was translated into Thai by the standard translation method. At the translation phase, back-translated technique was used to assume the accuracy of the translation. The following steps were used: 1) the researcher translated the instruments into Thai language from the English version, 2) two bilingual translated the Thai version back to the English version, 3) the researcher and adviser examined the discrepancy between the original English version and the back translation English version to assure the accuracy of translation, and 4) the refinement was done until no discrepancy was found. The questionnaire was administered to 10 parents to check the understanding and acceptability of questions and answers. The participants understood and agreed with all items of the instrument. In the present study, the Cronbach's alpha tested in 10 parents in a pretest study was 0.85. The HCAT is a 22-item with five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The possible total scores ranged from 22 to 110, with higher scores indicating better communication. The scores are classified into three levels: low (22-51), moderate (52-80), and high (81-110).

Families' Importance in Nursing Care-Nurses Attitudes (FINC-NA). This instrument was used to evaluate nurses' attitudes toward parent participation. It was developed by Benzein *et al.* [25]. Back translation was used the same as HCAT. The questionnaire was administered to 10 nurses to check the understanding and acceptability of questions and answers. The participants understood and agreed with all items of the instrument. In the present study, the Cronbach's alpha tested in 10 nurses in a pretest study was .83. It consists of 26 items with a four-point Likert scale ranging from 1 (totally disagree) to 4 (totally agree). Total scores ranged from 26 to 104, with higher scores indicating a more supportive attitude. The scores are classified into three levels: low (26-52),

moderate (52-78), and high (78-104). The original version of the FINC-NA provided good content validity, and Cronbach's alpha was 0.88 [25]. After receiving permission from the owner, the original version was translated into Thai by the standard translation method.

Nurses' Knowledge of Parent Participation Scale (NPPS). This instrument was used to assess the overview of parent participation, benefits of parent participation on children, benefits of parent participation on parents, including routine care activities, nursing care activities, information sharing, and decision making. It was developed by the researcher based on the concept of parent participation [14] and relevant literature review. The scale consists of 20 items with response choices namely, true, not sure, and false. The score of one point is given to a correct answer, while the score of zero is given to an incorrect answer. The possible scores ranged from 0 to 20 and divided equally into three levels of low (0-7), moderate (8-15), and high (16-20). In this study, the content validity was verified by six experts (four nurse instructors with expertise in children with chronic diseases and two nurse instructors with expertise in instrument development), a CVI of .90, and S-CVI/Ave of .98. The reliability using KR-20 was tested with 10 nurses in a pilot study which was .78.

The parents were willing to participate in filling the questionnaires in a private area in the pediatric unit which included the following: the demographic data form, the parent participation scale, the maternal perceived self-efficacy scale, the information support scale, and the health communication assessment tool. There was approximately 90-100 minutes to answer the questionnaire. Concerning the exhaustion, the respondent was free to have refreshments served during the session. The nurses would be asked to complete questionnaires in a private area in the pediatric unit, including the following items: the demographic data form, the families' importance in nursing care-nurses attitudes, and the nurse's knowledge of parent participation scale. They had approximately 15-20 minutes to answer the questionnaire.

2.3. Data Analysis

The quantitative data were analyzed using SPSS version 22.0 software, and descriptive statistics were used to describe the demographics data of participants; Spearman rank correlation was used to examine the relationship between independent variables and parent participation for child care. Finally, ordinal regression was used to test the ability of all independent variables in predicting parent participation in caring for hospitalized children with chronic diseases due to the distribution of some data.

2.4. Ethical Consideration

Prior to data collection, this study was approved by the Research Ethics Committee of the Faculty of Nursing, Chiang Mai University (Research ID: 034-2559 Study Code: EXP-018-2559), the Human Research Ethics Committee of Nakhon Pathom Hospital (NPH-REC N0.003/2017), the Human Research Ethics Committee of Ratchaburi Hospital (COA-RBHEC 004/2017), and the Ethics Review Committee for Research in Human Subjects of two hospitals. The

researcher and well-trained Research Assistants (RAs) approached potential participants. After the participants agreed to take part in the study, they were asked to sign a consent form. In this study, the participants' names and information were treated confidentially. No individual identity was detectable in written reports. Data were not shared with other people.

