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UNIVERSITY OF EDUCATION

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(MENTAL HEALTH AND COPING STRATEGIES AMONG CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY)

DOCTORAL DISSERTATION

IN CLINICAL PSYCHOLOGY

HANOI - 2023

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DOCTORAL DISSERTATION
IN PSYCHOLOGY

Major: Children and Adolescent Clinical Psychology
Code: 91310401.01

Supervised by: 1. Prof. Bahr Weiss
2. Assoc. Prof. Tran Van Cong

HANOI - 2023

DECLARATION

I, the undersigned, hereby declare that this thesis “Mental health and coping strategies among caregivers of children with cerebral palsy” is entirely my work without plagiarism.

All information sources used in this dissertation have been acknowledged and its authors have been referenced.

This research was only submitted to the University of Education, Vietnam National University, Hanoi under the framework of the Children and Adolescent Clinical Psychology Doctoral Training Program.

Name: Nguyen Thi Mai Hien

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LIST OF ABBREVIATIONS

CDS : Caregiver Difficulties Scale
COPE : Coping Orientation to Problems Experienced
CP : Cerebral Palsy
CPFAV : Cerebral Palsy Family Association Vietnam
CWD : Children with Disabilities
GSO : General Statistics Office
GMFCS : Gross Motor Function Classification System
GAD-7 : Generalized Anxiety Disorder-7
MoH : Ministry of Health
PHQ-9 : Patient Health Questionnaires- 9
PWD : People with Disabilities
QoL : Quality of Life
CRPD : United Nations' Convention on the Rights of Persons with Disability
UNICEF : United Nations International Children's Emergency Fund
WHO : World Health Organization

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INTRODUCTION

1. Rationales

Vietnam has made strong commitments to support people with disability (PWD) including children with disability (CWD) by the endorsement of the National Assembly's Law for PWDs in 2010, issuing the Government's Decree on supporting PWDs in 2012, ratifying the United National Convention on the Rights of Persons with Disabilities (CRPD) in 2014, approving Government's Decree on social welfare policies in 2021, and issuing the Decision Number 1190/QD-TTg for approving the program to support people with disability for 2021-2030 executed by Ministry of Labor, Invalid and Social Affairs.

Following UNICEF's report, CWDs in Vietnam, like many other countries, have faced more difficulties than those without disabilities including higher rates of CWDs not going to school, less accessibility to health care and rehabilitation services, and less quality of life (UNICEF, 2018).

Cerebral Palsy (CP) is seen as the leading cause of disability in children. The prevalence of CP worldwide ranges from 1.5 to 3.4 per 1,000 live births (McIntyre et al., 2022). In Vietnam, about two children per 1,000 babies born live with CP, accounting for 30-40 percent of CWDs (MoH, 2018).

It is not uncommon that children with CP to have multiple impairments of motor, sensory, communicative, and intellectual functions, activity limitations, and participation restrictions. The majority of children with CP require lifetime extensive support in daily living activities and completely depend on caregivers, mostly parents in their families. CP has made a big impact on the quality of life of those affected and their families (Parisi, Ruberto & Precenzano, 2016).

Caring for a CP child requires an enormous effort and will to deal with a child experiencing long-term functional limitations and dependence. One of the main challenges is to manage their child’s chronic health issues while maintaining the role of daily living earnings (Parisi et al., 2016).

Quite a few research show that caregivers of CWDs like those with CP children experience chronic stress caused by daily care demands, marital conflicts associated with rearing CWDs, financial burdens to get treatment services for the child, loss of leisure time due to care taking responsibilities, worrying about the future of the child when the parents are no longer able to care for their child, negative attitudes from others (Basaran et al., 2013; Larson & Bishoff, 2014; Al-Gamal, 2015; Maridal et al., 2021).

All those mentioned issues have put caregivers of children with CP at a higher risk of common mental health problems such as depression, anxiety, and lower quality of life. A system review of 14 articles published in 10 years from 2006 to 2016 released that the prevalence of depression and anxiety among CP children’s caregivers was much higher than those of typically developing children or those of children with other diseases (Barreto et all., 2019). Depression and anxiety have significant effects on life functioning as well as the quality of life of caregivers. Thus, suffering common mental health issues like depression and anxiety, and the overall quality of life could be among essential indicators for mental health situations of caregivers (Parisi, Ruberto & Stewart, 2016; Maridal et al., 2021).

One of the objectives to support children with CP is not only to improve the functions of the child but also to support their caregivers and families as effectively as possible. The values of the family-focused principles in provision of the support services for children with CP have been mentioned (Saloojee, Rosenbaum & Stewart, 2011).

It will be helpful for both children and their parents if the parents’ problems and the determinants of parents’ quality of life are taken into consideration in the overall plan of support for children with CP. The strategies to maximize the health of the caregivers including mental health have been proposed (Parisi, Ruberto & Stewart, 2016).

UNICEF emphasizes that the caregiver is central to maternal and child health programs and that the caregiver is central to achieving nurturing care. Efforts to support children are not likely to get achievement unless support for the caregivers is simultaneously provided. A common barrier to caregiving is poor caregivers' emotional well-being, then improving the mental health of caregivers is crucial (Rochat T.J et al, 2019).

In Vietnam, research on caregivers' mental health and its associated factors is rather rare contributing to the knowledge gap in understanding their problems and their needs. This could lead to the ignorance in plan of support for this group. Additionally, there is no study so far on how caregivers of children with CP cope with caregiving burdens so that the appropriate support program could be developed. Thus, our study is important and helpful that would pave the way to call for more attention from the involved stakeholders to prioritize resources on improving the health and well-being of the caregivers in the coming time.

2. Objectives of the study

We hope that the results of this research could contribute to the existing literature by investigating the relationship between mental health and coping strategies among caregivers of children with CP in a different cultural context and by exploring other individual, family, and social factors in this interaction.

The specific objectives of this study are to have a better understanding of the current mental health status of primary caregivers of children with CP more specifically for depression, anxiety, quality of life, the coping strategies used by caregivers, the relations between caregivers' mental health and coping as well as other associated factors. The research findings could be served as useful inputs for the development of relevant interventions to support caregivers of children with CP to improve their mental health.

3. Research questions

Q1: What is the prevalence of depression, anxiety and quality of life among studied primary caregivers of children with cerebral palsy?

Q2: How do the studied caregivers cope with caregiving difficulties?

Q3: What are the relations between identified mental health issues and coping as well as other associated factors?

The research hypothesis is:

(i) The primary caregivers of children with cerebral palsy are at high risk of common mental health problems such as depression and anxiety and have a low quality of life

(ii) The caregivers use all possible ways to cope with the obstacles related to CP child caring burdens in which self-reliance mechanism is most applied.

(iii) The caregivers' coping strategies could have significant effects on their mental health. The other factors including caregivers' characteristics, features of CP children, family situations, and social support could have significant relations with caregivers' mental health issues.

4. Research design

The analytical cross-sectional study with a quantitative data collection method was chosen to provide a snapshot of the mental health outcomes of the selected target population and the associated factors at a specific point in time.

Scope of the research

The data collection method was restricted to quantitative but not qualitative one. The google forms based online survey through the self-administered questionnaires was applied to reach out to the investigated participants. The total samples of the study were 340 main caregivers of CP children at the ages of 18 years old and below. They were within the network of the Cerebral Palsy Family Association Vietnam all over the country.

The evaluation of the mental health status of surveyed caregivers of the children with CP focused on three selected aspects including depression, anxiety, and quality of life. Given the community-based survey, screening tools rather than diagnostic measures were used to assess mental health in which the Patient Health Questionnaires-9 (PHQ-9) was used to assess depression; Generalized Anxiety Disorders-7 (GAD-7) was used to evaluate anxiety, and the WHO's Quality of Life (QoL) selected questions was used to investigate general mental health wellbeing.

The coping of the caregivers studied in the research was limited to the existing strategies used by the caregivers to cope with the caregiving burdens. The 28-item Brief Coping Orientation to Problems Experienced Inventory (Brief COPE Inventory) was selected to assess how caregivers of children with CP coped with caregiving difficulties.

The perceived factors relating to the mental health issues of the caregivers were studied including demographic and social-economic features of the family of children with CP; characteristics of child with CP; features of caregivers of children with CP, burdens of care for children with CP through the Caregiver Difficulties Scales (CDS); and social support for the caregivers.

5. Contribution of the thesis

Theoretically, the thesis helps provide an overview of existing research internationally and locally on the mental health situation of caregivers of children with disabilities, more specifically for depression, anxiety, and quality of life among caregivers of children with cerebral palsy, the different mechanisms caregivers used to cope with adversity, and the risk factors associated with mental health and existing coping mechanisms of caregivers.

Practically, the dissertation provides a relatively comprehensive picture of the prevalence of depression, anxiety, and quality of life among surveyed caregivers of children with CP, on how they cope with the caregiving burdens, and the main predictors for their mental health; clarifying the relationship between mental health and the coping strategies among caregivers of children with CP in a different cultural context and by exploring other related individuals, family, and social factors.

The study findings could be of use to stakeholders, especially for CP Children Family Association Vietnam, professionals, and policy makers to develop a plan of action to improve the mental health of the caregivers that in turn contributes to improved quality of care and quality of life for children with CP. Furthermore, this study could pave the way for further investigations to confirm the causal effects of mental health issues among caregivers of children with CP as well as for other applied research in this area.

CHAPTER 1

THEORETICAL BASIS

This chapter will provide a review of the literature on relevant aspects of the dissertation, the theoretical framework, and the key concepts based on which the research proposal and instruments have been developed. The information in this section is also used for discussion about the similarities and differences between the thesis results and the existing research findings, and appropriate explanations for the observed phenomena happening in the research samples.

1.1. Literature review on mental health and coping strategies

1.1.1. Overview of the research on mental health

1.1.1.1. Mental health of the general population

Over time, there has been more awareness of the important role mental health plays in reaching global development goals as reflected by including mental health in the Sustainable Development Goals (SDG). The COVID-19 pandemic and its impacts have made human beings more vulnerable to mental health problems given the unimaginative, inevitable life changes and the fear of uncertainty and insecurity.

A systematic analysis for the global burden of diseases (GBD) study in 2019 reported that depressive disorders were the 6th top cause of disability-adjusted for life years (DALYs) among people aged 25-49 years old. Depressive and anxiety disorders were the top three causes of DALYs among females (GBD, 2019).

In a comparison of GBD between 1990-2019 at all ages, it is observed that the burdens of depression and anxiety have increased, in which the percentage of DALYs caused by depressive disorders was 1.1 (0.8-1.5) in 1990 and 1.8 (1.4-2.4) in 2019, by anxiety disorders 0.7 (0.5-1.0) in 1990 and 1.1 (0.8-1.5) in 2019. Among the adolescent group aged 10-24 years old as well as the adults aged 25-49 years old, an increase in the burden of depressive and anxiety disorders between 1990 and 2020 has been observed (GBD, 2019).

In 2019, the World Health Organization (WHO) estimated that more than 264 million people (about 3.4% of the world population) suffer from depression. During the pandemic of COVID-19, the pooled prevalence of depression was seven times higher, about 25% (95% CI: 18% − 33%) (Bueno-Notivol, J et al, 2020).

A systematic review and meta-regression analysis on the prevalence of common mental disorders in South Asia which include countries like India, Pakistan, Nepal, Sri Lanka, Bhutan, Bangladesh, Afghanistan, and the Maldives, comprise one-quarter of the world's population, released that the prevalence of any mental disorders was 14.2% (12.9 – 15.7%), the rate of depression was 26.4% (23.6 – 29.4%), the prevalence of anxiety was 25.8% (19.4 – 33.5%), mixed depression and anxiety rate was 28.4% (13.9-49.3%), alcohol abuse 12.9% (8.8 – 18.6%) (Sadiq et al., 2020).

In China, following the results of the China Mental Health Survey in which 32,552 respondents completed the survey between 2013 and 2015, the prevalence of any disorder not including dementia was 9.3% (5.4 – 13.3%) during the 12 months before the interview and 16.6% (13.0 - 20.2%) during the participants' entire lifetime before the interview. Anxiety disorders were the most common disorders, about 5.0% (4.2 - 5.8%) in the 12 months before the interview, and about 7.6% (6.3 - 8.8%) in a lifetime (Yueqin, H et al., 2019).

Quite a few research on mental health-related issues has been carried out during and after COVID-19. Among those, Tianchen Wu and colleagues conducted a system review and meta-analysis on 66 studies with 221,970 participants to identify the prevalence of mental health problems during the COVID-19 pandemic. The results showed that the overall pooled proportion of insomnia, anxiety, and depression was 37.9%, 31.9%, and 31.4% respectively (Wu, T et al., 2020).

As for Vietnam, the national level available epidemiological survey in Vietnam was conducted in early 2000 by the National Psychiatric Hospital number 1 which showed that the ten most common mental disorders affected 14.9% of the population (i.e., around 12 million people). Amongst them, the most prevalent ones were alcohol abuse (5.3%), depression (2.8%), and anxiety (2.6%). Nearly 3 million people in Vietnam suffer the most severe mental disorders (schizophrenia, manic depression, and other severe forms of anxiety and depression) (NPH No 1, 2002).

Following the epidemiological and risk factor assessment of child mental health in Vietnam by Bahr Weiss and colleagues, among 591 children aged 12-16 years old assessed by the Child Behaviors Checklist Vietnamese version (CBCL) scale in 10 provinces of Vietnam, 11.9% reported to have mental health problems, 18.3% had internalizing problems, 6.6% had externalizing problems, 5.9% had depression, 7.3% had both depression and anxiety, 9.6% somatic complaints, 6.4% social problems, 4.4% thought problems, 4.0% attention problems, 2.9% aggressive behaviors, and 2.5% rule-breaking behaviors (Weiss, B et al., 2014).

Some observational studies on the prevalence of common mental disorders in Vietnamese people during the COVID-19 period were implemented. Generally, the rate of depression among studied Vietnamese was from 14.6% to 34.7% [Quang Duc Tran, 2022], and the rate of anxiety was 14.1% (Khanh Ngoc Cong Duong, 2020).

In short, mental health problems generally tend to increase over time and become the common cause of the global burden of diseases and emerging public health issues. Of which depression and anxiety are most prevalent, accounting for about 25% of the population. One of the important statements by The World Health Organization in its 2022 report was that expanding the intervention for depression and anxiety provides a benefit-cost ratio of 5 to 1 (WHO, 2022).

1.1.1.2. Mental health of the caregivers

* Mental health among caregivers of people with chronic conditions/ disabilities

A lot of people with chronic conditions or disabilities especially those with severe and very severe impairments must live dependently on their caregivers for living in which quality of life of people with disabilities has been influenced by the health status of caregivers. About 90% of persons with chronic diseases are cared for by relatives, who generally live with the patient (Muller, K. N., Slabbert, I., 2018). The challenges faced by the caregivers are known as the caregiver burden which was described as a feeling of heavy responsibility, constant worries, and uncertainty about the needs of PWDs and constraints in caregivers' social life. As the burden increases, caregivers may be subjected to physical and mental health problems (Yu, C. H., et al., 2018).

Yu Chi Ang and colleagues conducted a survey on mental health status and Suicidal Ideation (SI) among 255 caregivers of individuals with physical or mental disabilities in a tertiary hospital in southern Taiwan. He reported that 32.9% had probable depression, 37.6% had probable common mental disorders, and 18.8% experienced SI. The level of SI was correlated with lack of support from co-caregivers ($p=0.023$), caring for younger patients ($p=0.010$), caring for patients with mental disability ($p=0.019$) or catastrophic diseases ($p=0.005$), and caregivers' probable depression ($p<0.001$) and CMDs ($p<0.001$) (Yu, C. H., et al., 2018).

Grant, J.S., conducted the survey on family caregivers of people with stroke and indicated that family members often experience depressive symptoms in caring for stroke survivors who may have a physical disability as a result of the stroke with rates ranging from 34% to 52% or even higher in the first three months after return to the community (Grant, J. S. et al., 2006). Caro, C.C., in the research on the quality of life of family caregivers of stroke patients also reported approximately 67% of caregivers had burden scores suggesting they were at risk of depression (Caro, C. C et al, 2018).

As related to the burden of family caregivers of people with dementia and its consequences on mental health problems of caregivers, Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. implemented a study to investigate the burden experienced by families giving care to a relative with dementia, the consequences of care for the mental health of the primary caregiver and the strategies families use to cope with the care giving stressors. It was found that out of 172 caregivers of people with dementia involved in the study, 68.02% of caregivers were highly burdened and 65% exhibited depressive symptoms. The patient’s behavior was predictive of caregiver depression as well as burden (Papastavrou, E et al, 2007).

Miyashita, M., Narita, Y., Sakamoto, A., Kawada, N., Akiyama, M., and Kayama, M., carried out a cross-sectional survey among 418 caregivers who provided home care to patients with neurological diseases-borne disabilities in Japan. This study was to describe the care burden on caregivers of individuals with intractable neurological diseases and to clarify the prevalence of depression in caregivers and factors related to the presence of depression. The results showed that the prevalence of depression was high for caregivers, ranging from 42 to 63%. The factors related to depression in caregivers included hours required for close supervision of the patient (odds ratio [OR] = 1.06, P= 0.015), the intensity of caregiving (OR = 1.26, P= 0.024), and household income (OR = 0.76, P= 0.013) (Miyashita, M., et al., 2009).

Singer, G. H. S through a meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities (DD) stated that although women of child-bearing age in general are at high risk of depression, the addition of extra challenges associated with caregiving further raises the risk for psychological distress. On average, 29% of mothers of children with DD had depressive symptoms compared to 19% of parents in the comparison group, a difference in the prevalence of 10% (Singer, G. H. S., (2006).

Resch, J. A., Elliott, T. R., & Benz, M. R. identified the rate of depression among 110 parents of children with disabilities using PHQ-9 and found out that 19.1% of the parents were classified as depressed (Resch, J. A et al. 2012). The percentage of depressed parents in the Resch study is similar to rates observed in research on depression among individuals caring for family members with spinal cord injuries, 15.7% (Dreer, L. E et al. 2007), and substantially lower than the study to determine depression status among family caregivers of persons with traumatic brain injuries, 48.0% (Rivera, P. et al, 2007), or survey on depression among family caregivers of stroke survivors, 38% (Grant, J. S et al., 2004). Parents raising children with disabilities may be at higher risk for depression than the general public, but this risk is varied by studies using different depression assessment measures as well as the different kinds of disabilities of the target population.

Yang C, and colleagues carried out a cross-sectional survey in 2018 on the prevalence and influencing factors of depression and anxiety of more than 300 caregivers in children with epilepsy in Western China. It showed that 5.3% of participants were classified as depressed using the Zung Self-Rating Depression Scale while 25.7% of caregivers of children with epilepsy presented the symptom of anxiety using the self-rating anxiety scale (Yang, C et al., 2021).

Park, E.-Y., & Kim, J.-H. with research in 2019 on depression and life satisfaction among parents caring for children with developmental disabilities (CDD) in South Korea revealed that 22.3% of parents caring for CDDs showed significant depressed mood which was relatively higher than that of parents of children without the disability and behavioral problems. 18.4% of mothers and 20.6% of fathers caring for children without disability and behavioral problems reported a depressed mood in Korea following the Korea Institute of Child Care and Education 2016 (Park, E. Y et al., 2019).

In Vietnam, few studies on the mental health of caregivers of the dependent care recipients including children with disabilities carried out.

Pham Thi Thu Cuc and her colleagues carried out a descriptive cross-sectional survey on stress, depression, and anxiety among 157 parents of children with autism going for examination and treatment at Thai Binh Children's Hospital from October 2020 to October 2021 by using Depression-Anxiety-Stress 21 scale (DASS 21). It was reported that 24.8% of parents had symptoms of depression in which 8.9% had moderate and severe depression. The rate of anxiety was 21.7%, and 13.9 had average and severe anxiety (Pham. T.T.C. et al., 2022).

Vi Ngoc Tuan and Nguyen Thanh Binh investigated 100 caregivers of people with dementia coming to National Geriatrics Hospital for examination and treatment during the period from June 2020 to May 2021 to identify caregiver burdens and their consequences. They announced that the percentage of caregivers with depression and anxiety evaluated by the DASS-21 scale was 37.0% and 44.0% respectively (Vi.N.T & Nguyen.T.B, 2021).

A cross-sectional study on 172 mothers of children with disabilities in Ninh Binh and Quang Nam provinces showed that mothers of children with disabilities had very high levels of distress and low levels of community participation. 81.4% of mothers had moderate distress, and 15.1% had severe distress (Nguyen & Helen, 2013).

Research conducted in 2006 on 199 parents of children aged 3-6 years old with cognitive delays in Vietnam found that mothers experienced more stress than fathers. Mothers with female children, those with children of lower intellectual functioning, and those whose husbands had health conditions experienced more stress than the other mothers. Fathers with lower economic status and a smaller social support network were more stressed than the other fathers. Both mothers and fathers were more stressed when they experienced a stronger stigma (Shin, J. Y., et al., 2006).

Shin. J.Y., and Nguyen, V.N., conducted another study in 2009 on 225 mothers of children with and without cognitive delays from Hue City showing that mothers of children with cognitive delays experienced more stress. Mothers living in poorer conditions, less educated, and perceived less social support experienced more stress. Having a child with cognitive delay was the strongest predictor of stress after controlling other demographic and psychosocial variables in Vietnam (Shin & Nhan, 2009).

A cross-sectional research on 150 mothers of children with disabilities going to the Lam Dong Province’s Social Protection Centers released that 50% of mothers of children with disabilities has psychological distress, 27% had mild, 18% had moderate and 5% had severe distress (Vu, 2019).

Tran.T.Q, et al surveyed 106 people caring for mentally ill people being treated at Mai Huong Daycare Psychiatric Hospital to identify depression using PHQ-9 and caregiver burdens. They reported that the rate of caregivers with depression assessed by the PHQ-9 tool was 7.5%. It was found that the percentages of caregivers with depression were significantly higher in the group with the perceived financial burden, disruption of routine family activities, disruption of family leisure, and disruption of family interaction (Tran.T.Q, Nguyen.T.T.Huong, Nguyen.M.H. (2023).

In summary, the burdens of giving care to people with chronic conditions/disabilities put caregivers at high risk of mental health problems while caregivers tend to place a low priority on their health compared to the time and effort they spend for unwell and dependent care receivers. Thus, the mental health of caregivers of people with chronic conditions/disabilities is frequently neglected. Depression rather than other mental disorders is the most prevalent for caregivers of people with chronic conditions/disabilities, which ranges from 7.5% to 65% following different studies.

* Mental health among caregivers of children with cerebral palsy

Taking care of children with CP creates a tremendous burden on caregivers due to intensive and long-term special care given to the CP child, decreased incomes and increased expenditures, recreation loss, low social interaction, etc. All those issues have put caregivers at a higher risk of mental health problems such as depression and anxiety and lower quality of life. Quite a few studies on mental health problems among caregivers of children with CP were carried out.

A system review on the prevalence of depression, anxiety, and substance-related disorders in parents of children with CP selected 14 articles published between 1st January 2006 and 31st December 2016 investigating 1264 mothers and 105 fathers of children with CP. The results indicated that the prevalence of depression and anxiety is much higher in parents of children with CP than in parents of typically developing children or those with other diseases studied (Barreto, Bento, Jagersbacher, Jones, Lucena & Bandeira, 2019).

One study reported that about 95.7% of mothers and 83.3% of fathers had some degree of depression. Another study showed 52.74% of mothers of children with CP and 20.77% of mothers of typically developing children presented symptoms of depression. This data demonstrated that the prevalence of depression symptoms is 2.53 higher among mothers of children with CP than those with typically developing children. Another study indicated that 44.0% had depressive symptoms. They suggested that poor sleep quality is an independent factor that increases the prevalence of depression among mothers of children with CP and was related to 50% of cases (Barreto et al., 2019).

The results of this review suggest that having a child with CP is related to a higher prevalence of mental illness and that this relationship is more established for depression than for other disorders. In addition, the severity of the child's illness is a risk factor for mental illness in mothers and fathers of children with CP. Concerning the duration of care, the more time spent on childcare, the higher the risk of mental illness among the mothers of children with CP. Depression is the most frequently studied mental disorder in the population of parents of children with CP and is more prevalent than anxiety in this group (Barreto et al., 2019).

Another cross-sectional study among 232 mothers of CP children aged 5–18 years to assess the relationship between maternal anxiety and depression and parent-reported quality of life (QOL) of children with CP showed that 55.1% of mothers with CP had different degrees of depression. 69.0% of mothers with CP suffered from anxiety. Worldwide, the prevalence of depression among mothers of children with CP was estimated to range from 6% to 40.5%. The need for CP children to routine special care, frequent medical checkups, continuous physiotherapy treatment modalities, social stigma and discrimination in society toward disabilities leading to low social relationships of the CP children's mothers are those factors for mental health issues of caregivers of children with CP (Rasha, Rahaf, Nourah & Abdulrahman, 2019).

Another study in 2020 showed that the prevalence of depression in the mothers of children with CP (52.5%) was significantly higher than the mothers with healthy children (30%) ($p < 0.05$). However, no significant difference was found between the groups in terms of frequency of anxiety (Bueno et al., 2020).

An observational cross-sectional study on 203 primary caregivers (mothers) of children with CP who visited the outpatient department in India from July 2015 to June 2016 showed that 17.2% mothers had no depression, 31.0% had mild depression, 25.1% had moderate depression and 26.6% had severe depression (Sonune et al., 2021).

Ata Farajzadeh and colleagues performed a web-based cross- sectional study to investigate the mental health issues and the associated factors among 160 caregivers of children with CP during the COVID-19 pandemic in Iran. They reported that 45.0% of caregivers had symptoms of anxiety and 40.6% of caregivers had signs of depression (Farajzadeh et al., 2021).

Basaran A and colleagues studied 143 caregivers of children with CP in Turkey to identify the effect of having a child with CP on quality of life, burn-out, depression and anxiety scores of caregivers. The research indicated that 58% of caregivers had symptoms of depression, 30.8% had mild depression, 11.2% had moderate and 16.0% had severe depression. 71.3% caregivers had signs of anxiety, 31.1% has mild, 21.7% had moderate, 12.6% had severe anxiety (Basaran et al., 2013).

