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Depressive symptoms, social support, cognitive function, and stigma: predictors of resilience in caregivers of children with intellectual disabilities

Original Article

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Abstract: **Objective:** Family plays an important role in taking care of children with intellectual disabilities (IDs). Resilience supports coping strategies for caregivers with their children caring. However, factors influencing the resilience of caregivers with ID in Thailand are yet to be identified. Therefore, the aim of this study was to identify the predictors of resilience in caregivers of children with moderate to severe ID.

Methods: A cross-sectional study was implemented in caregivers of children with ID aged 18 years and older who had children diagnosed with ID aged 6–18 years and classified as moderate to severe ID. Descriptive statistic and multiple linear regression were used for data analysis.

Results: The study sample consisted of 85 caregivers who took care of their children older than 5 years (95.30%). Depression, social support, cognitive function, and stigma could predict the resilience ($F [4, 80] = 26.79$, $P < 0.001$) and explain the variability of resilience by 57.3%.

Conclusions: Caregivers have to take care of their children for a long period, which could develop a burden to the caregivers. The resilience and influencing factors should be monitored and managed by developing a campaign to promote caregivers' health and well-being.

Keywords: *caregiver • cognitive function • depressive symptoms • intellectual disability • social support • stigma*

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1. Introduction

Intellectual disability (ID) is defined as the mental disability causing the lack of necessary skills for daily living including intellectual functioning and adaptive functioning.[1] Intellectual functioning focuses on the ability to learn, make decisions, and solve problems, while adaptive functioning addresses learning and performing

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skills in everyday life consisting of conceptual, social, and practical skills.[2] The systematic review showed that the prevalence of ID was approximately 0.62%–1.58% in Europe.[3] Compared with high-income countries, low- and middle-income countries (LMICs) have a higher prevalence of ID. In addition, the prevalence of ID is strongly inversely correlated with the economic status of a country.[4] Thailand is categorized as an LMIC, with a reported ID prevalence of 1%.[5]

Children with ID have been confronted with several health issues affecting the individual, family, and society. Children with ID have developmental delays across domains such as physical, language, learning, and behavior domains[6] as well as have poor quality of life.[7] Family plays an important role in taking care of children with ID. Sometimes the conflict between real life and expectation may trigger difficulties within the family due to lack of knowledge, delayed development, mismatch with expected need, burnout, unemployment, poverty, and social stigma.[8] Hence, caring for children with ID is related to psychological problems for the family such as stress, anxiety, and depression.[9]

The resilience theory refers to the human ability to transform disaster into a growth experience.[10] Families of children with ID mostly have the experience of taking care of their children for a long time. Resilience supports the coping strategies for caregivers with their children caring. The theory focuses on transforming and reinterpreting the challenges into opportunities using a positive reappraisal technique.[11] The framework addresses the following four components related to resilience: (1) the dispositional pattern was the caregivers' perception about their competency to take care of their children; (2) relational pattern was the willingness to seek for support and social interactions; (3) situational pattern was the capacity to deal with unpleasant situation; and (4) philosophical pattern was one's personal belief and knowledge.[10]

This study explored the four components of resilience using the resilience theory of Polk.[10] The dispositional pattern is defined as a psychological domain related the manifestation of resilience; this study explored depressive symptoms of caregivers. The relational pattern is defined as the perception of support and health benefit resources; this work focused on social support of caregivers. The situation pattern is defined as the competency to engage in problem-solving and judgment; this study explored the cognitive function of caregivers. Lastly, the philosophical pattern is defined as a personal belief influencing resilience skills, and this study captured that component by examining stigma related to the caregivers.

Previous studies found several factors related with resilience skills,[12–16] such as depression, cognitive function, and social support. Families of children with ID reported higher stress and depression scores than families of children with other psychiatric disorders.[17] The strengthening of social relationships was also found to be associated with resilience skill.[13] Family resilience was found to be associated with the well-being of the caregivers of children with ID.[14] Moreover, several studies implemented resilience as a framework to develop interventions to improve quality of care in caregivers of children with ID.[8]

Stigma was found to be related with the family capacity to deal with unfamiliar and unexpecting events in their family life.[15] In addition, stigma is a sensitive issue in Thai culture, particularly among children and families with mental illness.[16] This has contributed to the lack of research on stigma as it is rarely explored in the country. Then, cognitive function is the executive function of the brain that relates with problem-solving skills.[18] However, the relationship between cognitive function and resilience had limited supporting evidence. In addition, factors influencing the resilience of caregivers with ID in Thailand are yet to be studied. This study was used a resilience framework including caregivers' demographic data, depressive symptoms, social support, stigma, and cognitive function. The findings from this study could provide the information to develop further interventions to improve the outcome of children with ID, using caregiver resilience programs.

