A Causal Model of Health Status of Children with Cerebral Palsy

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Abstract: The health status of children with cerebral palsy can vary greatly. While some children experience healthy others children experience severe impairments and a greater number of health conditions and need long-term dependence on the family. To improve the health status of children with cerebral palsy, it is critical to estimate the effects of the factors on the child's health. The objective of this study was to test a causal model of health status among 208 Thai children with cerebral palsy. Data were collected via eight questionnaires including a demographic data questionnaire, the severity of disability, the Social Support Questionnaire, the Family Hardiness Index, the Access Items, the Family Crisis Oriented Personal Evaluation Scales, the Family Management Measure, and the Pediatric Quality of Life Inventory 3.0 Cerebral Palsy Module. The hypothesized model was validated by LISREL program.

The hypothesized model (Model of Health Status of Children with Cerebral Palsy) fitted the empirical data and explained 49.9% of the variance in health status of the children. Family coping and family management had significant direct positive effects on health status; whereas, family hardiness and severity of disability had significant direct negative effects on health status. The nursing implication from this study includes developing a program focused on enhancing family coping and management to help the children improve their health status. Future studies of hardiness in Thai families are needed to fully understand the relationship between the family hardiness and the health status of children with cerebral palsy.

Pacific Rim Int J Nurs Res 2017; 21(4) 291-304

Keywords: Cerebral palsy, Family coping, Family management, Health status, Social support

Introduction

Having good health is important and beneficial for children with cerebral palsy (CP), especially in the early years of life. Based on the International Classification of Functioning, Disability and Health: Children and Youth version: ICF-CY,[1] the health of children with CP is described in terms of functioning and disability encompassing body structures and functions, activities and participation, as a dynamic interaction between personal and environmental factors. Children with CP who are healthy can survive into adulthood

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without being burdensome to the family or to society. On the other hand, children with CP who have poor health are likely to have a higher level of morbidity moreover, both their families and healthcare system are likely to encounter even more problems and to incur increased expenses.[2-4]

As CP is a non-progressive disorder of motor control which occurs in the developing brain, it affects children as a major consequence of developmental disabilities (DD) with long-term care needs. The early years of life before the age of 7 are a critical period for children with CP to receive the benefits of early intervention for prevention of health conditions associated with disabilities which is developmental issue. Children who had CP between the ages of 5 and 7 years, a transition period from preschool to school age, were the focus of this study because the period of 2 to 7 years is an age during which caregivers are still very confused and insecure about their child's development and need information to help them adjust with it.[3] Children with severe CP might have physical limitations and other developmental disabilities that require an access to and utilization of healthcare services and depend greatly on their caregivers over time. Family plays a significant role in managing the lifetime care of a child with CP and is considered to be a key to success in early intervention. Families are often inevitably and continuously faced with particular stressors and demands. Some families are able to adapt well and this can be shown in the health outcomes of children with CP but some families do not.[5-7]

Knowing the health status of children with CP and its significant predictors in specific social contexts, will guide healthcare providers in developing effective interventions to improve the health status of these children. This study aimed to validate a causal model displaying the relationships between the selected factors and health status of children with CP in Thailand.

Conceptual Framework and Literature Review

The conceptual framework was derived from the Resiliency Model[8] and review of the literature. The Resiliency Model is a useful framework for explaining the family's effort to work within a stressful situation in which the accomplishment results in positive outcomes in the family. The Model provides structure to examine determinants of family adaptation. A successful family adaptation contributes to the positive health status of a family member with chronic illness.[8] Furthermore, it is characterized by (a) positive physical and mental health of individual family members, (b) the continued facilitation and promotion of individual member development, (c) optimal role functioning of individual members, (d) the maintenance of a family unit that can accomplish its life-cycle tasks, and (e) the maintenance of family integrity and sense of control over environmental influence.[9] Family who can stay healthy and do well in the face of stressful situations will provide benefits to family members.[10] Such a family can provide protective care and support for vulnerable members, develop strengths and competences to restore and to adapt the family's situation, and carry out tasks and responsibilities, resulting in a better health outcome of family members.[8] In the face of a stressful situation, a successful or unsuccessful family adaptation is determined by stressors and demands, as well as the strengths and capabilities of the family unit. Stressors and their severity are vulnerability factors that affect all areas of family life; while, the strengths and capabilities are protective factors that help family to manage or successfully response to the situation.

Caring for a child with CP is a cause of hardships and changes in the family life.[4, 6] Families of children with CP encounter a crisis situation beginning with the first diagnosis and continually face inevitable difficulty.[6] However, some families can adapt to this situation and promote positive health outcomes for their children

with chronic illness.[5-7] Like the Resiliency Model, the health status of children with CP defined as the problems in functioning of the children, in which the functioning encompasses body functions and structures, activities and participation, is determined by the interaction of the vulnerability and protective factors. The vulnerability factors include the severity of disability. The protective factors include social support, family hardiness, access to healthcare, family coping and the family management.

