Prevalence of and Factors Associated with Depression in Caregivers of Children with Cerebral Palsy

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ABSTRACT

Objectives: To investigate the prevalence of depression in caregivers of children with cerebral palsy including the quality of life of caregivers and factors associated with depression

Study design: Cross-sectional study

Setting: Department of Rehabilitation Medicine, Faculty of Medicine Siriraj Hospital, Mahidol University

Subjects: Ninety-two caregivers of children with cerebral palsy

Methods: Caregivers of children with cerebral palsy were recruited and asked to complete a three-section questionnaire: demographic and personal information of both caregivers and the children they care for, The Patient Health Questionnaire-9 (PHQ-9) Thai version, and The World Health Organization Quality of Life Brief Thai version (WHOQOL-BREF-THAI).

Results: Sixty-three percent of the participants were female, with a median age of 39 and an interquartile range (IQR) of 32-44. The children with cerebral palsy had a median age of 8 years (IQR: 4-11). The prevalence of depression in the primary caregivers of children with cerebral palsy was 20.7%, with statistically significant findings indicating that caregivers of children with cerebral palsy who were non-verbal were more likely to experience depression at a rate 3.4 times higher than caregivers of children who could communicate using language ($p < 0.05$). Overall, the quality of life of the primary caregivers of children with cerebral palsy was moderate (65.5%). Caregivers with depression had significantly lower quality of life scores in all domains with the exception of social relationships.

Conclusions: The prevalence of depression among primary caregivers of children with cerebral palsy at Siriraj Hospital was 20.7%, with lack of language communication of their children with cerebral palsy a significant factor

Keywords: prevalence, cerebral palsy, caregivers, depression, quality of life

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Notice of Correction:
This article has been corrected for duplicated data in Table 1.
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Introduction

Cerebral palsy (CP) is one of the most common neurological disorders in children. According to the Centers for Disease Control and Prevention (CDC), cerebral palsy affects 1 to 4 individuals per 1,000 births, representing 0.1-0.4% of all births.[1] The condition results from abnormalities in brain development during childhood, either during pregnancy or in the early years of life during brain development. Causes include oxygen deprivation, head injuries, meningitis, and near drowning. Cerebral palsy tends to be a persistent and non-progressive condition which can lead to motor control problems, muscle weakness, spasms, and intellectual disability resulting from its impact on brain development during childhood.

Primary caregivers of children with cerebral palsy bear a significant caregiving burden beginning from the birth of the child and involving endless assistance with daily activities and medical care. A study by Basaran in 2013[2] indicated that the quality of life and mental health of primary caregivers of children with cerebral palsy are worse than those of caregivers for typically developing children. Additionally, Srinuan's study,[3] which used the Zarit Burden Interview questionnaire, concluded that 45% of primary caregivers of children with cerebral palsy felt burdened by their responsibilities.

Beyond the challenges of caregiving, studies in many countries have suggest that there is a high prevalence of depression among primary caregivers of children with cerebral palsy. For example, a survey by Farajzadeh[4] found a prevalence of depression of 45%, a study by Sonune[5] reported a prevalence of 82.8%, and a study conducted in Thailand by Hongrapipat[6] found a prevalence of 71.4%. Moreover, these studies stated that depression could negatively impact the caregiver's health, emotions, relationships, and work capabilities and, in severe cases, might even lead to suicidal tendencies.

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Irwin's review[7] found that behavioral family intervention significantly reduced depression in caregivers of individuals with cerebral palsy and that early awareness, prevention, and management of depression in these caregivers is beneficial.

The existing studies of caregiver depression were conducted in many countries where the social, economic, and healthcare system contexts were different from those in Thailand. The study in Thailand by Hongrapipat in 2014[6] included only 28 participants at Surin Hospital, a small sample size, and did not indicate the relationship between the caregiver and the patient. Our study aimed to investigate the prevalence of depression in primary caregivers of children with cerebral palsy in Thailand and to analyze factors associated with caregiver depression, potentially enabling early detection and treatment.