This study hadf two aims: (1) Document demographic data, depressive symptoms, social support, stigma, cognitive function, and resilience in caregivers of children with IDs; and (2) explore the predictors of resilience with demographic data, depressive symptoms, social support, stigma, and cognitive function in caregivers of children with IDs.

2. Methods

This study was a cross-sectional study that recruited caregivers of children with ID aged 18 years and older who had children diagnosed with ID aged 6–18 years and classified as moderate to severe using the intelligence quotient (IQ) test score between 20 and 49. The exclusion criteria were as follows: (1) caregivers who are not consanguineous; (2) caregivers with a history of psychiatric disorders or existing neurological deficit, including aphasia; and (3) caregivers who were not able to communicate in Thai.

2.1. Power analysis

Multiple linear regression was used to analyze the relationship between predictors and rehospitalization. The G-power program was used to analyze power for the

analysis. Assumptions for this power analysis include a two-tailed hypothesis, an alpha significance level of 0.05, medium effect size,[19] and a power of 0.8. The study required a sample size of 85.

2.2. Measurements

Depressive symptom was assessed using the Patient Health Questionnaire-9 (PHQ-9), a multipurpose instrument for screening, diagnosis, monitoring, and measuring the severity of depressive symptoms.[20] The instrument rates the frequency of the symptoms as the severity index. The PHQ-9 score can range from 0 to 27 since each of the 9 items can be scored from 0 (not at all) to 3 (nearly every day). The questionnaire included the question on suicidal idea. If the participant indicates positive suicidal idea, the researcher would transfer caregiver for further management. The Thai version of the PHQ-9 had satisfactory internal consistency (Cronbach's alpha = 0.79). Used as a continuous measure, the optimal cut-off score of PHQ-9 ≥ 9 revealed a sensitivity of 0.84 and a specificity of 0.77.[21] A higher score indicates a high level of depressive symptoms. In this study, internal consistency using Cronbach's alpha was 0.86.

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS).[22] This instrument is a 7-point Likert scale (1 = very strongly disagree to 7 = very strongly agree) with a total of 12 questions. The MSPSS has three subscales including the support from families, friends, and significant other support. A high score indicates high perceived social support. The instrument has been translated into Thai by Wongpakaran et al.[12] using back-translation technique. The internal consistency using Cronbach's alpha was 0.87.[12] In this study, the internal consistency using Cronbach's alpha was 0.95.

Caregiver-related stigma was explored using the Internalized Stigma of Mental Illness Scale (ISMI) consisting of a 4-point Likert scale (1 = strongly disagree, 4 = strongly agree), with a total of 29-item.[23] Higher total scale scores indicate greater internalized stigma. The ISMI has been translated into Thai using the back-translation technique. The internal consistency using Cronbach's alpha was 0.88.[24] In this study, the internal consistency using Cronbach's alpha was 0.87.

Cognitive function was assessed using the Montreal Cognitive Assessment (MoCA).[25] The MoCA was developed by health professionals to assess mild cognitive impairment (MCI). MCI is defined as a cognitive decline greater than expected, but it does not interrupt activities of daily life.[26] MoCA is a 30-point scale with seven cognitive subtests including visuo-executive, naming, attention, language, abstraction, delayed recall, and orientation. The internal consistency of the Thai-MoCA test using Cronbach's alpha coefficient was 0.74.[27] A higher score indicates good cognitive function.

Resilience was examined using the Connor–Davidson Resilience Scale (CD-RISC-10)[28] consisting of 4-point Likert scale (0 = not true all time, 4 = true nearly all time), with a total of 10 items.[29] The CD-RISC-10 is a short form of the original version, which comprises 25 items. A higher score indicates higher resilience capacity. The CD-RISC-10 has been translated into Thai using a back-translation technique. The internal consistency using Cronbach's alpha was 0.86.[30]

2.3. Data analysis

Aim 1

A profile of demographic data, depressive symptoms, social support, stigma, cognitive function, and resilience in caregivers of children with ID was presented by level of measurement. Nominal and ordinal data level were used frequency and percentage and interval and ratio data were used mean with 95% confidence interval (CI).