The severity of disability is the caregivers' perception about the level of disability of the children with CP. Children with severe disability tend to be less independent with activities of daily living[11,12] and exhibit more associated problems such as feeding difficulties, communication problems and respiratory illness.[2,3] The severity of disability not only depletes family energy and resources, but also causes difficulty in dealing with the special needs.[6] A previous study has showed that when the severity of child behavior problems increased, mothers of children with DD perceived a greater impact of condition on their family life, which in turn increased the levels of the mothers' depressive symptoms.[13] The higher the behavior problems in children with DD, the poorer family functioning.[14]

Social support is the resources that the family and its members use to manage situations. It includes information, emotion, and tangible support given by: 1) family members; 2) siblings and relatives; 3) friends, coworkers, and neighbors; 4) other providers in the community; and 5) health care providers. It helps the family relieve stress and perform tasks with greater efficiency and ease. The use of coping strategies by parents is by social support.[15] Parents reporting high psychological distress, less well-being, family sense of coherence and family functioning, perceive less family support and connection.[16] Furthermore, social support not only encourages parents to cope with the cumulative demands in daily life, but also helps increase family functioning, leading to better health outcomes for the child with DD.[17,18]

Family hardiness is the internal strengths and durability of the family unit. It plays a role in the process of family adaptations as it mitigates the demands placed on the family, and helps family to recover by maintaining integrity and well-being.[8] Being committed to helping a family member with DD, working together as a family, and making the family member top priority are family strengths contributing to better family functioning.[19] When families are functioning well, harmonious relationships may serve to provide additional support and protective care for their children with DD.[20] Mothers of children with autism spectrum disorder (ASD) who had high family hardiness reported low family distress;[21] as well as, parents of children with Duchenne muscular dystrophy who had greater family hardiness reported healthy family functioning.[19]

Access to healthcare is a person's ability to find and to get healthcare services. It is a major domain of quality of care because without access to care, an individual has no opportunity to receive clinically appropriate or effective care. The access to healthcare helps family learn effective behavior in managing the chronic conditions of family members and in coping with the situation.[22-24] Families having children with DD who have difficulties in access to healthcare tend to have increased levels of stress.[22] Accessing healthcare services, family and their children will receive health interventions influencing on the improvement of health outcome of their children, and can share their questions and concerns with professionals. Furthermore, they will be supported by other parents in a similar situation that allows them to share their anxieties and learn from other experiences.[18]

Family coping and family management mediate the relationship among social support, family hardiness, access to healthcare and the health status of children with CP. Furthermore, family management mediates the relationship between the severity of disability and the health status of children with CP. Family coping is the caregivers' appraisal of behaviors used to maintain

the family as a whole and the emotional stability and to obtain resources. Families utilizing coping strategies when faced with a stressful situation, have better functioning,[7, 25, 26] and higher quality of life.[25] These families also tend to give more attention to and provide appropriate care and management for their children.[7] Family management is the family's ability to manage and care for a child with CP. Mothers who had difficulties in family management experienced a high level of depression[13]; moreover, their children with chronic illness had a high level of psychosocial problems.[27]

Based on both the related literature and the Resiliency Model, the hypothesized Model of Health Status of Children with CP is shown in Figure 1. It was hypothesized that the model would fit with empirical data. This study aimed to validate the causal model displaying the relationships between selected factors and health status of children with CP in Thailand.

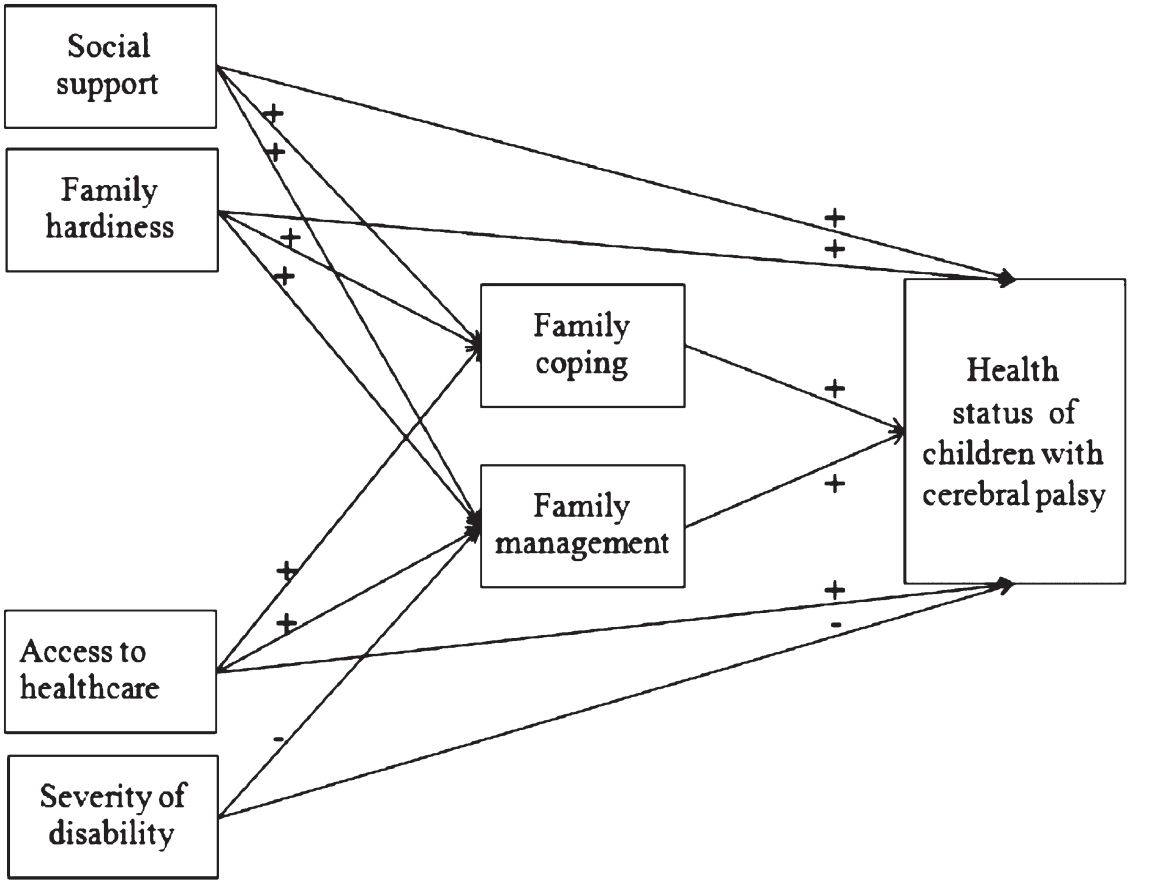


Figure 1: The Model of Health Status of Children with Cerebral Palsy (MHSCCP)

Method

Design: This study used a cross-sectional, correlational design.

