Factors Influencing Family Functioning related to Preschool Children with Down Syndrome

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Abstract: Families of preschool children with Down syndrome face a number of challenges from the condition itself and in normative transitions in the preschool age group.The accumulated stress undermines the family functioning. This cross-sectional study tested the pattern of relationships between factors of the Resiliency Model of Family Stress, Adjustment, and Adaptation and family functioning among families of children with Down syndrome. The convenience and network samplings were used to recruit 120 mothers of preschool children with Down syndrome from two university hospitals and one national institute for intellectually and developmentally disabled children in Bangkok. Data were obtained using the demographic interviewing questionnaire, Family Stressors and Strains Questionnaire, Family Hardiness Index, Social Support Questionnaire, Family Crisis Oriented Personal Evaluation Scales, and Chulalongkorn Family Inventory. The data were analyzed using descriptive statistics and path analysis.

The results showed that the model offered a good fit with the empirical data and could explain 47% of the variance in the family functioning. Family hardiness was the most influential factor directly affecting family functioning, followed by social support, and family demands, respectively. Neither family hardiness nor social support had indirect effects on family functioning through family problem-solving and coping. Nurses need to develop further intervention programs in Thailand for the families of preschool children with Down syndrome by teaching family members the essential skills to reduce their stress, strengthen hardiness in families, and mobilize a social support network to keep a balance of family functioning. They can learn from international experiences of such programs.

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Introduction

Down syndrome (DS) is the most common chromosomal disorder resulting in intellectual disability. Raising a child with DS is very challenging for a family, as it affects all aspects of the family system. Previous studies have reported that such parents are emotionally exhausted and depressed,[1-2] stressed and anxious about the future of their child, given developmental delay and

social neglect of the child, and their work-life balance.[3-4] Moreover, one of the couple may stop working to care for the child with DS, while the other works hard outside the home resulting in less time with the at-home spouse and resentment in their relationship.[4-5] In addition, siblings of a child with DS feel left alone as their parents spend more time with the child with DS and may resent their parents doing this.[6-7]

Under such difficult situations, some positive aspects may arise within the families of children with DS. Bonding among family members may become better and their views of the world, themselves, and others become more positive. It has been reported in previous studies that children with DS can bring the families closer in terms of parent-child and siblings interactions, and also bring joy to their families with a positive outlook on life.[8-9] However, it is an undeniable that extra demands associated with the child's developmental delays, daily caregiving needs, health problems, and the social and behavioral difficulties experienced by these families become significant family stressors. Such accumulated demands affect the family functioning.[10]

Facing long-term stress, the family often becomes more vulnerable, especially during the transition from preschool to school age. As children with DS get older, their delayed behavioral patterns become more noticeable, causing increased stress on the parents. During the preschool period, children in general are prepared to get ready for kindergarten and school. Parents will expect their child with DS to enter mainstream schools with other children. A qualitative study indicated that managing children's educational needs is a significant stressor; parents have to optimize the child's self-care ability through daily life activities and find a school that serves as a positive learning environment to meet the child's needs.[11] Thus, compared to raising an infant, parenting a preschool child with DS is typically more stressful for a family.

Interestingly, despite being burdened with enormous demands, some families of children with DS are resilient and healthy whereas others are vulnerable. The resilience of some families results from their effective family function, or the family's capability in adapting to stressful situations and keeping its integrity and the well-being of its members.[12] Thus, the need to optimize family functioning in families of children with DS is of paramount importance, especially in families having children at preschool age; and prior to the development of an intervention for enhancing their family functioning, the modifiable factors that can influence the family functioning and the pattern of relationships among these factors should be introduced. Literature regarding the theoretical framework of the Resiliency Model of Family Stress, Adjustment and Adaptation[12] supports that the accumulated stress from enormous family demands, family hardiness, social support, family problem solving, and coping skills have been identified as factors associated with family functioning in families of children with DS.[13-15] However, there is no existing study that focuses on family functioning and its influencing factors in Thai families of children with DS. A review of Thai literature shows that only one published study applied a qualitative design to explore the experiences and supporting factors in care for children with DS.[16] Due to a paucity of studies regarding this phenomenon, the present study sought to determine the pattern of relationships among family demands, family hardiness, social support, family problem solving and coping, and family functioning in families of preschool children with DS. Understanding which factors can influence family functioning in families of children with DS and its path of influence is important for nurses and other health professionals to further develop an appropriate intervention program for strengthening family functioning among this population.

Review of Literature

The Resiliency Model of Family Stress, Adjustment, and Adaptation[12] (hereafter referred to as the Resiliency Model) provided a guiding framework

for this study. This model was developed to describe how families respond to stressors and use their strengths and capabilities as well as resources to protect their families from adversities and crises. Within the model family hardiness and social support as available family resources, and family problem solving and coping are protective factors that will help family function adaptively under the accumulated demands. The concepts delineated under the model are consistent with the phenomena of family functioning in families of preschool children with DS; thus, it was logical to apply this as the underlying framework for this study.