Objectives

Primary outcome

- To investigate the prevalence of depression in primary caregivers of children with cerebral palsy in Siriraj Hospital, Thailand

Secondary outcome

- To identify factors associated with depression in primary caregivers of children with cerebral palsy in Siriraj Hospital, Thailand
- To investigate the levels of quality of life and their association with depression in caregivers of children with cerebral palsy in Siriraj Hospital, Thailand

Methods

Participants and study design

This cross-sectional study was conducted at the Rehabilitation Medicine Outpatient Department Unit of Siriraj Hospital. Primary caregivers of children with cerebral palsy who came to the Rehabilitation Medicine Outpatient Department Unit were invited to participate in the study. They signed an informed consent form prior to beginning the questionnaires. The research assistant provided information about the questionnaires and separated the participants from the children with cerebral palsy while the participants filled out the questionnaires. The inclusion criteria for the participants were: relative and primary caregiver of children with cerebral palsy, age 18-75 years, able to read and understand the Thai language, having cared for children aged 2-18 years old who had had cerebral palsy for more than six months. Caregivers who were diagnosed with a psychiatric disorder (with the exception of a major depressive disorder) were excluded from the study.

The sample size of n=93 was calculated with a significance level of 5%, an allowable error of 0.1, and the reported prevalence of depression among primary caregivers of individuals with cerebral palsy from a previous study, which was 45.0%.[4] A sample size of 103 was required, with a 10% likelihood of being excluded.

The Siriraj Institutional Review Board (No. 450/2565 (IRB2)) approved this study.

Outcome measurements

1. From July 2022 to January 2024, demographic data and personal information of caregivers and children with cerebral palsy were obtained through questionnaires and medical records.
2. Patient Health Questionnaire-9 (PHQ-9) scores was obtained using The Patient Health Questionnaire-9 (PHQ-9) Thai version[8] which consists of 9 questions about symptoms in the previous two weeks and the frequency of each symptom. Each symptom was assigned a score of 0-3 points, where 0 points indicating no occurrence, 1 point for a few days but not often, 2 points for quite often, and 3 points for almost every day. Total scores ranged from 0-27 points. A score ≥ 9 indicates depression and a score < 9 indicates no depression.
3. The quality of life (QOL) level was obtained using the World Health Organization Quality of Life Brief Thai version (WHOQOL-BREF-THAI).[9] The questionnaire consisted of 26 questions covering four aspects of QOL as follows: Physical Health (questions 2, 3, 4, 10, 11, 12, 24), Mental Health (questions 5, 6, 7, 8, 9, 23), Social Relationships (questions 13, 14, 25), and Environmental health (questions 15, 16, 17, 18, 19, 20, 21, 22). Questions 1 and 26 also served as a measure of overall QOL. For questions with negative connotations (2, 9, 11), the scoring was as follows: 1 (highest), 2 (high), 3 (moderate), 4 (low), 5 (not at all). For the remaining positively worded questions, the scoring was 1 (not at all), 2 (low), 3 (moderate), 4 (high), 5 (highest). The overall QOL score, ranging from 26 to 130 points, can be interpreted as follows: 26-60 points (poor QOL), 61-95 points (moderate QOL), and 96-130 points (good QOL).

Statistical methods

The demographic data of caregivers and cerebral palsy patients were described using descriptive statistics and are presented as frequency, percentage, mean, standard deviation (SD), median and interquartile range (IQR). The prevalence of depression obtained by the questionnaire is presented as a percentage. Factors associated with the PHQ-9 depression (cut-off value ≥ 9 for depression) were evaluated using logistic regression analysis. We compared the means of the WHOQOL-BREF scores between caregivers in the with and without depression groups using the independent sample T-test. A *p*-value less than 0.05 was considered statistically significant. Statistical analyses were performed using IBM SPSS Statistics version 28.0 for Windows, IBM Corporation, Armonk, NY, USA.

Results

Characteristics

Participants included 92 caregivers of children aged between 2 and 18 with cerebral palsy. The demographic data

Table 1. Demographic data of the children with cerebral palsy

Characteristics of the children (n=92)	Median (IQR) or number (%)
Age in years^1	8 (4, 11)
Gender^2	
Male	51 (55.4)
Epilepsy^2	
Yes	19 (20.7)
Communication^2	
Non-verbal	53 (57.6)
Verbal	39 (42.4)
Participated in school^2	
No	50 (54.3)
Route of feeding^2	
Oral	78 (84.8)
Tube feeding	14 (15.2)
CP type^2	
Spastic diplegia	38 (41.3)
Spastic hemiplegia	18 (19.6)
Spastic quadriplegia	35 (41.3)
Other	1 (1.1)
GMFCS level^2	
I	9 (9.8)
II	18 (19.6)
III	16 (17.4)
IV	22 (23.9)
V	27 (29.3)