In Vietnam, only one survey on mental health of caregivers of children with CP has been found. That was a cross-sectional study on 117 mothers having children with CP going to Ninh Binh Rehabilitation Hospital for treatment and rehabilitation services in 2021. The results showed that 50.4% of mothers had severe depression, and 49.6% of mothers had moderate depression (Tong, Duong & Nguyen, 2022).

In conclusion, caring for children with CP makes carers more vulnerable to mental health problems in which the prevalence of depression and anxiety is much higher in parents of children with CP than in parents of typically developing children or those with other disabilities. In Vietnam, study on this issue is rare which create a knowledge gap in understanding the problems of caregivers that could lead to the ignorance in plan of support for this group. Therefore, the investigation of mental health focusing on the most prevalent mental disorders of caregivers is essential given the mental health condition of caregivers may positively or negatively affect the family's involvement in rehabilitation strategies, as well as the quality of life of children with CP.

1.1.2. Overview of the research on coping strategies

1.1.2.1. Coping strategies among caregivers of dependent care receivers.

The World Health Organization announced that approximately 349 million people worldwide are care dependent whose needs are met by carers. Among those, 18 million, accounting for 5%, are children at the ages of 15 years old and below, and 101 million, making up 29%, are the elderly from 60 years old and above. In most countries, care for the dependent recipients is delivered by informal caregivers, mostly family members, especially women. Generally, caretakers of those with severely impaired functions are at high risk of experiencing psychological distress and depression (WHO. 2017). To deal with and overcome hardship and difficulties in caring, the caregivers use different coping strategies to manage the caring burdens emotionally and behaviorally.

Angela Paster and colleagues carried out a study to identify the differences in coping strategies used by parents of children with and without disabilities. 112 parents, 50 having children with disabilities and 62 having children without disabilities were assessed their coping through the tool "the Ways of Coping Questionnaire". The results showed that parents of children with disabilities used different coping strategies and they used them more often than those of children without disabilities. All surveyed coping strategies including planful problem solving, seeking social support, confrontive coping, distancing, self-control, escape avoidance, accepting responsibilities, and positive reappraisal were actively employed by caregivers of children with disabilities. Among those coping, seeking social support was more commonly used by parents of children with disabilities (Paster, A et al., 2009).

It was claimed through another literature review by Norah G.Alkhaledi published in 2021 about coping of caregivers for children with physical disabilities that caregivers of disabled children used different coping ways to reduce the demands of a stressful situation or to expand resources to deal with the situation. Of which problem-focused coping strategies were preferred more than emotion-focused engagement coping strategies (Norah G. A. 2021).

It was also found that utilization of a wide variety of coping responses was more helpful than having only one or two coping ways. With support from others, caregivers were better able to cope with the challenges of providing care for a child with special needs. Applying problem-focused coping strategies resulted in lesser psychological distress and better mother-child interaction while the use of negative emotion-oriented coping strategies intensified the risks of depression and stress-related problems of caregivers (Norah G. A. 2021).

As for another dependent group, people with Alzheimer, a systematic review of 24 articles published from 2005 to 2017 on coping strategies used by caregivers released that carers of people with Alzheimer used different coping mechanisms including problems-based coping, emotion-oriented coping, or dysfunctional coping. Of which emotion-based coping was the most frequently used strategy among those caregivers. It was mentioned that the specific emotional coping of religion and spirituality may help reduce symptoms of depression and anxiety. Problem-solving coping may have eased the impact of acute psychological stressors on activity. Dysfunctional coping strategies such as behavioral disengagement, denial, self-blame, and self-distraction partially mediated the links between care burdens and depressive symptoms of caregivers (Monteiro, A. M. F. et al., 2018).

To conclude, caring for unwell and dependent people such as children with disabilities or the elderly with dementia is a big stressful task requiring that the caregivers tried to apply different strategies to deal with different situations and to help caregivers to manage their psychological distress. It seems to be a consensus through a variety of research that the selection of appropriate coping could be beneficial for caregivers and care receivers. In the reverse, dysfunctional coping mechanisms such as behavioral disengagement, avoidance, and escape are seen to be negative and harmful for caregivers.

1.1.2.2 Coping strategies among caregivers of children with cerebral palsy

Caring for children with CP is a lifelong responsibility and created dreadful burdens that caregivers must find ways to overcome.

Krstic and colleagues carried out research on coping with stress and adaptation in mothers of children with CP. Sixty mothers of two- to seven-year-old children with diagnosed cerebral palsy were interviewed to assess the strategies used by families to cope with stress. The research reported that caregivers used sometimes all studied strategies including social support, reframing, seeking spiritual support, institutional support, and passive appraisal. Of which reframing was a more often used strategy. Caregivers of children with severe CP frequently used institutional support, which is a strategy less often used by those of children with mild CP. Mothers from rural areas use passive appraisal more often. All caregivers tended to seek spiritual and social support less frequently (Krstic et al., 2012).

Guillamon and colleagues conducted a cross-sectional study on the influence of self-efficacy and coping strategies on quality of life and mental health among the primary caregivers who were parents of children with CP in Spain in 2013. 62 parents of children with CP aged under 18 years old participated in the survey through different Spanish associations and communities of people affected with CP and their caregivers. The results showed that the primary caregivers used sometimes different strategies to cope with caregiving stress. They included: (i) maintaining family integration, cooperation, and an optimistic definition of the situation; (ii) maintaining social support, self-esteem, and psychological stability; (iii) understanding the healthcare situation through communication with other parents and consultation with the healthcare team (Guillamón et al., 2013).

Sharma and Subedi implemented a study on stress and coping among 102 caregivers of children with disabilities in Nepal published in 2022. The authors found out that the coping styles most frequently used by caregivers were acceptance, self-distraction, positive reframing, active coping, use of informational support, planning, and emotional support. While humor, denial, substance use, and behavioral disengagement were less frequently used by the main caregivers (Sharma & Subedi, 2022).

A cross-sectional study on coping strategies of caregivers of children with a disability including children with CP attending a special education center in Abakaliki, Southeast Nigeria, stated that commonly utilized coping strategies by the caregivers were turning to religion, acceptance, planning, positive reinterpretation, and active coping whereas venting emotions, substance uses, social disengagement were the least utilized (Ezeonu, 2021).

In summary, caregivers of children with CP often used a variety of coping ways to overcome caregiving hardships. The selection of coping ways depends on the situation and the capacity of the caregivers. Acceptance is among the coping strategy used the most. In Vietnam, no research on how caregivers of children with CP cope with stressful caregiving work that leads to the gaps in knowledge on what and how to develop the appropriate intervention program to assist caregivers in better adaptation and resilience.

1.1.3. Factors associated with mental health and coping strategies among caregivers of children with CP

1.1.3.1. Factors associated with the CP caregivers' mental health

Several studies reported the link between some specific factors and the mental health status of caregivers of children with disability in general, those of children with CP in particular. Parminder Raina, a professor of the Faculty of Health Science of the Canadian McMaster University, and a member of the National Canadian Seniors Council from 2018 – 2021, carried out research and proposed a multi-dimensional model of the caregiving process and caregiving burden of caregivers of children with disability including children with CP. The model showed a comprehensive and systematic way how the different factors influence the physical and psychological health of caregivers (Marquis, 2019; Raina, 2003).

The first factors associated with the mental health of the caregivers were geographical, social, and economic conditions of the caregivers' families as well as personal characteristics of caregivers such as age, education qualification, occupation, employment status of caregivers, and the economic situation of the family. Some research revealed that the families of caregivers with higher education qualifications, with employment, with higher income levels have better mental health (Marquis, 2019; Raina, 2003). The important predictors of anxiety and depression of caregivers of children with CP included the poor economic status of the family, as well as the difficult living conditions of the family (Gugała et al., 2019).

An article published in 2021 about a web-based cross-sectional study on 160 caregivers of CP in Iran reported that some demographic characteristics associated with the mental health of the caregivers in which the factors of being married, low educational level, and low income were significantly related to high anxiety scores based on the Hospital Anxiety and Depression Scale (HADS) (Farajzadeh, 2021).

Rosalie Power and colleagues published an article on depression, anxiety, and stress among caregivers of adolescents with cerebral palsy in rural Bangladesh in 2019. Following that, caregivers with depression correlated to older age, lower education levels of caregivers, lower monthly family income, and household overcrowding. Caregivers with anxiety were associated with older age, female sex, lower education levels, household overcrowding, lack of access to running water, and lack of access to a sanitary latrine. Caregivers with stress were related to older age, female sex, lower education levels, lower monthly family income, living in impermanent housing, household overcrowding, and lack of access to running water (Power et al., 2018).

Another research on 62 Nepalese primary caregivers of children with developmental disabilities aged from 2 to 12 published in 2021 showed the low level of education of caregivers was statistically associated with common mental health problems of the caregivers measured by the 12-item General Health Questionnaires – GHQ12 (Maridal et al., 2021).

A study of 199 parents of children with intellectual developmental delays aged from 3- 6 years old told that mothers were more stressed than fathers. Mothers of female children with disability, those of children with lower intellectual functions, and those whose husbands had health problems experienced more stress than the other mothers. The research also revealed traditional gender roles in which mothers were more affected by the child’s characteristics and the spouse’s functioning. They anticipated future problems related to the child’s functioning more than fathers did. Fathers were more affected by concerns about the family’s connection to the wider world such as economic issues and the social support network (Shin & Nhan, 2009).

Another research on 114 caregivers of children with intellectual disabilities in Kenya showed that 79% of caregivers were at risk of clinical depression measured by the Beck Depression Inventory – BDI. The study indicated the statistical correlation between unemployment and depression among caregivers of children with disabilities. The married caregivers had statistically significantly higher risks of depression than the single, divorced, or separated mothers. This was explained that it may be due to a lack of emotional support from the spouse. The divorced/separated and single may on the other hand have adapted coping strategies to deal with the situation (Mbugua et al., 2011).

The second factors related to the mental health of caregivers are those of children with disabilities such as age, sex, status of disability, severity level of disability, child's dysfunctions towards movement, cognition, activities of daily living, and comorbidities. Child behavior problems such as conduct disorders, hyperactivity as well as emotional disorders, and somatization are associated with the mental health of the caregivers (Marquis, 2019; Raina, 2003).

Hans Kristian Maridal and colleagues carried out a study on psychological distress among caregivers of children with neurodevelopmental disorders in Nepal. They found that there was a statistically significant relationship between the caregiver's psychological distress and the degree of disability in the child through measurement of the Gross Motor Function Classification System-GMFCS. Another study also revealed that children with the highest GMFCS level meaning with more severe motor function impairment were linked to higher maternal depression rates (Yilmaz, Erkin&Nalbant, 2013).

A relationship between the feeding problems of the disabled child with the mental health of caregivers was identified (Maridal et al., 2021). Hearing impairment in children with CP was statistically associated with anxiety and stress of caregivers (Power et al., 2018).

Caregiving demands or the burden of giving care for children with CP are among the most important factors influencing the mental health of caregivers. Daily caregiving demands including longer duration of caregiving, higher caring intensity, and activities of caring for a child with CP were those related to higher risks of mental health problems for caregivers (Barreto et al., 2019). Frequent medical checkups and continuous physiotherapy treatment for children with CP were the risk factor for depression in caregivers (Rasha et al., 2019).

An online survey on predictors of mental health among 160 parents of children with CP during the COVID-19 pandemic in Iran informed that the burden of care significantly predicted caregivers' anxiety, and depression in which significant correlations were found between the burden of care and anxiety, caregiving burden and depression (Farajzadeh, 2021). Another research also mentioned the significant relationship between the caregiver's psychological distress and the degree of caregiver burden (Maridal et al., 2021).

Another cross-sectional study on 375 primary caregivers of children with CP to identify the prevalence and predictors of psychological problems among principal caregivers of children with CP in Sri Lanka revealed that the level of caregiver burden measured by the Caregiver Difficulties Scale – CDS was statistically associated with caregiver psychological problems evaluated by the General Health Questionnaires – GHQ. The lower educational level of the caregiver and the younger age of the child were also predictive of psychological problems (Wijesinghe et al, 2014).

The psychological factors of caregivers such as self-esteem and the sense of self-mastery were reported to correlate with the mental health of caregivers. Sandra Marquis and colleagues conducted a systematic review of articles published from 2000 to 2017 to identify factors affecting the health of caregivers of children with intellectual/developmental disability. The results showed that caregiver self-esteem/perception of mastery of the caregiving situation was associated with caregivers ‘stress (Marquis et al., 2019).

Another factor reported to predict the mental health of caregivers was the accessibility and utilization of social support from family, neighbors, community, and government. Several studies indicated that maintaining the relationship with family, friends, neighbors, and community was positively associated with the better mental health status of caregivers. Poor social support was associated with increased parental stress, and depression (Marquis et al., 2019).

Mothers with low levels of support experienced a significant increase in stress over time, and mothers with high levels of support experienced lower and stable levels of stress over time. Greater spousal support was reported to be related to lower maternal depression (Marquis, 2019; Raina, 2003). Advice and assistance from health staff, the social subsidizes were those to help reduce the mental distress of the caregivers. The increased stress of caregivers was associated with a lack of social support and a dysfunctional family (Maridal et al., 2021). Stigma and discrimination were the risk factors for the mental health of the caregivers (Rasha et al., 2019).

There is no study in Vietnam in this topic so far. Thus, it is essential to carry out a survey to understand the factors linked to mental health issues and the way caregivers choose to response to the caregiving stress.

Table 1.1: Summary of factors associated with mental health among caregivers of children with disabilities

Factors	Statistical correlation	Studies
Social and economic characteristics of the caregivers' families	Low education, unemployment, and low incomes of parents were related to low level of mental health of caregivers Married caregivers had higher risks of anxiety and depression than those single, divorced, or separated. There was a statistically	Raina, P., 2004 Marquis, A. 2019 Farajzadeh, A., 2021 Margaret, N., M., 2011 Maridal HK 2021

Factors	Statistical correlation	Studies
	associated between unemployment and the depression of the caregivers.	Shin. J.Y 2006, 2009
Characteristics of children with disabilities	The level of disability, level of independence in activities of daily living, comorbidities, and behavioral disorders of children with disabilities were related to caregivers' mental health.	Raina, P., 2004, Marquis, A. 2019
Caregiving burden	More time for taking care of children with disabilities was linked to higher risks of mental health problems for caregivers. More frequent medical check-ups and rehabilitation services for children with disabilities correlated with the higher risks of depression of caregivers.	Barreto, T. M., 2019 Raina, P., 2004, Marquis, A. 2019
Psychological aspects of caregivers	Self-esteem and sense of self-mastery of caregivers were linked to the better mental health of caregivers.	Raina, P., 2004, Marquis, A.2019
Social support	Maintaining social relationship with family, friends, neighbors, and community, and maintaining the family function has negative relations with the mental health problems of caregivers. Stigma and discrimination were the risk factors for the mental health of caregivers. The increased stress of caregivers was associated with the lack of social support and dysfunctional families.	Raina, P., 2004, Marquis, A.2019 RashaH, S., 2019 Maridal, H.K., 2021

1.1.3.2. The factors associated with the coping strategies used by the caregivers of children with CP

The results of the study on 60 mothers of 2-7 year old children with CP to examine the coping strategies used by mothers of children with CP and the associated factors in Serbia showed that there were statistically significant differences between mothers from urban and rural areas in the use of passive appraisal in which mothers from rural areas use the passive appraisal more than those from urban area. The passive appraisal was based on the belief that parents could not change the circumstances caused by children with disabilities, more specifically for those in rural areas. However, the perception of their ability to influence the outcomes related to the child's condition positively provides a healthier and more successful adaptation for parents of children with CP (Krstic & Oros, 2012).

In addition to that, mothers of children with severe forms of CP seek the coping strategy of institutional support more often than mothers of children with moderate forms, while mothers of children with mild forms of CP seek this support rarely. The difference was statistically significant. This was because these mothers of severe children were often referred to various medical procedures and they were the most frequent users of medical services (Krstic & Oros, 2012).

Another cross-sectional study on 40 caregivers of children with disabilities including children with CP attending a special school in Nigeria was conducted to assess caregivers´ coping strategies in raising a child with a disability in a resource-poor country. The finding showed that most of the coping strategies had no significant relationship with gender or income. Active coping strategies such as taking additional actions to get rid of the problem or seeking advice from others did not have a significant relationship with the type of disability. Positive reinterpretation of the problem was significantly associated with the type of disability, being more for speech/hearing impairment. Turning to God and hoping for the best was significantly related to the forms of disabilities (Ezeonu, 2021).

In summary, the ways caregivers of children with CP coped with caregiving stress were influenced by different factors including demography, the severity level of CP child, the perceptions and belief of caregivers themselves towards their capacity and their hopes for situation improvement.

1.1.3.3. The association between coping strategies and mental health among caregivers of children with CP

A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability including children with CP revealed the significant associations between coping strategies used by caregivers and caregiver's quality of life. Some studies reported the maladaptive coping strategies (behavioral disengagement, avoidance, emotion-oriented) were negatively associated with global QoL (Fairfax et al., 2019).

In some studies, strategies considered to be adaptive such as problem-oriented and acceptance were also negatively associated with global QoL. Avoidance-oriented and cognitive appraisal-oriented coping responses were both positively associated with psychological QoL. Some coping strategies could play an important role in mediating the association between caregiving complexity and psychological aspects of QoL (Fairfax et al., 2019).

Guillamon and colleagues implemented a cross-sectional correlation study on 62 parents of children with CP aged less than 18 years old in Spain to explore the quality of life and mental health of caregivers and the associated factors relating to self-efficacy and coping strategies. The researchers reported that although no statistically significant association between coping strategies used by caregivers and their mental health be found, the trend in the regression analyses suggested that those with higher scores on the scale of the coping pattern relating to maintaining social support, self-esteem, and psychological stability had better mental health (Guillamón, et al., 2013).

Another observational study on 102 Nepalese caregivers of children with disabilities including 49% of children with CP to examine caregivers' stress and different coping styles used by caregivers showed that the most frequently used coping styles were self-distraction, acceptance, and positive reframing. Caregivers' stress had a significant positive correlation with different coping styles including active coping, denial, behavioral disengagement, humor, acceptance, religion, and self-blame. In reverse, stress had a negative correlation with substance use, positive reframing, and planning (Sharma & Subedi, 2022).

A study on the relationship between coping styles and depression among 132 caregivers in Nigeria revealed that planning, active coping, use of instrumental support, positive reframing, and humor had a negative relationship with depression in caregivers of children with CP. Whereas, denial, self-distraction, behavioral disengagement, and self-blame had a positive association with depression. Religion was found not to have any relationship with depression. The key message conveyed the importance of using problem-focused strategies such as active coping and planning in maintaining psychological wellbeing in stressful conditions of raising children with CP. Applying problem-focused coping styles helps caregivers alter or improve the source of their caregiving stresses like recovery of some adaptive functions in the child with CP. Additionally, using emotion-focused coping responses help caregivers regulate stressful emotions (Obembe, et al., 2019).

Although it was not investigation on caregivers of CP children, Moritz, S. and colleagues' research on the relationships between coping styles and some mental disorders including depression is worth paying attention to. They concluded that maladaptive and adaptive coping strategies are not reciprocal. It is more important for mental health outcomes to mitigate maladaptive coping styles than to strengthen adaptive coping responses. It is because maladaptive coping was found to be more strongly associated with psychopathology than adaptive coping in both cross-sectional and longitudinal studies (Moritz, S et al., 2016).

The key findings of the above mentioned studies showed the statistically significant relationship between caregivers' coping strategies and their mental health status in which the so-called maladaptive coping mechanisms had positive correlations with higher risk of common mental health disorders such as depression and anxiety. In the reverse, the adaptive copings ways had a negative relationship with caregivers' mental health problems. However, the classifications of adaptive or maladaptive coping responses are different from one study to another. Thus, it seems not relevant to apply the coping category from other research into this thesis.

1.1.4. Research on the intervention to support caregivers to improve mental health

A key to successful parental adaptation is the capacity of the families to access appropriate resources and services that both support them in coping with their children's needs and reduce disability-related problems. The development of effective external support services such as respite care facilities for temporary caregiving relief services would assist families with care, reduce the level of stress, and prevent possible family breakdown.

Social support networks including relatives, neighbors, friends, and peers could serve as coping resources in optimizing caregiver's well-being and health outcomes among caregivers of children with CP (Oh, H. & Lee, K. O. 2009). It is not the extent or frequency of social contact that matters but rather individuals' satisfaction with their relationships. The level of social support in the early period after learning about the child's disability is crucial and it can affect both short-term and long-term coping adaptation (Krstic, T., & Oros, M. 2012). Education on the disability for caregivers and the community is an important element that could help families of children with CP to cope with and adapt to caregiving (Ross, E., & Deverell, A. 2004).

Hu et al., (2010) informed about an effective program to support caregivers including health information on stress management tips, information on difficulties connected to the behavior of children living with disabilities, respite care, and social support services. Most of their participants in Taiwan benefited from the face-to-face workshops with professionals and thus can speak to social workers, teachers, and psychiatrists. Hu et al. (2010) also reported that in one study carried out in Saudi Arabia it was noted that the more informal support resources are available to the mothers, the lower the level of stress and the higher the sense of well-being they experienced. Positive thinking tips and techniques, visualization, and scheduling activities for time management are also useful as they reduce emotional exhaustion and burnout (Hu et al., 2010).

Lucia Parisi, Maria Ruberto, and Francesco Precenzano et al., 2016 reported that the quality of life of mothers of children with CP is different from those who have a child with minor health problems. Different coping strategies and psychosocial programs must be designed and implemented to decrease the burden of care. The intervention program should consider bio psychosocial approach family/patient-centered, not simply technical and short-term rehabilitation interventions focused on the child. Providing parents with cognitive and behavioral strategies to manage their child’s behaviors may have the potential to change caregiver health outcomes (Parisi, L et al., 2016).

Saloojee. GM, Rosenbaum. PL, Stewart AV. (2011) emphasized the differences between well-resourced and poorly resourced settings regarding caregiver perceptions of the components contributing to good service provision. Caregivers in Australia expressed the need for more general support for the whole family through exploring their feelings for having a child with special needs; helping them to feel more competent as parents; and tailoring treatment plans to the different lifestyles of families, while caregivers in South Africa expressed a greater need for being treated with respect and for practical support in the form of handling ideas, assistive devices, physical resources (food and transport) and access to schools rather than support for the whole family (Saloojee, G.M et al., 2011).

Elaine E. MacDonald, Richard P. Hastings, and Richard P. Hastings (2009) proposed support for caregivers of children with disabilities following the acceptance-based approach. Psychological acceptance was found to partially mediate the impact of child behavior problems on paternal stress, anxiety, and depression. Acceptance was also a positive predictor of fathers' perceptions of positive gain associated with raising their child with an intellectual disability. However, it could not function as a potential mediator of positive gain in the present research because fathers' ratings of their child's behavior problems were not associated with paternal positive gain (Macdonald, E. E. et al., 2009).

A further approach is that of positive re-appraisal, the cognitive strategies for reframing a situation to see it more positively. Positive reappraisal enables the individual to appraise a difficult situation more positively. It often involves deeply held values that are activated by the stressful situation. This kind of coping encourages people to focus on the value of their efforts and is especially important in helping people sustain efforts, such as those associated with caregiving, over long periods. There is a stage of adaptation that is beyond acceptance that might be called "appreciation" or the "all right" stage. Parents at this stage may be a resource to families facing difficulties. Parents involved in a parent-to-parent support group reported an increase in their positive perceptions of their child with a disability (Gupta, A., & Singhal, N. 2004).

Some key themes about the nature and structure of parents' positive perceptions and experiences of their child with a disability and the caregiving experience can be summarized as follows: pleasure/satisfaction in providing care for the child; child as a source of joy/happiness; a sense of accomplishment in having done one's best for the child; sharing love with the child; child providing a challenge or opportunity to learn and develop; strengthened family and/or marriage; giving a new or increased sense of purpose in life; development of new skills, abilities, or new career opportunities; becoming a better person towards more compassionate, less selfish, more tolerant; increased personal strength or confidence; expanded social and community networks; increased spirituality; changed perspective on life e.g., clarified what is important in life, more aware of the future, and making the most of each day and living life at a slower pace ((Gupta, A., & Singhal, N. 2004). The Australia Ministry of Health's report on best practices in caring for carers mentioned several interventions for improving the health and well-being of caregivers including but not limited to respite care services, regular health-checkup programs, pharmacology interventions, counseling, education and training, coping skills programs and psychology programs. It was grouped into three main programs: (i) an Educational program to strengthen caregivers' mastery and preparedness; (ii) a Psychosocial support program focusing on coping skills, relationship issues, and problem-solving strategies; (iii) and self-care program to promote health and well-being of carers. It also pointed out the advantages and disadvantages of different intervention modalities: telephone-based, web-based strategies, and individual, group-oriented sessions (Strobel NA, Adams C. 2015).

Recognition of the crucial roles of primary caregivers in a child's healthy development, UNICEF has developed an implementation guide on caring for caregivers. Based on the key barriers to careers including a lack of physical, psychological, and social capacity to care for their children and the persistent threats of high adversity of living conditions to their own well-being and caregiving resources, it is proposed to the guide on practical activities focusing on self-care training, family engagement promotion, and social support program (Rochat T.J et al, 2019).

In Vietnam, there were not much research on the psychological burnout and coping responses of caregivers of children with disability including children with CP, and then not support programs are available to improve the mental health and well-being of the caregivers and family members of children with disabilities generally and children with CP particularly. UNICEF's research in 2011 on knowledge, attitude, and practices of caregivers of children with disabilities in An Giang and Dong Nai proposed some solutions for parents as well as caregivers of children with disabilities. That includes: enhancing knowledge, skills, practices, and hopes for caregivers on treatment and rehabilitation services for children with disabilities; providing guidance for caregivers on making simple, locally made assistive devices; guiding caregivers on time management; setting up a caring support model among caregivers of children with disabilities (UNICEF. 2011).

1.2. Theoretical framework

1.2.1. Key concepts

1.2.1.1. Overview of cerebral palsy (CP)

Basic knowledge of cerebral palsy including definition, classification, etiology, complex impairments, and management of CP help to understand the challenges caregivers would face which may impact caregivers and family members during the process of adjustment and adaptation to the life change because of the birth of the children with CP.