According to the model, family demands refer to the accumulation of demands in the family created by a family member with chronic illness or disability, changes of family life cycle, previous unsolved family strains, and consequences of family endeavors to cope. The pile up of stress can propel the family into a crisis situation or a state of disorganization and imbalance in the family system. Previous studies in Taiwan and Korea reported that family demands could significantly predict the functioning of families with DS children.[13,15]

Family hardiness refers to the family's inner strength and durability, characterized by a sense of control over life events, a commitment to manage stress together, and a view of challenge as a normal and positive part of life for family growth.[12] Recent studies of young adults and children with DS indicated that families with greater hardiness were more likely to report better family functioning;[10,13-14] that is, families with high level of strengths are more likely to perceive the demands as challenges or opportunities, and be able to work together to manage such demands related to the care for children with DS.

Furthermore, social support plays a vital role as external family resource that is helpful for coping with stressful life events and maintaining family functioning by acting as an informational, emotional, and tangible support.[17] Previous studies indicated that families of children with DS used social support as a coping mechanism to perform effective parenting roles contributing to adaptive family functioning.[1,15,18]

In raising a child with DS, each family has various problem solving and coping strategies to manage difficult situations and maintain family function by becoming more religious, believing one's strength in facing difficulties, positively defining the problems encountered, reducing workload, and facilitating the routine by changing the workplace to be closer to home and looking for a school near home, for example.[19,20] Even though few studies that examined the influence of family problem solving and coping on functioning of families with DS were found, the findings evidently supported the posit that the families of children with DS who had ability to solve and cope with problems in the face of hardships tended to function effectively. For example, studies in Ireland, and South Korea revealed that the family adaptation and functioning in families of children with DS was best explained by family problem solving and coping communication.[10,13] Moreover, based on the Resiliency Model, family problem solving and coping not only influences family functioning but also probably mediates the influences of family hardiness and social support on family function. Such a mediating function of family problem solving and coping has never been examined in the context of families having children with DS. Rather than causal relationship, only bivariate relationship and direct effect of family hardiness and social support on family problem solving and coping were examined in previous studies. Moreover, the findings of some studies were based upon data from over a decade. For example, social support was positively correlated with problem solving and coping in families of children with DS[13] and in families of children with other intellectual disabilities;[21] and parent hardiness was a significant predictor of engagement coping and distracting coping in families of children with DS.[22]

In sum, the previous studies did not provide a comprehensive picture to explain the phenomena of

adaptive family functioning in this population of interest; only direct effects of these factors on family functioning were focused on while indirect effects have never been examined. Thus, under the Resilience Model, a conceptual model of family functioning was developed (See **Figure 1**). It was hypothesized that family demands and family problem solving and coping had direct effects on family functioning, whereas family hardiness and social support had both direct and indirect effects on family functioning through family problem solving and coping.

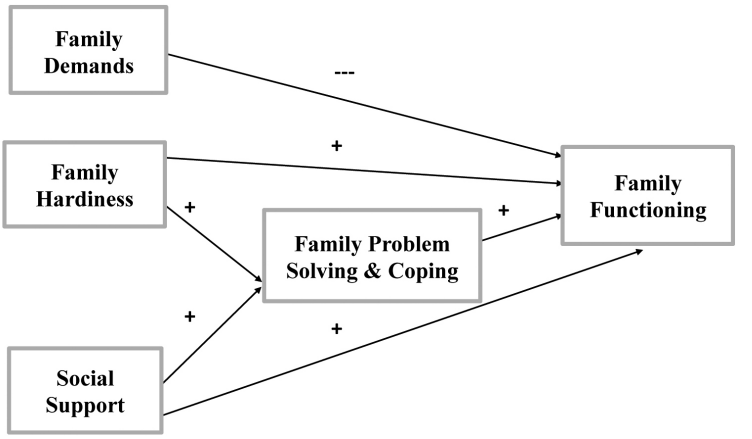

Figure 1 A hypothesized model of family functioning in families of children with DS

Methods

Design: A cross-sectional design with path analysis was used in this study.

Sample and Setting: Mothers of children with DS who received healthcare services at two university hospitals and an institute providing services for intellectually and developmentally disabled people were recruited using convenience and snowball sampling techniques. Inclusion criteria were mothers who had preschool children with DS aged 3-6 years and who were primary caregivers since the birth of their child. Exclusion criteria were mothers whose children with DS had health problems that affected their learning, such as vision impairment, hearing loss, and movement disabilities. The sample size was determined based on structural-equation modeling by using at least ten participants per an estimated parameter to obtain a better model fit.[23] In this study, the hypothesized model consisted of 11 estimated parameters yielding 110 participants; an additional 10% of the sample size was added in case of incomplete responses on the questionnaires. Finally, 120 participants were involved in this study.

Ethical Considerations: This study was approved by the Institutional Review Board of the Faculty of Nursing, Mahidol University (2017/415.0611), the two university hospitals (379/2018 and 405/2019), and one institute (01/2561). The study was conducted in accordance with the ethical principles of respect, beneficence, and justice, and participants were informed of their rights prior to joining the study. Informed consent form was obtained from each participant prior to data collection.