Sample: The desired level of the ratio of sample size to an estimated parameter in the structural equation modeling is 10:1.[28] The total number of estimated parameters was 20, and an additional 10 % of participants were calculated to compensate for expected attrition; thus, the estimated sample size was 220. Convenience sampling with inclusion criteria was used to recruit the children with CP and their caregivers. For the children with CP, the criteria were: 1) aged 5 to 7 years, 2) having no co-morbidity such as heart disease, diabetes mellitus or Down's syndrome to avoid confounding effect, and 3) not receiving intramuscular injection for the reduction of spasticity or muscle lengthening/surgery in the previous 3 months. For the caregivers, the inclusion criteria were: 1) being a child's blood relative, 2) providing care for at least 1 year, 3) being able to read and communicate in Thai, and 4) living in the same household with the children with CP.

Ethical considerations: Approval to conduct the study was granted by the Institutional Review Board of the Faculty of Medicine Siriraj Hospital, Mahidol University, approval No.Si534/2014. Participants were informed about the purpose and processes of the study, confidentiality and anonymity issues, and the right to withdraw from the study at any time without repercussions. All participants willing to participate were asked to sign the written informed consent form prior to data collection.

Instruments: There were eight instruments used with permission in this study. All instruments except demographic questionnaires and the Severity of Disability were examined for content validity index (CVI) by six experts in pediatric nursing and caring for children with chronic illness: five nursing faculty members, and a pediatric rehabilitation medicine physician. These instruments were pilot-tested for internal consistency reliabilities with 30 dyads of children with CP and their primary caregivers.

The demographic questionnaires developed by the principle investigator (PI), collected information from caregivers and children with CP. The caregivers' questionnaire included characteristics of: age, gender, religion, marital status, current residence, education, occupation, family income, adequacy of income, relationship to the child with CP, duration of caregiving, and general health status. Information obtained regarding demographic characteristics of the children comprised: age, gender, age at CP diagnosis, hospitalization, medical payment, and general health status.

The Severity of Disability is a global rating scale measured by a single-item scale.[29] It was translated into Thai by the PI. Caregivers were asked about the severity of their child's disability using a 5-point rating scale from "not at all severe" (1) to "very severe" (5). Higher scores indicated greater severity of disability.

The Social Support Questionnaire (SSQ) developed by Pipatananond was used in the study of Santati[37] to measure the social support of caregivers having children with asthma. It consists of a 35-item scale to measure support from five sources: (1) family members, (2) siblings and relatives, (3) friends, co-workers, neighbors, (4) health care providers, and (5) other providers in the community. Each source is comprised of seven items including three types of support: information, emotion, and tangible support. All were scored on a 5-point rating scale ranging from 0 = not at all to 4 = a great deal. An example of items is: "How much did family members give you information, suggestion, and guidance during your giving care to this child that you found helpful?". The total scores range from 0 to 140. Higher scores indicate higher perceived social support. The CVI for the scale (S-CVI) was 0.95 and the Cronbach's alpha coefficient was 0.97 for the pilot study and 0.94 for the main study.

The Family Hardiness Index (FHI) was developed by McCubbin et al.[30] and translated and

modified into a Thai version by Santati.[31] It consists of a 20-item scale with three subscales: commitment (8 items), challenge (6 items), and control (6 items). All are scored on a 4-point rating scale ranging from 0 = false to 3 = true. An example of items is: "It is not wise to plan ahead and hope because things do not turn out anyway". The total scores range from 0 to 60. Higher scores indicate higher levels of family hardiness. The S-CVI was 0.95 and the Cronbach's alpha coefficient was 0.76 for the pilot study and 0.82 for the main study.

The Access Items was developed by Cunningham et al.[32] It consists of four subscales to measure perceived problems with healthcare access: affordability (2 items), availability (3 items), convenience (3 items), and access to specialists (1 item). Each item is measured on a 5-point Likert-type scale from "strongly agree" (5) to "strongly disagree" (1). An example of items is: "A child able to get medical care whenever a child needs". The total scores range from 9 to 45. Higher scores reflect a higher level of healthcare accessibility. The S-CVI was 0.95 and the Cronbach's alpha coefficient was 0.67 for the pilot study and 0.56 for the main study.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) was developed by McCubbin et al.[33] and is used to assess family coping in response to stressful situations. Rungreangkulkij[34] translated and modified the questionnaire into Thai. Three items were added in her study because most individuals in Thai culture believe in spirits and most are Buddhist, such as: "Be predicted by fortune to solve problems". The 33-item scale with a five-point Likert-type response format is comprised of 5 subscales: (1) acquiring social support (9 items), (2) reframing (8 items), (3) seeking spiritual support (5 items), (4) mobilizing family to acquire and accept help (4 items) and (5) passive appraisal (7 items). Each item is measured on a 5-point Likert-type scale from "strongly agree" (5) to "strongly disagree" (1). An example of items is: "Defining the family problems in a more positive way so that we do not become too discouraged". The total scores range from 33 to 165. Higher scores indicate higher utilization of coping strategies. The S-CVI was 0.97 and the Cronbach's alpha coefficient was 0.77 for the pilot study and 0.73 for the main study.