Cerebral palsy (CP) is a disorder of muscle control that causes difficulty with moving and positioning the body. This neurodevelopmental condition beginning in early childhood and persisting through the lifespan disables children. A small part of the brain that controls movement has been damaged early in life before or after birth. The muscles receive the wrong instructions from the damaged part of the brain. This makes them feel stiff or floppy. The muscles are not paralyzed. The damage can affect other parts of the brain which may cause difficulty with seeing, hearing, communicating, and learning (WHO, 1993).

CP was originally reported by Little in 1861 called ‘cerebral paresis’. In 1959, Mac Keith and Polani defined CP as a persisting but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, the result of interference during its development (Rosenbaum & Stewart, 2004).

In 1964, Bax followed by an international working group stated that CP is a disorder of movement and posture due to a defect or lesion of the immature brain. For practical purposes, it is usual to exclude from cerebral palsy those disorders of posture and movement which are of short duration, due to progressive disease, or due solely to mental deficiency (Rosenbaum et al., 2004).

In April 2006, an executive committee on CP definition and classification got international consensus on the definition of CP as follows: “Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that is attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; epilepsy, and by secondary musculoskeletal problems (Rosenbaum et al., 2007). Observation of slow motor development, abnormal muscle tone, and unusual posture are common initial clues to the diagnosis of cerebral palsy (Kuban & Leviton, 1994).

Classification of CP

Cerebral Palsy affects each child differently. A mildly affected child will learn to walk slightly unsteady balance. Other children may have difficulty with using their hands. A severely affected child needs help learning to sit and may not be independent in daily tasks (WHO, 1993).

The aim to categorize individuals with CP into groups are to make descriptions, prediction, comparison, and evaluation of change (Rosenbaum et al., 2004). Cerebral palsy can be classified into different types, according to the European classification of cerebral palsy: (a) spastic type, characterized by the presence of at least two of the following: abnormal patterns of posture and/or movement, increased muscle tone; (b) dyskinetic type, characterized by abnormal patterns of posture and/or involuntary, uncontrolled, recurrent and occasionally stereotyped movements, (c) ataxic type, characterized by abnormal patterns of posture and/or movement, loss of coordination, and change in force, rhythm, and movement; and (d) mixed type of the above mentioned (Cans, 2000).

70-80% of patients with cerebral palsy have spastic clinical features. The athetoid or dyskinetic type of cerebral palsy affects 10-20% of patients; the rarest form, ataxic cerebral palsy, affects 05-10% percent of patients. Intellectual impairment occurs in about two-thirds of patients with CP, and about one-half of pediatric patients have seizures (Krigger, 2006). Surveys have shown that about 60% of children with CP have an intelligence quota (IQ) below 70 (Kuban, 1994).

Currently, there is a scientific tendency to use the degree of functional impairment through scales as a classifying measure, especially the Gross Motor Function Classification System (GMFCS). The GMFCS is a graded scale of the gross motor function of children with CP. Its categorization goes from level 1 (lower functional impairment) to Level 5 (most severe form of CP). In detail, five levels include Level I: Walks without limitations, level II: Walks with limitations; level III: Walks using a hand-held mobility device; level IV: Self-mobility with limitations, may use powered mobility; Level V: Transported in a manual wheelchair (Rosenbaum, et al., 2007; HI, 2018).

Etiology

Cerebral palsy is a static neurologic condition caused by brain injury occurring before cerebral development is completed. Because brain development continues during the first two years of life, CP can result from brain injury occurring during the prenatal, perinatal, or postnatal periods (Bass 1999). 70-80% percent of CP cases are acquired prenatally and from largely unknown causes. Birth complications, including asphyxia, are currently estimated to account for about 6 percent of patients with congenital CP. Neonatal risk factors for CP include birth after fewer than 32 weeks' gestation, birth weight of less than 2,500 g, intrauterine growth retardation, intracranial hemorrhage, and trauma. In about 10 to 20 percent of patients, CP is acquired postnatal, mainly because of brain damage from bacterial meningitis, viral encephalitis, hyperbilirubinemia, motor vehicle collisions, falls, or child abuse (Taylor, 2005).

CP can happen (i) before birth due to infection in the mother in the early week of pregnancy, uncontrolled diabetes, and high blood pressure in the mother during the pregnancy; (ii) around the time of birth due to damage to the brain in babies born before nine months, difficult birth causing injury to the head of the baby; baby fails to breath properly; the baby develops jaundice; (iii) after birth because of brain infection such as meningitis; accidents causing head injuries; very high fever due to infection or water loss from diarrhea. The cause is not known in many cases (WHO, 1993).

CP can affect the development of the child's temperament. Given children with CP have difficulties in moving and communicating, he/she may become easily frustrated or angry when doing something, he/she may give up and not try to learn to walk, to talk. It is important to always be patient and encouraging, to try to understand the child. It is also more helpful to concentrate on other areas of development, learning for activities for daily living such as eating, washing, dressing, playing, and communicating that will allow them to join in with family life (WHO 1993).

Prevalence of CP

Cerebral Palsy can happen in every country, in both developed and developing countries, and in all types of families. The percentage of children with CP is higher than those with other developmental disabilities in children (Miller, 2005; WHO, 2006). The global prevalence of CP is estimated to be from 1.5-3.4 cases per 1,000 live births (McIntyre, et al., 2022). The estimated figure of the global prevalence of CP is lower than the actual given the late diagnoses of many cases and the number of mild cases that remain undiagnosed. Thus, the rate of CP could be as high as 5 cases per 1,000 live births (Krigger, 2006). The incidence of CP is significantly higher in developing countries than in developed countries. The prevalence of CP in high-resource countries is 1.4-2.1 per 1000 live births [90]. The precise burden of CP in low- and middle-income countries (LMICs) is unknown, however, it is estimated to be 5 to 10 times higher than in high-income countries (HICs) (Cruz, Jenkins & Silberberg, 2006).

Globally, 85% of children with a disability live in LMICs. However, less than 5% have access to basic rehabilitative and support services (Maloni et al., 2010). Those in LMICs face additional challenges when the complex interplay between disability and culture is exacerbated by poverty. For example, unavailability or inaccessibility of medical services can lead to unmanaged comorbidities including pain and epilepsy; limited knowledge and access to information on CP such as feeding strategies compounded by poor food insecurity may result in malnutrition and increased morbidity (Khan et al., 1998; Lagunju & Fatunde, 2009).

In China, the rate of children with CP is 3 per 1000 Chinese children under seven years old at birth per year (Shen & Liyingm, 2016). The incidence of CP in Vietnam is not yet known given Vietnam does not yet have a national cerebral palsy register (HI, 2018). Following the internal report on members of the Cerebral Palsy Parents Association Vietnam, there were 2,857 CP children from the age of 16 years and below, as of October 2021, in all 63 provinces of Vietnam (CPFA, 2021).

Management of CP

Cerebral palsy cannot be cured. However, children with CP can receive rehabilitation therapy including physiotherapy, occupational therapy, speech and language therapy, assistive devices, and surgery when needed to help them improve their functions in life. Professionals and parents can, by working together, minimize the secondary problems associated with CP to make sure each child could achieve as much of their potential as possible (Miller, 2005).

The goal of the management of CP is not to cure or to gain normalcy but to increase functionality, improve capabilities, and sustain health in terms of locomotion, cognitive development, social interaction, and independence. The goals include enhancing person with CP and caregiver interactions while providing family support (Krigger, 2006).

CP management requires a multidiscipline team approach. Caregivers are identified to play a primary role in the rehabilitation of children with CP (Mobarack et al., 2003). The rehabilitation program relied primarily on caregivers being trained in specific skills to be able to help their children to develop. The family of a child with a disability plays a central role in the well-being of the child. The family of the child, more specifically primary caregivers, needs to be actively involved in the rehabilitation process of the child. Participation of caregivers in the rehabilitation process gives them opportunities to seek information that is useful for improving the children’s functional performance in daily living activities, to transfer the learning acquired in the therapeutic environment to the domestic context, and to gain insight into the impairments of their children (Brandao et al., 2014).

1.2.1.2. Caregiving for children with cerebral palsy

Definition of caregiving

Following World Health Organization (WHO), *caregiving* involves many activities including the provision of assistance to an individual who is not able to care for himself or herself, to ensure that critical activities for human living or functioning are done. The concept of caregiving might involve a wide range of physical activities depending on the disability’s nature and extent and resources that are available. Activities of daily living that the primary caregivers assist with include but are not limited to positioning or transferring a child who is not mobile, dressing, eating, drinking, carrying the child to the toilet as well as bathing (WHO, 2023).

Definition of caregiver

A caregiver is any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an individual with a chronic or disabling condition. *The primary caregiver* is the person who takes primary responsibility for someone who cannot fully care for themselves, and who meets their physical needs more than anyone else. In most cases, the primary caregiver is the mother (Family Caregiver Alliance, 2021).

The most common type of caregiver is the family caregiver, a relative who provides emotional, financial, nursing, social, homemaking, and other services on a daily or intermittent basis for an ill or disabled loved one at home. Most family caregivers volunteer their time, without pay, to help with the care needs of a loved one (Griswold Home Care, 2021).

A professional caregiver is hired to provide care for a care recipient. These caregivers can provide medical or non-medical care in the home or a facility. Their career is to assist another person in a way that enables them to live as independently as possible. Professional caregivers work for an agency, and the care recipient hires the agency to provide care. There are also other types of caregivers such as Independent Caregivers, Private Duty Caregivers, and Volunteer Caregivers (Griswold Home Care, 2021).

Burdens experienced by caregivers of children with CP

The burden of caregivers, a complex and multidimensional concept, is a series of negative responses that occur while undertaking the role of primary caregiver. The negative responses include both subjective and objective outcomes. Caregivers often provide long-term care for loved ones. The conflict between caregivers, caregiving responsibilities, and family needs places higher levels of burden on the caregiver (Zhu et al., 2020).

Raising a child with CP, a multiple disabled condition, is much more stressful for caregivers because it requires intense physical engagement as well as the ability to cope with any emotional reactions to the child’s condition, leading to poorer QoL (Krstic & Oros, 2012). Potential stress of CP child’s caregivers can include strained family relationships, and social isolation because of the child’s limited mobility or behavioral problems. Besides, parents of CP children have no hope of the future of their children which leads to emotional distress (Uldall, 2013).

The burden of care for children with CP in many families is borne by women, many of whom are disempowered due to being unemployed, illiterate, or uneducated. Many of those have very little knowledge about the disability and available services (Levin, 2006). Social structural constraints are also the main burden of care for caregivers of children with CP. Social structural constraints refer to the general contact with authorities and assistance with the child’s needs. Children with CP have multiple needs however, in reality, a considerable number of unmet needs reported by caregivers increase the burden experienced by caregivers (Uldall, 2013).

Given the importance of the roles played by various professionals in the rehabilitation of children with CP, several studies found dissatisfaction in the relationships between caregivers and professionals. Caregivers report that there is a lack of transparency and specificity about the child’s diagnosis which inhibits their support for their child’s eligibility and access to much-needed support (Fereday et al., 2010). In general, parents are dissatisfied with the amount of information provided regarding the diagnosis and its impact on the child and the family (Reid et al., 2011). An unsupportive professional relationship exacerbates the difficulties faced by parents and families of children with CP (Dempsey et al., 2009).

Through the study on caregivers’ burden among parents of children with CP in 2021, Kiani. H.S, and colleagues reported that a CP child increases the severity and duration of their parenting tasks and needs sufficient time for supervision of their normal activities of daily living performed in a tailor-made way. Almost all of the parents of children with CP are not satisfied with the care services. This is one of the reasons that these parents are closely involved in providing care to these children which is time-consuming activity as such children are fully dependent on their caregiver for activities of living. Not many families can cope with such children (Kiani et al., 2021).

The research concluded that most of the caregivers needed relief and other services to manage the caregiver's burden. Inadequate public-services design and negative behaviors of others can result in the withdrawal of children and caregivers of CP children from community engagement (Kiani et al., 2021).

Research to find the difference in burden between caregivers with CP and those with autism children found that the caregivers of CP children experienced more burden than those of autism children due to a higher degree of disability and dependence on children (Pushpalatha & Shivakumara, 2016).

1.2.1.3. Coping strategies

Definition of coping

Coping, a stabilizing and mediating factor benefitting individuals during stressful periods, has functions of problem-solving and emotion regulation. Coping responses are interpreted as constantly changing cognitive and behavioral efforts to manage specific external or internal demands that are appraised as exceeding the resources of the person. Coping contains any effort to deal with stress, irrespective of how sound it works. Coping strategies also comprise attempts to change the origin of stress and attempts to regulate emotional answers to the stressors. The short- or long-term duration; the strong or weak intensity of stress could influence how people respond to it (Feeley et al., 2014).

It was defined that coping is the ongoing process of cognition, emotion, and behavior to manage stressful events and minimize their negative effects in terms of biological, psychological, and social aspects on human beings' lives. To cope successfully depends on both intrinsic factors such as personality traits; and extrinsic ones such as a supportive social network. Coping strategies can emphasize directly avoiding, reducing, or eliminating the stressor itself, or they can help us feel better about ourselves or the situation. Given stress is inevitable, the effective coping capacity is vital for keeping health and well-being (Blum, S., Brow, M., Silver, R.C. 2012).

Classification of coping strategies

Given coping strategies are individual ways to overcome obstacles on the living journey that help human beings alive and functioning at best, there are plenty of coping strategies listed and grouped into different categories.

Traditionally, coping strategies are classified into three primary styles: (i) Problem-focused coping (mechanisms aimed directly at changing or managing the stressor itself); (ii) Emotion-based coping (strategies aimed at managing negative feelings related to a stressor to reduce the impact of those feelings); (iii) Avoidance based coping (ways to avoid, escape, distract from the stressor or associated feelings of distress) (Blum et al 2012; Carver, C. S et al 1989).

Additionally, coping strategies could be categorized into (i) adaptive/positive/healthy coping (strategies help individuals effectively manage stress and promote well-being); (ii) maladaptive/negative/unhealthy coping (strategies are ineffective, harmful in dealing with stress, adversity, or difficult situations leading to negative physical and mental health outcomes) (Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. 2003)

Coping strategies could be grouped into active coping and passive coping. Active coping is generally related to more adaptive adjustment and featured strategies such as problem-focused coping, whereas passive coping is defined as maladaptive strategies when faced with stressful situations, such as negative self-targeting and avoidance (Perez-Tejada, J et al., 2019).

Utilization of coping strategies by caregivers of children with disabilities/CP

Parents with children with disabilities can use different coping strategies to meet their needs. Parents using problem-focused coping strategies emphasize social support, actively deal with the problem, remain optimistic about life, and tend to cope better than those who do not. Those parents using emotionally focused coping responses when confronting problems by blaming themselves, believing the problem will go away, engaging in activities that prevent confronting an issue, and trying to keep their feelings from others are all evidence of passive appraisal (Feeley et al., 2014).

Caregivers of children living with severe physical disabilities with greater distress and lower self-esteem may focus on using emotion-focused coping strategies more often, which may increase their stress levels. Low levels of self-esteem and mastery were associated with increased depression. Those with greater self-esteem may use more tasks-focused coping methods, and this may have positive results such as reduced stress and finding the caring role more fulfilling. Therefore, enhancing a sense of growth or self-efficacy empowers mothers and is therefore mainly a sustainable kind of support (Savage & Bailey, 2004).

Families of children with CP go through a period of adjustment and adaptation following the diagnosis of a developmental disability such as CP. They re-assess the expectations they had for their children as well as cope with the stress associated with the daily care demands. There is a wide variation in coping strategies that are utilized by caregivers at different times and in response to different circumstances. Coping strategies include acceptance of the child, faith, and social support which include the utilization of external support such as family members and relatives is considered helpful by caregivers in managing challenges of raising children with CP. Parents adopt the position that there is nothing they can do to change the situation and therefore have to accept it and make the most of it. Several caregivers turn to religious sources for help to alleviate the caregivers ‘stress (Greef & Nolting, 2013).

Some caregivers may use avoidant-based styles to overcome difficult situations such as not taking their children to events where they would meet many people or in some cases when they do not expect their children to behave within expected norms. Avoidance strategy may reduce stress for a short time, but it could lead to maladaptive family functioning (Krstic et al., 2012).

1.2.1.4. Mental health among caregivers of children with cerebral palsy

Definition of mental health and mental disorder

Based on the World Health Organization (WHO)’s summary report on promoting mental health in 2004, *mental health* is defined as “a state of well-being in which the individual realizes his or her abilities, can cope with the normal stresses of life, can work productively and fruitfully, and can make a contribution to his or her community” (WHO, 2004).

Because “well-being” is difficult to understand and explain in different cultural contexts, a group of experts from the European Psychiatric Association proposed in 2015 a new definition of mental health as follows “*Mental health* is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society” (Silvana et al., 2015).

That includes basic cognitive and social skills, the ability to recognize, express and modulate one's own emotions, as well as empathize with others, flexibility, and the ability to cope with adverse life events and function in social roles, and harmonious relationship between body and mind represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium” (Silvana et al., 2015).

Relating to *mental disorders,* in 2013, the American Psychiatric Association (APA) redefined mental disorders in the DSM-5 as "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning" (APA, 2013).

The WHO’s International Statistical Classification of Diseases and Related Health Problems 11th Revision (*ICD-11*) contains a similar definition of mental disorder as DSM-5 (14). Following World Health Organization, 2004, mental illness disrupts the normative functioning in the domains of family, interpersonal, occupational, and wider community social relationships due to abnormal moods, emotions, thoughts, and cognitions, manifesting as aberrant behaviors and functional impairments (WHO, 2004).

Mental health among CP children's caregivers

The long-lasting and multifactorial caregiving burdens have made caregivers of children with CP more likely to have significantly poorer physical and mental health than the general population. The psychological health of the caregivers is adversely affected by the increasing disability in the children and by deficits in cognitive and sensory functions, problems commonly associated with CP (Al-Gamal, 2015).

The caregivers' poorer psychological health could be attributable to the extra heavy daily tasks preventing the caregivers from adequate self-care for themselves. The provision of the enormous required care for children with CP may result in compassion fatigue in the caregivers that lead to various experiences like a sense of helplessness, confusion, isolation from family and friends, hyper-arousal, sleep disturbances, concentration difficulties, agitation, irritability, hyper-vigilance, distress, decrease in pleasurable activities and contagion (Vijesh et al., 2007).

Caregivers of children with CP also have feelings of loss and grief as well as depression, anxiety, and post-traumatic stress. Parents experience profound loss when their children do not meet their expectations. Feelings of sorrow and anxiety reappear at various times such as when new complications are discovered when parents think about the future of their children, or at developmental milestones such as the moment of speaking or walking (Fernandez et al., 2015). Parents' reactions to the diagnosis of a chronic and long-term disability in their children such as CP can include disbelief, fear, loss of normal family life, hopelessness, despair, and feelings of unable to cope. These responses are considered the primary indicators of anticipatory grief. When it occurs, parents have to live through a long period of uncertainty, death, or permanent damage to their child (Al-Gamal, 2015).

Stigma is reported to make an impact on the emotional well-being of caregivers of children with CP. Caregivers feel adverse reactions to the community leading to increased emotional distress and isolation (Green, 2003). Members of the community may believe that children with CP are shameful and should be hidden from other people. Such perceptions are a consequence of social stigma hence the isolation of loneliness felt by caregivers that may lead to emotional distress (Hartley, 2004).

Cultural values and expectations may also result in stigmatization leading to the poorer psychological well-being of individuals caring for CP children. A Chinese study indicated that giving birth to a child with a disability is regarded as a disruption to the ancestry especially when a disability like CP is more visible and leads to social stigma. It is in direct contrast to the Chinese collective value and cultural expectations that emphasize the importance of not being different from others (Huang et al., 2011). Similarly, many cultures in South Africa consider disability to be unacceptable and believe it to be punishment by ancestors or retribution for acts of sin. This stigma in turn causes psychological distress on caregivers (Levin, 2006).

Definition of depression, anxiety, and quality of life

Depression is a leading cause of disability and contributes remarkably to the global burden of diseases. Following World Health Organization, depression is defined as “a common mental disorder featured by sadness, feelings of tiredness, and poor concentration” (World Health Organization, 2015c, para. 1).

Clinicians use diagnostic manuals like the WHO’s International Classification of Diseases 11th Revision (ICD-11) and the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) to diagnose depression. Following this, depression is a mood disorder defined by the following nine criteria. They are depressed mood, loss of interests or pleasure, significant weight loss/gain; insomnia/ hypersomnia;

psychomotor agitation/retardation; fatigue/loss of energy; feelings of worthlessness/ excessive guilt; having difficulty in thinking or concentrating; recurrent thoughts of death or suicide.

Major depressive disorder (MDD) includes symptoms of depressed mood or loss of interest, most of the time for at least 2 weeks, that interfere with daily activities.

In community settings where there is no psychiatrist, it is common to use screening tools to identify whether people present symptoms of depression or not. In our study, the 9-item Patient Health Questionnaires were used to screen depression. Based on PHQ-9, a person is identified to have symptoms of depression over the last two weeks if he or she meets the following criteria: the total scores of PHQ-9 is from 10 above, having symptoms of depressed mood or loss of interest, and those symptoms influence in life functioning.

Anxiety, following WHO, is also common mental disorders characterized by excessive fear, worry, and related behavioral disturbances. Anxiety results in significant distress or significant impairment in functioning. The DSM-5 and ICD-11 classify anxiety into different kinds such as generalized anxiety disorder (GAD) characterized by excessive worry, a panic disorder characterized by panic attacks, social anxiety disorder characterized by excessive fear and worry in social situations, separation anxiety disorder characterized by excessive fear or anxiety about separation from those individuals to whom the person has a deep emotional bond, and others (WHO.2019; APA.2013a).

In community settings, different tools are used to screen anxiety. In our survey, the 7-item Generalized Anxiety Disorder Scale (GAD-7) was used to identify whether the caregiver has symptoms of anxiety or not. Following GAD-7, a caregiver is identified to have symptoms of anxiety over the last two weeks if he or she has a total score of GAD-7 from 05 above.

WHO defined quality of life as individuals’ perceptions of their position in life in the context of the culture and value systems in which they live with their goals, expectations, standards, and concerns. It is a multidimensional concept including the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationships to the environment.

WHO developed a tool, called WHOQOL, a full version of 100 items, and a short version of 26 items (WHOQOL-BREF) to evaluate the quality of life in five categories: Overall quality of life, physical health, psychological health, social relationships, and environment quality of life. In our survey, 6 items were selected from all 5 above-mentioned groups to assess caregivers’ quality of life in the last two weeks from the survey time. They include the overall quality of life, general health, level of enjoying life, level of feeling life to be meaningful; opportunity for leisure activities; and satisfaction about personal relationships. The more scores caregivers have the better quality of life they perceived (WHO.2012).

1.2.2. The underlying theoretical models

This session provides some conceptual models relevant to our research. The models are grouped into three categories: (i) The theoretical model of mental health; (ii) The theoretical model of coping strategies; (iii) The conceptual framework of caregiving and caregiver’s mental health. Based on those models, our research design was formulated, and our measurements were developed.

1.2.2.1. Theoretical model of mental health

So far there are quite a few conceptual models developed to explain the nature of mental health and the cause of mental health problems. About 34 paradigms are categorized into 5 broader groups of biological, psychological, social, consumer, and cultural models. Several models mixed two or more categories (Richter, D & Dixon, J. 2023).

Given no single factor could explain fully how mental health problems developed and maintained, we applied the multidimensional approach to explain different factors associated with mental health problems called the biopsychosocial model (BPS).

Realizing the limitations and flaws of the biomedical model emphasizing mental illness as brain diseases leading to pharmacology-based treatments which have dominated since the mid-20th century, George L. Engel and Jon Romano of the University of Rochester presented in 1977 the more holistic and systematic approach of the interaction among three key factors of biology, psychology, and sociology towards mental health issues. The BPS model was formulated as a dynamic, interactional, dualistic view of human experience influenced by both mind and body (Borrell-Carrio, F. 2004).

BPS indicated how biological, psychological, and social factors could be attributable to mental health problems. Biological elements could be genetic-related issues, neurochemistry, the immune system, body-related diseases, brain injuries, etc. Psychological factors could include an individual’s thinking patterns, and beliefs, emotions/feelings, behaviors, personality, coping skills, self-esteem, will, motivations, expectations, etc. Social aspects could involve a variety of external conditions/ecological systems that the individuals interact with such as family circumstances, socio-economic status, social norms, cultural differences, social services, politics, media, religion, technology, stigma and discrimination, etc. (Engel, G.L.1980; Borrell-Carrio, F. 2004; Richter, D. & Dixon, J. 2023).

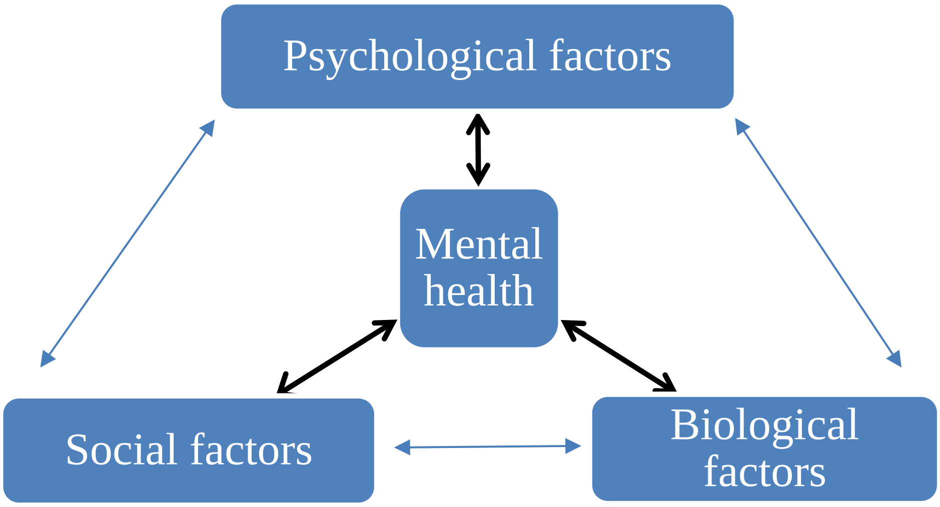


Figure 1.1: Biopsychosocial Model

It is noted that the effects of each dimension in mental health vary by different disorders, by each individual, by different periods of life. Applying the BPS model in explaining the factors associated with mental health problems of caregivers, it could be summarized as follows:

As for biological factors, research indicated that caregivers with older age, female sex, and comorbidity are at high risk of mental health problems such as depression and anxiety (Raina, 2004; Power et al, 2021, Shin&Nhan 2009).