Aim 2

Simple linear regression is used to examine the relationship between predictors (demographic data, depressive symptoms, social support, stigma, and cognitive function) and dependent variables (resilience). Variables were used in multiple linear regression models. The data were checked for basic assumptions including normal distribution, linear relationship, constant variance, and multicollinearity. The final model selected considered dependent and dependent coefficients (crude and adjusted tables).

All tests were two-tailed, and statistical significance was accepted as a *P*-value of < 0.05. All data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 25.

3. Results

The sample consisted of 85 participants, and a majority of them were female (80%) and married (65.90%). Almost one-third of the participants graduated from elementary school (31.80%) and were housewives (36.50%). Almost all caregivers have been caring for their children for >5 years (95.30%), and more than a half of them were mothers (64.70%), as shown in Table 1.

The mean age of the participants was 50.19 (±9.56) years. The mean score of depressive symptoms was 4.16 (±4.91), and most of them had no depressive symptoms (72.9%). The social support mean score was 59.99 (±18.79), and more than a half reported a high level of perceived social support (60%). The cognitive

Demographic data	*n* (%)	M ± SD
Sex		
Female	68 (80.0)	
Age (years)		50.19 ± 9.56
Marital status		
Single	4 (4.7)	
Married	56 (65.9)	
Widow	15 (17.6)	
Divorced	10 (11.8)	
Education		
Elementary or lower	41 (48.3)	
High school	12 (14.1)	
College or higher	32 (37.6)	
Occupation		
Employee	18.8	
Selling	16.5	
Housewife	36.5	
Official staff	5.9	
Other (e.g., not prefer to answer)	22.4	
Duration of caring (years)		
<5	4 (4.7)	
>5	81 (95.3)	
Primary caregiver		
Parents	68 (80.0)	
Caregivers	17 (20.0)	
Depression		4.16 ± 4.91
No depression	62 (72.9)	
Mild depression	14 (16.5)	
Moderate depression	7 (8.2)	
Severe depression	2 (2.4)	
Social support		59.99 ± 18.79
Low social support	11 (12.9)	
Moderate social support	23 (27.1)	
High social support	51 (60.0)	
Cognitive function		20.68 ± 6.02
Normal cognitive function	38 (44.7)	
Cognitive impairment	47 (55.3)	
Caregiver-related stigma		69.87 ± 22.66
No stigma	60 (70.6)	
Mild stigma	18 (21.2)	
Moderate stigma	7 (8.2)	
Resilience		69.87 ± 22.66
Low resilience	42 (49.3)	
Intermediate resilience	21 (24.7)	
High resilience	22 (25.9)	

Note: M, mean; SD, standard deviation.

Table 1. Baseline characteristics.

function mean score was 20.68 (±6.02), and more than a half had cognitive impairment (55.3%). The stigma mean score was 1.76 (±0.48), and almost three-fourths reported no stigma (70%). Finally, the resilience mean score was 69.87 (±22.66), and almost a half reported a low level of resilience (49.3%), as shown in Table 1.

Table 2 shows the relationship among depression, social support, cognitive, stigma, age, and resilience of the participants as calculated by Pearson's product–moment correlation coefficient. According to the findings, depression was found to be negatively related to resilience at a moderate level ($r = 434$, $P < 0.01$). Social support was positively correlated with resilience at a high level ($r = 0.718$, $P < 0.01$). Moreover, depression was found to be negatively correlated to social support at a moderate level ($r = 0.448$, $P < 0.01$). All correlations were not statistically significant, except for one variable between age and resilience. Therefore, depression, social support, cognitive, and stigma were used in simple and multiple linear regression analyses to predict resilience.

Simple linear regression explored the effect of each independent variable with resilience. The resilience score decreased two points with each one unit increase in depressive symptom (B = −2.00, 95% CI = −1.09 to −2.91, $P < 0.01$). The resilience score increased 0.87 points with each one unit increase in social support (B = 0.87, 95% CI = 0.68–1.05, $P < 0.01$). The resilience score increased 1.09 points with each one unit increase in the cognitive score (B = 1.09, 95% CI = 0.30–1.87, $P = 0.007$). The resilience score decreased 0.94 points with each one unit increase in stigma (B = −0.94, 95% CI = −0.54 to −1.34, $P < 0.01$), as shown in Table 3.