Instruments: There were six instruments used for data collection including the Demographic Interviewing Questionnaire, the Family Stressors and Strains Questionnaire, the Family Hardiness Index, the Social Support Questionnaire, the Family Crisis-Oriented Personal Evaluation Scales, and the Chulalongkorn Family Inventory. All study instruments, except for

the Chulalongkorn Family Inventory, were initially developed in English; and the use of back-translation technique has been reported.[24-27] Permissions to use the study instruments were obtained from the original developers in English, and those who had translated the questionnaires into Thai. Content validity for all of the study instruments was not checked as these instruments have been used widely with Thai families responsible for taking care of a family member with a certain chronic illness and faced the prolonged difficulty and crisis situations. The internal-consistency reliability of each study instrument was examined in a pretest study involving 18 mothers of children with DS at three care centers under the Foundation for the Welfare of Mentally Retarded of Thailand in Bangkok. Reliabilities and sample items from the questionnaires in both pretest and main studies are displayed in **Table 1.** The details of each questionnaire are described below.

Table 1 Reliabilities and sample items from the questionnaires

Questionnaires	Cronbach's alpha coefficients	
	Pretest study (N = 18)	Main study (N = 120)
The Family Stressors and Strains Questionnaire:	.87	.83
"*Increased difficulty in providing care to a disabled or chronically ill family member.*"		
"*Increased difficulty in managing child(ren).*"		
Family Hardiness Index:	.88	.83
"*We have a sense of being strong even when we face big problems.*"		
"*We do not feel we can survive if another problem hits us.*"		
Social Support Questionnaire:	.93	.91
"*How much helpful is the advice you received?*"		
"*How much assistance do you receive in your daily living?*"		
Family Crisis Oriented Personal Evaluation Scales:	.70	.72
"*Defining the family problem in a more positive way so that we do not become too discouraged.*"		
Chulalongkorn Family Inventory:	.88	.91
"*Family members help each other to solve the problems happened in the family.*"		

Demographic Interviewing Questionnaire was developed by the researchers to ask for general information of the mothers (including age, religion, marital status, education level, occupation, financial status, number of family members, care for other family members, and quality of sleep) and their children with DS (including age, gender, birth order of the child, the time of being diagnosed with DS, current health problem, health status, and childcare assistance).

Family Stressors and Strains Questionnaire – Thai version[24] was used to measure the accumulation of family demands. The 20-items with a 'yes' or 'no' option asked if each change on the list happened to their families within the past 12 months, and how serious it was, ranging from 0 (not serious at all) to 10 (extremely serious). The total scores range from 0 to 200 points with the higher scores indicating the higher family demands.

Family Hardiness Index-Thai Version,[25] designed to measure the characteristics of hardiness as a stress-resistance and adaptation resource, consists of three subscales: commitment, challenges, and control. It contains 20 items with a 4-point rating scale, ranging

from 0 (false) to 3 (true). The negative items must be reverse-coded when scoring. The total scores range from 0 to 60 points with the higher scores indicating the higher levels of family hardiness.

Social Support Questionnaire[26] consists of five items for each source of support (including family members, relatives and friends, and healthcare providers). The five items are the same in each source and cover 3 types of informational, emotional, and tangible support. A respondent is asked to rate how much support she receives by rating on a four-point scale, ranging from 0 (none) to 4 (a great deal). The total scores range from 0 to 60 with the higher scores indicating the greater perceived social support.

Family Crisis Oriented Personal Evaluation Scales (F-COPES)-Thai Verson[27] was designed to identify problem-solving and behavioral strategies that a respondent's family uses when faces with difficult or crisis situations. The original F-COPES containing 30 items assess five subscales of acquiring social support, reframing, seeking spiritual support, mobilizing family support, and passive appraisal on a 5-point rating scale, ranging from 1 (strongly disagree) to 5 (strongly agree). For the Thai version, 3 items were added by Rungreangkulkij for the specific purpose of her study;[27] however, these 3 items were not included in the current study so that the findings would yield more benefit for the comparison with other international studies. The total scores range from 30 − 150 points with the higher scores indicating more positive coping.

Chulalongkorn Family Inventory[28] was designed to evaluate family functioning in Thai context. This 36-item scale with seven subscales of problem-solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning are assessed on the 4-point Likert scale, ranging from 1 (strongly disagree) to 4 (strongly agree). The total scores range from 36 − 144 points with the higher scores indicating healthier family functioning.

Data Collection: This study was performed at the outpatient departments between November 2017 and December 2018. Nurses identified the eligible mothers and introduced them to the first researcher. The researcher explained the study objectives, the process of data collection, and the rights of the mothers. After signing the consent forms, the mothers were interviewed using the demographic interviewing questionnaire, then, a set of self-administered questionnaires was given to them to fill out. Afterwards, the mothers were asked for help in getting in touch with acquaintances who met the inclusion criteria to participate in this study. Through a phone call, if a mother showed interest in being a participant, an appointment for a home visit was made to explain the study further and collect the data.