^{1}Median (interquartile rage, IQR); ^{2}mumber (%); CP, cerebral palsy; GMFCS, Gross Motor Function Classification System

Table 2. Demographic data of caregivers of children with cerebral palsy

Caregivers' characteristics	Median (IQR) or number (%)
Age in years^1	39.0 (32.0, 44.0)
Gender^2	
Female	82 (89.1)
Relationship to the children	
Father	8 (8.7)
Mother	69 (75)
Others	15 (16.3)
Marital status^2	
Married	67 (72.8)
Divorced/single	25 (27.2)
Education^2	
Below bachelor's degree	56 (60.9)
At least a bachelor's degree	36 (39.1)
Employment^2	
Employed	51 (55.4)
Unemployed	41 (44.6)
Income^2	
0-20,000 baht/month	61 (66.3)
More than 20,000 baht/month	31 (33.7)
Health problems^2	
Yes	22 (23.9)
Another dependent family member requiring care	
Yes	27 (29.3)

^{1}Median (IQR, interquartile rage); ^{2}mumber (%)

of the children with cerebral palsy are shown in Table 1. The median age of the children was 8 years (IQR: 4, 11). Fifty-three of the children with cerebral palsy (57.6%) were unable to communicate verbally. Most of the children with cerebral palsy could eat through their mouths (84.8%), while the remaining 15.2% relied on tube feeding. Ten percent (n=9) of the participating children were diagnosed at the Gross Motor Function Classification System (GMFCS) level I, 19.6% (n=18) at level II, 17.4% (n=16) at level III, 23.9% (n=22) at level IV, and 29.3% (n=27) at level V.

The median age of caregivers was 39 years (IQR: 32.0, 44.0). Among the 92 caregivers, 89.1% were female, 72.8% were married, 55.4% were employed, 39.1% had at least a bachelor's degree, 33.7% had an income of more than 20,000 baht per month, and 76.1% had no health problems.

Prevalence of depression

The 92 participants' PHQ-9 scores ranged from 0 to 14 points, with a median of 5 points (IQR: 3 to 8). Utilizing a cut-off value of ≥ 9 for depression, the prevalence of depression was 20.7% (n = 19) (Table 3).

Quality of life

Table 3 shows the quality of life of caregivers of children with cerebral palsy. The study found that most of the sample group had a moderate overall quality of life (65.2%), followed by a good quality of life (34.8%). Considering the quality of life across all four domains, it was found that most participants had a moderate quality of life in terms of physical health, mental health, social relationships, and environmental domains (62.0%, 50.0%, 63.0%, 66.3% respectively).

Association between demographic characteristics and depression

The characteristics of caregivers and the children with cerebral palsy are presented in Tables 4 and 5 according to the presence of depression in the caregivers. The majority of caregivers experiencing depression were found among those who cared for children with cerebral palsy who were unable to communicate verbally and who were classified as GMFCS level IV-V (78.9% and 68.4%, respectively). All caregivers in the depression group were female. The majority of caregivers experiencing depression were mothers of the patient, married, had an education below a bachelor's degree, and reported no health problems (89.5%, 73.7%, 63.2%, and 73.7%, respectively).

The degree of association between demographic characteristics of children with cerebral palsy and depression in caregivers was analyzed using binary logistic regression (Table 4). The odds of depression among caregivers of non-verbally communicating cerebral palsy children was 3.4 times higher than among caregivers of verbally communicating cerebral palsy children (*p*-value = 0.042, OR = 3.4, 95% CI: 1.05-11.41). However, other demographic characteristics of

Table 3. Demographic data of caregivers of children with cerebral palsy

Health status and quality of life	Characteristics	Number (%)
Depression	No (PHQ-9 score 0-8)	73 (79.3)
	Yes (PHQ-9 score ≥ 9)	19 (20.7)
WHO-QOL brief Thai domain		
Physical health	Poor	2 (2.2)
	Moderate	57 (62.0)
	Good	33 (35.9)
Mental health	Poor	0 (0.0)
	Moderate	46 (50.0)
	Good	46 (50.0)
Social relationships	Poor	5 (5.4)
	Moderate	58 (63.0)
	Good	29 (31.5)
Environmental Health	Poor	2 (2.2)
	Moderate	61 (66.3)
	Good	29 (31.5)
Overall quality of life	Poor	0 (0.0)
	Moderate	60 (65.2)
	Good	32 (34.8)

Median (interquartile rage, IQR); PHQ-9, The Patient Health Questionnaire-9; WHOQOL, he World Health Organization Quality of Life

children with cerebral palsy were not statistically significantly associated with depression in caregivers.