Concerning psychological aspects, many studies revealed that subjective perceptions of caregivers towards caring responsibilities and burdens of care, sense of self-mastering, and coping skills of caregivers have remarkable impacts on caregivers' mental health (Sharma&Subedi, 2022; Marquis et al, 2019; Fairfax et al,. 2019; Obembe et al, 2019; Raina 2004).

Concerning the social factors, quite a few surveys emphasized that family issues, social economic status, stigma and discrimination, and social support were significantly related to the mental health of caregivers (Gugala et al., 2019; Barreto et al, 2019; Rasha et al, 2019; Farajzadeh, 2021; Maridal et al., 2021).

1.2.2.2. Theoretical model of coping strategies

Stress is unavoidable and everyone has experienced it during their life journey. It is essential to know how people cope with stress so that it can be predicted in what directions, better or worse, stress can influence people's life and health. The research on coping is radical because the ways of coping could mitigate or intensify the effects of life adversities on people's physical and mental health and the level of vulnerabilities to mental health problems.

Several theoretical models of coping and stress have developed so far. Among the commonly used theories of coping, the Transactional Model of Stress and Coping developed in 1984 by Lazarus and Folkman was considered as a foundation to guide our research.

The Transactional Model of Stress and Coping (TSC) was outlined based on the key principles/points of view: (i) Coping is seen as a process of interaction between an individual and their environment, aims at managing demands put on an individual, entailing cognitive and behavioral response to minimize demands resulting from an interaction between an individual and their environment; (ii) Coping requires an evaluation of individual's situation and coping resources. It is the subjectively perceived appraisal by an individual that decides the event is stressful rather than the event itself, that find out whether coping strategies are developed and whether the stressor is ultimately sorted out (Lazarus, 1984, 1987; Biggs, A., Brough, P., & Drummond, S. 2017).

This model presented the theoretical explanations of the stress appraisal process and coping strategies development in which people are continuously assessing the stimuli within their context and the emotions generated during this process.

The stress evaluation is the cognitive appraisal process which is divided into 4 phases. The first step is the primary appraisal to identify whether the stimuli are perceived to be threatening (harmful or loss) or challenging (potential for personal growth, mastery, gain). Then the second step, secondary appraisal, happens to evaluate the levels of control over the situation a person could do. The third step is to find out the available ways of control over the stressors called coping strategies development. The fourth step is to re-assess whether the original stressor has been successfully managed (Lazarus, 1984, 1987).

The individual’s primary stress appraisal which identified the meaning and significance of the individual-environment transaction to well-being is impacted by internal factors such as previous experiences, values, goals, beliefs, and external factors (demands, resources). The second assessment which decided what could be done to eliminate stressors and manage the distress was affected by the individual’s perception of coping resources such as self-efficacy, social capital, and social networks, and their own experiences in dealing with life adversity in the past (Dewe and Cooper, 2007; Folkman, 1984).

Coping strategies are initiated after the first and second appraisals to determine whether the situation is stressful and whether efforts are needed to overcome it. Following this model, coping is process-oriented and changeable toward cognitive and behavioral efforts to manage internal/external demands. The goals of coping development are to directly mitigate stressors and/or to moderate emotions created by stressful events. Thus, there are two main types of coping following Larazus’s model: problem-based coping and emotion-oriented coping (Lazarus and Folkman, 1984).

Problem-oriented coping strategies are goal-oriented to directly change the elements of the stressful situation. This type of coping involves cognitive and behavioral problems solving strategies such as collecting information, planning, taking actions towards stressors to make situations better, or looking for something good in what is happening (Lazarus & Folkman, 1984; Carver et al, 1989).

Emotion-focused coping strategies are those of cognitive and behavioral efforts to regulate emotion and reduce emotional distress as a result of individual-environment transactions. This type of coping includes specific actions such as denial, acceptance, venting, and practicing religion (Lazarus & Folkman, 1984; Carver et al, 1989).

Researchers also seek the answers to the questions on the effectiveness of the above-mentioned coping strategies. Generally, problem-focused coping is seen as adaptive, and effective which is related to better psychological well-being, and better health-related quality of life. Emotion-based coping is considered maladaptive and ineffective which is associated with negative outcomes such as increased anxiety, and emotional distress (Folkman and Moskowitz, 2004; Taylor and Stanton, 2007; O'Driscoll, Brough, and Kalliath, 2009; Boyd et al. 2009; Graven et al. 2014).

However, it is viewed by Lazarus and Folkman's transactional theory of stress and coping model that neither problem nor emotion-based coping strategy is inherently effective or ineffective given the effectiveness of a coping strategy depends on how well the coping strategy goes in line with appraisals and situational conditions (Lazarus & Folkman, 1984, 1987, 1999, 2000). Emotion-oriented coping strategies could have short-term effective effects when emotional distress is intensive as a result of cognitive appraisals when stressors are assessed to be uncontrollable, and when available resources for problems solving solutions are lacking (Cummings and Cooper, 1998; Dewe and Cooper, 2007; Folkman and Moskowitz, 2004).

A specific way of coping can be adaptive under certain conditions and maladaptive in other situations. For example, for people with non-communicable diseases such as asthma, diabetes, or cancer requiring close and regular monitoring and self-care interventions, problems-based coping could be effective. On the contrary, for people with cerebral palsy, being focused on the problem seems not effective but acceptance or self-distraction can be useful to reduce anxiety and depression (Dewe and Cooper, 2007).

It was found in some studies that active coping and acceptance could be seen as adaptive coping. It highlighted the differential contribution to the well-being of those strategies: the acceptance of negative circumstances that are not possible to be changed and active coping to resolve situations that can be changed (Dewe and Cooper, 2007, Doron et al. 2014).

Self-blaming, behavioral disengagement, and substance use have a negative relation with well-being and a positive with stress so they can be considered as maladaptive or dysfunctional. These three strategies together with denial have been considered in other studies as being part of a second-order coping strategy of avoidance (Doron et al. 2014).

Coping strategies could be assessed to be effective if they help reduce negative outcomes and increase positive outcomes (Dewe and Cooper, 2007).

Despite the remarkable contribution of the TCS model to the areas of stress and coping, shortcomings are identified, especially for classifying ways of coping. It seems not useful and relevant to separate coping strategies by functions such as problem-based or emotion-based because most coping ways can be used for both functions and can fit into both categories. For example, positive reframing could aim at problem-solving but could help regulate emotion. Additionally, some other coping mechanisms seem not to belong to those groups. Seeking social support coping is neither problem-based nor emotion-based. This type focuses on other people. Active efforts to adjust to the environment appear to be focused on the self. Given coping options are dependent on many factors including individual and environment, it is recommended that factor analysis is the best way to identify relevant coping styles (Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. 2003).

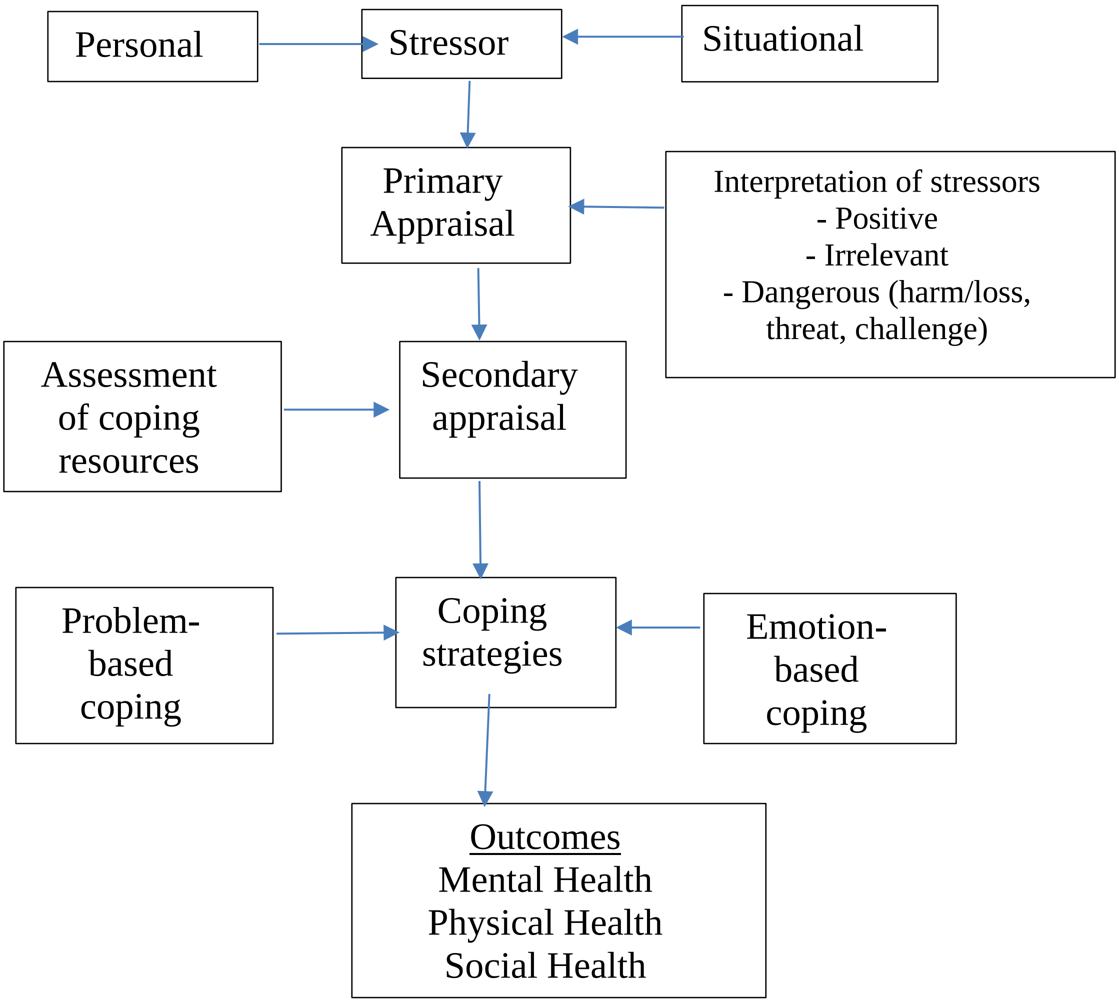


Figure 1.2: Theoretical model of stress, appraisal, and coping of Larazuz and Folkman

1.2.2.3. Conceptual framework of caregiving and caregiver's mental health

Several studies were conducted to understand the mental health among caregivers of children with CP and its associated factors (Power et al., 2019; Rasha et al., 2019; Reid et al., 2011, Savage et al., 2004). The comprehensive multi-dimensional model of different factors relating to mental health among caregivers of children with CP proposed by Parminder Raina and colleagues was used to guide this research (Raina, O'Donnell, Schwellnus, Rosenbaum, King, Brehaut & Wood, 2004).

There are five constructs included in the framework: Caregivers related factors, children with CP-related features, factors relating to family, social support factors, and the coping strategies used by caregivers. The caregivers' features included age, gender, marital status, education background, occupation, changing the job for caring for the CP child, and situation of affecting COVID-19. The perceived burden of caregiving for CP children is the most important factor, a stressor associated with the mental health of caregivers. The hypothesis could be more burden of care would be associated with a higher risk of mental health problems for caregivers (Raina et al., 2004).

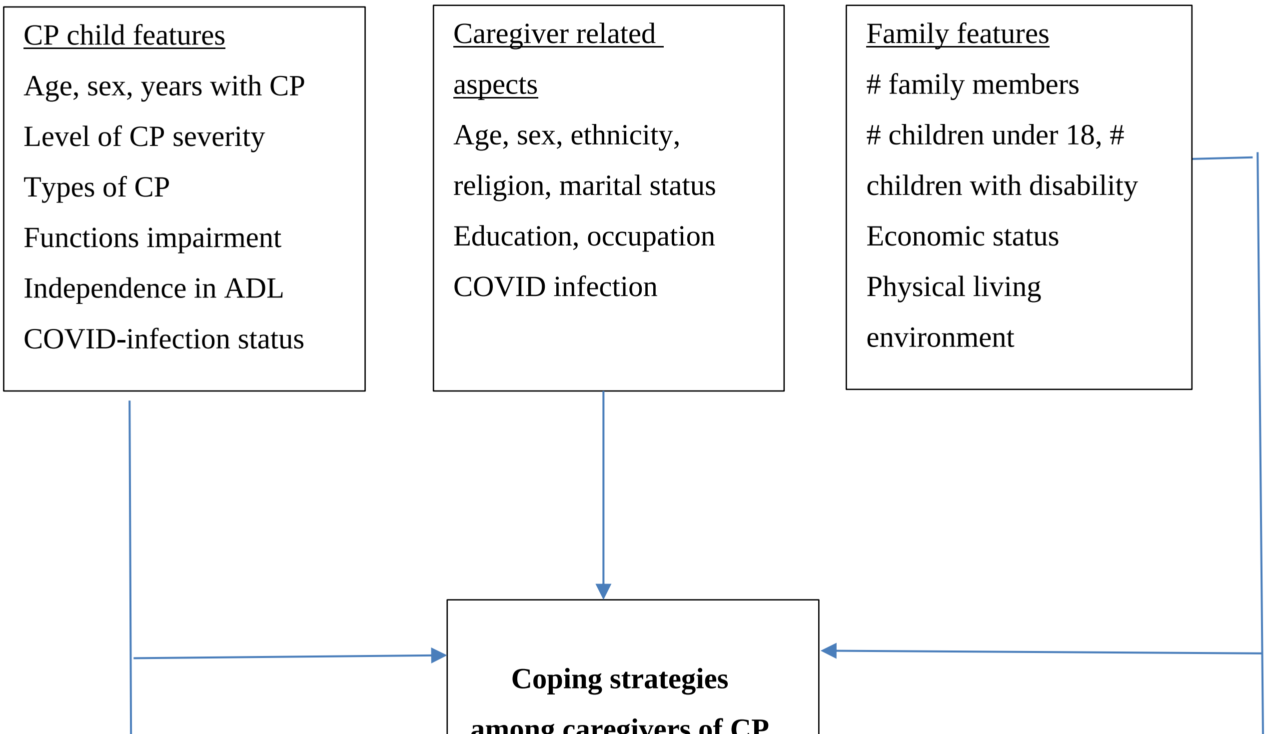
The characteristics of a child with CP would be explored including the classification of the CP conditions, the severity level of CP conditions, the level of impairments, the level of motor functions, and the extent of dependence in activities of daily living (ADL). The hypothesis could be the less severe disability, the less dependence on ADL would be associated with a lower risk of mental health problems for the caregivers (Raina et al., 2004).

The family-related factors comprised the size of the family, the geographical, economic status, and the physical living environment for taking care of the CP child such as sufficient place, separate room, and accessible toilet. The hypothesis could be the poor economic and physical living environment of the family would correlate with the poor mental health of caregivers (Raina et al., 2004).

Coping factors used by caregivers to response to the stress of caregiving burden were assessed. Internationally, three main coping strategies included problem-focused coping, emotion-focused coping, and avoidant coping. The problem-focused coping is characterized by the facets of active coping, the use of informational support, planning, and positive reframing. This coping style aimed at changing the stressful situation, a practical approach to solving the problem, therefore, could be predictive of positive psychological health. The emotion-focused coping featured the aspects of venting, the use of emotional support, humor, acceptance, self-blame, and religion. This type of coping aimed to regulate emotions linked to the stressful situation. Positive emotion-focused coping such as acceptance, venting, and use of emotional support could be linked to better mental health while negative ones such as self-blame could be correlated to worse psychological health. Avoidant coping is marked by self-distraction, denial, substance use, and behavioral disengagement in which a high score indicates physical or cognitive efforts to disengage from the stressor, low scores are typically indicative of adaptive coping (Carver, 1997).

Social support measures formal support from the government such as monthly allowance, and health insurance card provision as well as informal support derived from the social relationships of the caregiver with extended family, friends, and peers. The hypothesis could be higher scores on social support would be associated with better psychological health of caregivers (Raina et al., 2004).

The mental health status of caregivers is measured by identifying common mental health problems such as depression and anxiety as well as the level of quality of life of caregivers. The following is the conceptual framework of the mental health of caregivers of children with CP and associated factors used for our research.



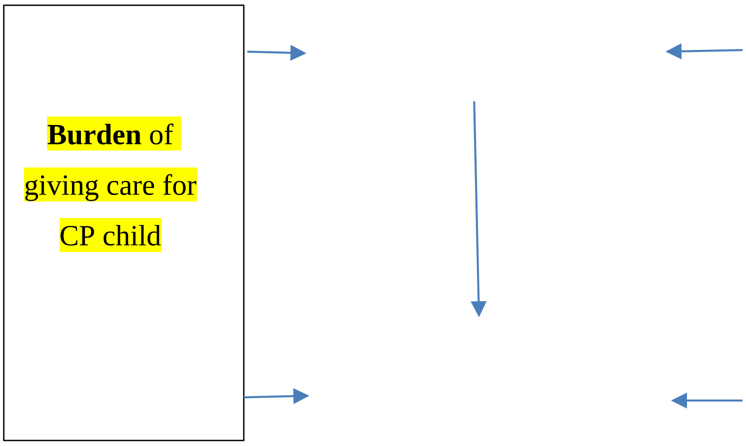


Figure 1.3: Conceptual framework of mental health and associated factors among caregivers of children with CP.

CHAPTER 2

METHODOLOGY

2.1. Research design

This current study aims to (i) have a better understanding of the current mental health status among primary caregivers of children with CP with a focus on depression, anxiety, and quality and life, on the coping strategies used by the caregivers to deal with the caregiving stressful situations; (ii) explore the factors associated with the identified mental health issues as well as the coping mechanism of caregivers so that further plan/study could be ignited for development of interventions to support the caregivers of children with CP to improve their psychological well-being.

The research questions are:

(1) What is the prevalence of depression, anxiety and quality of life among studied primary caregivers of children with cerebral palsy?

(2) How do the studied caregivers cope with caregiving difficulties?

(3) What are the relations between identified mental health issues and coping as well as other associated factors?

The research hypothesis are:

(i) The primary caregivers of children with cerebral palsy are at high risk of common mental health problems such as depression and anxiety and have a low quality of life

(ii) The caregivers use all possible ways to cope with the obstacles related to CP child caring burdens in which self-reliance mechanism is most applied.

(iii) The caregivers' coping strategies could have significant effects on their mental health. The other factors including caregivers' characteristics, features of CP children, family situations and social support could have significant relations with caregivers' mental health issues.

The research design: An analytical cross-sectional study with the quantitative data collection method was chosen. This type of observational study design is most used in many areas of health research as well as in other social sciences. They are usually conducted to estimate the prevalence of the health outcomes for a given population commonly for the purposes of public health planning, to understand determinants of health, and to describe features of a population. Thus, this design is appropriate for answering the research questions to achieve the research purposes.

Data were collected for both mental health outcomes and the determinants at one specific point in time to compare outcome differences between various variables. This survey provided a snapshot of the prevalence of the caregivers' common mental health problems focusing on depression, anxiety, and the overall quality of life, to understand determinants of mental health including the coping styles used by the caregivers.

The quantitative data collection method through questionnaires-based online surveys was applied to quantify the research variables of mental health outcomes. The associated factors such as the socio-economic situations of the caregivers' families, the features of caregivers, features of children with CP, the burdens of caregiving, the different coping strategies used by the caregivers, the services accessibilities, and social support were also assessed.

2.2. Research procedures

There were several steps for carrying out the research from the research preparation, data collection, data analysis, and report writing. It took a year for this process including one month for literature review, two months for research proposal and tools development, two months for research ethical review and approval, one month for field survey arrangement and research assistant training, two months for quantitative data collection, two months for data cleaning, data analysis, two months for thesis writing.

- *Step one: Overall literature review*

This literature review aimed to have better knowledge of the nature of cerebral palsy, the experiences of the caregivers in regards to the care they gave to children with CP, the burdens of caring for children with CP, especially for psychological distress, the coping strategies used by the caregivers and the supports given to caregivers to overcome the difficulties caused by the care demands for children with CP. Through reviewing the existing research in this field, the theoretical framework of how the caregiving process, the burden of care, and other factors related to the mental health of the caregivers was examined. The findings of existing studies are also used to make comparison with the results of this thesis.

Methodology: Literature searches were undertaken in key bibliographic databases to identify the prevalence of common mental disorders among caregivers of people with disabilities including children with cerebral palsy, coping strategies, and associated factors relating to mental health issues. The databases searched were Google scholar, PubMed, and other open online databases and websites of relevant organizations like the World Health Organization, and the American Psychological Association. The key words were used for searching papers and documents including depression, anxiety, quality of life, children with disabilities, children with cerebral palsy, caregivers, caregiving, burdens of care, mental health, and psychological distress.

To further identify studies/papers/document meeting the inclusion criteria, we first screened the titles, then read abstracts for papers, and the table of contents for documents/books. After that, papers/articles/studies were categorized into different groups for analysis and presentation of summarized results narratively including the prevalence of mental disorders in the general population, the prevalence of mental disorders of caregivers of people with disabilities, of children with cerebral palsy, coping strategies used by caregivers, the relationships between mental health issues of caregivers and coping mechanisms, and others associated factors.

- *Step two: Research proposal development*

Based on the information from the literature review as well as consultation with various experts working on areas of mental health care, and rehabilitation, especially those with experiences with children with disabilities and children with CP, the questions for research were developed, the research design of the analytical cross-sectional study was selected. The research objects, the criteria to select the objects, and the way to implement the research were identified.

- *Step three: Research tools development*

Given the difficulties in directly reaching the group of caregivers of children with CP and the past experiences of conducting the studies by the Cerebral Palsy Family Association Vietnam (CPFAV), we decided to carry out the online survey using self-administered questionnaires. A detailed description of the questionnaires is presented in section 2.4. To develop the tools, several activities were implemented as follows: Firstly, based on the conceptual framework and the results of the literature reviews on the measurements commonly used, some parts of the questionnaires were self-developed, and some parts were those of the existing instruments used locally and/or internationally.

For those having Vietnamese versions such as the Patient Health Questionnaires (PHQ-9) for screening depression, and Generalized Anxiety Disorders Questionnaires (GAD-7) for screening anxiety, we selected the tools used officially by National Mental Health Institute (NIMH), cross-checked the translation to make sure the accuracy and clarity of the tools. For those only English versions available, we translated them into Vietnamese and cross-checked them with some professionals with good English to fine-tune.

The first draft of questionnaires was sent to ten experts who have relevant knowledge and experiences in the areas of mental health, rehabilitation, and disability for their comments. Then the questionnaires were revised based on the inputs from the experts. The second draft of the questionnaire was given to five caregivers of children with CP from the network of CPFAV for filling out the tools. Following their feedback on the clarity of the questions, the length of the tools, the format, etc., the questionnaires were updated. After that, the nearly final draft was sent to my research supervisors for their final look and comments. We refined the tool and transferred them into online-based questionnaires of Google form. In the last round, the researcher and the other three persons tested to fill out the online form to check the content as well as the way the online form operated. Then we finalized the tools based on those experiences.

- *Step four: Preparation, presentation, and getting approval from the Research Ethical Committee of the University of Education, Hanoi National University*

Several steps were made to get approval from the Institutional Review Board (IRB) of the University of Education, Hanoi National University. Firstly, the researcher prepared a set of documents based on the IRB’s guidelines including a letter asking for IRB’s approval, the checklist for the selection of the relevant procedure, an information sheet for the full assessment procedure, a summary of the research proposal, consent form, researcher’s CV, research tools. Then the full package of required documents was sent to the IRB for consideration. The next step was that IRB organized a meeting to review the document where the researcher presented the research proposal and answered the questions raised by IRB members. IRB sent the meeting minute with comments to the researcher for revision. The researchers revised the research proposal following the IRB’s comments and sent the updated versions of the document for IRB's final approval. We received the letter of approval from IRB on May 13th, 2022.

- *Step five: Recruitment and training of research assistance*

Two research assistances from the Central Office of the Cerebral Palsy Family Association Vietnam were recruited based on the following criteria: have experiences in conducting research; willingness to assist in data collection, can be available and arrange time for this work when required; have sufficient skill in information technology. After that, they were trained on the research proposal, research tools, and research implementation. The whole team of researchers and research assistances was responsible for the data collection process which included: informing CPFAV's network about the survey, identifying those who voluntarily agreed with participating in the online survey, creating the zalo-based group of participants, sending out the online-google forms, instructing the caregivers to complete the questionnaires, providing daily supporting during the data collection process, calling the participants to check information, and data cleaning.

- *Step six: Contacting CPFAV, recruiting participants, and data collection*

In this cross-sectional quantitative research, data was collected at a one-time point in May- June 2022. 340 caregivers of children with cerebral palsy within the network of CPFAV voluntarily agreed to participate in the study. The detailed procedures were as follows: Firstly, the researcher met with the president of the Cerebral Palsy Family Association Vietnam to present the study framework including the objectives, its design, and benefits/requirements of the participants. Once CPFAV agreed to collaborate in conducting this research, we met with staff at the central office of CPFAV to discuss how to conduct the research and their roles in supporting this.

Then CPFAV provided the updated list of children with CP and their caregivers. A letter with an introduction to the research was sent to their caregivers. They were informed that participation in this study was voluntary, and their names would be replaced with an identification code to ensure their confidentiality. Contacts of the researcher were included in the questionnaires with clear notice that the researchers would be available to answer any queries from them.

CPFAV's research assistant created the zalo-group of participants to send around the Google form-based questionnaires for their filling. The researcher's group had regular interaction with the group of participants daily to make sure that everything went smoothly. Every day, the researcher checks the form filled and sent by participants, then called back participants to clarify information or asking missing information.

Given it is electronic Google form-based data collection, information filled in by the participants was automatically and immediately entered into a master Excel file that the researcher could monitor and check daily. It was impressed that not much missing data was seen. Just information on family incomes was not filled by some caregivers. Then researchers telephoned to ask for adding that information.