Data Analysis: Descriptive and inferential statistics were analyzed using PASW statistics for Windows version 18.0 (SPSS, Chicago, IL, USA). The assumptions for statistical use were tested before performing the main analysis. Normal P-P plot showed non-normal distribution for the family demands and family hardiness. However, skewness and kurtosis of all study variables were less than 2 and 7, respectively; thus, the maximum likelihood was fairly robust to use for estimating the parameters in path analysis.[29] Multicollinearity issue was not found as the values of variance inflation factor (VIF) did not exceed 10 (ranging between 1.12 and 1.43) and the magnitudes of correlation among the study variables were not greater than .85 (ranging between .03 and .58). Path analysis using the LISREL version 8.80 (Scientific Software International, Lincolnwood, IL, USA) was conducted to test the hypothesized model, which was comprised of three exogenous variables (family demands, family hardiness, and social support) and two endogenous variables (family problem-solving and coping, and family functioning).

Results

Characteristics of the Mothers and Children with DS: The participants included 120 mothers with a mean age of 38.78 ± 5.58 years, 95% of

whom were Buddhist, and 88.3% married. Slightly over half of the mothers (53.3%) had completed higher education; 64% were employed and 87.5% reported having a sufficient income. More than two-thirds (70.8%) had helpers, mainly grandparents, to care for their child with DS. In spite of having such help, 29.2% of mothers said they did not get enough sleep, and nearly half (45.8%) had to take care of other family members as well. The mean age of children with DS was 53.06 ± 12.38 months. Slightly more than half (51.7%) were males, and 88.3% were diagnosed with DS after birth. Most children (85%) were perceived by their mothers as having good to excellent health.

Description of the Study Variables: Table 2 displays the total and average scores pertaining to the study variables. The mean total scores regarding demands on the family were relatively low when compared to the potentially maximum score (that is, 24.86 from 200 points). Family commitment was noticeably highest in the family-hardiness category. Most mothers got their support from family members and the most common type was emotional support, followed by tangible support (not displayed in Table 2). Reframing (or redefining stressful events to make them manageable) was the most-used strategy for family problem-solving and coping. Families in our study did best for their general functioning.

Table 2 Descriptive statistics regarding the study variables (N = 120)

Variables (Items)	Total scores			Average scores		
	Possible range	Mean	SD	Possible range	Mean	SD
Family Demands (20)	0-200	24.86	20.63	0-20	1.24	1.03
Family Stress (10)	0-100	10.68	11.77	0-10	1.07	1.18
Family Strains (10)	0-100	14.18	12.17	0-10	1.42	1.22
Family Hardiness (20)	0-60	47.66	7.65	0-3	2.38	.38
Commitment (8)	0-24	20.42	3.42	0-3	2.55	.43
Challenge (6)	0-18	13.78	3.10	0-3	2.35	.47
Control (6)	0-18	13.47	3.15	0-3	2.24	.53
Social Support (15)	0-60	39.60	10.24	0-4	2.64	.68
Family members (5)	0-20	15.28	3.93	0-4	3.06	.79
Relatives and friends (5)	0-20	11.91	4.35	0-4	2.38	.87
Healthcare providers (5)	0-20	12.41	3.78	0-4	2.48	.76
Family Problem-Solving and Coping (30)	30-150	109.57	9.50	1-5	3.65	.32
Acquiring social support (9)	9-45	29.68	5.85	1-5	3.30	.65
Reframing (8)	8-40	33.45	3.37	1-5	4.18	.42
Seeking spiritual support (5)	5-25	17.73	2.71	1-5	3.55	.54
Mobilizing family support (4)	4-20	16.53	2.52	1-5	4.13	.63
Passive appraisal (4)	4-20	12.18	2.01	1-5	3.04	.50
Family Functioning (36)	36-144	113.14	12.60	1-4	3.14	.35
Problem-solving (6)	6-24	19.32	2.96	1-4	3.22	.49
Communication (5)	5-20	15.05	2.22	1-4	3.01	.44
Roles (3)	3-12	9.94	1.37	1-4	3.31	.46
Affective responsiveness (5)	5-20	15.38	2.09	1-4	3.08	.42
Affective involvement (5)	5-20	15.37	2.58	1-4	3.07	.52
Behavior control (4)	4-16	11.32	1.95	1-4	2.83	.49
General functioning (8)	8-32	26.77	3.80	1-4	3.35	.47

Model Testing: The findings revealed that the hypothesized model fitted to the sample data; that is, χ^2 = 1.95, *df* = 2, *p* = .38, RMSEA = .00 with 90% CI [.00, .18], GFI = .99, AGFI = .95, CFI = 1.0, RFI = .94, and standardized RMR = .03.

