Original Article

Factors Associated with Well-Being of Family Caregivers of Children with Cerebral Palsy in Bangkok

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Objective: This correlational study was conducted to investigate the factors related to the well-being of family caregivers of children with cerebral palsy (CP).

Materials and Methods: Seventy-five participants meeting the inclusion criteria were family caregivers of children with CP in Bangkok. Data were collected using structured interviews following eight questionnaires including personal factors of children with CP and their family caregivers, knowledge of CP, beliefs of rehabilitation, perceived self-efficacy in care, the burden of care, social support, and well-being of family caregivers. Data were analyzed using descriptive statistics, Pearson product moment correlation, Spearman rank order correlation, and chi-square test.

Results: Findings showed that the mean age (±SD) of children with CP was of 11.0±4.2 years. The perceived self-efficacy in care and social support were significantly positively correlated with the well-being of the family caregivers ($p<0.05$, 0.01, 0.05, respectively) while the mean the burden of care was significantly negatively associated with the well-being of the family caregivers ($p<0.01$).

Conclusion: The important keys of caring for children with CP should be to provide the knowledge of care and self-support, the social support, and perceived self-efficacy in care of family caregivers to enhance their confidence to solve problems and reduced care burden resulting in the well-being of the family caregivers for children with CP.

Keywords: Factors, Well-being, Family caregivers, Children with cerebral palsy

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Cerebral palsy (CP) is the most common motor disability in childhood. The global prevalence estimates of children with CP have been reported at 1.5 to more than 4 per thousand live births identified with spastic CP (77.4%)(1-3). Similarly, in Thailand the prevalence rate of CP is 0.61 per thousand live(4). Most CP survivors have remained disabled needing help from parents or family caregivers (FCs) in necessary care(1,2). Thus, FCs have to support children with CP in continuously performing the activities of daily living (ADL), growth and development, rehabilitation and seeking resources. Furthermore, children aged under six years with high severity need to receive more than older children with low severity(5-7) resulting in increased burden of care and well-being(7,8). This may cause a low level of caregiving behaviors and poor quality of life of FCs. Therefore, the factors related to the well-being of FCs of children with CP should be studied.

According to the limited literature review, education, family income, and social support were positively correlated with the well-being of FCs(6,7,9-11). However, the severity of disease and the burden of care were negatively associated with the well-being of FCs(7,8,10,11). Similarly, previous qualitative studies reported that the burden of care affected their well-

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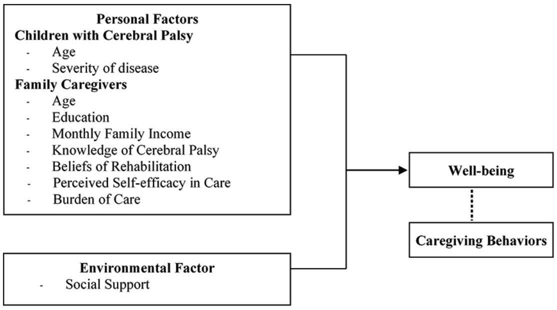

Figure 1. Conceptual framework of factors associated with the well-being of FCs of children with CP.

being, but social support could help them better(12,13). However, most studies examined in the hospital or online questionnaires being limiting factors related to caregiving behaviors of FCs for children with CP especially in the community context, particularly in Thailand(6,7,13). Therefore, these current studies were extended to conduct thoroughly and comprehensively the factors correlated with the well-being of FCs for children with CP in community contexts using Bandura's Social Learning Theory. Bandura reports that the behaviors of a person can be changed by not only environment factors, but by needed personal factors, especially well-being. These factors are reciprocal determinism having greater influence together. As a person have well-being or perceived self-efficacy toward any particular things, they will exhibit behaviors based on their well-being or perceived self-efficacy(14).