3. RESULTS

For parent sample, the participants included 234 parents whose children were hospitalized with chronic diseases in four hospitals, including Nakhon Pathom Hospital (n = 78, 33.3%), Ratchaburi Hospital (n = 60, 25.7%), Chaophraya Yommarat Hospital (n = 46, 19.7%), and PhahonPhonPhayuhaSena Hospital (n = 50, 21.3%). More than half were mothers (n = 210, 89.7%). Almost half of the parents were in the age range of 31-40 years (n = 105, 44.9%). Nearly half of the parents (49.1%, n = 115) had only one child. Most participants were married and lived with their spouses (87.6%, n = 205), were non-government employees (47.0%, n = 110), had secondary school education (38.0%, n = 89), and had family income of 5,000 to 10,000 baht/ month (32.0%, n = 75). Most of the parents had experienced caring for their hospitalized child 1-5 times (31.2%, n = 73).

Regarding the nurse sample, the participants comprised 125 registered nurses working full time at pediatric units of four hospitals, including 45 (36.0%) from Nakhon Pathom Hospital, 31 (24.8%) from Ratchaburi Hospital, 27 (21.6%) from Chaophraya Yommarat Hospital, and 22 (17.6%) from Phahon Phon Phayuha Sena Hospital. Most participants were in the age range of 41 to 50 years (30.4%), and had bachelor's degree education (n=115, 92.0%). Most of them (50%) had little experience in taking care of hospitalized children with chronic diseases.

Pairwise relationships among variables showed a significant moderately positive relationship between parent participation and perceived self-efficacy, perceived information support from health care providers, and perceived quality of communication with nurses (r = .39, r = .34, r = .39, p < .01, respectively (Table 1).

Table 1. Correlation matrix of parent participation in caring for hospitalized children with chronic disease and independent variables.

Variables	Parent Participation	
	Spearman's Rank Correlation	p value
Parents' perceived self-efficacy in care	.39	.000**
Perceived information support from health care providers	.34	.000**
Perceived quality communication with nurses	.39	.000**
Nurses' attitude toward parent participation	.00	0.99 ^{ns}
Nurses' knowledge of parent participation	-.06	0.37 ^{ns}

** p < .01

The results of the ordinal regression analysis revealed that parents' perceived self-efficacy was the only significant

predictor of parent participation in caring for hospitalized children with chronic diseases ($p < .01$) (Table 2). Furthermore, descriptive measures of goodness-of-fit, including Cox and Snell pseudo R^2 and Nagelkerke pseudo- R^2 were .156 and .211, respectively. Perceived self-efficacy accounted for 72.65% of the parent participation in caring for hospitalized children with chronic diseases (Table 3).

Table 2. Ordinal regression analysis for predicting factor of parent participation in caring for hospitalized children with chronic diseases.

Factor	B	S.E	Wald	df	Sig.
Parents' perceived self-efficacy in care	.032	.008	17.18	1	.000**
Perceived information support from health care providers	.006	.017	.130	1	.719
Perceived quality communication with nurses	.026	.018	1.991	1	.158

** $p < .01$.

Table 3. Classification table for predicted parent participation in caring for hospitalized children with chronic diseases.

	Level of parent participation			Percentage Correct
	Low (1) N(%)	Moderate (2) N(%)	High (3) N(%)	
Moderate (0)	3 (100)	17 (24.6)	9 (5.6)	29 (12.4)
High (1)	0 (0)	52 (75.4)	153 (94.4)	205 (87.6)
Percentage of classification				72.65

Overall percentage of classification = $\frac{17+153}{234} \times 100 = 72.65\%$

4. DISCUSSION

In the present study, the results demonstrated a significant moderate positive relationship between parent participation in caring for hospitalized children with chronic diseases and perceived self-efficacy. This finding was consistent with previous studies [20 - 22]. It may be possible that the parents generally have stayed with their hospitalized children 24 hours a day. They observed the practices or caring behaviors of other parents that could help speed up the recovery of hospitalized children [8, 9]; thus, they were confident that they could perform the practice of care for their child. Theoretically, perceived self-efficacy or belief in performance is the person's belief to have the capability to deal with things and look forward to a successful practice [36]. When parents believed in their capability, they participated more in caring for their hospitalized child.

In this study, the parents had high perceived information support from health care providers, and it was positively related to parent participation in caring for hospitalized children with chronic diseases. These findings are concordant with research that has identified factors related to caring for hospitalized children [20]. Information support helps parents understand the disease, treatment, caring for the child and makes them participate more diligently in caring for their child [37].