The degree of association between demographic characteristics of caregivers and caregiver depression was analyzed by binary logistic regression (Table 5). All caregivers with depression were female; the lack of a control group of male caregivers limits the ability to make definitive conclusions. There was no significant association between the various variables and depression in caregivers.

The association between WHOQOL-BREF domains and PHQ-9 scores is shown in Table 6. Caregivers without depression (PHQ-9 score ≤ 9) had a statistically significantly higher overall quality of life score than the caregivers with depression (PHQ-9 score > 9). The mean WHOQOL-BREF scores of each domain were statistically significantly lower for caregivers with depression, except for the social relationships domain.

Discussion

This study found a 20.7% incidence of depression among caregivers of children with cerebral palsy. Caregivers of non-verbal or minimally verbal children were three times more likely to experience depression compared to those caring for verbally communicative children, a statistically significant

Table 4. Characteristics of children associated with depression of caregivers (n=92)

Characteristics of children	Number of caregivers (%)		OR (95%CI)	*p*-value
	Without depression (n=73)	With depression (n=19)		
Age				0.704
2 to 6 years	30 (41.7)	10 (52.6)	1.27	
6 to 10 years	23 (31.9)	4 (21.1)	0.66	
More than 10 years	19 (26.4)	5 (26.3)	1	
Gender				0.429
Female	31 (42.5)	10 (52.6)	1.50 (0.55-4.15)	
Epilepsy				0.748
Yes	15 (20.5)	4 (21.1)	1.03 (0.30-3.57)	
Communication				0.042
Non-verbal	38 (52.1)	15 (78.9)	3.45 (1.05-11.41)	
Participated in school				0.728
No	39 (53.4)	11 (57.9)	1	
Route of feeding				0.430
Oral	63 (86.3)	15 (78.9)	1	
Tube feeding	10 (13.7)	4 (21.1)	1.68 (0.46-6.10)	
CP type				N/A
Spastic diplegia	30 (41.1)	8 (42.1)	1.33 (0.31-5.77)	
Spastic hemiplegia	15 (20.5)	3 (15.8)	1	
Spastic quadriplegia	27 (37.0)	8 (42.1)	1.48 (0.34-6.44)	
Other	1 (1.4)	0 (0.0)	N/A	
GMFCS level				0.143
I-III	37 (50.7)	6 (31.6)	1	
IV-V	36 (49.3)	13 (68.4)	2.23 (0.76-6.50)	

OR, odd ratio; CI, confident interval; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System

Table 5. Characteristics of children associated with depression of caregivers (n=92)

Caregiver characteristics	Number of caregivers (%)		OR (95%CI)	*p*-value
	Without depression (n=73)	With depression (n=19)		
Age				0.417
Under 25 years	4 (5.5)	3 (15.8)	3.00 (0.21-42.62)	
26 to 60 years	65 (89.0)	15 (78.9)	0.92 (0.10-8.86)	
> 60 years	4 (5.5)	1 (5.3)	1	
Gender				N/A
Female	63 (86.3)	19 (100.0)	N/A	
Relationship to the children				0.119
Mother	52 (71.2)	17 (89.5)	3.43 (0.73-16.18)	
Father/Other relative	21 (28.8)	2 (10.5)	1	
Marital status				0.925
Divorced/Single	20 (27.4)	5 (26.3)	0.95 (0.30-2.97)	
Education				0.819
Below bachelor's degree	44 (60.3)	12 (63.2)	1.13 (0.40-3.21)	
At least a bachelor's degree	29 (39.7)	7 (36.8)	1	
Employment				0.809
Unemployed	33 (45.2)	8 (42.1)	0.88 (0.32-2.45)	
Income				0.386
0-20,000 baht/month	50 (68.5)	11 (57.9)	0.63 (0.22-1.78)	
More than 20,000 baht/month	23 (31.5)	8 (42.1)	1	
Health problems				0.783
Yes	17 (23.3)	5 (26.3)	1.18 (0.37-3.74)	
Having another dependent family member requiring care				0.156
Yes	24 (32.9)	3 (15.8)	0.38 (0.10-1.44)	