Similarly, the well-being of FCs might be related to personal factors of children with CP such as age and severity, individual factors of FCs such as age, level of education, and monthly family income, knowledge of CP, beliefs of rehabilitation, and perceived self-efficacy in care and social support. Thus, different personal factors and social support including experience exchanges, problem-solving, and encouragement, may affect the well-being of FCs of children with CP leading better caregiving behaviors, as shown in Figure 1.

Some children with CP in Thailand have more activities in community clubs or organizations established by parents or the government to provide support, encouragement, and strengthen families for delivering care, rehabilitating, and promoting growth and development. This performance only in hospitals are insufficient. Children with CP should be continuously provided with community-based rehabilitation. As a community nurse, researchers recognize the importance of care for children with CP in communities. However, there were limited studies factors related well-being of FCS of children with CP in Thailand. Therefore, studying the factors correlated with the well-being of FCS of children with CP should be examined to enhance guidelines for planning the care of children with CP and their families in community settings.

Materials and Methods

The present study used a correlational research design.

Population & Sample

FCs of children with CP aged up to 18 years participating in activities at eight disabled children rehabilitation centers using these inclusion criteria 1) care for children with CP for at least six months without profits, 2) aged 20 years and up, 3) ability to speak and communicate in Thai, 4) having a score of Short Portable Mental Status Questionnaire (SPMSQ) of 8 points or more if FCs aged more than 60 years, and 5) willingly signing informed consent forms.

The sample size was calculated using power analysis of Cohen(15) based on the finding of a similar study having effect size equal 0.36(7). Finally, the authors enrolled 75 FCs of children with CP to obtain sufficient statistical power (80%) in predicting the study outcomes with a statistically significant p-value of less than 0.05.

Research instruments

Research instruments consisted of eight parts, as follow:

- The demographic questionnaire consisted of FCs' gender, age, occupation, marital status, level of education monthly family income, religion, networks supporting FCs, and the children's gender, age, communication ability, and characteristics.
- The severity scale of children with CP was used from the Thai version of the Gross Motor Function Classification System (GMFCS) of the Can Child Center translated by Siritaratiwat and Thomas in 2007(16). It had a question for assessing mobility classified by child age with a Likert scale scoring range of 1 to 5 points. High scores meant limited motor function. Inter-rater reliability and Intra-rater reliability were 0.90 and 0.89, respectively.
- The rehabilitation belief questionnaire was adapted from the beliefs concerning rehabilitation in stroke patient questionnaire developed by Unruan Sornarkas et al(17) with ten questions. Each item was assessed on a Likert-type scale from 1 to 5 where

1="Disagree" and 5="Strongly Agree" with a possible score of 10 to 50 points. Higher scores indicated higher beliefs regarding the rehabilitation for children with CP. Content validity (CVI) was tested by three experts being obtained equal to 1 and Cronbach's alpha coefficient revealed the reliability of 0.79 and 0.77 for the main study.

- The perceived self-efficacy in the care questionnaire created by Pada et al(18) with 17 questions with a Likert scale ranging from "Least Confident" to "Most Confident" on a scale of 1 to 5 points with a possible score of 17 to 85. Higher scores indicated higher confidence in taking care of children with CP. CVI obtained at 1 and Cronbach's alpha coefficient presented reliability of 0.84 and 0.88 for the present study.
- The knowledge of CP questionnaire adapted from Inthachom et al(19) had 20 questions with "Yes" or "No" answer earned 1 or 0, respectively with a possible score of 0 to 20. Higher scores meant good knowledge about CP. CVI achieved at 0.95 and Cronbach's alpha coefficient revealed reliability of 0.55 and 0.74 for the present study after revision.
- The social support questionnaire was adapted from the Thai version, developed by Schaefer and colleague in 1981 and translated into Thai version by Hanucharurnkul in 1988(20) with 20 questions in four dimensions consisting of emotional support, material and service support, news and information support, and social network and responses on a Likert scale ranging from "None" to "Most" on a score of 1 to 4 with a possible score of 20 to 80 points. Higher scores indicated a higher level of care support. CVI obtained at 0.95 and Cronbach's alpha coefficient presented reliability of 0.91 and 0.85 for the present study.
- The burden of care questionnaire was used questionnaire belonged to Viriyaprasart's questionnaire(7) in Thai version adapting from the questionnaire of Oberst in 1991. It contained 16 questions with a Likert scale ranging from "no burden of care" to "most burden of care" on a score of 1 to 5 with a possible score of 16 to 80 points. Higher scores indicated a higher level of care burden. CVI obtained at 1 and Cronbach's alpha coefficient presented reliability of 0.85 and 0.89 for the present study.
- The well-being questionnaire was used Viriyaprasart's questionnaire(7) translated into Thai and adapted from the questionnaire of Dupuy in 1997. It contained 14 questions, consisting of anxiety, positive emotion, self-control, and general health, with a Likert scale ranging from "low well-being" to "high well-being" on 0 to 4 with a possible score of 0 to 56 points. Higher scores indicated higher well-being. CVI obtained at 1 and Cronbach's alpha coefficient presented reliability of 0.88 and 0.84 for the present study.