The study result showed that communication with parents

and nurses was significantly positively related to parent participation in caring for hospitalized children with chronic diseases. This finding is consistent with the findings from previous studies [30]. Good communication between parents and nurses makes the parents understand clearly what they are expected to do, so they feel more comfortable to participate in caring for their hospitalized child.

In the present study, nurse's attitude toward parent participation was found to have no relation to parent participation. This finding is congruent with previous studies on parent participation in caring for hospitalized children with acute diseases in Thailand [31]. In contrast, it is different from the results of Western studies [24 - 28], which revealed that the higher the nurse's attitude, the higher the parent participation in caring for their child. In this study, the sample of pediatric nurses was taken from tertiary hospitals where policies and guidelines were characteristic and guided the nursing practice. Therefore, having a clear policy on parent participation in the hospital makes all nurses enhance parent participation in caring for hospitalized children, no matter positive or negative attitude toward parent participation in child care they have.

The findings from this study showed that nurses' knowledge of parent participation did not have a significant correlation with parent participation in caring for hospitalized children with chronic diseases. This finding is inconsistent with prior studies [23, 29], which suggested that the participants who were previously trained on parent participation in looking after sick children had a better understanding and consequently led to a significant correlation between the nurse knowledge and parent's level of participation. Although most of the participants in this study had a high level of parent participation knowledge ($n = 81, 64.8\%$), it was surprisingly found that there was no correlation between the knowledge of parent participation and parent participation. This was probably due to the principles and techniques of nurses to implement such knowledge into nursing practices in order to encourage the involvement of parents [38, 39]. In addition, there was a lack of clear goals of parent participation in nursing care for pediatric patients [39]. Besides, from the statistical perspective, the data used in Spearman's correlation coefficient is supposed to be a monotonic relationship between paired data [40]. This study, however, used non-monotonic relationship data, which might show no correlation between nurses' knowledge of parent participation and parent participation.

Regarding predicting factors of parent participation in caring for hospitalized children with chronic diseases, perceived self-efficacy was the only predictor accounting for 72.65% of the variance in child care. The finding is partly consistent with the previous study that showed perceived self-efficacy was predictive of parent participation in caring for hospitalized children, even with an acute illness [24, 32]. Perceived self-efficacy is well accepted as the factor influencing individual behaviors. Because caring for a hospitalized child is a difficult task, the parent may be uncertain that they can safely provide care to the child. Those with low confidence are therefore likely not to participate in care. On the contrary, those with high confidence will be more

likely to participate. Therefore self-efficacy shows its strong predicting ability for parent participation in child care.

CONCLUSION

A predictive correlation design was used to identify and explain predicting factors of parent participation in caring for hospitalized children with chronic diseases. The results of the study showed that there was a significant positive relationship between parent participation in caring for hospitalized children with chronic diseases and perceived self-efficacy, information support from health care providers, and communication between parents and nurses. However, parents' perceived self-efficacy in child care was the only predictor with a strong influence on parent participation in child care. Therefore, nurses can enhance parent participation by enhancing parent's self-efficacy. Also, nurses should realize that effective communication between parents and nurses as well as information support is vital for encouraging parent participation in child care.

LIMITATIONS

There are a few limitations in this study. First, this research was a cross-sectional descriptive design which limits its ability to present a causal relationship among the study variables. Second, the study sample was recruited from tertiary hospitals; thus, the generalizability of findings to other types of hospitals may be limited.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by the Research Ethics Committee of the Faculty of Nursing, Chiang Mai University, Thailand (Research ID: 034-2559 Study Code: EXP-018-2559), the Human Research Ethics Committee of Nakhon Pathom Hospital, Thailand (NPH-REC N0.003/2017), the Human Research Ethics Committee of Ratchaburi Hospital, Thailand (COA-RBHEC 004/2017), and the Ethics Review Committee for Research in Human Subjects of two hospitals.

HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All human research procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

The researcher and well-trained research assistants (RAs) approached potential participants. After the participants agreed to take part in the study, they were asked to sign a consent form. In this study, the participants' names and information were treated confidentially. No individual identity was detectable in written reports. Data were not shared with other people.

AVAILABILITY OF DATA AND MATERIALS

Not applicable.

FUNDING

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CONFLICTS OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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