The Family Management Measure (FaMM) was developed by Knafl and colleagues[35] to measure how families managed caring for a child with a chronic condition and illness and the extent to which they incorporated condition management into everyday family life. The FaMM comprises of five subscales: child's daily life (5 items), condition management ability (12 items), condition management effort (4 items), family life difficulty (14 items), and view of condition impact (10 items). The 45 items are measured on a 5-point Likert-type scale from "strongly agree" (5) to "strongly disagree" (1). An example of items is: "We have not been able to develop a routine for taking care of our child's condition". The total scores range from 45 to 225. Higher scores indicate higher ease in managing the child's condition and care for the CP child. The S-CVI was 0.98 and the Cronbach's alpha coefficient was 0.83 for the pilot study and 0.85 for the main study.

The Pediatric Quality of Life Inventory 3.0 Cerebral Palsy Module (PedsQL 3.0 CP Module) was developed by Varni and colleagues[36] to measure components in the domains of body functions and structures, activities, and participation in the ICF Model of World Health Organization (WHO).[1] It assesses the impact of disease and treatment on the functioning of children with CP with questions asking about severity of problems regarding functioning of the children from the perspective of the caregivers or parents during the past month. It was translated into Thai by Tantilipikorn et al.[37] The 35-items scale of the PedsQL 3.0 CP Module with a 5-point Likert-type response format consists of seven subscales: (1) daily activities: 9 items, (2) school activities: 4 items, (3) movement and balance: 5 items, (4) pain

and hurt: 4 items, (5) fatigue: 4 items, (6) eating activities: 5 items, and (7) speech and communication: 4 items. All items are scored on a 5-point rating scale from 0 = never a problem to 4 = almost always a problem. Responses are converted into a score from 0 to 100 with a reverse pattern (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0) for standardized interpretation. An example of items is: "How much of a difficulty has it been for your child in the past month to move one or both legs?". The total scores for 35 items range from 0 to 3500. Higher scores indicate a better health status. The S-CVI was 0.99 and the Cronbach's alpha coefficient was 0.93 for the pilot study and 0.96 for the main study.

Data collection: Two hundred and forty-eight potential participants were approached from four rehabilitation centers in Bangkok Metropolitan Area, Thailand. Most caregivers completed the questionnaires in a private room at the clinic (n=160). Others preferred to answer the questionnaires at home (n=68), and return them to the PI by mail using the stamped envelope provided. Twenty caregivers were interviewed face-to-face by the PI to complete the questionnaires due to physical impediments (i.e. short- or long- eye sighted) or illiteracy of the participants. In summary, the total number of participants was 208.

Data analysis: Data were analyzed using descriptive statistics, Pearson's correlation coefficient and path analysis. Path analysis was used to test the hypothesized model through the Linear Structural Relationship (LISREL) program. The assumptions of normality, linearity, homoscedasticity, and absence of multicollinearity were met.

Results

Characteristics of caregivers: Forty caregivers did not return the questionnaires (attrition rate = 58.82%). Caregivers ranged in age from 19 to 66 years (mean = 38.04, SD = 8.93). Most caregivers were mothers (63.5%), married (82.7%), and Buddhists (96.6%), lived in Bangkok Metropolitan Region (87.6%), and had assistants in caring for the children (73%). More than half of the assistants were husband (51%). Approximately a quarter of the caregivers finished primary school (24%) and secondary school (27.9%), and 30.3% graduated with bachelor's degree and higher. Almost one-third (32.2%) of caregivers were unemployment and 28.8% were employees. The monthly income ranged from 2,000 to 600,000 Baht (mean = 31,732.22, median = 15,000, SD = 59,432.59). The majority of caregivers (59.6%) had insufficient income. The duration of caregiving ranged from 1 to 7 years (mean = 5.94, SD = 1.33) and the duration of daily caregiving ranged from 3 to 24 hours (mean = 18.40, SD = 6.92). About 62.5% of caregivers reported good to very good health, and 34.1% were fair.

Characteristics of children: The average age of the children was 6.23 years (SD = 0.89). Most children (61.1%) were male. The majority were diagnosed in the first year of life (71.6%) and had a universal coverage card for health welfare (87.5%). About 61% of the children had a level of severity ranged from rather severe to profound. Most children were reported to be in fair or good health (77.4%). Nearly 30% of the children were hospitalized in the last 2 months due to illness.

Characteristics of the key variables: As shown in **Table 1**, access to healthcare, family coping and family management were slightly high, whereas social support and family hardiness were at a moderate level. Meanwhile, disability was rather severe and health status was rather low. When considering the seven subscales of health status as shown in **Table 2**, the average score of daily activities was lowest; whereas, that of pain and hurt was highest.

Model testing: The proposed model accounted for 49.9% of the variance in the health status of children with CP. The model provided a good fit with the empirical data with $\chi^2 = 0.91$, df = 3, p = 0.82, χ^2/df = 0.30, RMSEA = 0.00, 90% CI for RMSEA = 0.00; 0.07, GFI = 0.99, AGFI = 0.98, CFI = 1,

RFI = 0.98, and SRMR = 0.01 (**Figure 2**). The largest and the smallest standardized residual values were 0.91 and −0.94, respectively. The causal effects of the variables on health status of children with CP are displayed in **Table 3** in terms of direct, indirect and total effects.