2.3. Research samples

2.3.1. Research sites

Caregivers of children with CP within the network of CPFAV from 47 provinces of three regions of Vietnam participated in this survey in which the northern region had the highest number of participants (194), the highest number of provinces (25), followed by the central region of 105 participants from 13 provinces. The southern region had the lowest number of participants joining the study (41 caregivers) and the lowest number of provinces (9).

Cerebral Palsy Family Association Vietnam (CPFAV), founded by parents of children with CP in 2017, is a local non-government organization managed by Vietnam Federation on Disability. CPFAV is a network of more than 2,500 CP children's families and 53 branches in all over Vietnam.

Table 2.1: List of provinces having caregivers joining the study

Regions	**n**	**%**
Northern (25 provinces)	**194**	**57.1**
Hanoi	88	25.9
Others	106	31.2
Central (13 provinces)	**103**	**30.3**
Nghe An	47	13.8
Others	56	16.5
Southern (9 provinces)	**43**	**12.6**
Ho Chi Minh	20	5.9
Others	23	6.8
Total (47 provinces)	**340**	**100.0**

2.3.2. Samples

Given there is no information management system available in Vietnam to track and monitor the group of children with cerebral palsy. It is not feasible to do randomized sampling. Thus, within our research, convenient sampling was applied in which 340 caregivers of children with CP within the CPFAV network voluntarily who agreed to join were included in the survey. The inclusion criteria were: (1) primary caregivers who have spent most of the time taking care of children with CP; (2) caregivers of children with CP aged 18 years old and below; (3) the child was assessed and diagnosed by the health facility. Caregivers who were not the main caregivers, whose children have not been diagnosed by a health facility, whose children aged above 18 years old, and who could not be able to fill out the online forms were excluded from the study.

Table 2.2: Age, ethnicity, religion, marital status among primary caregivers

Characteristics of caregivers	**Frequency (n)**	**Percentage (%)**
Sex		
Female	330	97.1
Male	10	2.9
Age		

Characteristics of caregivers	**Frequency (n)**	**Percentage (%)**
<25	17	5.0
25-34	173	50.9
35-44	136	40.0
≥ 45	14	4.1
Mean (SD)	34.1 (5.6)	
Relationship to child		
Mother	328	96.5
Father	8	2.4
Others (grant-parents/uncles)	4	1.1
Residence		
Rural area	200	58.8
Urban area	140	41.2
Ethnicity		
Kinh	311	91.5
Ethnic Minorities	29	8.5
Religion		
None	252	74.1
Buddhism	62	18.2
Christian	24	7.1
Others	2	0.6
Marital status		
Married	312	91.8
Divorced	15	4.4
Separated	7	2.0
Widowed	3	0.9

Characteristics of caregivers	Frequency (n)	Percentage (%)
Not married	3	0.9

The ages of the studied caregivers ranged from 19 to 60 years old, with a mean age of 34.1 (5.6), majority of caregivers were aged from 25 to 44 accounting for 90.9%. Almost caregivers were mothers of children with CP (96.5%). More than half of caregivers (58.8%) lived in rural areas. 8.5% of caregivers were ethnic minorities including Dao, Muong, Nung, Tay, Thai, Tho, and Gie. Three-quarters of participants had no religion (74.1%). 91.8% of caregivers were married.

Table 2.3: Education and occupation of primary caregivers

Variables of caregivers	**n**	**%**
Education		
Never attended school	01	0.3
Primary school	10	2.9
Secondary school	46	13.5
High school	76	22.4
Vocational, college, university	207	60.9
Main job		
Farmer	33	9.7
Worker	25	7.4
Business	21	6.2
Odd job	16	4.7
Office staff	91	26.8
Housework	142	41.8
Others	12	3.4
Place of work		
At home	177	52.1
Outside	112	32.9
Both at home and outside	51	15.0
Quit/change the job for CP child caring		

Variables of caregivers	**n**	**%**
Yes	232	68.2
No	108	31.8

In our study sample, primary caregivers had a high level of education with vocational, college, and university education making up for the vast majority (60.9%). There were the highest proportions of caregivers doing the housework (41.8%) and working at home (52.1%). Understandably, the main responsibilities of caregivers are to take care of the children with CP whose lives have been dependent on caregivers. In addition to that, more than two third of the primary caregivers (68.2%) had to quit the job or changed the job to spend time taking care of the children with CP.

Table 2.4. Caregiving responsibilities

Variables	**n**	**%**
Tasks in the family		
Housework	340	100.0
Caring for the CP child	340	100.0
Earning for living	01	0.3
Duration of caring		
Mean (years for caring)	6.3 (3.4)	
< 5 years	116	34.2
5-10 years	179	52.8
> 10 years	44	13.0
Mean (hours/day for caring for CP child)	12.7 (7.0)	

All primary caregivers are responsible for both doing housework and taking care of the children with CP. Almost caregivers rely on others for earning for living. The average number of years taking care of children with CP was 6.3 years (±3.4). Most (52.8%) of the participants had been primary caregivers for between 5 to 10 years while 13.0% were those for more than 10 years. The average number of hours per day the caregivers spent time for caring children with CP was 12.7 hours (±7.0). Caregivers spending 24 hours taking care of CP children accounted for the highest percentages, 18.5%. The above information showed the burden of care of the participants.

Besides that, during the COVID-19 pandemic, more than three fourth (78.5%) of participants were affected with positive COVID-19, 72.4% of those having moderate and severe symptoms. It was noted that 68.8% of children with CP also suffered from COVID-19, 69.8% of them got moderate and severe symptoms. That situation might create more difficulties for caregivers that could lead to more stress on the caregivers.

Table 2.5. Socio-economic conditions of the caregivers' families

Variables	**n**	**%**
The average number of people in the family	4.8 (1.6)	
Multi-generations families	176	51.8
Average # children under 18 yo	2.1 (0.9)	
Economic status		
Poor	34	10.0
Near poor	41	12.1
Better-off	265	77.9
The average income per month (million VND)	12.7 (14.1)	
Physical living environment		
Convenient	119	35.0
Normal	168	49.4
Inconvenient	53	15.6

The average number of people living with caregivers was 4.8 (±1.6) in which more than half (51.8%) caregivers lived with parent(s) and had 2 children under 18 years. Most of the participants' families were not poor with total incomes per month of nearly 13 million. Only 15.6 percent of families of caregivers lived in inconvenient physical living environments such as insufficient space, no separate rooms, and not easily assessable toilets.

Table 2.6: Characteristics of the Child with CP

Variables	**n**	**%**
Sex		
Female	122	35.9
Male	218	64.1
Ages		
Mean (SD)	6.5 (3.2)	
≤ 5	158	46.5
6-10	139	40.9
> 10	43	12.6
Kinds of CP		
Spastic CP	170	50.0
Dyskinetic CP	23	6.8
Ataxic CP	2	0.6
Soft paralyzed CP	37	10.9
Mixed CP	56	16.5
Level of movement severity following GMFCS		
Level 1 (least dependent)	29	8.5
Level 2	49	14.4
Level 3	72	21.2
Level 4	64	18.8
Level 5 (totally dependent)	115	33.8

Variables	**n**	**%**
Prognosis of CP situation		
Much improved	84	24.7
Little improved	164	48.2
Keep the same	61	17.9
Get worse	31	9.1

The number of male children with CP (218) was nearly double the number of female children (122). Most of the children with CP were under five years old (46.5%). Children with spastic CP accounted for the highest percentages (50.0%). More than half of children with CP (52.6%) had severe levels of movement impairments measured by the Gross Motor Function Classification System – GMFCS. The higher rate of children with CP got little improvement in their CP conditions, accounting for 48.2%. However, there were still more than 20% of children whose CP conditions keep the same or get worse.

2.4. Research measures

To carry out the research, instruments/measurements to collect information to answer the research questions are pivotal.

The measurements for my Ph.D. dissertation were developed in consideration of the criteria below:

+ Answering the research questions about the mental health of primary caregivers, what coping strategies are used by the caregivers; and what factors associated with the mental health and coping strategies of the caregivers were.

+ Appropriate to the research design/approach: Online survey through self-administered questionnaires: questions are straightforward, easy to understand and answer, and questions are not ambiguous nor sensitive.

+ Relevant, specific to the research objects

Therefore, the following measurements will be used to collect information for each research question.

2.4.1. Measurement of mental health among caregivers of children with CP

It is a universal conclusion through a literature review that caregivers of children with disability especially caregivers of children with CP are more likely to suffer from common mental health problems such as depression and anxiety and lower quality of life (QoL). Thus, in our research, the focus was put on the measures being used to assess depression, anxiety, and QoL.

** Measurements for evaluation of depression*

There are many measurements developed and used for depression assessment worldwide. However, the 9-item Patient Health Questionnaire (PHQ-9) was selected to assess depression among caregivers of children with CP in our study based on the following reasons: (i) This tool has been commonly used by some projects in Vietnam to assess depression at community level; (ii) PHQ-9 is included in the psychometric tests approved by the Ministry of Health (MoH) of Vietnam in 2021 (MoH, 2021). PHQ-9 is also recommended by the American Psychological Association (APA) as the screening tool for depression in the community for the non-specialist group (APA, 2019).

PHQ-9, developed by experts from Columbia University in 1999, is a self-report measure designed to screen depressive symptoms in the community as well as to measure the severity levels of depression among participants, based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria. There are nine questions scored using a 4- Likert scale according to the duration of symptoms, from 0 (not at all), 1 (several days), 2 (more than half the days) to 3 (nearly every day). The total score ranged from 0 to 27. In our study, the cutoff point for the determination of caregivers having depression was 10 in which the intensity of depression was classified as none (0–9 points), mild depression (10–14 points), moderate depression (15–19 points), and severe depression (20 -27 points). It takes five to ten minutes to complete.

We did evaluate the internal reliability of PHQ-9 using Cronbach's Alpha coefficient analysis. The results showed that Cronbach's Alpha coefficient was 0.910, and all items with a Corrected Item-Total Correlation value were above 0.5. Thus, the PHQ-9 demonstrated good internal reliability for the identification of depression among the caregivers of children with CP in our study.

** Measurements for evaluation of anxiety*

The tool of Generalized Anxiety Disorder 7 (GAD-7) was chosen to be used in our study for the assessment of anxiety among caregivers of children with CP. GAD 7 is commonly used in mental health facilities as well as at community-based intervention projects in Vietnam. This tool is included in the psychometric tests approved by the MoH of Vietnam in 2021 (MoH, 2021).

The GAD-7 with seven items is a self-reported questionnaire for screening and measuring the severity of generalized anxiety disorder (GAD). It is normally used in outpatient and primary care settings for referral to a psychiatrist pending outcome (Spitzer et al., 2006).

On the GAD-7, subjects were asked how often, during the last 2 weeks, they have been bothered by each of the 7 core symptoms of generalized anxiety disorder. Response options are “not at all,” “several days,” “more than half the days,” and “nearly every day,” scored as 0, 1, 2, and 3, respectively. Total GAD-7 scores range from 0 to 21, with a cutoff point of 5 to indicate caregivers having anxiety. The intensity of anxiety was classified as none (0–5 points), mild (6–9 points), moderate (10–14 points), and severe (15 -21 points).

The internal reliability of GAD-7 was analyzed using Cronbach's Alpha coefficient, which was 0.921, and all items with a Corrected Item-Total

Correlation value were above 0.6. Thus, the GAD-7 appeared a good internal consistency reliability scale for the identification of anxiety among the caregivers of children with CP in our research.

** Measurements for quality of life*

Following World Health Organization (WHO), mental health is among the main domains of quality of life. There is a strong correlation between good mental health and good quality of life and vice versa. WHO developed the tool to assess the quality of life, both the full version and brief version, called WHO QoL-100 and WHO QoL-Brief respectively (WHO, 1996).

Given the lengths of the questionnaires and time-consuming, we selected six items among the 26-item WHO QoL-Brief tool for our study. Those six items were related to the self-perception of participants on their overall quality of life, their general health, their abilities to enjoy life, their purpose in life, their satisfaction with their relationship with their spouse/partner, and the opportunity for leisure activities. The participants were asked about their subjective thinking of their life in the last two weeks and were scored using a 5- Likert scale according to a level of satisfaction, from 1 (not at all) to 5 (an extreme amount). The total score ranged from 5 to 30. The higher scores mean the higher quality of life perceived by participants.

We conducted the internal reliability of the 6-item QoL by using Cronbach's Alpha coefficient which was 0.759, and all items with a Corrected Item-Total Correlation value were above 0.3. Therefore, the 6-item QoL scale seems the acceptable internal consistency reliability tool for the evaluation of the quality of life among the caregivers of children with CP in our survey.

2.4.2. Measurement of coping strategies used by caregivers of children with CP.

There are several self-reported instruments used by the international community to measure the coping strategies of caregivers, but no Vietnamese instrument was available for use in Vietnam. Through the literature review, we selected the Brief Coping Orientation to Problem Experiences (Brief-COPE) which is mostly used in health-related areas to identify how someone copes with a wide range of adversity including mental distress caused by caregiving for children with a disability like children with CP (Kato, 2013; Fairfax, 2019; Obembe et al., 2019; Sharma & Subedi, 2022).

The Brief-COPE was a short version of the original 60-item COPE (Coping Orientation to Problems Experienced) Inventory which was modified in 1997. This is a self-report questionnaire developed by an American psychologist, Charles S. Carver, in 1989. The theoretical development of the COPE was based on the model of stress and coping by Lazarus & Folkman in 1984 and the behavioral self-regulation model by Carver & Schreier in 1981. Several studies provided evidence to support the reliability and validity of the COPE (Carver, 1997; Kato, 2013; García et al., 2018).

The Brief-COPE, a 28-item self-administered questionnaire, was developed to measure a variety of ways to cope with a stressful life event such as giving care for children with CP, an effort used to minimize distress associated with negative life experiences. It is scored using a 4- Likert scale according to the amount of response to stressful situations, from 1 (I haven't been doing this at all), 2 (I haven't been doing this a little bit), 3 (I haven't been doing this a medium amount), to 4 (I haven't been doing this a lot). The total score ranged from 28 to 112.

It is flexible for the tool to evaluate either situational or dispositional coping, using three-time formats. Questions using present tense (i.e., I criticize myself) are used to appraise dispositional coping styles. Situational coping ways are evaluated through either question using past tense to determine coping responses completed during a specific period; or questions using present perfect tense to understand coping used during a specific period up to the present. In our research, we used a situational version of brief-COPE with questions put in the present perfect tense.

Originally, the measurement can commonly recognize the primary coping styles on the three subscales: (i) Problem-Focused Coping; (ii) Emotion-Focused Coping, and (iii) Avoidant Coping. Under each overarching subscale, scores are also grouped and analyzed following different facets (Carver, 1997).

As for Problem-Focused Coping, there are 4 subscales: (1) active coping style means concentrating the efforts on doing something about the situation/taking action to try to make it better; (2) use of informational support means getting help and advice from other people/trying to get advice or help from others about what to do; (3) positive reframing means seeing the situation from a different light, making it seem more positive, looking for something good in what is happening; and (4) planning means trying to come up with a strategy about what to do/thinking hard about what steps to take (Carver, 1997).

Relating to Emotional-Focused Coping, the sub-scales include emotional support (obtaining emotional support/comfort and understanding); venting (saying things to let unpleasant feelings escape/expressing negative feelings), use of humor (making jokes about it/ making fun of the situation), acceptance (accepting the reality that has happened/learning to live with it), use of religion (finding comfort in religious or spiritual beliefs/praying or meditating), and self-blame (criticizing myself/blaming myself for things that happened) (Carver, 1997).

Under Avoidant Coping, there are four sub-groups of self-distraction (turning to work or other activities to take my mind off things/doing something to think about it less), denial (saying to myself “this is not real”/refusing to believe that it has happened, substance use (using alcohol or other drugs to feel better/to help me get through it), and behavioral disengagement (giving up trying to deal with it/the attempt to cope) (Carver, 1997).

It was mentioned by Carver that the Brief COPE is also beneficial given researchers can modify the instrument to fit their specific communities (Carver, 1997). It leads to the fact that the factor structure of the brief-COPE varies from one to another research. A system review of 85 peer-reviewed articles published from1997 and 2021 to assess the factor structure of the Brief COPE since its development released that the situational version of brief-COPE was the most frequently used, the number of factors varied from 2 to 15, and dichotomous factors most frequently identified (Solberg, M. A et al., 2021).

For the tool of brief-COPE to fit the specific characteristics of our targeted participants as well as their environments, we did exploratory factor analysis (EFA) for identifying the practical model of coping factors to be used in our survey. The criteria for selecting a factor are that (i) The internal reliability of Cronbach Alpha of the scale is a minimum of 0.6; (ii) a factor should include minimum 3 items to ensure the internal reliability values; (ii) the factor loading value of each variable should be minimum of 0.3 to show how well the item represents the underlying factor; (iv) The Kaiser-Meyer-Olkin (KMO) measuring sampling adequacy is from 0.5 and above; (v) Bartlett’s test of sphericity with significance lower than 0.5; and (vi) Eigenvalues greater than or equal to 1.0.

It was found that two variables of substance use appeared separately and repeatedly in one factor. Additionally, among the total studied samples of 340 caregivers, 330 were female, and 10 were male. Most of them (88%) did not use alcohol or other substance as a coping strategy. Thus, we removed two variables of substance use from the coping items.

We did factor analysis again with 26 items (not including 2 items of substance use). Then the results showed that the four factors met the set criteria as mentioned above with the acceptable internal consistency values of Cronbach's alpha, α>0.6. The detailed analysis results are in Annex 3.

In our study, four factors of the coping styles among caregivers of children with CP were used for descriptive and inferential analysis including:

(i) Factor 1: Self-support-oriented coping style including several specific coping instances such as planning, acceptance, positive reframing, problem-solving, use of humor, and religious practice.

(ii) Factor 2: Self-blame-based coping mechanisms such as self-criticize, blaming self for things that happened, giving up the attempt to cope

(iii) Factor 3: Seeking external support focused coping style comprising specific coping ways like getting advice or help from other people, venting, getting emotional support from others

(iv) Factor 4: Self-distraction-directed coping style with specific ways of coping such as doing other things to take the mind off the situation, and doing leisure activities to think less about the situation.

In summary, the factor structure of coping strategies based on EFA in our study is different from the original one. Among 28 items, 23 items were included, and 05 items were excluded from the coping measurement scale.

2.4.3. Measurement of associated factors to mental health

The development of questionnaires to measure the factors associated with the mental health problems of caregivers of CP is based on the followings:

- The literature review shows that mental health problems of caregivers of children with disability generally, of caregivers of children with CP particularly depends on several factors, which can be grouped into categories including Socio-economic-demographic factors; caregivers related factors; children with CP-related factors; caregiving-related factors, and social support-related factors.

- Specific features among Vietnam’s caregivers of children with CP through the quick exploration of some households of children with CP.

The followings were the proposed questions to collect information on associated factors.

** Socio, economic and demographic information*

These were self-developed questions on the number of people, the number of children under 18 years, the number of children with disabilities under 18 years living in the family; family living in urban or rural areas; the economic status of the family following the Government criteria of the poverty (poor, near poor, better-off); the total monthly income of the family, the physical living conditions such as sufficient space, separate room, accessible toilet (convenient, normal, inconvenient).

** Characteristics of the child with CP*

We developed questions on the year of birth, sex, attending to school (do not go to school, go to special education school, other); years living with CP; diagnosis of CP type (spastic, ataxic, dyskinetic, soft paralyzed, mixed, no classified). The severity level of CP was measured following the Gross Motor Function Classification System- GMFCS with 5 levels from level 1 (can move) to level 5 (cannot move, need 100% support). Level of impairments in functions of movement, seeing, speaking, hearing, communicating, learning, self-care, behavioral, and emotional problems were also assessed with the 5-Likert scale from 0 (no difficult at all) to 4 (cannot do) (HI, 2018).

The level of independence in daily living activities of the child with CP was evaluated using the Barthel Index Scale, the tool commonly used globally and used in Vietnam as well. Ten personal activities include feeding, bathing, grooming, dressing, getting on and off a toilet, controlling the bladder, controlling the bowel, moving from bed to chair and back, ability to move on level surfaces, and ascending and descending stairs. Each item was scored in terms of whether the child with CP can perform the task independently, with some assistance, or was dependent on help. The higher score the higher the independent level the child had (Mahoney, 1965).

** Characteristics of the caregiver*

The questions were self-developed concerning caregivers' age, sex, ethnicity, religion, marital status, education qualification, main job, work at home or work outside, relation with the CP child, responsibilities in the family, duration of caring for CP child in a year, the average number of hours per day taking care for CP child, the COVID-19 affection.

*** Burden of care for CP child**

Caregiver Difficulties Scale (CDS) was chosen given some researchers used in evaluating the burden of caregiving for children with CP (Wijesinghe et al., 2015; Farajzadeh, 2021; Park, 2021). It is a self-administered, multidimensional instrument developed. The CDS contains 25 items and is divided into four sub-factors, namely, Concern for the Child (8 items), Impact on Self (7 items), Lack of family support for caregiving (5 items), and Social and Economic Strain (5 items). There was a 5-point (1–5) Likert scale indicating the frequency/extent of each caregiving experience as perceived by the caregivers, with a final total score ranging from 1 to 125 (0: Never, 1: Rarely, 2: Sometimes, 3: Often; 4: Always). Higher scores indicated a higher caregiving burden on the lives of caregivers.

We did an exploratory factor analysis of the CDS and the results showed 4 factors of items that meet the following criteria including (i) The internal reliability of Cronbach Alpha of the scale is above 0.6; (ii) a factor includes more than 3 items to ensure the internal reliability values; (ii) the factor loading value of each variable is above 0.3 to show how well the item represents the underlying factor; (iv) The Kaiser-Meyer-Olkin (KMO) measuring sampling adequacy is more than 0.5; (v) Bartlett's test of sphericity with significance lower than 0.5; and (vi) Eigenvalues greater than or equal to 1.0 (see details in annex 4).

Our factor structure based on EFA is slightly different from the original one. Among 25 items, 20 items were included, and 05 items were excluded from the CDS measurement scale.

They included:

(i) Factor 1: Worry for the Child including 6 items (worrying for the child's future, for the child's inability to function like other children, for the child’s present state, worrying for stigma and discrimination against the child; being fear of the child will have accidents as a result of disability, feeling said about the child’s total dependence;

(ii) Factor 2: Lack of family support including 4 items (spouse’s support in other family responsibilities; in caring for CP child, sharing the child’s problems with other family members; family members’ awareness on the CP child's condition

(iii) Factor 3: Impact on Self including 5 items (feeling tired and exhausted; health affected by caring for the child; cannot relax, cannot care for other family members, facing embarrassing situations when travelling with CP child)

(iv) Factor 4: Lack of Time including 5 items (insufficient time for basic daily needs of sleeping, eating, bathing; for looking after own health; for getting things done;

We used total CDS scores and 4 sub-groups of CDS as mentioned above to analyze caregiver burden in the thesis.

** Services accessibility and social support*

We developed the questions on the accessibility of the child with CP to different services of special education, rehabilitation, assistive devices, the accessibility of the caregivers to information, legal support services, mental health services, and psychological counseling. The formal support of the Government in terms of monthly financial allowance, health insurance cards as well as informal support from the CP Family Association was also examined.

2.5. Statistical analyses

Data was analyzed by SPSS for Windows version 22.

The data analysis strategies included the following actions: (i)To test whether the data used are normally distributed; (ii) To perform Exploratory Factors Analysis (EFA) of some scales such as brief-COPE, and Caregiver Difficulties Scales to identify main constructs among a wide range of variables of each measure and then to test the internal reliability of those constructs using values of Cronbach's Alpha; (iii) To conduct the descriptive statistical analyses to identify the prevalence of depression, anxiety, and mean scores of quality of life of caregivers; to learn the current ways of coping used by caregivers; (iv) To make simple analysis tests to compare the differences in mental health outcomes, differences in coping strategies by different demographic features of caregivers, family and children with CP using T-test, ANOVA; (iv) To carry out the advanced analysis using the regression model to determine the relations between mental health outcomes and coping strategies as well as other factors.

Normal distribution of synthesized variables including total PHQ-9 scores, total GAD-7 scores, total quality of life scores, total ADL, total CDS, and total functional impairments scores were tested using Kurtosis and Skewness measures. The results showed that the values of those tested variables are symmetric, and normally distributed (see annex 2).

Exploratory Factors Analysis (EFA) was applied for identifying factors of some scales such as brief-COPE (for coping strategies), Caregiver Difficulties Scale-CDS (for the burden of care). The reliability analyses were run to determine the internal consistency values of some key measurements used for our targeted participants among caregivers of children with CP. They were PHQ-9, GAD-7, QoL, brief-COPE, and CDS scales.

Descriptive analyses including frequencies, means, and standard deviations (SD) were done to describe the studied sample features, to identify the prevalence of common mental health problems focusing on depression, anxiety, to classify depression and anxiety into categories (mild, moderate, severe), to report the rate of caregivers with comorbidity of anxiety and depression; to express frequencies of Likert scale for the 6- quality of life items, to specify coping ways used by caregivers.

Independent Samples T-test and One-way ANOVA were employed to analyze the variance in mean scores of different coping strategies, in mean scores of depression, anxiety, and quality of life among caregivers with different characteristics (categorical variables).

Bivariate Analysis with Pearson Correlation was operated to determine the correlation between the continuous dependent variables (caregivers' mental health status; coping strategies); and several continuous independent variables such as ages, incomes, number of hours per day caregivers taking care of the CP child, number of years the child living with CP, caregiving burden scores, total scores of function impairments of CP child, total scores of independent living in daily activities, total scores of different types of social support.

The inferential analyses applying General Linear Model (GLM) were run to interpret what factors are related to caregivers' mental health including moderators (coping mechanism, societal support, family circumstances), risk factors (caregivers' responsibilities, burden of care, functional impairments of CP child, level of independence in daily living activities of CP child, types of CP conditions, and prognosis of CP situations). The total effects of some key independent variables such as the burden of care, coping strategies, and social support on the dependent variables (depression, anxiety, quality of life of caregivers); and the effects of interaction between independent variables towards the changes in caregivers 'mental health outcomes were also explored.

GLM is also called the general multivariate regression model. The big advantage of this model is that it is so flexible. It can be used to analyze regressions, ANOVAs, and ANCOVAs with all sorts of interactions, and with both continuous and categorical independent variables. That's why we use GLM in our research.