OR, odd ratio; CI, confident interval; N/A, not applicable

Table 6. Demographic data of caregivers of children with cerebral palsy

WHO-QOL brief Thai domain	No depression (n=73) (PHQ-9 ≤ 9) Mean (SD)	Depression (n=19) PHQ-9 > 9 Mean (SD)	*p*-value
Physical health	26.08 (3.64)	22.42 (4.11)	<0.001
Mental health	23.25 (2.97)	19.63 (2.73)	<0.001
Social relationships	10.81 (1.96)	10.11 (1.79)	0.161
Environmental health	27.78 (4.13)	25.47 (4.20)	0.033
Overall quality of life	94.97 (11.55)	84.21 (12.26)	0.001

Median (IQR, interquartile rage); PHQ-9, The Patient Health Questionnaire-9; WHOQOL, The World Health Organization Quality of Life

finding. The study also suggests that the prevalence of depression tends to be higher among female caregivers, particularly mothers, though this was not statistically significant. Depression prevalence was 26.5% among caregivers of children at GMFCS levels IV and V, compared to 14.0% for children at GMFCS levels I, II, and III, but this difference was not statistically significant. Additionally, caregivers with depression had significantly lower WHOQOL-BREF scores in all domains except social relationships. Most caregivers reported a moderate overall quality of life.

Our study found a notably lower prevalence of depression compared to the 71.4% reported by Hongrapipat in 2018[6] which involved a small sample of 28 participants. This substantial difference may be due to methodological variations, including sample size. The smaller sample in the previous study might have biased the findings and overstated depression rates. Also, the Hongrapipat study involved primarily children with severe impairments (GMFCS levels IV-V) who are more likely to experience communication issues than those with less severe impairments (GMFCS I-III).[10] The differences in participant characteristics and the level of medical care – quaternary in our study versus tertiary in the previous study – may also help account for the differences in prevalence rates.

Caregivers of non-verbal or minimally verbal children with cerebral palsy are more likely to experience depression, as highlighted by Unsal-Delialioglu's 2009 study[11] which found that mothers' depression was significantly affected by their children's speech problems.

Hewawitharana et al.[12] (2023) found that the GMFCS level of children with cerebral palsy significantly predicts caregiver burden. Basaran (2013) also linked the severity of functional limitations in these children to caregivers' mental health and quality of life.[2] Our study found that 26.5% of caregivers of children at GMFCS levels IV and V experienced depression, compared to 14.0% for those at levels I, II, and III. These results, consistent with Gugala's 2019 study[13], suggest that lower GMFCS levels are associated with increased likelihood of caregiver depression, though statistical significance was not reached.

Our study found that the mean WHOQOL-BREF scores for caregivers with depression were consistent with the previous findings of Arrieta.[14] The quality of life of caregivers of children with cerebral palsy impacts both the well-being of the care giver and the care provided to the children. Pandit's 2021 study[15] in Nepal found that most primary caregivers had a poor quality of life. Basaran's 2013 study[2] reported moderate overall quality of life levels among caregivers, which aligns with our results.

One strength of this study is that it was executed at a major tertiary and quaternary-care medical center, marking the first exploration of this topic at Siriraj Hospital. Our findings suggest that assessing a child's language ability may help identify caregiver depression, potentially guiding future prevention and treatment strategies.

It is essential, however, to also acknowledge the limitations of this study. Multiple factors can influence depression, adding an additional level of complexity to the analysis. The study was conducted at a single hospital center. Additionally, the majority of participants were female and had no health problems. Finally, differences in cultural attitudes toward disability and social support systems could affect caregiver depression. As a result, these results may not accurately reflect or generalize the condition of participants of all genders or represent the entire population of Thailand.

Furthermore, this was a cross-sectional study. Longitudinal, multicenter studies are needed to establish the factors associated with depression among caregivers of children with cerebral palsy.

Conclusions

The prevalence of depression among primary caregivers of children with cerebral palsy in Thailand is 20.7%. Factors related to depression among primary caregivers include the child's ability to use language for communication. The majority of caregivers of children with cerebral palsy reported a moderate overall quality of life. The group of primary caregivers experiencing depression tended to have lower average scores in all quality-of-life domains with the exception of the social relationships domain.

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