Table 1 Descriptive statistics of key variables (n = 208)

Variables	Possible range	Actual range	Mean	Level	SD
Social support	0 – 140	25 – 140	72.63	Moderate	21.03
Family hardiness	0 – 60	23 – 60	45.12	Moderate	8.31
Access to healthcare	9 – 45	17 – 45	30.29	Slightly high	4.51
Severity of disability	1 – 5	1 – 5	2.92	Rather Severe	1.05
Family coping	33 – 165	84 – 147	116.62	Slightly high	9.84
Family management	45 – 225	77 – 185	137.74	Slightly high	18.79
Health status	0 – 3500	100 – 3400	1638.94	Rather low	792.8

Table 2 Descriptive statistics of health status and its subscales (n = 208)

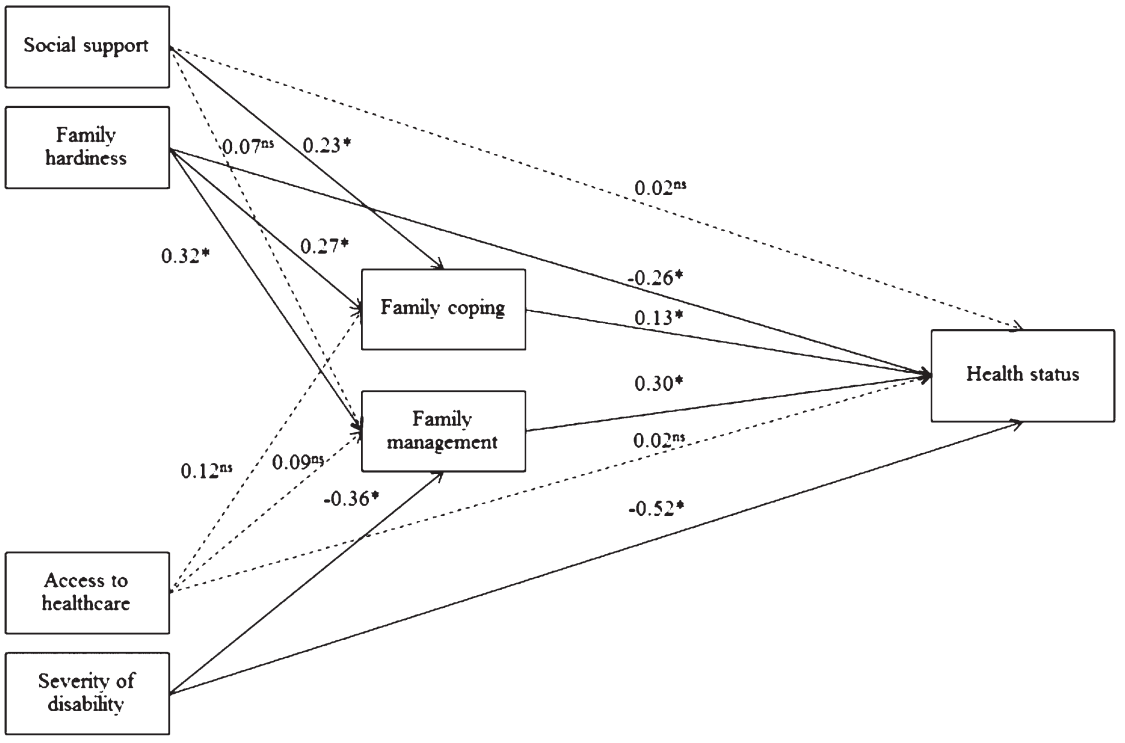
Variables	Possible range	Actual range	Mean	SD
Health status	0 – 100	2.85 – 97.14	46.82	22.65
Daily activities	0 – 100	0 – 100	29.32	27.06
School activities	0 – 100	0 – 100	30.83	32.72
Movement and balance	0 – 100	0 – 100	53.99	29.00
Pain and hurt	0 – 100	0 – 100	72.66	28.33
Fatigue	0 – 100	0 – 100	59.01	30.18
Eating activities	0 – 100	0 – 100	48.79	32.29
Speech and communication	0 – 100	0 – 100	52.76	36.04

Table 3 Direct effect, indirect effect, and total effect in the model (n = 208)

Cause – Effect	Standardized parameter estimates		
	Direct effect	Indirect effect	Total effect
FCOPES–HEALTH	0.13*	–	0.13*
FAMM–HEALTH	0.30*	–	0.30*
SSQ–FCOPES	0.23*	–	0.23*
SSQ–FAMM	0.07^{ns}	–	0.07^{ns}
SSQ–HEALTH	0.02^{ns}	0.03*	0.05^{ns}
FHI–FCOPES	0.27*	–	0.27*
FHI–FAMM	0.32*	–	0.32*
FHI–HEALTH	−0.26*	0.13*	−0.13*
ACCESS–FCOPES	0.12^{ns}	–	0.12^{ns}
ACCESS–FAMM	0.09^{ns}	–	0.09^{ns}
ACCESS–HEALTH	0.02^{ns}	0.04^{ns}	0.06^{ns}
SEVERITY–FAMM	−0.36*	–	−0.36*
SEVERITY–HEALTH	−0.52*	−0.11*	−0.63*

R^2 of family coping = 19.9%, R^2 of family management = 31.7%, R^2 of health status = 49.9%

Note: *p < 0.05, ns = Non-significant, R^2 = Squared multiple correlations for structural equations



c^2 = 0.91, df = 3, c^2/df = 0.30, p = 0.82, RMSEA = 0.00, 90% CI for RMSEA = 0.00 ; 0.07, GFI = 0.99, AGFI = 0.98, CFI = 1, RFI = 0.98, SRMR = 0.01

Note: *p < 0.05, ns = Non-significant

Figure 2: The Model of Health Status of Children with Cerebral Palsy (MHSCCP)

Discussion

The Model of Health Status of Children with Cerebral Palsy (MHSCCP) as proposed fitted with the empirical data, but partially supported the Resiliency Model. The finding that severity of disability had a negative direct effect on health status of children is congruent with previous studies in which the children with CP who had a higher level of severity of disability, had a poorer health outcomes.[11, 12]