Data collection

After receiving approval from the Institutional Review Board, Faculty of Medicine, Ramathibodi Hospital in the project titled "Factors Associated with Well-Being and caregiving behaviors for Children with CP of FCs, Bangkok (ID MURA2018/469)", all participants received written and verbal explanations to learned of the objectives, methods, risks, benefits, and the right to withdraw from the study at any time throughout the study before giving written informed consent. Then, the researcher and research assistants collected data by structured interviews using 30 to 40 minutes per person. All data would be kept strictly confidential and reported overall data.

Statistical analysis

The descriptive statistics, including means, standard deviation (SD), frequency, and percent, were used to explain the demographic data and all study variables. Pearson's product moment correlation, Spearman's rank correlation, and chi-square test were used to test factors correlated with the well-being of FCs of children with CP.

Results

Seventy-five FCs of children with CP participated in the present study at the eight disabled children rehabilitation centers. The findings revealed that most participants were female (88.0%) with a mean age of 43.11 years (SD 10.8). The participants were housewives (57.3%), married and graduated secondary education (69.3% and 36.0%, respectively). The monthly family income averaged at 16,666.67 Baht per month (SD 11,487.16). Most of the participants were Buddhists and can read (82.7% and 92.0%). The participants received support from social networks and family members (100.0% and 88.0%, respectively). Moreover, over half of the children with CP were male (52%) with a mean age of 11.0 years (SD 4.2). Most children communicated indistinctly (42.7%) with mobility, physical, and intellectual impairments (28.0%). In addition, more than half of the children had severity at Level 4 and Level 5 (32% and 28%, respectively).

Mean scores on knowledge of CP had a good level and beliefs of rehabilitation had a high level (mean ± SD: 16.56±2.44, 42.35±10.55, respectively).

Table 1. Means of Knowledge of CP, beliefs of rehabilitation, perceived self-efficacy in care, social support, the burden of care, and well-being of care of FCs (n=75)

Variables	Range		Mean±SD	Level
	Possible score	Real score		
Knowledge of cerebral palsy	0 to 20	10 to 20	16.56±2.44	Good
Beliefs of rehabilitation	10 to 50	33 to 50	42.35±10.55	High
Perceived self-efficacy in care	17 to 85	56 to 85	75.72±7.55	High
Social support	20 to 80	36 to 80	56.65±9.91	Moderate
Burden of care	16 to 80	16 to 64	28.81±10.80	Low
Well-being	0 to 56	18 to 56	44.65±7.73	High

SD=standard deviation

Table 2. Correlations between the age of children with CP and FCs, beliefs of rehabilitation, perceived self-efficacy in care, social support, the burden of care and well-being of FCs using Pearson product moment correlation (n=75)