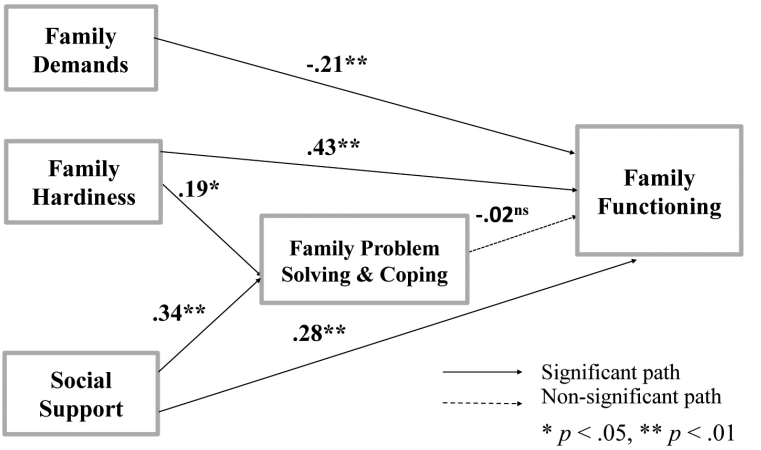

Figure 2 The final model of the family functioning in families of children with DS

As shown in **Figure 2** and **Table 3**, the model explained 47% of the variance in overall family functioning. Only direct effects were identified in the model. Family hardiness was the most influential factor directly affecting family functioning (β = .43, p < .01), followed by social support (β = .28, p < .01), while the least influential factor was family demands (β = -.21, p < .01). Both family hardiness and social support had positive effects on family problem-solving and coping (β = .19, p < .05; and β = .34, p < .01, respectively). However, family problem-solving and coping showed no significant effect on family functioning (β = -.02, *p* > .05).

Table 3 The direct effect, indirect effect, and total effect of the study variables in the model tested (N = 120)

Causal variables	Family problem- solving & coping			Family functioning		
	DE	IE	TE	DE	IE	TE
Family Demands	-	-	-	-.21**	-	-.21**
Family Hardiness	.19*	-	.19*	.43**	-.01ns	.42**
Social Support	.34**	-	.34**	.28**	-.01ns	.27**
Family Problem- Solving & Coping	-	-	-	-.02ns	-	-.02ns
R^2		.21			.47	

Note The values in the table were standardized values; *DE:* Direct effect; *IE:* Indirect effect; *TE:* Total effect; * *p* < .05; ** *p* < .01; ns = non-significance

Discussion

Family demands were obviously low in our study (**Table 2**) and this finding was similar to a study in Taiwan by Hsiao.[15] The reason was probably that the study mothers had supportive characteristics such as being mature mothers (with an average age of 38.78 years) to manage their family demands, and having an intact family (88.3%), higher education (53.3%), sufficient income (88%), and childcare

help from a relative (70.8%). These supportive characteristics were probably helpful for mitigating the stress and strains they faced. Despite the low family demands, the negative and direct effect of these demands on family functioning did exist. This finding is consistent with previous studies in Korea,[1] Ireland,[10] and Taiwan.[15] Rearing children with DS involves some major challenges such as delayed development, health problems, education, and finance. The challenges also include behavioral problems and schooling of the children with DS. Managing oppositional behavior in such children requires that parents spend more time and effort on that child, and this can adversely affect parents' mental health and family relationships.[11] Moreover, with this age group, parents have to prepare their child to be included in mainstream kindergartens and primary schools, and to find the most suitable school.[11] Years of raising a child with DS takes a toll on parents' physical and psychological health, and ongoing childcare-related stress and increased demands will often undermine the functioning of families.

Family hardiness in this study was found to be the strongest influential factor having a positive and direct effect on family functioning, consistent with the Resilience Model which focuses on a vital role of family hardiness in the process of overall resilience.[12] Similar to previous studies,[10,13] this family characteristic functions to resist the effects of stress or demands on family functioning. It is noteworthy that, among the three features of family hardiness (**Table 2**), commitment (or the tendency of the individual to be involved in an event) obtained the highest average scores. This finding implies that the families actively worked together to solve problem, supported for each other in times of needs, perceived the extra demands as challenges or opportunities, and had confidence in their abilities to manage stress and overcome difficulties. Consequently, such strengths helped the function of their families stayed balancing. This finding also revealed that family hardiness had a positive direct effect on family problem solving and coping which were consistent with previous studies.[13,15] The finding was not surprising as their family hardiness in terms of their high commitment reflecting the strong bond among family members to cope with the demands associated with raising a child with DS and walk through the problems together.

While family hardiness is an important factor as an internal family resource, social support plays a vital role as an external family resource to buffer the negative consequences of stressful life events, thus leading to effective family functioning.[12] Our finding, consistent with previous studies conducted in East Asian countries,[30] confirms that social support has a beneficial effect on family functioning in families of children with DS. The positive support received particularly and mostly from family members as well as relatives and friends, and healthcare providers would relieve their demands associated with raising preschool children with DS by providing encouragement, childcare help, household chores, childrearing related information, and resources (such as daycare services, schools, healthcare services) during the period of stress and difficulty.[31-32] That is why the families with high levels of support tend to be more effective in functioning. Furthermore, the study also revealed that social support had a positive, direct effect on family problem solving and coping which is consistent with previous studies.[13,21] It is interesting to note that the most-used strategy for family problem-solving and coping in this study was reframing the problem, followed by mobilizing family support. That is, with the help of their family members, relatives and friends, and healthcare providers, the families of preschool children with DS redefined their stress as a challenge that they could manage and then acquired and accepted the support they needed.