The mediating effect of family management on the relationship between severity of disability and health status was also found. This finding is congruent with the finding reported by Kim and colleagues.[27, 38] When the severity of behavior problems of children with ASD was high, the mothers appeared to perceive greater difficulty in managing their child's condition, which in turn increased the levels of the mothers' depressive symptoms. Furthermore, the children with chronic illness showed high level of psychosocial problems when their family perceived greater difficulty in managing the child conditions.[27] Family management had a positive direct effect on health status of children with CP. This finding is consistent with the previous studies.[13, 27] In the Resiliency Model, the family's management played an important role in organizing stressors and hardships into manageable components, and in identifying alternative courses of action to deal with each component.[8] A family who has greater ease in managing the condition of and

care for a child with CP is inclined to accept and understand situation, and to view, manage and care for the child as normally as possible. The family who has the ability to focus on the normal aspects of the child and family life, despite having a child with chronic illness, is inclined to achieve higher functioning with less negative effects on all family members.[13]

Family coping had a positive direct effect on the health status of children with CP. This result is consistent with the finding of previous studies.[25] Family coping played important role in maintaining the emotional stability and well-being of its members, and in obtaining or using family resources to manage the situation.[8] Families of children with DD who make more use of coping strategies with the situation, are likely to have the better functioning.[7, 25, 26] Also, they have the ability to act responsibly and care for the child's physical and psychological needs, to take responsibility for the child's upbringing, to solve their problems and conflicts by themselves, and to get enough support.[7]

This study also revealed that family hardiness had significant positive direct effects on family coping and family management, and had significant indirect effects on the health status through family coping and family management. Family hardiness is an important factor to understand coping in mother having a child with DD, and avoids mothers in distress.[21] Also, higher family hardiness brings about greater family management.[31] This can be further explained that family with having a commitment to work together, believe in their abilities to solve problems and have a sense of control over stressors, use more coping behaviors to cope with many changing demands related to special needs of their children. Their children also are given effective health interventions.[20] These lead them to feel greater ease in managing the child's condition and caring for the child without difficulty.

It has been hypothesized that the higher the family hardiness, the better the health status of children with CP. Surprisingly, in this MHSCCP, children with CP who had a higher level of family hardiness had a poorer health status. It may be possible that families with a high level of hardiness may have hope for and high expectations of child's health improvement. However the health status of children with CP improves quite slowly, caregivers might be disappointed and discouraged by continual rehabilitation for their child.[39] The children with CP who discontinued rehabilitation often developed poor health conditions. Caregivers with unrealistic expectations regarding child's outcomes are likely to have higher disappointment and higher stress.[5] As well, the caregivers might get used to looking after their children and feel abandoned, which later lead to have the poor health status of their children.

Social support did not have a significantly direct effect on the health status and indirect effect on the health status through family management. This opposes previous studies.[17, 18] However, social support had a significantly indirect effect on health status through family coping. This is congruent with a previous study.[15] Families of children with DD having greater social support reported healthy family functioning.[17] In the current study, it may be possible that support resources might not help caregivers much in taking care of the children and managing the child's chronic conditions. These sources help caregivers to greatly utilize coping strategies and to relieve some stress which in turn helps increase some of the caregivers' managements in caring for the children,[6, 8, 15, 31] and also result in better health status of the children.

Access to healthcare has neither a significant direct effect nor indirect effect on the health status of children with CP through family coping and family management. Healthcare services are indeed important for families to help them to reduce stress and care demand, to cope with stress associated with their child, and to learn effective forms of behavior management.[22-24] Our finding about this is not congruent with previous studies.[23, 24, 40] This may be related to homogeneity in access to healthcare and a measurement error as the reliability coefficient of access to healthcare is low.

The children with CP already had healthcare services and had received care from specialists, so access to healthcare was not an issue for these families. The participants represented a population that could access healthcare; while, those with less accessibility or no accessibility were not included in the current study.

Limitations

The study used convenience sampling with inclusion criteria. Thus the findings have the limitation of generalizability to a more diverse population. Although, this study was based on the Resiliency Model and used path analysis to test a causal model, the cross-sectional design used has the limitations in causal inferences. Future studies need to consider the use of a longitudinal design.

Conclusions and Implications for Nursing Practice

Although the severity of disability can have negative effects on the health status of children with CP, the children can still have good health if the family as a whole has good management and coping strategies as well as high levels of social support and high family hardiness are present. Family management and coping have been shown to be beneficial in protecting and improving health status of children with CP in this study. To promote the health status of the children with CP, efforts should be made to improve family management and coping by mobilizing existing resources for the family to have proper support and promoting family hardiness. There is very little research on nursing intervention programs to improve or enhance health status of children with CP through enhancing the strength and capability of the family. Thus, these kinds of nursing intervention programs should be developed. It is the responsibility of the nurses working with children with CP to have an ongoing assessment of the child's health status and family in order to identify child and family at risk. Their family management and coping with the child with CP, social support, and family hardiness should also be addressed during the child's visit.

Acknowledgements

Special thanks go to the participants in this study.

References

1. World Health Organization. International classification of functioning, disability and health : children & youth version : ICF-CY. Geneva: World Health Organization; 2007.
2. Blackmore AM, Bear N, Blair E, Gibson N, Jalla C, Langdon K, et al. Factors associated with respiratory illness in children and young adults with cerebral palsy. The Journal of Pediatrics. 2016;168(January):151-7.e1.
3. Bertule D, Vetra A. The family needs of parents of preschool children with cerebral palsy: The impact of child's gross motor and communications functions. Medicina. 2014;50(6):323-8.
4. Basaran A, Karadavut KI, Uneri SO, Balbaloglu O, Atasoy N. The effect of having a children with cerebral palsy on quality of life, burn-out, depression and anxiety scores: A comparative study. European Journal of Physical and Rehabilitation Medicine. 2013;49(6):815-22.
5. LaForme Fiss A, Chiarello LA, Bartlett D, Palisano RJ, Jeffries L, Almasri N, et al. Family ecology of young children with cerebral palsy. Child: Care, Health and Development. 2014;40(4):562-71.
6. Ribeiro MF, Vandenberghe L, Prudente CO, Vila VD, Porto CC. Cerebral palsy: How the child's age and severity of impairment affect the mother's stress and coping strategies. Ciencia & saude coletiva. 2016;21(10):3203-12.
7. Taanila A, Syrjala L, Kokkonen J, Jarvelin M-R. Coping of parents with physically and/or intellectually disabled children. Child: Care, Health & Development. 2002; 28(1):73-86.
8. McCubbin MA, McCubbin HI. Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crisis. In: McCubbin HI, Thompson AI, McCubbin MA, editors. Family assessment: Resiliency, coping and adaptation-Inventories for research and practice. Madison, WI: University of Wisconsin Publishers; 1996. p. 1-64.