Variable	1	2	3	4	5	6	7
1. Age of children	1						
2. Age of family caregivers	0.04	1					
3. Beliefs of rehabilitation	0.07	0.10	1				
4. Perceived self-efficacy in care	0.19	−0.11	0.34**	1			
5. Social support	0.00	−0.11	0.05	0.26*	1		
6. Burden of care	−0.11	0.09	−0.04	−0.25*	0.01	1	
7. Well-being	0.24*	0.07	0.18	0.32**	0.26*	−0.50**	1

* p<0.05, ** p<0.01, the statistically significant at p<0.05

Table 3. Correlations between monthly family income, knowledge of CP, and well-being of FCs using Spearman's rank correlation (n=75)

Variable	1	2	3
1. Monthly family income	1		
2. Knowledge of cerebral palsy	0.06	1	
3. Well-being	0.02	0.13	1

Table 4. Correlations between education, the severity of disease and well-being of family caregivers using chi-square test (n=75)

Variable	Well-being		χ^2	p-value
	Low	High		
Level of education			0.82	0.342
None/primary school	1	24		
Secondary school & up	5	45		
Severity of disease			0.00	0.585
Levels 1 to 3	2	23		
Levels 4 to 5	4	46		

χ^2=chi-square

Similarly, mean score of perceived self-efficacy in care and well-being had a high level (mean ± SD: 75.72±7.55, 44.65±7.73, respectively). However, average score of social support and burden of care had a moderate and low level (mean ± SD: 56.65±9.91, 28.81±10.80, respectively) as shown in Table 1. Besides, mean age of children with CP, perceived self-efficacy in care and social support were significantly positive correlated with well-being of FCs (r=0.24, p=0.039; r=0.32, p=0.005; r=0.26, p=0.025, respectively), while mean burden of care was significantly negative associated with well-being of FCs (r=-0.50, p=0.000) as shown in Table 2-4.

Discussion

The findings of the present study partially supported the hypothesis that the mean age of children with CP, perceived self-efficacy in care, and social support were significantly positively correlated with well-being (p=0.039, 0.005, 0.025, respectively) as well as the mean burden of care was significantly negatively associated with the well-being of FCs

($p<0.001$). These findings were consistent with the concepts of Bandura's Social Learning Theory, stating that all factors including personal, environmental, and behavioral aspects, are reciprocal determinism at different times. Well-being is a factor in personal factors that may be related to other personal factors and the environment(14). Some studies found that children aged under six years with high severity receive more ADL support than older children with low severity(5). Thus, FCs received more burden of care leading to low well-being of FCs(5-7). However, social support would support that burden and motivate perceived self-efficacy in care being developed by knowledge of CP and vicarious or enactive mastery experience(14).

Similarly, in the present study, the FCs that received care technique, rehabilitation knowledge, and exchanged learning experience from experts and self-help groups at the eight disabled children rehabilitation centers resulted in high perceived self-efficacy in care leading to their well-being. These findings were in accordance with some studies that found perceived self-efficacy in care(10,21) and social support(7,21) were significantly positively correlated with well-being, but the mean burden of care was significantly negatively associated with the well-being of FCs(7). However, it was different from some studies that found severity of disease(7,8,10,21) and education(7) were significantly correlated with the well-being of FCs. This may be because the present study was conducted at the disabled children rehabilitation centers for children with CP that organize self-help groups with the same problem continually and systematically as part of the daily life of children with CP and FCs. Thus, they could solve their problems well.

Conclusion

The important keys of caring for children with CP should be to provide the knowledge of care and self-support, social support for FCs to reduce the burden of care and enhance their confidence to solve problems resulting in well-being, good caregiving behaviors, and quality of life. Further research should examine factors predicting well-being and caregiving behaviors of FCs of children with CP at home.

What is already known on this topic?

Limited studies found that the severity of the disease, education, monthly family income, perceived self-efficacy in care, the burden of care, and social support were significantly correlated with the well-being of FCs in the hospital.

What this study adds?

This current study added some factors, including knowledge of CP, beliefs of rehabilitation, and social support, to cover related factors that influence the well-being of FCs in the community context.

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Conflicts of interest

The authors declare no conflict of interest.

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