After adjusting for age, sex, marital status, educational attainment, primary caregivers, depression, social support, cognitive function, and stigma were still the significance predictors. The resilience score decreased 1.93 points with each one unit increase in depressive symptom (B = −1.93, 95% CI = −1.00 to −2.85, $P < 0.01$). The resilience score increased 0.89 points with each one unit increase in social support (B = 0.89, 95% CI = 0.69–1.08, $P < 0.01$). The resilience score increased 1.12 points with each one unit increase in cognitive score (B = 1.12, 95% CI = 0.22–2.01, $P = 0.016$). The resilience score decreased 0.95 points with each one unit increase in stigma (B = −0.95, 95% CI = −0.54 to −1.36, $P < 0.01$), as shown in Table 3.

Finally, the model selection of predictors of resilience was carried out using a backward selection technique. The selected model found at least one of the predictors could predict resilience [F (4, 80) = 26.79, $P < 0.001$]. Depression, social support, cognitive function, and stigma could explain the variability of resilience by

Variable	Resilience	Depression	Social support	Cognitive	Stigma
Resilience	1				
Depression	−0.434**	1			
Social support	0.718**	−0.448**	1		
Cognitive	0.289**	−0.193	0.345**	1	
Stigma	−0.456**	0.353**	−0.341**	−0.169	1

Note: **Correlation is significant at the 0.01 level (two-tailed).

Table 2. Relationships among depression, social support, cognitive, stigma, and resilience by Pearson's product–moment correlation coefficient.

Variable	Crude			Adjusted*		
	B	95% CI	*P*-value	B	95% CI	*P*-value
Depression	−2.00	−2.91, −1.09	<0.001	−1.93	−2.85, −1.00	<0.001
Social support	0.87	0.68, 1.05	<0.001	0.89	0.69, 1.08	<0.001
Cognitive	1.09	0.30, 1.87	0.007	1.12	0.22, 2.01	0.016
Stigma	−0.94	−1.34, −0.54	<0.001	−0.95	−1.36, −0.54	<0.001

Note: CI, confidence interval.
*Adjusted for age, sex, marital status, educational attainment, and primary caregivers.

Table 3. Crude and adjusted coefficients of resilience.

Factor	B	SE (b)	β	*t*	*P*-value	95% CI
Depression	−0.39	0.40	−0.08	−0.99	0.324	−1.16, 0.39
Social support	0.72	0.11	0.60	6.83	<0.001	0.51, 0.93
Cognitive	0.12	0.29	0.03	0.39	0.696	−0.47, 0.70
Stigma	−0.45	0.17	−0.22	−2.72	0.008	−0.78, −0.12
Constant	51.95	13.43		3.88	<0.001	25.22, 78.69

Note: F (4, 80) = 26.79, $P < 0.001$, $R^2 = 0.573$, adjusted $R^2 = 0.551$.
CI, confidence interval.

Table 4. Final model of factors predicting resilience.

57.3% ($R^2 = 0.573$, adjusted $R^2 = 0.551$). Social support was a significant predictor of resilience when adjusting for depression, cognitive function, and stigma ($t = 6.83$, $P < 0.01$). Moreover, stigma was a significant predictor of resilience when adjusted for depression, social support, and cognitive function ($t = -2.72$, $P = 0.008$), as shown in Table 4.

4. Discussion

In the current study, we identified that most caregivers of children with ID had a low resilience level. The results concurred with the study of Rajan and John[31] that the resilience of caregivers of children with ID in India was low, with the mean score of 65.07 ± 15.97.[31] We also found positive relationships between social support, cognitive, and resilience in caregivers of children with ID, while depression and stigma were negatively associated with resilience in caregivers of children with ID. Our results also determined factors predicting resilience in caregivers of children with IDs and found them to be depression, social support, cognitive, and stigma that could predict resilience in caregivers of children with IDs.

We found the primary predictor of resilience in caregivers of children with ID was depression. Caregivers of children with ID such as autism and Down syndrome frequently reported higher burdensome manifestations than caregivers of commonly developing children.[32] Previous studies[33] asserted that depression was associated with resilience in caregivers of children with ID. Grant et al.[34] examined the association between depression levels and resilience factors in caregivers of children with ID in the United Kingdom; their results showed that depression was related with resilience in caregivers of children with ID. Previous qualitative studies also

confirmed that caregivers of children with autism spectrum disorder (ASD) had a high level of depression and high levels of psychological distress compared with the rest of the population.[33] Indeed, the unique symptoms experienced by children with ID are the reason parents[35] show such high levels of depression.