9. Kosciulek JF, McCubbin MA, McCubbin HI. A theoretical framework for family adaptation to head injury. Journal of Rehabilitation. 1993;35:40-5.
10. Leeman J, Crandell JL, Lee A, Bai J, Sandelowski M, Knafl K. Family functioning and the well-being of children with chronic conditions: A meta-analysis. Research in Nursing & Health. 2016;39:229-43.
11. Assis-Madeira EA, Carvalho SG, Blascovi-Assis SM. Functional performance of children with cerebral palsy from high and low socioeconomic status. Revista Paulista de Pediatria. 2013;31(1):51-7.
12. Keeratisiroj O, Thawinchai N, Siritaratiwat W, Buntragulpoontawee M. Prognostic predictors for ambulation in Thai children with cerebral palsy aged 2 to 18 years. Journal of Child Neurology. 2015;30(13):1812-8.
13. Kim I, Ekas NV, Hock R. Associations between child behavior problems, family management ability, and depressive symptoms for mothers of children with autism spectrum disorder. Research in Autism Spectrum Disorders. 2016;26:80-90.
14. Sikorová L, Bužgová R. Associations between the quality of life of children with chronic diseases, their parents' quality of life and family coping strategies. Central European Journal of Nursing and Midwifery. 2016; 7(4):534-41.
15. Lai WW, Oei TPS. Coping in parents and caregivers of children with autism spectrum disorders (ASD): A review. Review Journal of Autism and Developmental Disorders. 2014;1:207-24.
16. Moen ØL, Hedelin B, Hall-Lord ML. Family functioning, psychological distress, and well-being in parents with a child having ADHD. SAGE Open. 2016;6(January-March):1-10.
17. Hsiao CY. Family demands, social support and family functioning in Taiwanese families rearing children with Down syndrome. Journal of Intellectual Disability Research. 2014;58(6):549-59.
18. Araújo CACd, Paz-Lourido B, Gelabert SV. Types of support to families of children with disabilities and their influence on family quality of life. Ciencia & saude coletiva. 2016;21:3121-30.
19. Chen J-Y. Mediators affecting family functioning in families of children with Duchenne muscular dystrophy. Kaohsiung Journal of Medical Sciences. 2008; 24(10):514-21.
20. Mitchell DB, Hauser-Cram P. Early predictors of behavior problems. Journal of Early Intervention. 2009;32(1):3-16.
21. Weiss JA, Robinson S, Fung S, Tint A, Chalmers P, Lunsky Y. Family hardiness, social support, and self-efficacy in mothers of individuals with autism spectrum disorders. Research in Autism Spectrum Disorders. 2013;7(11): 1310-7.
22. Gomes PT, Lima LH, Bueno MK, Araujo LA, Souza NM. Autism in Brazil: A systematic review of family challenges and coping strategies. Journal de Pediatria. 2015;91(2): 111-21.
23. Bannink F, Idro R, van Hove G. Parental stress and support of parents of children with spina bifida in Uganda. African Journal of Disability [Internet]. 2016 [cited 2017 March 30]; 5(1). Available from: http://www.ajod.org/index.php/ajod/article/view/225.
24. Tessier DW, Hefner JL, Newmeyer A. Factors related to psychosocial quality of life for children with cerebral palsy. International Journal of Pediatrics. 2014;2014:6.
25. Sikora D, Moran E, Orlich F, Hall TA, Kovacs EA, Delahaye J, et al. The relationship between family functioning and behavior problems in children with autism spectrum disorders. Research in Autism Spectrum Disorders. 2013;7(2):307-15.
26. Xue J, Ooh J, Magiati I. Family functioning in Asian families raising children with autism spectrum disorders: The role of capabilities and positive meanings. Journal of Intellectual Disability Research. 2014;58(5):406-20.
27. Kim DH, Im YJ. The influence of family management style on psychosocial problems of childhood cancer survivors in Korea. European Journal of Oncology Nursing. 2015; 19(2):107-12.
28. Hair JF, Black WC, Babin BJ, Anderson RE. Multivariate data analysis: A global prespective. 7th ed. Upper Saddle River: NJ: Pearson Education; 2010.
29. Manuel JC, Balkrishnan R, Camacho F, Smith BP, Koman LA. Factors associated with self-esteem in pre- adolescents and adolescents with cerebral palsy. Journal of Adolescent Health. 2003;32:456-8.
30. McCubbin MA, McCubbin HI, Thompson AI. FHI: Family Hardiness Index In: McCubbin HI, Thompson AI, McCubbin MA, editors. Family Assessment: Resiliency, Coping and Adaptation: Inventories for Research and Practice Madison: University of Wisconsin; 1996. p. 239-305.