It is also noteworthy that family members were considered the major source of support for the mothers. Emotional support followed by tangible support were the types of help the mothers received most. This is because emotional and tangible support (that involved consistent interactions and contribution in

families' daily lives) are most effective when the support-giver is an intimate network member.[33] Thus, family members who have intimate relationships with parents can play a dominant role of frequent interactions and involvement in families' daily lives (such as encouragement and help with childcare) while facing stress and difficulties in the family.

It is surprising that both family hardiness and social support had direct effects on family problem-solving and coping, whereas the problem-solving and coping did not have a direct effect on family functioning. This unexpected finding is hard to explain as it is contradictory to the theoretical explanation in the Resilience Model. One possible reason may be the measurement used in this study. Interestingly, a significant relationship between the problem-solving and coping and family functioning was not identified in studies using the F-COPES, but in those using the Family Problem-Solving Communication Index, or FPSC.[10,13] The F-COPES focuses more on the various support needed for coping and managing the demands, while the FPSC emphasizes affirming (positive) and incendiary (negative) patterns of communication used in families coping with hardships and life disasters.[12] Previous studies emphasize a significant role of family problem solving and coping by indicating that intra-family communication was used as one of the internal resources to solve problems related to the different demands that arise overtime;[20] and family members' style of communicating with one another that could resolve the problems was significant predictor of DS children's quality of life.[34] Thus, it would be premature to conclude that family problem solving and coping does not have a direct effect on family functioning and cannot mediate the family functioning-inducing effects of family hardiness and social support. Further literature review and studies are needed to explore how Thai families of children with DS solve their problems and cope with the demands, so that an appropriate measurement of family problem-solving and coping for use in Thai families of children with DS can be determined.

Limitations

Some limitations of the study should be considered. First, the data were obtained from mothers only, which did not represent the whole family, because almost all the primary caregivers of children with DS were mothers. As a result, the data obtained were the mothers' perspectives on the family factors. Second, both convenience and snowball sampling (also called network-sampling) techniques were used, due to the limited number of preschool children with DS in the settings and the difficulty in accessing within the sampling timeframes. Thus, the generalizability of this study is limited. Next, the mothers in this study were more likely to be educated and affluent and their preschool children with DS received regular developmental stimulation at three tertiary clinical settings located in Bangkok metropolitan area. Such characteristics could be source of potential selection bias for the study. Lastly, caution is needed when interpreting these findings as the cross-sectional study design is not considered sufficient to establish causation.

Conclusion and Implications for Nursing Practice

Our study contributes to professionals,' parents,' and caregivers' understanding of the factors influencing the family functioning during the preschool period of their children with DS. The direct effects found between family demands, family hardiness, social support and family functioning suggest that nurses should incorporate these factors through further intervention programs which are developed to strengthen family hardiness, resources, and skills to cope with the stress and strains.

As existing programs mostly focus on children with DS through comprehensive health supervision and educational programs, a program focusing on parents or the whole family is very rare in Thailand. The findings of our study provide evidence useful for

urging policy makers in related authorities and organizations, as well as health professionals, to have more holistic perspectives on enhancing the quality of life of this group by not only offering services focusing on the children with DS, but also incorporating services for their families and caregivers. The feasibility of using mHealth intervention with Korean families of children with DS to improve the family adaptation is evidently confirmed.[35] Thus, it might be interesting to apply digital technology into a further intervention program aimed at equipping Thai families with essential skills to reduce their stress, strengthen their family hardiness, and mobilize the families to acquire and accept the support. Future research is needed to assess how such intervention works.