2.6. Ethical considerations

Our research was approved by the Institutional Review Board (IRB) of the University of Education, Hanoi National University following the full procedures of evaluation that all requirements have been met. The IRB President of the University of Education endorsed the meeting minute number 22-01/HDDD-DHGD dated 9 May 2022 about the results of the review on the ethical aspects of our research, followed by the official letter of approval dated

13 May 2022.

Before the actual data collection, the President of the CPFAV sent an electronic letter to introduce the research and to ask for members who agreed to join voluntarily into the research. Then the online Google form-based questionnaires were sent to those registered for participation in which the introduction part of the questionnaires also emphasized that the participant could stop filling in the form at any time they want. Participants were informed that the principal researcher, a clinical psychologist, and her professional network within Vietnam Psychotherapy Association, are available for support who experienced distress if required.

CHAPTER 3

RESULTS

This chapter presented the results based on three specific objectives set for this study: The mental health status of caregivers focusing on depression, anxiety, and quality of life; the differences in mental health by different features; coping strategies used by caregivers; and the relations between identified mental health and coping, and other associated factors, especially the important predictors for identified mental health issues of caregivers.

3.1. The mental health status of the studied caregivers of children with CP

3.1.1. Prevalence of depression, anxiety, and quality of life

3.1.1.1. Prevalence of depression

Table 3.1. Percentage of caregivers with depression and the level of severity

Variable	**n**	**%**
No depression	214	62.9
Having symptoms of depression	**126**	**37.1**
Mild depression	68	20.0
Moderate depression	31	9.1
Severe depression	27	7.9
Total	**340**	**100**

The result showed that 37.1 percent out of 340 primary caregivers of children with CP presented symptoms of depression measured through the screening tool of PHQ-9. 17.0 percent had moderate and severe level of depression which imply the professional support needed to help them get through this disturbance. Among the three regions, caregivers living in the Southern regions have the lowest rate of moderate and severe depression, 9.3%, and those living in the Central areas have the highest percentage, 24.3%.

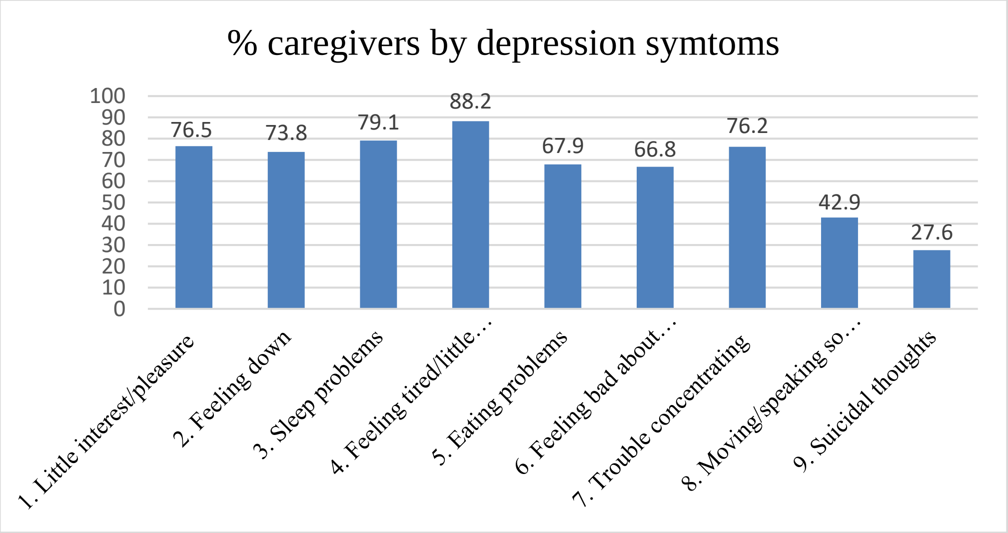


Figure 3.1. Percentage of caregivers by depression symptoms

The above figure indicated that somatic symptoms such as sleep disorders, feeling tired, or having little energy appeared most frequently as compared to other symptoms. The paired-sample T-test among those symptoms also pointed out the significant difference with $p<0.01$.

It was noted that 27.6% of caregivers had suicidal thoughts with a mean score of 1.3, implying the less frequency of those thoughts within the two weeks. Further suicide risk assessment needs to be taken by mental health specialists for those with suicidal thoughts to determine how likely they will try to end their own life then the plan of support will be given to prevent a tragic outcome.

3.1.1.2. Prevalence of anxiety

Table 3.2. Percentage of caregiver with anxiety and the level of severity

Variable	**n**	**%**
No anxiety	113	33.2
Have symptoms of anxiety	**227**	**67.8**
Mild anxiety	140	41.2
Moderate anxiety	46	13.5
Severe anxiety	41	12.1
Total	**340**	**100**

More than two third of caregivers of children with CP (67.8%) had symptoms of anxiety through the screening tool of GAD-7. One-fourth, 25.6% of caregivers, presented a level of moderate and severe anxiety in which caregivers living in the Southern regions having the lowest rate of moderate and severe anxiety, 16.2%, and those living in the Central areas having the highest percentage, 33.0%.

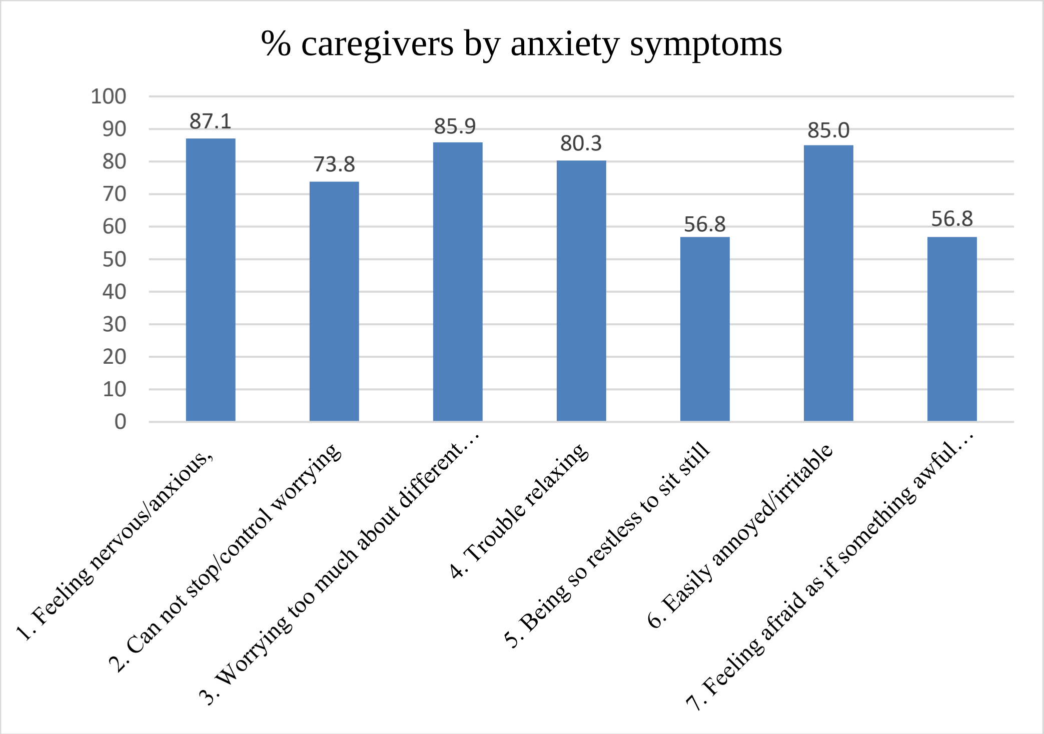


Figure 3.2. Percentage of caregivers by anxiety symptoms

Feeling anxious and worrying too much about different things presented most frequently while feeling afraid as if something awful might happen and being so restless, easily annoyed/irritable appeared the least. Caregivers kept worrying about the CP child’s health conditions, the future of the child, worried about their health, worrying about not having enough materialized support for the child. The paired-sample T-test among those symptoms also indicated a significant difference with $p<0.05$.

3.1.1.3. Co-morbidity of depression and anxiety

If the participants had scores of PHQ-9 from 10 and scores of GAD-7 from 5 above, they suffered from both depression and anxiety.

Table 3.3: Caregivers with both depression and anxiety

Depression and anxiety	**n**	**%**
Depression and anxiety	125	36.8
Severe depression and severe anxiety	21	6.2

The above results proclaimed that 36.8% of the total 340 caregivers of children with CP had both symptoms of depression and anxiety. Of which 6.2% had severe depression and anxiety. Professional support needed to be given to this group to confirm the cases and to have appropriate treatment.

3.1.1.4. The quality of life among caregivers of children with CP

The higher scores of the total selected 6 items of the WHO Brief Quality of Life measurement mean the better quality of life caregivers have. The mean score among 340 caregivers was 16.7 out of 30 scores. That means the caregivers perceived their quality of life at the average level.

Table 3.4: Caregivers' quality of life by items

Quality of life	**Poor& very poor**	**Neither poor nor good**	**Good& very good**	**Means (SD)**
Total QoL	**16.7 (3.6)**			
1. How would you rate your quality of life?	54 (15.9)	209 (61.5)	77 (22.7)	3.05 (0.77)
2. How would you rate your health?	77 (22.7)	191 (56.2)	72 (21.2)	2.96 (0.74)
	Not at all& a little	**Average**	**Great deal**	
3. How much do you enjoy life?	196 (57.6)	117 (34.4)	27 (8.0)	2.38 (0.89)
4. To what extent do you feel your life to be meaningful?	118 (34.7)	135 (39.7)	87 (25.6)	2.92 (1.05)

Quality of life	**Poor& very poor**	**Neither poor nor good**	**Good& very good**	**Means (SD)**
5. To what extent do you have the opportunity for leisure activities?	262 (77.1)	71 (20.9)	7 (2.1)	1.93 (0.81)
	Dissatisfied	**Normal**	**Satisfied**	
6. How satisfied are you with your spouse's relationships?	53 (15.6)	113 (33.2)	174 (51.2)	3.43 (1.03)

The above table disclosed that the participants who had no or little opportunity for leisure activities accounted for the highest percentages (77.1%) followed by the second-highest proportion of those with no or little enjoying life (57.6%). The most satisfaction that the caregivers had was the relationship with their spouse (51.2%). That information could be valuable input for planning support to improve the quality of life of caregivers.

3.1.2. Differences in depression, anxiety, and quality of life among caregivers by demographic characteristics.

3.1.2.1. Differences in depression, anxiety, and quality of life by localities

Table 3.5. Mean scores of depressions, anxiety and QoL by localities

Regions	**Depression**		**Anxiety**		**Quality of life**	
	Mean (SD)	*p*	*Mean (SD)*	*p*	*Mean (SD)*	*p*
Northern	8.6 (5.6)	*<0.05*	7.3 (4.9)	*<0.05*	16.4 (3.6)	*>0.05*
Central	10.2 (6.8)		8.5 (5.1)		16.6 (3.4)	
Southern	7.9 (5.9)		6.1 (4.1)		17.8 (4.0)	
Urban	7.9 (5.6)	*<0.01*	6.4 (4.2)	*<0.01*	17.5 (3.5)	*<0.01*
Rural	9.7 (6.3)		8.3 (5.2)		16.1 (3.5)	

Caregivers living in the Southern region have the lowest mean scores of depression and anxiety and the highest mean scores of quality of life. While caregivers living in the central region have the highest mean scores of depression and anxiety and lower mean scores of quality of life. The differences in depression and anxiety are statistically significant with p<0,05. Caregivers living in rural areas have higher mean scores of depression, and anxiety and lower scores in quality of life than those living in urban areas ($p<0.01$).

3.1.2.2. Differences in depression, anxiety, and QoL by caregivers' Characteristics

Concerning the depression mean scores, there were no significant differences among caregivers with different ethnicity, religion, marital status, education qualification, occupations, or working inside or outside the house ($p>0.05$). Caregivers who had to change or quit their jobs had higher mean scores of depression than those without changing/quitting their job ($p<0.05$).

As for mean scores of anxiety, there were no significant differences among caregivers with different ethnicity, religion, marital status, education qualification, or occupations ($p>0.05$). However, caregivers who work both at home and outside the house, who must change or quit their jobs had higher mean scores of anxiety than those who work outside the house, who did not change or quit their jobs with $p<0.05$.

Relating to mean scores of quality of life, there were no significant differences among caregivers with different ethnicity, religion, occupation, job changes, or not ($p>0.05$). However, caregivers who get married had the highest QoL mean scores and caregivers who were not married had the lowest QoL mean scores ($p<0.05$). Caregivers who have more education qualifications, who work outside the house had more QoL mean scores than those who have less education, and who work inside the house ($p<0.05$).

The mean scores of depression, anxiety, and quality of life among caregivers having COVID were not significantly different from those without COVID ($p>0.05$).

Given the research samples are members of the CPFAV network, they have better education and better economic conditions. Thus, the samples are not representative of caregivers of children with CP all over the country. That could be one of the reasons why no significant difference in mental health status has been found among caregivers with some demographic features such as ethnicity, religion, or occupation. Further studies with randomly representative sample sizes could explore more in these issues.

3.1.2.3. Differences in depression, anxiety, and quality of life by the caregiver family conditions

Table 3.6. Mean scores of depression, anxiety and QoL by family conditions

Family Conditions	**Depression**		**Anxiety**		**Quality of life**	
	Mean (SD)	*p*	*Mean (SD)*	*p*	*Mean (SD)*	*p*
Economic condition						
Poor	12.1 (7.5)	*<0.01*	10.4 (5.9)	*<0.01*	14.8 (3.7)	*<0.01*
Near poor	10.6 (5.7)		8.9 (4.9)		15.1 (3.4)	
Better off	8.3 (5.8)		6.9 (4.6)		17.1 (3.5)	
Physical living environment						
Very convenient	6.5 (5.5)	*<0.01*	5.1 (3.6)	*<0.01*	19.9 (4.2)	*<0.01*
Convenient	7.7 (5.3)		6.8 (7.8)		17.0 (3.3)	
Normal	9.6 (6.3)		7.8 (4.8)		16.3 (3.3)	
Inconvenient	10.6 (6.2)		9.0 (5.6)		15.5 (3.2)	
Very inconvenient	11.1 (5.4)		10.0 (4.0)		13.7 (3.0)	

The table reported that there were statistically significant differences in mean scores of depression, anxiety, and quality of life among caregivers having different economic and physical living conditions with p<0.05. The caregivers having better economic and physical living conditions are less likely to have depression, anxiety and are more likely to have better quality of life than those having lower economic and physical living conditions. The more monthly incomes the caregivers' family earn the less likely risk of depression and anxiety, and the more quality of life the caregivers have with p<0.05.

3.1.2.4. Differences in depression, anxiety, and quality of life by CP children's characteristics

Table 3.7. Mean scores of depression, anxiety and QoL by CP children' features

CP children's Features	**Depression**		**Anxiety**		**Quality of life**	
	Mean (SD)	*p*	*Mean (SD)*	*p*	*Mean (SD)*	*p*
Sex						
Male	9.4 (6.5)	*>0.05*	7.8 (5.1)	*>0.05*	16.3 (3.4)	*<0.05*
Female	8.2 (5.3)		6.9 (4.4)		17.3 (3.9)	
Attending schools						
No	9.5 (6.2)	*<0.05*	7.9 (4.9)	*>0.05*	16.2 (3.4)	*<0.01*
Special education school	8.2 (5.9)		6.6 (4.2)		17.8 (4.0)	
Typical school	6.5 (4.8)		6.1 (5.2)		18.3 (3.5)	

It tended that caregivers of male CP children, of children not attending school had higher depression and anxiety mean scores, and lower quality of life scores than those of female CP children and those of children attending school. However, only differences in QoL scores and the difference in depression scores among caregivers with CP attending school were significant ($p<0.05$).

There was a negative significant correlation between the ages of the CP child, the number of years the child living with CP, and the caregivers' depression and anxiety scores in which the younger the child is, the less year the child living with CP, the higher depression anxiety scores the caregivers have ($r<0.05$).

It was found no significant differences in depression, anxiety, and quality of life scores among caregivers by different kinds of cerebral palsy conditions, by different impairment levels of gross motor functions of CP child, by CP conditions prognosis, and by CP child having COVID or not having COVID or severity levels of COVID (*$p>0.05$*).

There was a strong correlation between the level of independence in daily living, level of functioning impairments of vision, hearing, speaking, communicating, and learning of children with CP, and the mental health status of caregivers. The more dependence in daily living, the more functional impairments of CP child, the more likely caregivers are at risk of depression, anxiety, and lower quality of life (*$r<0.05$*)

3.1.2.5. Differences in depression, anxiety, and QoL by social support

Table 3.8. Mean scores of depression, anxiety and QoL by social supports

Social supports	**Depression**		**Anxiety**		**Quality of life**	
	Mean (SD)	*p*	*Mean (SD)*	*p*	*Mean (SD)*	*p*
Getting necessary information on how to care for CP child						
No	9.6 (6.4)	*<0.01*	8.2 (5.1)	*<0.05*	16.3 (3.7)	*<0.01*
Sometimes	9.0 (6.0)		7.4 (4.6)		16.6 (3.4)	
Often	6.0 (4.0)		5.4 (4.3)		18.5 (3.4)	
Getting special education services for CP child						
No	9.3 (6.2)	*<0.05*	7.8 (5.1)	*<0.01*	16.2 (3.6)	*<0.05*
Sometimes	9.7 (6.0)		8.2 (4.8)		17.0 (3.5)	
Often	6.9 (5.3)		5.7 (4.0)		17.9 (3.5)	
Getting rehabilitation services for CP child						
No	9.4 (5.6)	*>0.05*	7.8 (4.2)	*<0.05*	16.4 (3.8)	*>0.05*
Sometimes	9.8 (6.5)		8.2 (5.2)		16.2 (3.5)	
Often	8.1 (5.8)		6.7 (4.8)		17.2 (3.6)	

Social supports	**Depression**		**Anxiety**		**Quality of life**	
	Mean (SD)	*p*	*Mean (SD)*	*p*	*Mean (SD)*	*p*
Getting monthly allowance from government						
No	9.1 (6.9)	*>0.05*	8.2 (5.2)	*>0.05*	16.5 (3.3)	*>0.05*
Yes	9.0 (5.9)		7.4 (4.8)		16.7 (3.7)	
Having health insurance for CP child						
No	10.7 (6.5)	*>0.05*	9.2 (5.3)	*>0.05*	15.0 (2.8)	*>0.05*
Yes	8.9 (6.1)		7.4 (4.9)		16.7 (3.6)	
Joining CPFAV						
No	10.4 (7.7)	*>0.05*	7.8 (4.7)	*>0.05*	16.4 (3.5)	*>0.05*
Sometimes	8.9 (5.8)		7.5 (4.9)		16.5 (3.7)	
Often	8.7 (6.0)		7.5 (5.1)		17.1 (3.3)	

It is noted that there were statistically significant differences in mean scores of depression, anxiety, and quality of life among caregivers receiving information on how to care for CP children with $p<0.05$. Caregivers who often received information were likely to be at lower risk of depression and anxiety and higher quality of life.

The differences were statistically found in mean scores of depression, anxiety, and quality of life among caregivers whose CP child getting special education services. Caregivers receiving regular special education for the CP child were less likely to be at risk of depression, and anxiety. Caregivers sometimes receiving special education for the CP child were likely to be at higher risk of depression and anxiety.

The mean scores of depression, anxiety, and quality of life among caregivers whose CP child getting rehabilitation services were different with the tendency that caregivers receiving regular rehabilitation for the CP child were likely to be at lower risk of depression, anxiety, and higher quality of life. Caregivers sometimes receiving rehabilitation services for the CP child were likely to be at higher risk of depression and anxiety and lower quality of life. However, only the difference in mean scores of anxiety was statistically significant ($p<0.05$).

No significant differences were identified in mean scores of depression, anxiety, and quality of life among caregivers who received or not received other social support services including monthly allowance from the government, having health insurance, and joining the Cerebral Palsy Family Association (CPFAV) ($p>0.05$).

3.1.2.6. Perceived reasons for mental health problems of caregivers

Table 3.9. Rate of caregivers reporting reasons for their emotional problems

Reasons	**n**	**%**
No time to relax	203	59.7
No good health	179	52.6
Too much work to do	175	51.5
Difficulties in caring for CP child	150	44.1
Unable to attend social activities	136	40.0
Much spending for CP child	122	35.9
No job/lose the job	104	30.6
Criticism, blaming by relatives	79	23.2
Conflict in family	66	19.4
Scold and hit CP child	54	15.9
Stigma, discrimination by others	48	14.1
Violence by spouse	15	4.4

The internal factors of caregivers such as having no time to relax, no good health, too much work to do, unable to attend social activities were reasons reported by most caregivers for their emotional problems, accounting for half of the surveyed caregivers. The problems relating to relationships with family, in the community including stigma and discrimination were reported by the least caregivers, lower than 20 percent of respondents.

Key messages on caregivers' mental health status

- Among 340 surveyed caregivers, 37.1% had symptoms of depression, 67.8% got symptoms of anxiety, 36.8% had both depression and anxiety, 77.1% had no/little opportunity for leisure activities, 57.6% did not enjoy life, 51.2% were satisfied with spouse relationship.
- Caregivers living in the Southern region, in urban areas, having higher economic conditions seemed to be at lower risk of depression, and anxiety, and had higher QoL. No significant difference in depression and anxiety scores was found among caregivers with different ethnicity, religion, marital status, education qualifications, or occupations. Caregivers getting married, having higher education, and working outside the house seem to have higher QoL.
- Caregivers of female CP children, of those attending school, of CP children with less dependence in activities of daily living, and less functional impairments tended to be less risk of depression, and anxiety and had higher QoL. No significant difference in depression, anxiety, QoL of caregivers by children with different kinds of CP, and severity levels of gross motor functions.
- Caregivers receiving more social support, especially getting regular information on how to care for CP children, and accessing special education, and rehabilitation services for CP children were less likely to be at risk of depression, anxiety, and having higher QoL.
- The factors relating to the caregivers themselves rather than to other people or the environment were reported to be the most common reasons for mental health distress among studied caregivers.

3.2. Coping strategies among caregivers of children with CP

3.2.1. The coping strategies used by caregivers of children with CP

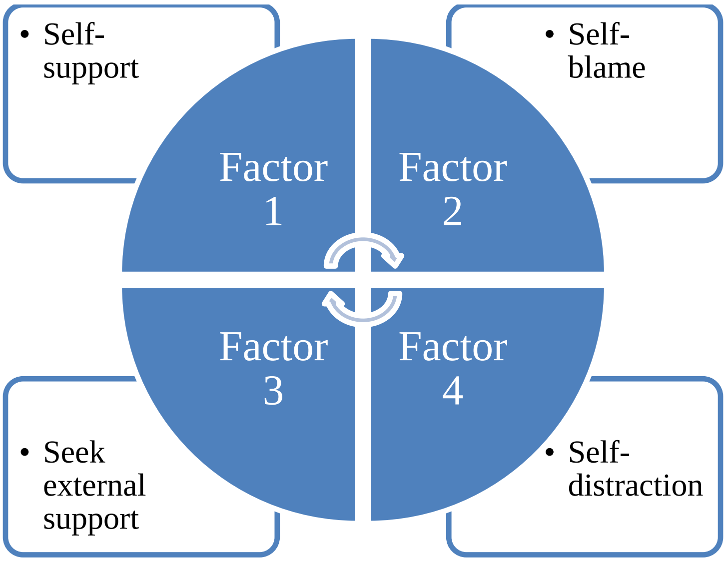


Figure 3.3. The four-factor coping strategies of caregivers

Through Exploratory Factor Analysis, the ways caregivers in our research respond to caregiving stress are categorized into four types of coping resources in which three mechanisms are self-oriented such as self-support, self-blame, and self-distraction; and one coping way is to mobilize support from outside.

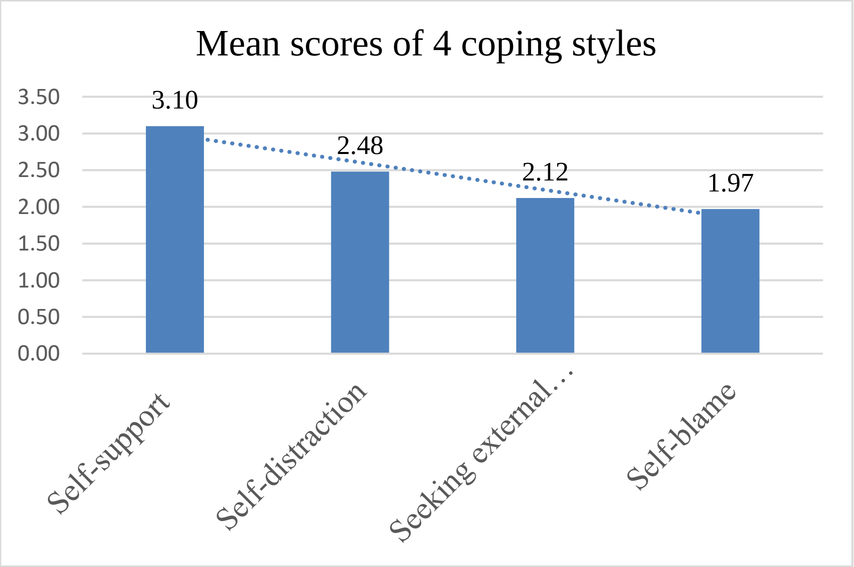


Figure 3.4. Frequency of coping strategies used by caregivers

The above figure indicated that caregivers generally tend to utilize positive coping more than negative ones. Of which they used the most frequent self-support coping to respond to caregiving stress with a mean score of 3.10. Self-blame and behavioral disengagement were those ways of coping they used the least with a mean of 1.97.

To look deeply into the lower-order coping responses, called the instances of coping, it was found that acceptance-oriented coping was applied the most frequently with mean scores of 3.6, followed by positive reframing (3.24), planning (3.21), and problem-solving (3.10). Behavioral disengagement-focused coping was used the least by caregivers (1.49). Practice of religion, seeking emotional support from others, expressing negative emotions, and use of humor are those coping the caregivers used the less (2.0).