The second factor that predicted resilience in caregivers of children with ID was social support. To explain this, caregivers of children with ID have mostly experienced physical and psychological burden from their personal responsibility, particularly during pandemic circumstances.[36] In fact, mental health issues are buffered by social support[37] because caregivers have the responsibility to take care of caring children with intellectual disability and need professional support and services to provide good care for their children. Our results were similar to those of the study by Willner et al.[38] which examined the effectiveness of the level of ID, autism, and challenging behaviors on perceptions of social support by caretakers of children with ID. Their result showed that social support decreased as the severity of challenging behavior increased (F[3, 96] = 6.90, $P < 0.001$; linear trend: F[1, 96] = 12.28, $P < 0.001$). Mohan and Kulkarni[39] also noted that caregivers who had lower social support coupled with the strain of poverty could affect lower levels of self-efficacy with regard to childcare. In fact, social support is a significant factor that links to health and tends to be stronger when support indices are aggregated, and several mechanisms, such as behavioral, psychological and biological mechanisms, are considered.[40]

The third factor that predicted resilience in caregivers of children with ID was cognitive function. Children with developmental disabilities still need caregivers to assist with activities daily living (ADL) health management, self-care, emotional, social as well as cognitive and educational development in order to improve positive life assets.[19] In line with Bekhet et al.[41] found that cognitive appraisal was associated with resilience in family members of persons with ASD. A previous study also indicated that cognitive ability was related to resilience for caregivers of children with intellectual and developmental disabilities.[11] Caregivers provided support for persons with ASD through activities designed to improve positive cognitions of persons with ASD.[41] In addition, our result was similar to those of previous studies that showed that cognitive function was associated with families of children with ASD in Australia[42] and better family adjustment.[43]

In addition, a factor that can predict resilience in caregivers of children with IDs was stigma. People with developmental disabilities such as ASD frequently experience stigmatizing or negative reactions from the public.[44] Relative to caregivers of children with ID, longer treatment durations and affiliated stigma tend to be higher in caregivers of children with ASD.[45] In line with Chan and Leung,[46] we found a positive relation between children with ASD severity, experienced public stigma, and affective symptoms in caregivers of children with ASD. Previous research has suggested that mothers reported feeling bad about having a child with IDs and significant stigmatization from society and families.[47] Therefore, given the mental health challenges of caregivers of children with IDs, healthcare providers should develop activities or interventions to enhance psychological resilience in caregivers of children with IDs in order to improve emotional well-being of the caregivers.[48]

In Thailand, caregivers of children with ID were sensitive to the word “dek-au, dek-uur,” which means ID resulting in caregivers’ stigma.[49] Caregivers reported high levels of emotional distress, particularly depression. Caregivers also reported their children may not be able to live without them.[49] A previous study emphasized several factors related with resilience in caregivers of children with ID in Southeast Asian countries, such as social support, severity of ID, financial problem, parents’ anxiety, and religious belief.[50] Social determinants of health in Southeast Asian countries created the uniqueness of resilience issues that required the attention from policy-makers to resolve this issue. However, the support system for caregivers of children with ID in Southeast Asian countries was lower than that in Western countries.[50] Therefore, policy-makers should consider a support system to support caregivers of children with ID in order to reduce caregivers’ burden and improve resilience of the family. The support system should consider the strength of the family structure of Southeast Asian countries where the primary caregivers were parents of the children.[51] The support system should consist of caregiver support programs, special education programs for children with ID, and financial support, particularly in rural areas.[49]

This study has limitations that should be considered. First, this study is a cross-sectional analysis, so the causal relationship between predictors and outcomes may not be concluded. The sample size can also be considered small due to the limitation of the study setting; however, the power analysis was still sufficient for regression analysis. In addition, a majority of the caregivers of children with ID were parents, with the duration of childcare of >5 years. With these considerations, our findings may be generalized to parents of children with ID with a longer duration of care in Southeast Asian countries.

5. Conclusions

This study aimed to explore the predictors of resilience with demographic data, depressive symptoms, social support, stigma, and cognitive function in caregivers of children with IDs. We demonstrated that caregivers' depression, cognitive function, social support, and stigma were the significant predictors of caregivers' resilience. Future interventions should aim to reduce caregiver burden and improve caregiver well-being, considering social determinants of health and cultural sensitivity of caregivers of children with ID.

Ethical approval

This study was endorsed by the Committee for Research Ethics (protocol number RI 004/2562). The study was conducted in accordance with the Declaration of Helsinki. The participants in the study signed informed consent forms affirming their willingness to participate in the research.

Conflicts of interest

All contributing authors declare no conflicts of interest.

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