31. Santati S, Wittaya-soonporn J, Hanucharurnkul S, Vangveeravong M, Kanjanawasee S. Asthma management abilities causal model: An empirical test among parent caregivers of the pre-school asthmatic children. Thai Journal of Nursing Research. 2006;10(2):98-112.
32. Cunningham WE, Hays RD, Williams KW, Beck KC, Dixon WJ, Shapiro MF. Access to medical care and health-related quality of life for low-income persons with symptomatic human immunodeficiency virus. Medical Care. 1995;33(7):739-54.
33. McCubbin HI, Larsen A, Olson D. Family Crisis Oriented Personal Scales (F-COPES). In: McCubbin HI, Thompson AI, McCubbin MA, editors. Family assessment: Resiliency, coping &adaptation: Inventories for research and practice Madison: WI: University of Wisconsin; 1981. p. 455-507.
34. Rungreangkulkij S. Experience of Thai families of a person with schizophrenia: Family stress and adaptation [Doctoral dissertation]: University of California San Francisco; 2000.
35. Knafl K, Deatrick J, Gallo A, Holcombe G, Bakitas M, Dixon J, et al. The analysis and interpretation of cognitive interviews for instrument development. Research in Nursing & Health. 2007;30(2):224-34.
36. Varni JW, Burwinkle TM, Berrin SJ, Sherman SA, Artavia K, Malcarne VL, et al. The PedsQL in pediatric cerebral palsy: Reliability, validity, and sensitivity of the Generic Core Scales and Cerebral Palsy Module. Developmental Medicine and Child Neurology. 2006;48(6):442-9.
37. Tantilipikorn P, Watter P, Prasertsukdee S. Feasibility, reliability and validity of the Thai version of the pediatric quality of life inventory 3.0 cerebral palsy module. Quality of Life Research. 2013;22:415-21.
38. Kim I, Ekas NV, Hock R. Associations between child behavior problems, family management, and depressive symptoms for mothers of children with autism spectrum disorder. Research in Autism Spectrum Disorder. 2016;26:80-90.
39. Lopundung T. Service needs of caregivers for people with cerebral palsy in rural areas of Chaiyaphum province [Master degree]: Mahidol University; 2007 [in Thai].
40. Law M, Hanna S, Anaby D, Kertoy M, King G, Xu L. Health-related quality of life of children with physical disabilities: A longitudinal study. BMC Pediatrics. 2014;14(1):14-26.

รูปแบบจำลองการวิเคราะห์เชิงสาเหตุของภาวะสุขภาพของเด็กสมองพิการ

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บทคัดย่อ: ภาวะสุขภาพของเด็กสมองพิการในแต่ละคนมีความแตกต่างกัน บางคนมีสุขภาพดี ขณะที่บางคนมีปัญหาสุขภาพ มีข้อจำกัดในการช่วยเหลือตนเอง และต้องพึ่งพาการดูแลอย่างมากจากครอบครัว เพื่อให้พยาบาลสามารถช่วยให้เด็กสมองพิการมีสุขภาพที่ดี จำเป็นต้องรู้ว่าปัจจัยอะไรที่ส่งผลต่อภาวะสุขภาพของเด็กเหล่านี้ งานวิจัยนี้เป็นการศึกษาเชิงสหสัมพันธ์ เพื่อทดสอบความตรงของโมเดลความสัมพันธ์เชิงสาเหตุของภาวะสุขภาพของเด็กสมองพิการในประเทศไทย กลุ่มตัวอย่างคือผู้ดูแลของเด็กสมองพิการและเด็กสมองพิการ จำนวน 208 คน เก็บรวบรวมข้อมูลโดยใช้แบบสอบถาม 8 ชุด ได้แก่ ข้อมูลส่วนบุคคล ความรุนแรงของความพิการ การสนับสนุนทางสังคม ความเข้มแข็งของครอบครัว การเข้าถึงระบบบริการสุขภาพ การเผชิญความเครียดของครอบครัว การจัดการของครอบครัว และสุขภาพของเด็กสมองพิการ วิเคราะห์ข้อมูลพื้นฐานด้วยสถิติบรรยาย ตรวจสอบความตรงของโมเดลสมมติฐานวิจัยด้วยโปรแกรมลิสเรล

ผลการศึกษา พบว่ารูปแบบจำลองมีความสอดคล้องกับข้อมูลเชิงประจักษ์ และความสามารถทำนายความแปรปรวนของสุขภาพของเด็กสมองพิการได้ 49.9% การเผชิญความเครียดและการจัดการของครอบครัวมีอิทธิพลโดยตรงทางบวกต่อสุขภาพของเด็ก ความเข้มแข็งของครอบครัวและความรุนแรงของความพิการมีอิทธิพลโดยตรงทางลบต่อสุขภาพของเด็ก การสนับสนุนทางสังคมมีอิทธิพลทางอ้อมต่อสุขภาพของเด็กผ่านการเผชิญความเครียดของครอบครัว ความเข้มแข็งของครอบครัวมีอิทธิพลทางอ้อมต่อสุขภาพของเด็กผ่านการเผชิญความเครียดและการจัดการของครอบครัว และความรุนแรงของความพิการมีอิทธิพลทางอ้อมต่อสุขภาพของเด็กผ่านการจัดการของครอบครัว พยาบาลสามารถนำผลการศึกษานี้ไปใช้ในการปฏิบัติการดูแลทั้งเด็กสมองพิการและผู้ดูแลเด็ก ด้วยการพัฒนาโปรแกรมเพื่อปรับปรุงหรือส่งเสริมภาวะสุขภาพของเด็กสมองพิการโดยการส่งเสริมการเผชิญความเครียด การจัดการและการสนับสนุนทางสังคมของครอบครัว นอกจากนี้ควรจะมีการศึกษาวิจัยในระยะยาว และศึกษาเกี่ยวกับความเข้มแข็งในครอบครัวของคนไทยมากขึ้น เพื่อให้เข้าใจถึงบทบาทของความเข้มแข็งในครอบครัวที่มีต่อภาวะสุขภาพของเด็กสมองพิการ

Pacific Rim Int J Nurs Res 2017; 21(4) 291-304

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