Table 3.10. Correlation among 4 factors of coping

Coping strategies		Self-support	Self-blame	Seeking external support	Self-distraction
Self-support	Pearson Correlation	1			
Self-blame	Pearson Correlation	0.138*	1		
Seeking external support	Pearson Correlation	0.301**	0.112*	1	
Self-distraction	Pearson Correlation	0.479**	0.160**	0.266**	1

**. Correlation is significant at the 0.05 level (2-tailed).*
***. Correlation is significant at the 0.01 level (2-tailed).*

It is a statistically significant positive correlation among all four styles of coping ($r<0.05$). It implied that the more caregivers used one way of coping, the more they used the other coping strategies. For caregivers to manage the stressors as well as to regulate their emotions derived from caregiving stress, they tried to apply different ways they could have within their capacity and resources, even both healthy and unhealthy ones.

3.2.2. The aspects associated with coping strategies used by caregivers

3.2.2.1. Difference in coping strategies among caregivers by geography

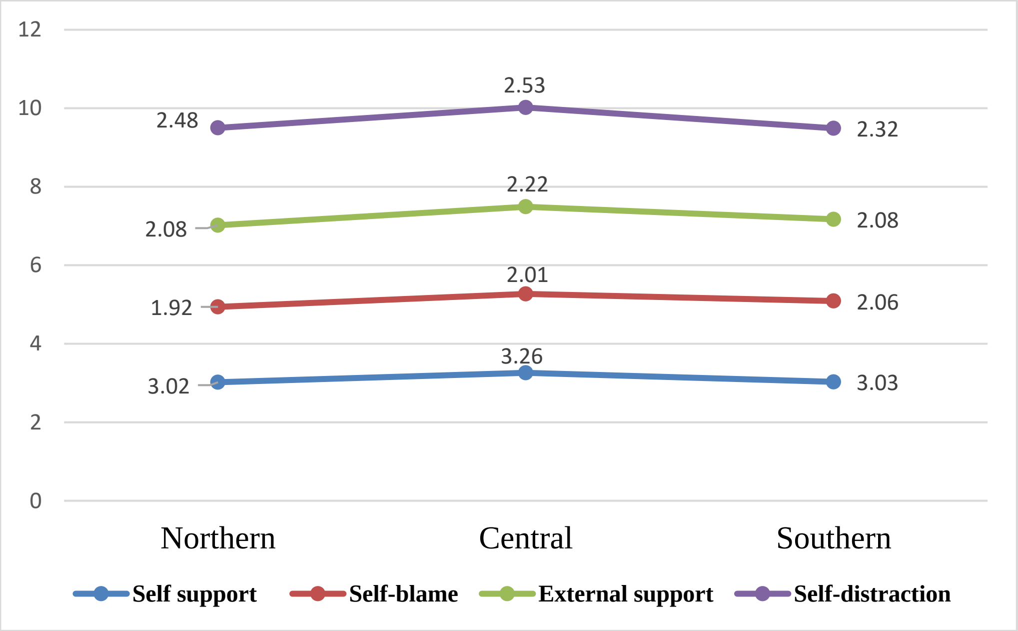


Figure 3.5. Differences in coping strategies by region

There were significant differences in self-support coping strategies by regions in which the caregivers in the central region used the most and those in the northern region used the least ($p<0.05$). The differences in other coping styles of self-blame, self-distraction, or seeking support from outsiders by region were not statistically significant ($p>0.05$). As for instances of coping, caregivers living in the Southern region used the most religious practice, and those in the North used the least ($p<0.05$).

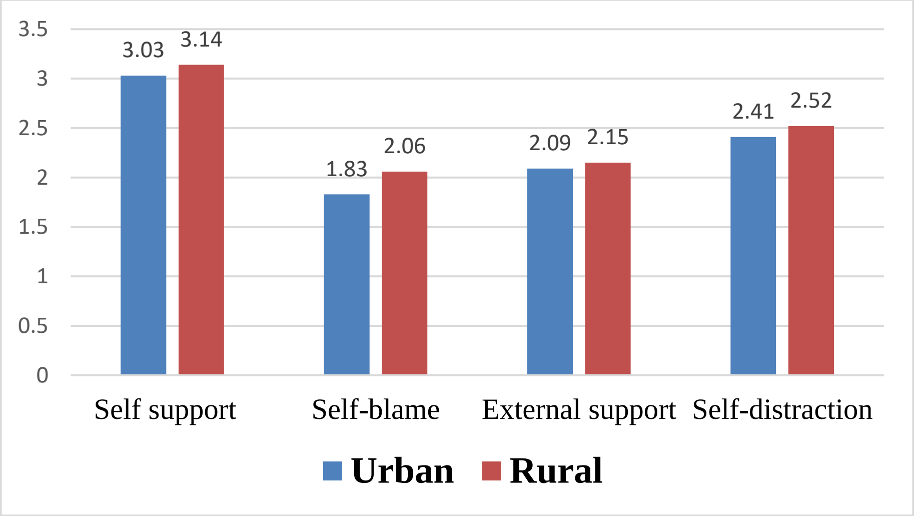


Figure 3.6. Differences in coping strategies by rural/urban areas

As indicated in the above figure, caregivers living in rural areas tend to use more different ways of coping than those living in urban areas. However, only the difference between rural and urban areas in using self-blame and behavioral disengagement strategies was statistically significant ($p<0.05$). No significant differences in using other coping styles among caregivers living in rural and urban areas were found ($p>0.05$).

3.2.2.2. Difference in coping strategies by caregivers' characteristics

Male caregivers tend to use more self-oriented coping strategies like self-support, self-blame, and self-distraction, and use less seeking support from outside than female ones. However, the difference was not significant ($p>0.05$). The small sample of males in the study (10) could be one of the reasons for that. Further investigation with higher samples could confirm the conclusion. When doing a deep analysis of coping instances, male caregivers used planning, concentrating on other work more than female ones, while female caregivers used venting-based coping, expressing the negative emotion, more than males ($p<0.05$).

There was a significant negative correlation between the ages of caregivers and self-blame coping in which the more ages caregivers have the less self-blame they use ($r<0.05$). No relation between caregivers' ages and other coping strategies such as self-support, self-distraction, and seeking external support ($r>0.05$).

There was a tendency that the indigenous caregivers used less self-support coping, and use more self-blame, more external support, and more self-distraction mechanisms than the Kinh caregivers. However, the difference was not significant ($p>0.05$). One of the reasons could be a small sample of minority ethnic groups in our study which is not representative of the wide ethnic community in Vietnam. Further research to test the phenomenon is needed.

Although no significant differences in the four coping styles were identified, it was interesting orientation for further in-depth investigation that caregivers with Christianity used the most self-support, the least external support, the least self-blame, and the least self-distraction while the caregivers with Buddhism used the least self-support, and the most self-blame and behavioral disengagement as strategies to cope with adversity situations.

It was worth noting that when making a comparison in mean scores of the specific coping way “acceptance”, caregivers with Buddhism used the least as compared to those without religion or those with Christianity ($p<0.05$).

The differences in coping strategies among caregivers with different marital status was not significant ($p>0.05$). However, the tendency was that caregivers without married used the least self-support and most self-blame as coping responses to the caregiving stress. It needs further research on that.

As for education-related factors, it was surprising that caregivers with higher education qualifications used less self-support coping ($p<0.05$). As for the occupation factor, only self-blame was found to be significant differences among caregivers with different occupations in which caregivers working as businessmen used the most, and those working as office staff used the least self-blame ($p<0.05$).

Regarding the working place, there was no significant difference in using self-support, external support, or self-distraction coping styles by caregivers working at home or outside ($p>0.05$). However, caregivers working outside used the least self-blame while those working both inside and outside the house used the most self-blame ($p<0.05$).

It has a tendency that caregivers who had to change or quit their jobs for taking care of CP children used self-support, external support, and self-blame more than those without changing the job. But the only difference in coping with self-blame was significant ($p<0.01$).

3.2.2.3. Difference in coping strategies of caregivers by CP child's features

There was no significant difference with p>0.05 in mean scores of all coping strategies used by caregivers of male and female CP children.

The correlation between the CP child's age and seeking external support, and self-distraction coping styles were statistically significant in that the younger the child is the more seeking external support and the less self-distraction coping strategies the caregivers used ($r<0.05$).

Table 3.11: Correlation between coping strategies and
 # years living with CP

Coping strategies	# years child living with CP (r)
Self-support focused	-0.01
Self-blame	-0.13^{*}
Seeking external support	-0.12^{*}
Self-distraction	0.07

**. Correlation is significant at the 0.05 level (2-tailed).*

The Pearson correlation between coping styles used by caregivers and the number of years the child living with CP was made. The result showed that the more years the child lived with CP, the less seeking external support and the less self-blame the caregivers used to cope with the CP child caring stress ($p<0.05$). It could be understood that the more time living with CP, the more adaptive the caregivers were to take care of the child.

* There were no differences in coping strategies used by caregivers with the child of different types of CP conditions (spastic, dyskinetic, ataxic, soft paralyzed, mixed CP, no classified) ($p>0.05$).

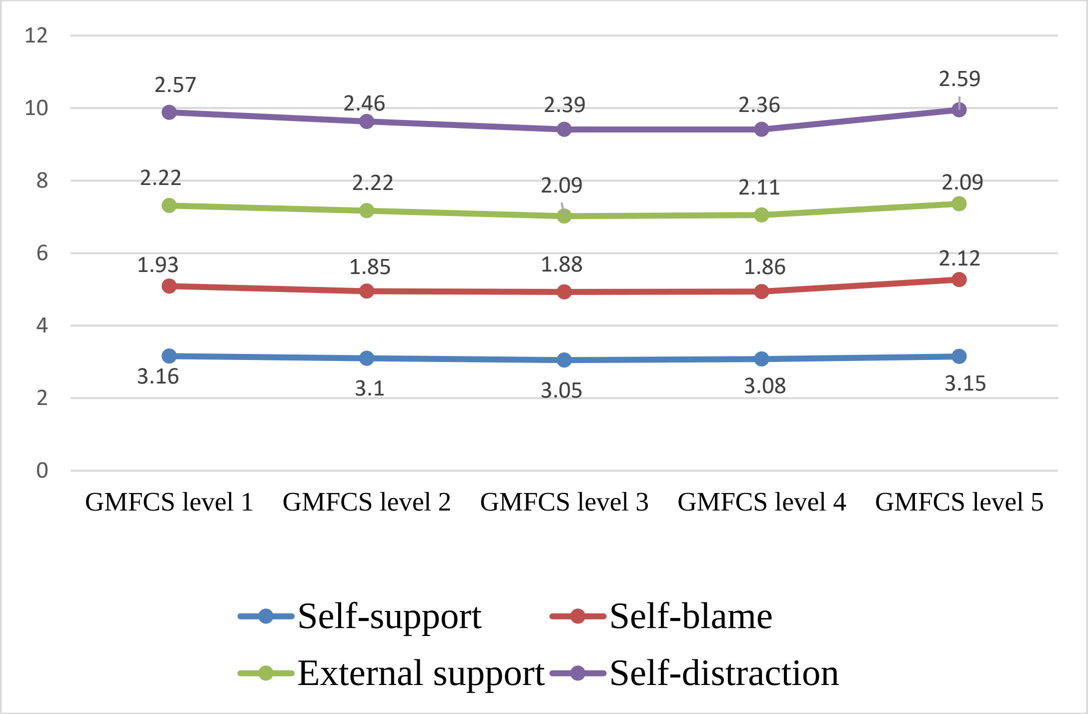


Figure 3.7. Differences in coping by CP child's motor function impairments

Caregivers of children with the most severity of gross motor function impairments measured by GMFCS were likely to use the most self-blame and behavioral disengagement coping strategies than those of children with the less severity of motor impairments. The different was significant with $p<0.05$. No distinction in using self-support, external support, or self-distraction coping by caregivers of different severity levels of motor functions ($p>0.05$).

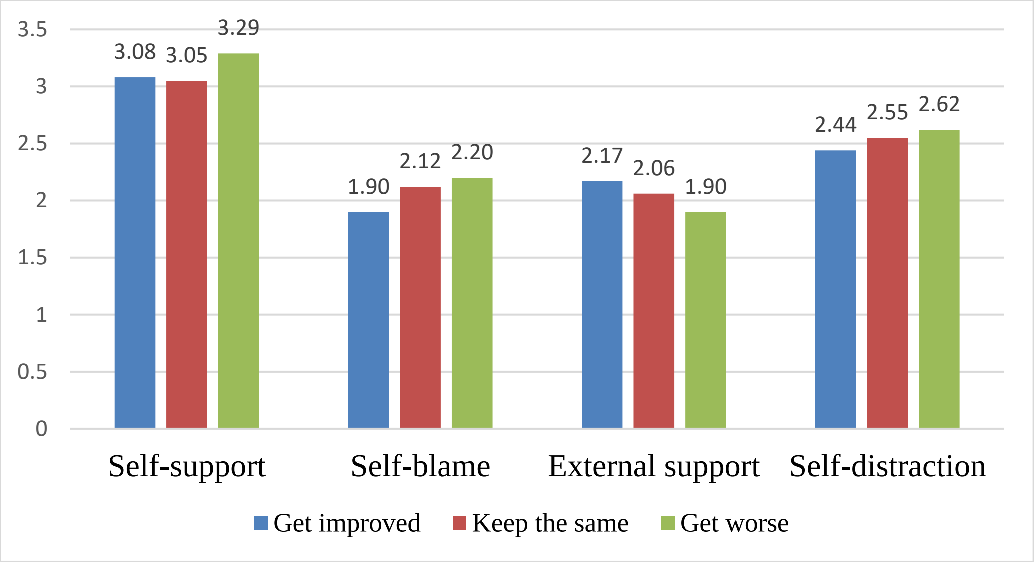


Figure 3.8. Differences in coping strategies by CP prognosis

Caregivers of children with improved CP conditions were likely to use more external support and less self-blame while those with CP children whose conditions get worse used less external support and more self-blame ($p<0.05$). No dissimilarity in using self-support, and self-distraction coping strategies among caregivers of children with different CP prognoses ($p>0.05$).

Table 3.12: Correlation between coping strategies and functional impairments, independent living of CP children

Coping strategies	Total functional impairments (r)	Independent living (r)
Self-support focused	0.16^{**}	-0.07
Self-blame	0.24^{**}	-0.18^{**}
Seek external support	0.01	0.03
Self-distraction	0.16^{**}	0.02

**. Correlation is significant at the 0.05 level (2-tailed).*

***. Correlation is significant at the 0.01 level (2-tailed).*

The above table suggested that the caregivers with CP children having more functional impairments in terms of vision, hearing, speaking, learning, and communication were likely to use more self-oriented coping styles such as self-support, self-blame, and self-distraction to cope with caregiving stress ($p<0.01$). The more independent living in the daily activity of CP children, the less self-blame the caregivers had ($p<0.01$).

3.2.2.4. Difference in coping strategies of caregivers by family conditions

Table 3.13: Correlation between coping strategies and family incomes

Coping strategies	Family incomes (r)
Self-support focused	-0.15^{**}
Self-blame	-0.13^{*}
Seek external support	-0.05
Self-distraction	-0.05

**. Correlation is significant at the 0.05 level (2-tailed).*

***. Correlation is significant at the 0.01 level (2-tailed)*

The above results implied that the more incomes caregivers' families earned, the less self-support and less self-blame strategies used by the caregivers to cope with stress ($p<0.05$).

Regarding the physical living environment such as living space, separate rooms, and accessible toilets, the caregivers with more inconvenient living conditions used more self-distraction coping than those with convenient situations ($p<0.05$). No significant differences in using self-support, self-blame, and seeking external support coping by caregivers with different living conditions ($p>0.05$).

3.2.2.5. Difference in coping strategies of caregivers by the burden of care

Table 3.14: Correlation between coping strategies and care responsibilities

Coping strategies	# years taking care of CP child (r)	# hours/day taking care CP child (r)
Self-support focused	-0.02	0.14^{**}
Self-blame	-0.09	0.11^{*}
External support	-0.16^{**}	0.04
Self-distraction	0.12^{*}	-0.04

**. Correlation is significant at the 0.05 level (2-tailed).*

***. Correlation is significant at the 0.01 level (2-tailed).*

The above table announced that the more years the caregivers care for CP child, the less external support and the more self-distract coping ways used by the caregivers ($p<0.05$), and the more. The more hours per day they spent caring for CP children the more likely they used self-support and self-blame to cope with stress ($p<0.05$).

Table 3.15: Correlation between coping strategies and burden of care

The burden of care was measured by total scores of Caregiver Difficulties Scales (CDS) as well as by mean scores of four specific caregiving burden types.

Coping strategies	Self-support *(r)*	Self-blame *(r)*	External support *(r)*	Self-distraction *(r)*
Total burden of care	0.14^{*}	0.46^{**}	0.05	0.11^{*}
Worry for Child	0.17^{**}	0.37^{**}	0.15^{**}	0.09
Impact on Self	0.05	0.40^{**}	0.15^{*}	0.14^{**}
Lack of Family Support	-0.10	0.13^{*}	-0.21^{**}	-0.03
Lack of Time	0.19^{**}	0.34^{**}	0.03	0.10

**. Correlation is significant at the 0.05 level (2-tailed).*

***. Correlation is significant at the 0.01 level (2-tailed).*

It seems obvious from the above table that the more caregiving burden caregivers experience, the more self-oriented coping strategies such as self-support, self-blame, and self-distraction are used by caregivers ($r<0.05$).

Further analyzing the relations among specific types of caring burdens and coping ways, we could say that:

- The more caregivers worry for the child, the more self-oriented coping they use to deal with that ($r<0.05$).
- The more caregiving burdens impact on self, the more self-blame, self-distraction, and external support coping they use ($r<0.05$);
- The more caregivers lack family support, the more self-blame and the less external support coping used by caregivers ($r<0.05$);
- The more burdens in terms of lacking the time for themselves, the more self-

support and self-blame-based coping applied by caregivers ($r<0.05$);

3.2.2.6. Difference in coping strategies of caregivers by social support

As for total social support, there was a statistically significant negative correlation between caregivers receiving comprehensive social support and self-blame used by them as a coping strategy to respond to stress ($p<0.01$). The more social support they get the less critique they had about themselves, and the fewer attempts of giving up trying to deal with caregiving stress they had.

In reviewing the specific type of support, we learned that:

- No significant difference in coping strategies used by caregivers who received or not received financial support from the government, got assistive devices or not, having health insurance or not ($p>0.05$).
- The more often the CP child attends special education services and rehabilitation facilities, the less self-blame caregivers used ($p<0.05$).
- The more they get information on how to care for a CP child, the more caregivers mobilize external support and vice versa ($p<0.05$).
- It was interesting to know that the more frequently caregivers participate in the activities of the Cerebral Palsy Family Association, the more self-support focused and less self-blame coping they used to overcome caregiving stress ($p<0.05$).

Key messages on coping strategies and their associated factors

- ➢ To respond to caregiving stressful situations, the studied caregivers generally tend to utilize positive coping more than negative ones. Of which they used the most frequent self-support coping such as acceptance and used self-blame the least. Caregivers living in Central regions used the most self-support-oriented coping and those living in the North used the least. The caregivers living in the Southern region used the most religious practice, and those in the North used the least.

- Caregivers using more self-blame & behavior disengagement coping were those: living in rural areas, working as businessman, working both inside and outside the house, having lower incomes, having younger CP child, having child with fewer years of living with CP, having CP children with more severe motor functions impairments, less improvement of CP conditions, those with more caregiving burdens, and those with less social support, especially less accessibility to special education services, to rehabilitation services for CP child, and not joining peer support group through CPFAV
- It was interesting to find that caregivers following Buddhism used specific coping ways of “acceptance” the least as compared to those without religion or those following the Christian religion.

3.3. The factors associated with the mental health status of the caregivers

3.3.1. Correlation among depression, anxiety, and quality of life

Table 3.16. Correlation among PHQ-9, GAD-7 and QoL

		PHQ-9	GAD-7
GAD-7	Pearson Correlation	0.84**	
QoL	Pearson Correlation	-0.44**	-0.45**

**. Correlation is significant at the 0.05 level (2-tailed).*
***. Correlation is significant at the 0.01 level (2-tailed).*

The above table showed that there was a strong positive correlation between PHQ-9 scores and GAD-7 scores with $p<0.01$ and $r>0.7$. That means caregivers with higher depression scores were likely to have higher anxiety scores. The PHQ and GAD scores had an average negative correlation with QoL scores with $p<0.01$ and $r<0.5$. The more scores of PHQ and GAD the caregivers had the fewer scores of QoL they got.

3.3.2. Factors associated with depression of caregivers

3.3.2.1. Association between coping strategies and depression

Table 3.17: Effects of different coping strategies on depression

Coping strategies	*p*	*Partial Eta Squared*
Total effects of each variable		
Self-support	*<0.05*	0.016
Self-blame	*<0.01*	0.155
Seeking external support	*<0.05*	0.018
Self-distraction	*<0.05*	0.017
Interaction effects among variables		
Corrected Model	*<0.01*	0.167
Intercept	*>0.05*	0.001
Self-support	*>0.05*	0.001
Self-blame	*<0.01*	0.051
Seeking external support	*>0.05*	0.003
Self-distraction	*>0.05*	0.001
Self-support*Self-blame*External support*Self-distraction	*>0.05*	0.000

General Linear Model (GLM) was applied to identify the main effects of independent variables (coping strategies) on the changes in mean scores of the dependent variable (depression). It is interpreted that the partial eta squared as a small effect (0.01), medium effect (0.06), or large effect (0.14). Partial Eta Squared also measures the proportion of the total variance in the dependent variable (depression) that is associated with the independent one (coping strategy) (Miles, J., & Shevlin, M. 2001).

The above table showed that when analyzing separately the total effects of each coping way on depression scores, all four coping strategies had significant effects on the PHQ-9 mean scores ($p<0.05$). It was notable that self-blame coping strategies had the biggest effect on depression, accounting for 15.5% of the total variance in PHQ-9 mean scores. While self-support, seeking external support, and self-distraction had small effects on the change of PHQ-9 mean scores, accounting for under 2% of the total variance in depression mean scores.

Effects of interaction among four coping styles were not significant with p>0.05. That means the effects of each coping strategy on the variance of caregivers' PHQ scores did not depend on the effects of the other coping on PHQ scores. In this interaction model, the main effects of self-blame coping responses are statistically significant with p<0.05 while the main effects of the other coping mechanisms are not significant with p>0.05. That means self-blame coping style, but not self-support, seeking external support, and self-distraction styles, had effects on the variance of depression scores when all of them were put together in the model of interaction towards changes in depression mean scores.

3.3.2.2. Effects of social support on caregivers' depression

Table 3.18: Effects of social support on caregivers' depression

Social support	PHQ-9 mean scores (SD)	*p*	*Partial Eta Squared*
Total social support		*<0.01*	0.021
CP child attending special education			
No	9.33 (6.22)	*<0.05*	0.026
Sometimes	9.74 (6.04)		
Often	6.93 (6.08)		
Getting information on caring CP child			
No	9.65 (6.38)	*<0.01*	0.030
Sometimes	9.03 (6.03)		
Often	6.03 (3.96)		

Social support	PHQ-9 mean scores (SD)	*p*	*Partial Eta Squared*
Interaction between special education and information support			
Corrected Model		<*0.01*	0.068
Intercept		<*0.01*	0.483
Special education support		>*0.05*	0.018
Information support		<*0.05*	0.022
Education*Information support		>*0.05*	0.016

Total scores of all kinds of social support (government monthly financial support for CP child, for caregivers, provision of health insurance, assistive devices for CP child, giving information on how to care CP child, education and rehabilitation services were used by CP child, joining activities of the CP Family Association…) were found to be negatively associated with the depression scores (p<0.01). The more social support received by caregivers the less likely the caregivers to be at risk of depression. However, the effect size was small, accounting for 2.1% of the total variance on PHQ-9 scores.

Analyzing the effects of each specific type of social support on the changes in PHQ-9 scores, no statistically significant effects on caregivers' depression have been found for monthly financial support of the government, health insurance provision, rehabilitation services for CP child, legal support services, joining activities of the CPFA (*p>0.05*).

Only special education and information support had significant effects on caregivers' depression (*p<0.05*).

The above table reported that PHQ-9 mean scores of caregivers with CP children often attending the special education centers were lower than those with CP children not attending the special education centers with p<0.05. Caregivers often receiving information on how to care for CP child has the least mean scores of PHQ-9 with p<0.05. However, the effect sizes of both mentioned social supports were small: effects of getting information on caring for CP child, and getting special education services for CP child accounted for about 3% of the variance in depression scores.

The effects of interaction between the two variables were not significant with p>0.05. That means the effects of special education support on the variance of caregivers' PHQ scores did not depend on the effects of information support and vice versa. In this interaction model, the main effects of information support were statistically significant with p<0.05 while the main effects of special education support were not significant with p>0.05. That means mainly information support, but not special education support, had effects on the variance of depression scores when both were put together in the model of interaction towards changes in depression.

3.3.2.3. Effects of family support and family incomes on caregivers' depression

Table 3.19: Effects of the family's support and incomes on depression

Independent Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
Family support	*<0.01*	0.031
Monthly incomes	*<0.01*	0.042
Interaction effects among variables		
Corrected Model	*<0.01*	0.067
Intercept	*<0.01*	0.163
Family support	*<0.01*	0.024
Monthly incomes	*>0.05*	0.000
Family support *family incomes	*>0.05*	0.006

Reviewing the total effects of each variable, family support, and family incomes had significant small effects on their depression scores ($p<0.05$) in which family support accounted for 3.1%, and family incomes accounted for 4.2% of the variance in depression scores. The more incomes caregivers get the less likely they were at risk of depression ($\beta=-.088$). The less family support they got the more likely they could suffer from depression ($\beta=-1.4$).

The effects of interaction between the two variables were not significant with p>0.05. That means the effects of family support on the variance of caregivers' PHQ scores did not depend on the effects of family incomes on depression scores and vice versa. In this interaction model, the family support, but not monthly incomes, had effects on the variance of depression scores when both of them were put together in the model of interaction towards changes in depression.