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References

1. Choi EK, Yoo IY. Resilience in families of children with Down syndrome in Korea. Int J Nurs Pract. 2015;21(5): 532-41. doi: 10.1111/ijn.12321.
2. Dinc GS, Cop E, Tos T, Sari E, Senel S. Mothers of 0-3- year-old with Down syndrome: effects on quality of life. Pediatr Int. 2019;61(9):865-71. doi: 10.1111/ped.13936.
3. Marshak LE, Lasinsky EE, Williams C. Listening to fathers: Personal impacts of raising children with Down syndrome. J Intellect Disabil. 2019;23(3):310-26. doi: 10.1177/1744629518801112.
4. Oti-Boadi M. Exploring the lived experiences of mothers of children with intellectual disability in Ghana. SAGE Open. 2017;7(4):1-12.doi:10.1177/2158244017745578.
5. Marchal JP, van Oers HA, Maurice-Stam H, Grootenhuis MA, van Trotsenburg ASP, Haverman L. Distress and everyday problems in Dutch mothers and fathers of young adolescents with Down syndrome. Res Dev Disabil. 2017;67:19-27. doi: 10.1016/j.ridd.2017.05.005.
6. Takataya K, Mizuno E, Kanzaki Y, Sakai I, Yamazaki Y. Feelings of siblings having a brother/sister with Down syndrome. Arch Psychiatr Nurs. 2019;33(4):337-46. doi: 10.1016/j.apnu.2019.01.001.
7. Lemoine L, Schneider B. Growing up with a brother or sister with Down syndrome: adult siblings' perceptions of their childhood relationships. J Intellect Dev Disabil. 2021. doi: 10.3109/13668250.2020.1855632.
8. Farkas L, Cless JD, Cless AW, Nelson Goff BS, Bodine E, Edelman A. The ups and downs of Down syndrome: a qualitative study of positive and negative parenting experiences. J Fam Issues. 2019;40(4):518-39. doi: 10.1177/0192513X18812192.
9. Bertrand R. Parents' perspective on having a child with Down syndrome in France. Am J Med Genet Part A. 2019;179(5): 770-81. doi: 10.1002/ajmg.a.61102.
10. Caples M, Martin A-M, Dalton C, Marsh L, Savage E, Knafl G, et al. Adaptation and resilience in families of individuals with down syndrome living in Ireland. Br J Learn Disabil. 2018;46(3):146-54. doi: 10.1111/bld.12231.
11. Pillay D, Girdler S, Collins M, Leonard H. "It's not what you were expecting, but it's still a beautiful journey": the experience of mothers of children with Down syndrome. Disabil Rehabil. 2012;34(18):1501-10. doi: 10.3109/09638288.2011.650313.
12. 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.
13. Choi H. Adaptation in families of children with Down syndrome: a mixed-methods design. J Korean Acad Nurs. 2015;45(4): 501-12. doi: 10.4040/jkan.2015.45.4.501.
14. Van Riper M, Knafl G. PS-359 Cross-cultural study of adaptation in families of individuals with Down syndrome. Arch Dis Child. 2014;99(Suppl 2):A241.
15. Hsiao CY. Family demands, social support and family functioning in Taiwanese families rearing children with Down syndrome. J Intellect Disabil Res. 2014;58(6):549-59. doi: 10.1111/jir.12052.
16. Teangsuk R, Jirapaet V. Experiences of caregivers in caring for children with Down syndrome. J Nurs Educ. 2015;8 (1):166-79 (in Thai).

17. Schaefer C, Coyne JC, Lazarus RS. The health-related functions of social support. J Behav Med. 1981;4(4):381-406. doi: 10.1007/BF00846149.
18. Gashmard R, Ahmadi F, Kermanshahi SMK. Coping strategies adopted by Iranian families of children with Down syndrome: a qualitative study. Medicine (Baltimore). 2020;99(28):e20753. doi: 10.1097/MD.0000000000020753.
19. Nurmalita T, Kristiana IF. Coping parents'strategy with Down syndrome (DS) children. J Fam Sci. 2019:4(1):54-75. doi: 10.29244/jfs.4.1.54-75.
20. Braga PP, Silva JB, Guimarães BR, Van Riper M, Duarte ED. Problem-solving and coping in family adaptation of children with Down syndrome. Rev Esc Enferm USP. 2021;55: e03708. doi: 10.1590/S1980-220X2020001803708.
21. McConkey R, Truesdale-Kennedy M, Chang M-Y, Jarrah S, Shukri R. The impact on mothers of bringing up a child with intellectual disabilities: a cross-cultural study. Int J Nurs Stud. 2008;45(1):65-74. doi: 10.1016/j.ijnurstu.2006.08.007.
22. Picardi A, Gigantesco A, Tarolla E, Stoppioni V, Cerbo R, Cremonte M, et al. Parental burden and its correlates in families of children with autism spectrum disorder: a multicentre study with two comparison groups. Clin Pract Epidemiol Ment Health. 2018;14:1430176. doi: 10.2174/1745017901814010143.
23. Kline RB. Principles and practice of structural equation modeling. 4 th ed. New York: Guilford Publications; 2015.
24. Phuphaibul R, Wittayasooporn J, Grisurapong S. The impact of economic crisis on children, youths and families and needs for assistance [Internet]. Bangkok: Thailand Research Fund; 1999 [cited 2020 Jan 7]. Available from: http://elibrary.trf.or.th/project_content.asp?PJID=RDG4210001 (in Thai)
25. Santati S, Wittayasooporn 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 J Nurs Res. 2006;10(2):98-112.
26. Kaveevivitchai J. Relationships among selected factors, uncertainty in illness, social support, and adaptation in breast cancer women receiving chemotherapy [master's thesis]. Bangkok: Mahidol University; 1993.
27. Rungreangkulkij S, Chafetz L, Chesla C, Gilliss C. Psychological morbidity of Thai families of a person with schizophrenia. Int J Nurs Stud. 2002;39(1):35-50. doi: 10.1016/s0020-7489(01)00005-0.
28. Trangkasombat U. Family functioning in mental illness: a study in Thai families with depressive disorders and schizophrenia. J Fam Psychother. 2008;19(2):187-201. doi: 10.1080/08975350801905046.
29. Finney SJ, DiStefano C. Nonnormal and categorical data in structural equation modeling. In: Hancock GR, Mueller RD, editors. Structural equation modeling: a second course. Greenwich, Connecticut: Information Age Publishing; 2006. p. 269-314.
30. Choi H, Van Riper M. Adaptation in families of children with Down syndrome in East Asian countries: an integrative review. J Adv Nurs. 2017;73(8):1792-806. doi: 10. 1111/jan.13235.
31. Hasan MdM, Kamrujjaman M. Comparative study of supporting services for children with Down's syndrome and their families: perspective of United Kingdom and Bangladesh. Curr Tr Clin & Med Sci. 2019;1(1):1-8. doi: 10.33552/CTCMS.2019.01.000501.
32. Murphy N, Epstein A, Leonard H, Davis E, Reddihough D, Whitehouse A, et al. Qualitative analysis of parental observations on quality of life in Australian children with Down syndrome. J Dev Behav Pediatr. 2017;38(2):161-8. doi: 10.1097/DBP.0000000000000385.
33. Gage EA. Social networks of experientially similar others: formation, activation, and consequences of network ties on the health care experience. Soc Sci Med. 2013;95:43-51. doi: 10.1016/j.socscimed.2012.09.001.
34. Lee A, Knafl G, Knafl K, Van Riper M. Parent-reported contribution of family variables to the quality of life in children with Down syndrome: report from an international study. J Pediatr Nurs. 2020;55:192-200. doi: 10.1016/j.pedn.2020.07.009.
35. Choi H, Van Riper M. mHealth family adaptation intervention for families of young children with Down syndrome: a feasibility study. J Pediatr Nurs. 2020;50:e69-e76. doi: 10.1016/j.pedn.2019.03.010.

ปัจจัยที่มีอิทธิพลต่อการทำหน้าที่ของครอบครัวที่มีเด็กดาวน์ซินโดรมก่อนวัยเรียน

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บทคัดย่อ: ครอบครัวของเด็กดาวน์ซินโดรมก่อนวัยเรียนต้องเผชิญกับปัญหาอันเนื่องมาจากกลุ่มอาการดาวน์ซินโดรมและการเปลี่ยนผ่านตามช่วงวัยของเด็กก่อนวัยเรียน ความเครียดสะสมเป็นเหตุบั่นทอนการทำหน้าที่ของครอบครัวได้ การศึกษาภาคตัดขวางนี้มีวัตถุประสงค์เพื่อทดสอบรูปแบบความสัมพันธ์ระหว่างปัจจัยภายในโมเดลความแข็งแกร่งในชีวิตกับการทำหน้าที่ของครอบครัวที่มีลูกดาวน์ซินโดรม เลือกกลุ่มตัวอย่างด้วยวิธีแบบสะดวกและแบบอาศัยเครือข่ายได้มารดาของเด็กดาวน์ซินโดรมก่อนวัยเรียนจำนวน 120 คน จากโรงพยาบาลมหาวิทยาลัยสองแห่งและสถาบันที่ดูแลเด็กที่มีสติปัญญาบกพร่องหนึ่งแห่ง เก็บรวบรวมข้อมูลโดยใช้แบบสัมภาษณ์ข้อมูลประชากร แบบสำรวจความเครียดของครอบครัว แบบสอบถามความเข้มแข็งของครอบครัว แบบวัดแรงสนับสนุนทางสังคม แบบสอบถามการเผชิญปัญหาของครอบครัว และแบบสอบถามการทำหน้าที่ของครอบครัว วิเคราะห์ข้อมูลด้วยสถิติพรรณนาและการวิเคราะห์เส้นทาง

ผลการศึกษาพบว่า แบบจำลองความสัมพันธ์มีความสอดคล้องกับข้อมูลเชิงประจักษ์เป็นอย่างดีและสามารถอธิบายความแปรปรวนของการทำหน้าที่ของครอบครัวได้ร้อยละ 47 ความเข้มแข็งของครอบครัวเป็นปัจจัยที่มีอิทธิพลมากที่สุดโดยส่งผลโดยตรงกับการทำหน้าที่ของครอบครัว รองลงมาคือ การสนับสนุนทางสังคม และความต้องการของครอบครัว ตามลำดับ และไม่พบอิทธิพลโดยอ้อมของความเข้มแข็งของครอบครัว และการสนับสนุนทางสังคมต่อการทำหน้าที่ของครอบครัวโดยส่งผ่านการแก้ปัญหาและการจัดการความเครียดของครอบครัว พยาบาลควรพัฒนาโปรแกรมสำหรับครอบครัวของเด็กดาวน์ซินโดรมก่อนวัยเรียนโดยสอนทักษะที่จำเป็นในการลดความเครียด เพิ่มความเข้มแข็งให้กับครอบครัว และนำเครือข่ายการสนับสนุนทางสังคมมาใช้ เพื่อรักษาสมดุลการทำหน้าที่ของครอบครัว

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