3.3.2.4. Effects of key risk factors on caregivers' depression

*** Care responsibilities**

Table 3.20: Effects of care responsibilities on depression

Independent Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
#years caring for CP child	*<0.05*	0.012
#hours/day caring for CP child	*<0.01*	0.035
Interaction effects among variables		
Corrected Model	*<0.01*	0.042
Intercept	*<0.01*	0.055
#years caring for CP child	*>0.05*	0.001
#hours/day caring for CP child	*<0.05*	0.019
#years * #hours/day	*>0.05*	0.005

To evaluate separately the total effects of two indicators of care responsibilities on the depression scores of caregivers: the number of years caregivers taking care of CP child; and the number of hours per day of caring for CP child, we found out that those mentioned indicators had significant effects with $p<0.05$ however the effects sizes were rather small. It was noted that the more year caring for CP child the less likely depression mean scores caregivers had ($\beta=-.202$). On the reverse, the more hours per day caregivers spend for the CP child the more likely risks of depression they would take ($\beta=.162$).

The general linear model was also used to identify the interaction effects between the number of years and the number of hours per day caregivers taking care of CP children on the caregivers' PHQ-9 scores. The interaction was not statistically significant with $p>0.05$. That means the effects of caring daily hours on caregivers' PHQ scores did not depend on the number of years taking care of CP child and vice versa. And the effect of number hours per day had significant effects, but the number of years caring had no significant effects on the caregivers' depression scores in the interaction model.

*** Burden of care**

The Caregiver Difficulties Scale (CDS) was used to evaluate the burden of giving care to children with CP. A higher score of CDS implies a greater burden on the lives of caregivers. The burden of care was also specified into four sub-groups including: Worry for the Child, Impact on Self, lack of family support, and lack of time for self-care and own living of caregivers. General Linear Model was applied to investigate the effects of total burden of care as well as the effects of specific burden types on the variance of PHQ-9 scores.

Table 3.21. Effects of caregiving burden on depression

Burden of care	*p*	*Partial Eta Squared*
Total effects of each variable		
Total CDS	*<0.01*	0.295
Worry for the Child (WC)	*<0.01*	0.159
Impact on Self (IS)	*<0.01*	0.212
Lack of Family Support (FS)	*<0.01*	0.031
Lack of Time (LT)	*<0.01*	0.210
Interaction effects among variable		
Corrected Model	*<0.01*	0.323
Intercept	*<0.05*	0.020
Worry for the Child (WC)	*<0.01*	0.024
Impact on self (IS)	*<0.01*	0.037
Lack of Family Support (FS)	*>0.05*	0.002
Lack of Time (LT)	*<0.01*	0.055
WC*IS*FS*LT	*>0.05*	0.000
WC*LT	*<0.01*	0.041

The burden of care had very big effects on the variance of depression of caregivers with $p<0.05$ in which the total caregiving burden accounted for 29.5% of the variance in the caregivers' depression scores.

Firstly, the identification of the total effects of each specific type of caregiving burden on the change in PHQ-9 mean scores expressed that all of them were significant effects on PHQ-9 mean scores ($p<0.01$). Of which, burdens relating to the impact self-created the biggest impacts on depression scores (21.2%), followed by lack of time (21.0%), and worry for the child (15.9%) while lack of family support had very small effects, accounted for 3.1% of the variance in depression scores.

Effects of interaction among all variables were not significant with $p>0.05$ when putting them in one model. The effects of each burden type were not influenced by the effects of the others on the variance of caregivers' PHQ scores. However, analyses of interaction effects between the worry of the child and lack of time were found significant ($p<0.01$). Effects of worrying for children created more effects of time lacking on depression and vice versa.

*** CP child's disability conditions**

Table 3.22. Effects of CP child-related factors on depression

Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
CP child ages	<0.05	0.016
Years living with CP	<0.01	0.021
Functional impairments	<0.01	0.030
Independence in daily living	<0.05	0.022
Interaction effects among variable		
Corrected Model	<0.01	0.054
Intercept	<0.01	0.034
CP child ages (A)	>0.05	0.001
Years living with CP (YL)	>0.05	0.009
Functional impairments (FI)	>0.05	0.004
Independence in daily living (I)	>0.05	0.007
A*YL*FI*I	>0.05	0.005

Ages of the CP child, the number of years living with CP, the level of functional impairments, and the independence level in the daily living of the CP child had small significant effects on the variance of the caregivers' depression scores, which accounted for less than 3% of the variance.

It was noted that caregivers of the younger CP children were likely to have a higher risk of depression than those of the older children with CP. The caregivers of children with more years living with CP are less likely to have depression than those of children with less years living with CP.

The caregivers of children with more severity of functional impairments, with lower independence in daily living activities are more likely to have depression than those of the children with less severity level of functional impairments and higher level of independence in daily living activities.

No significant effects of interaction among the above-mentioned CP child-related factors on the PHQ-9 mean scores were found (p>0.05).

There were no significant effects of CP types (spastic, dyskinetic, ataxic, soft paralyzed, mixed CP); level of motor functions following GMFCS, and level of CP prognosis on the variance of PHQ-9 scores (*p>0.05*).

3.3.2.5. Effects of interactions among moderators and risk factors on depression

This section analyzed the effects of interaction on the variability of depression scores among the so-called moderators (coping strategies used by caregivers, and social support-related factors) and risk factors (caregiving responsibilities including number of hours per day for caring for CP child, number of years taking care for CP child; functional impairment of CP child, level of independence in daily living of CP child, and all types of perceived caregiving burdens of caregivers (worrying for child, impact on self, lack of family assistance, lack of time for self-care and own living). Only the significant effects of interaction with p<0.05 among moderators and risk factors on depression scores were presented in the tables below.

*** Interaction between coping strategies and the risk factors for depression**

Table 3.23: Effects of interaction between coping strategies and risk factors on depression

Variables	*p*	*Partial Eta Squared*
Interaction between self-blame and number of hours per day caring CP child		
Corrected Model	<0.01	0.191
Intercept	<0.05	0.015
Self-Blame (SB)	>0.05	0.008
#hours/day caring for child (#H)	>0.05	0.007
SB*#H	<0.05	0.018
Interaction between seeking external support and worrying for the child		
Corrected Model	<0.01	0.175
Intercept	>0.05	0.007
External support (ES)	>0.05	0.007
Worry for Child (WC)	>0.05	0.000
ES*WC	<0.05	0.012

As for the first coping factor of self-support, no statistically significant effects of interaction were found among this coping with the risk factors ($p>0.05$). That means the effects of self-support focused support did not influence the effects of those risk factors on the depression scores and vice versa.

Relating to the second coping factor of self-blame, we found the statistically significant effects of interaction between this coping and the number of hours per day caregivers spent caring for CP child ($p<0.05$). That means the more self-blame caregivers had, the more effects the number of hours per day for caring for CP care on the depression scores and vice versa. There were no significant effects among self-blame coping mechanisms and other risk factors (number of years taking care of CP child, functional impairment of CP child, level of independence in daily living of CP child; all types of caregiving burden) ($p>0.05$).

Concerning the third coping factor of seeking external support, we found the effects of interaction between this coping and caregiving burden kind of worrying for the child were significant ($p<0.05$). That means the effects of seeking external support impacted the effects of worrying about the child on the depression scores and vice versa. Effects of interaction between the seeking external support coping way and other risks factors (caregiving responsibilities, functional impairment of CP child, level of independence in the daily living of CP child; types of caregiving burden like impact on self, lack of family assistance, lack of time) were not significant ($p>0.05$). Seeking external support did not control the effects of those mentioned risk factors on the PHQ-9 mean scores.

As for the fourth coping factor of self-distraction, no statistically significant effects of interaction were found among this coping with the risk factors ($p>0.05$). That means the effects of self-distraction did not influence the effects of those risk factors on the depression scores and vice versa.

*** Interaction between social support and the risk factors**

General Linear Model was used to analyze the effects of interaction on the change in depression scores among total social support and specific kinds of social support (government's monthly financial support, assistive device supply, getting special education, rehabilitation services, health insurance provision, information support, joining activities of CPFAV) and risk factors including caregiving responsibilities (number of hours per day for caring CP child, number of years taking care for CP child), functional impairment of CP child, level of independence in the daily living of CP child, and all types of caregiving burden (worrying for the child, impact on self, lack of family assistance, lack of time).

Table 3.24: Interaction between social support and risk factors on depression

Variables	*p*	*Partial Eta Squared*
Interaction between assistive device supply and worry for the child		
Corrected Model	*<0.01*	0.174
Intercept	*<0.05*	0.015
Assistive Device Supply (AD)	*<0.05*	0.017
Worry for Child (WC)	*<0.01*	0.069
AD*WC	*<0.05*	0.018
Interaction between getting rehabilitation services and impact on self		
Corrected Model	*<0.01*	0.235
Intercept	*<0.01*	0.043
Rehabilitation Services (RS)	*<0.01*	0.029
Impact on Self (IS)	*>0.05*	0.000
RS*IS	*<0.01*	0.028
Interaction between CP child’s health insurance and functioning impairments		
Corrected Model	*<0.01*	0.044
Intercept	*>0.05*	0.018
Health insurance (HI)	*<0.05*	0.014
Functioning Impairments (FI)	*>0.05*	0.009
HI*FI	*<0.05*	0.013
Interaction between joining activities of CPFAV and Impact on Self		
Corrected Model	*<0.01*	0.222
Intercept	*>0.05*	0.002
Joining CPFAV activities (CPFAV)	*>0.05*	0.008
Impact on Self (IS)	*<0.01*	0.056
CPFAV*IS	*<0.05*	0.012

The above table showed that the effects of providing an assistive device for a CP child could influence the effects of the caregiving burden relating to worry for the child towards the changes in depression mean scores and vice versa ($p<0.05$). Besides, the effects of going to rehabilitation facilities, or the effects of joining CPFAV activities could control the effects of impact on self towards the variance of depression scores and vice versa ($p<0.05$). There were significant effects of interactions among CP children having health insurance cards and total function impairments on the changes in PHQ-9 mean scores. Having health insurance for the CP child could impact the effects of functional impairments of the CP child on depression scores ($p<0.05$).

There were no statistically significant effects of interaction among the government's monthly financial support, the CP child attending special education centers and providing information on how to care for the CP child with all mentioned risk factors on the variance of depression scores ($p>0.05$).

Key points on predictors for caregivers' depression

- The statistically significant factors associated with caregivers' depression included: caregivers with anxiety, coping strategies used by caregivers, social support, especially for utilization of special education services, getting necessary information, family support, family incomes, number of years and number of hours per day caring for CP child, caregiving burdens, ages of CP child, total functional impairments and level of independence in the daily living of CP child ($p<0.05$)
- The most important predictors for caregivers' depression were self-blame based coping and perceived caregiving burden, more especially for the burden on unmet needs of caregivers' living. Of which 15.5% and 29.5% of changes in depression mean scores were attributable to self-blame and burden of care respectively.
- Coping strategies could reduce or increase the effects of caregiving burdens or caregiving responsibilities on caregivers' depression. The more self-blame caregivers use the more effects of the daily caring hours on depression scores. The more caregivers seek internal support the less effects of caregiving burdens "worrying about the child" on the depression mean scores.

- Some specific social support types (provision of assistive devices, rehabilitation services for the child, joining peer support groups of CPFAV, and providing health insurance) could help lessen the effects of caregiving burden or functional impairments on depression.

3.3.3. Factors associated with anxiety of caregivers

3.3.3.1. Association between coping strategies and anxiety

Table 3.25: Effects of different coping strategies on anxiety

Coping strategies	*p*	*Partial Eta Squared*
Total effects of each variable		
Self-support	*<0.01*	0.044
Self-blame	*<0.01*	0.138
Seeking external support	*<0.05*	0.015
Self-distraction	*<0.05*	0.016
Interaction effects among variables		
Corrected Model	*<0.01*	0.168
Intercept	*>0.05*	0.000
Self-support	*>0.05*	0.011
Self-blame	*<0.05*	0.025
Seeking external support	*>0.05*	0.000
Self-distraction	*>0.05*	0.002
Self-support*Self-blame*External support*Self-distraction	*>0.05*	0.003

The above table reported the results of the total effects of each coping response (self-support, self-blame, seeking external support, and self-distraction) on the anxiety scores when analyzing separately the simple main effects under the general linear model. All four coping strategies had significant effects on the GAD-7 scores (*p<0.05*). As the same as those coping effects on depression scores, self-blame coping strategies also made the biggest effect on anxiety scores, accounting for 13.8% of the total variance in GAD-7 scores. While self-support, seeking external support, and self-distraction coping mechanisms had small effects on the change of anxiety scores in which 4.4%, 1.5%, and 1.6% of the variability in the dependent measure (GAD-7 scores) were attributable to self-support, external support, and self-distraction respectively.

Additionally, GLM analysis results indicated the effects of interaction among three coping styles on the changes in anxiety scores which were not significant (*p>0.05*). That means the effects of each coping strategy on the variance of caregivers' GAD scores did not depend on the effects of the other coping on GAD scores. Under the interaction model, the main effects of self-blame coping responses were statistically significant with p<0.05 while the main effects of the other coping styles including self-support, seeking external support or self-distraction were not significant with p>0.05. That means self-blame coping style, but not self-support, seeking external support, and self-distraction styles, had effects on the variance of anxiety scores when all of them were put together in the model of interaction towards changes in anxiety mean scores.

3.3.3.2. Effects of social support on caregivers' anxiety

Table 3.26: Effects of social support on caregivers' anxiety

Social support	GAD-7 scores mean (SD)	*p*	*Partial Eta Squared*
Total social support		*<0.01*	0.025

Social support	GAD-7 scores mean (SD)	*p*	*Partial Eta Squared*
CP child attending special education			
No	7.79 (5.05)	*<0.01*	0.032
Sometimes	8.22 (4.79)		
Often	6.93 (6.08)		
CP child attending rehabilitation facility			
No	7.79 (4.17)	*<0.05*	0.020
Sometimes	8.23 (5.23)		
Often	6.69 (4.77)		
Getting information on caring CP child			
No	8.16 (5.14)	*<0.05*	0.027
Sometimes	7.37 (4.65)		
Often	5.40 (4.33)		
Interaction between education, rehabilitation and information support			
Corrected Model		*>0.05*	0.076
Intercept		*<0.01*	0.313
Special education support		*>0.05*	0.010
Rehabilitation support		*>0.05*	0.002
Information support		*>0.05*	0.011
Education*Rehabilitation*Information support		*>0.05*	0.016

General Linear Model analyzed the effects of total social support, the effects of each specific social support type, and the interaction effects among them on the anxiety scores. The above results expressed that total scores of all kinds of social support (government monthly financial support for CP child, for caregivers, provision of health insurance, assistive devices for CP child, giving information on how to care for CP child, education and rehabilitation services were used by CP child, joining activities of the CP Family Association…) were found to be negatively associated with the anxiety scores ($p<0.01$, $\beta=-0.3$). The more social support received by caregivers the less likely the caregivers be at risk of anxiety. However, the effect size was small, only 2.5% of the variability in the GAD-7 scores was attributable to this variable.

Evaluating the effects of each specific type of social support on the changes in GAD-7 scores revealed that no statistically significant effects of monthly financial support of the government, health insurance provision, assistive device supply, legal support services, joining activities of the CPFA on caregivers' anxiety scores were found ($p>0.05$).

Three types of support including special education, rehabilitation, and information support had significant effects on caregivers' anxiety ($p<0.05$).

The mean GAD scores of caregivers with CP child often attending the special education centers, often going to a rehabilitation facility, and often receiving information on how to care for CP child was lower than those with CP child not attending the special education centers, not going to rehabilitation facilities, not receiving information with $p<0.05$. Although the effect sizes of those mentioned social supports were small, the effect of getting special education services for CP children on anxiety scores was higher than those of using rehabilitation services, and getting information support on how to care for CP children, 3.2% of the variance on anxiety scores.

The effects of interaction between those three specific social supports were not significant with $p>0.05$. That means the effects of each above-mentioned social support on the variance of caregivers' GAD scores did not depend on the effects of the others and vice versa.

3.3.3.3. Effects of family support and family incomes on caregivers' anxiety

Table 3.27: Main effects of the family's support and incomes on anxiety

Independent Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
Family support	<*0.01*	0.047
Monthly Incomes	<*0.01*	0.041
Interaction effects among variables		
Corrected Model	<*0.01*	0.079
Intercept	<*0.01*	0.160
Family support	<*0.01*	0.032
Monthly incomes	>*0.05*	0.000
Family support *family incomes	>*0.05*	0.006

Results of the simple main effects analysis pointed out that family support and family income had small significant effects on their anxiety scores ($p<0.01$) in which 4.7% and 4.1% of the variance on GAD-7 scores were attributable to effects of family support, and family incomes respectively.

No significant effects of interaction were found between family support and family incomes (p>0.05). The effects of family support on the changes in anxiety scores did not depend on the effects of family incomes on the variance of GAD scores and vice versa. The family support, but not monthly incomes, had effects on the variance of GAD scores when both were put together in the model of interaction toward changes in anxiety scores.

3.3.3.4. Effects of key risk factors on caregivers' anxiety

*** Caregiving responsibilities**

Table 3.28: Effects of care responsibilities on anxiety

Care responsibilities	*p*	*Partial Eta Squared*
Total effects of each variable		

Care responsibilities	*p*	*Partial Eta Squared*
#years caring for CP child	<*0.05*	0.018
#hours/day caring for CP child	<*0.01*	0.035
Interaction effects among variables		
Corrected Model	<*0.01*	0.049
Intercept	<*0.01*	0.065
#years caring for CP child	>*0.05*	0.000
#hours/day caring for CP child	<*0.05*	0.019
#years * #hours/day	>*0.05*	0.005

The above table announced that the main effects of two indicators of care responsibilities on the anxiety scores of caregivers, the number of years caregivers taking care of CP child; and the number of hours per day of caring for CP child, had significant effects ($p<0.05$), the effects sizes of daily care on the changes in anxiety scores were higher than those of yearly care, 3.5% versus 1.8% although the effects sizes were rather small. It was noted that the more years caregivers care for CP children the less likely their anxiety mean scores got ($\beta=-.194$). On the reverse, the more hours per day caregivers spend for the CP child the more likely risks of anxiety they would take ($\beta=.139$).

The interaction effects between the number of years and the number of hours per day caregivers taking care of CP children on the caregivers’ GAD-7 scores were not statistically significant with $p>0.05$. That means the effects of caring daily hours on caregivers’ GAD scores did not depend on the number of years taking care of CP child and vice versa. Effect of number hours per day caregivers caring for the CP child had significant effects, but the number of years caring had not significant effects on the caregivers’ anxiety scores when putting two of them into the interaction model.

*** Burden of care**

The association between the burden of care through the Caregiver Difficulties Scale (CDS) and the anxiety mean scores were analyzed based on the general linear model.

Table 3.29. Effects of caregiving burden on anxiety

Burden of care	*p*	*Partial Eta Squared*
Total effects of each variable		
Total CDS	*<0.01*	0.328
Worry for the Child (WC)	*<0.01*	0.160
Impact on Self (IS)	*<0.01*	0.198
Lack of Family Support (FS)	*<0.01*	0.047
Lack of Time (LT)	*<0.01*	0.264
Interaction effects among variable		
Corrected Model	*<0.01*	0.356
Intercept	*<0.05*	0.031
Worry for the Child (WC)	*<0.01*	0.022
Impact on self (IS)	*<0.01*	0.029
Lack of Family Support (FS)	*>0.05*	0.007
Lack of Time (LT)	*<0.01*	0.096
WC*IS*FS*LT	*>0.05*	0.000
WC*LT	*<0.01*	0.022

The similarity of effects on depression scores, CP child caregiving burdens had large effects on the variance of caregivers' anxiety scores in which the total effects of burden of care accounted for 32.8% of the variance in the caregivers' GAD-7 scores ($p<0.01$). The more caring burdens caregivers had the more they were likely to be at risk of anxiety ($\beta=.250$).

In terms of the main effects of each specific burden category on the variance of GAD-7 mean scores, all of them had significant effects on anxiety scores ($p<0.01$). Of which, burdens relating to lack of time created the largest impacts on GAD-7 scores (26.4%), followed by impact on self (19.8%), and worry for the child (16.0%) while lack of family support had very small effects, accounted for 4.7% of the variance in anxiety scores.

There were no statistically significant effects of interaction among all patterns of caregiving burdens when putting them in one model ($p>0.05$). Therefore, the effects of each burden group did not be influenced by the effects of the others on the variance of caregivers' GAD-7 scores. However, analyses of interaction effects between two sets of burdens, worry for the child, and lack of time were found significant ($p<0.01$). Effects of worrying for the child created more effects of time lacking on anxiety and vice versa.

*** CP child's disability conditions**

Table 3.30. Effects of CP child-related factors on anxiety

Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
CP child ages	*<0.01*	0.028
Years living with CP	*<0.01*	0.026
Functional impairments	*<0.01*	0.026
Independence in daily living	*<0.01*	0.020
Interaction effects among variables		
Corrected Model	*<0.01*	0.054
Intercept	*<0.01*	0.034
CP child ages (A)	*>0.05*	0.001
Years living with CP (YL)	*>0.05*	0.009
Functional impairments (FI)	*>0.05*	0.004
Independence in daily living (I)	*>0.05*	0.007
A*YL*FI*I	*>0.05*	0.005

The CP child's age, number of years CP child living with CP, level of functional impairments, and independence level in daily living of CP child had small significant effects on the variance of the caregivers' anxiety scores, which accounted for 2.8% of the variance in GAD scores with $p<0.05$.

It was noted that caregivers of the younger CP children were likely to have a higher risk of anxiety than those of the older children with CP ($\beta=-.256$). The caregivers of children with more years living with CP are less likely to have the risk of anxiety than those of children with fewer years living with CP ($\beta=-.234$).

The caregivers of children with more severity of functional impairments were likely to have higher risks of anxiety than those of the children with less severity level of functional impairments ($\beta=.123$). In the reverse, the caregivers of children with higher levels of independence in daily living activities were likely to have lower risks of anxiety ($\beta=-.030$)

No statistically significant interaction effects among the above-mentioned CP child-related factors on the variance of anxiety scores ($p>0.05$). The effects of each above-mentioned independent variable on the change in anxiety scores did not control the effects of the other variables on GAD scores.

Effects of CP types (spastic, dyskinetic, ataxic, soft paralyzed, mixed CP); level of motor functions following GMFCS, and level of CP prognosis on the variance of GAD-7 scores were not statistically significant ($p>0.05$).

3.3.3.5. Interaction effects among moderators and risk factors on anxiety

Effects of interaction on the variability of anxiety scores among moderators (coping strategies used by caregivers, and social support-related factors) and risk factors (caregiving responsibilities including number of hours per day for caring for CP child, number of years taking care of CP child; functional impairment of CP child, level of independence in daily living of CP child, and all types of perceived caregiving burdens of caregivers (worrying for child, impact on self, lack of family assistance, lack of time for self-care and own living) were evaluated. Only the significant effects of interaction with p<0.05 among moderators and risk factors on anxiety were presented in the tables below.

*** Interaction between coping strategies and risk factors on anxiety**

Table 3.31: Effects of interaction between coping strategies and risk factors on anxiety

Variables	*p*	*Partial Eta Squared*
Interaction between self-blame and number of years for caring CP child		
Corrected Model	*<0.01*	0.163
Intercept	*>0.05*	0.000
Self-blame (SB)	*<0.01*	0.079
# years caring for child (#Y)	*>0.05*	0.009
SB*#Y	*<0.05*	0.017
Interaction between self-blame and total functional impairments of CP child		
Corrected Model	*<0.01*	0.160
Intercept	*<0.05*	0.014
Self-Blame (SB)	*<0.01*	0.049
Functional impairment (FI)	*<0.05*	0.025
SB*FI	*<0.05*	0.019

Relating to the coping pattern of self-support, there were no significant effects of interaction among this coping type and the risk factors (*p>0.05*). That means self-focused support coping did not interfere with the effects of those risk factors on the variance of anxiety scores.

As same as the self-focused support coping, we did not find the significant effects of interaction between seeking external support and self-distraction coping strategies and any risk factor (*p>0.05*). Seeking external support and self-distraction seems not control the effects of risk factors on the change in anxiety scores.

Regarding the second coping factor of self-blame& behavioral disengagement, we found the statistically significant effects of interaction between this coping type and the number of years caregivers spent caring for CP children ($p<0.05$). That means the effects of self-blame could deepen the effects of the number of years caring for CP children on the anxiety scores. Similarly, the significant interaction between self-blame and functional impairments of CP children ($p<0.05$) implied that the effects of self-blame coping ways used by caregivers could intensify the effects of functional impairments of CP children on the variance of anxiety scores.

*** Interaction between social support and the risk factors for anxiety**

To know whether effects of social support could moderate the effects of risk factors on the anxiety scores of caregivers, a general linear model was applied to analyze the effects of interaction on the change in anxiety scores among different kinds of social support (government’s monthly financial support, assistive device supply, getting special education, rehabilitation services, health insurance provision, information support, joining activities of CPFAV) and risk factors including caregiving responsibilities (number of hours per day for caring CP child, number of years taking care for CP child), functional impairment of CP child, level of independence in the daily living of CP child, and all types of caregiving burden (worrying for a child, impact on self, lack of family assistance, lack of time). Only the significant interaction effects were presented in the table below.

Table 3.32: Interaction between social support and risk factors on anxiety

Variables	*p*	*Partial Eta Squared*
Interaction between assistive device supply and total burden of care		
Corrected Model	<0.01	0.339

Variables	*p*	*Partial Eta Squared*
Intercept	<0.01	0.046
Assistive Device Supply (AD)	<0.05	0.014
Total burden of care (BC)	<0.01	0.108
AD*BC	<0.05	0.015
Interaction between getting rehabilitation services and total burden of care		
Corrected Model	<0.01	0.346
Intercept	>0.05	0.002
Rehabilitation Services (RS)	<0.05	0.027
The burden of care (BC)	>0.05	0.007
RS*BC	<0.01	0.027
Interaction between getting rehabilitation services and impact on self		
Corrected Model	<0.01	0.224
Intercept	<0.01	0.051
Rehabilitation Services (RS)	<0.01	0.032
Impact on Self (IC)	>0.05	0.000
RS*IS	<0.01	0.030
Interaction between getting rehabilitation services and lack of family support		
Corrected Model	<0.01	0.077
Intercept	<0.01	0.101
Rehabilitation Services (RS)	<0.01	0.032
lack of family support (FS)	>0.05	0.005
RS*FS	<0.01	0.023
Interaction between health insurance for CP child and functional impairments		
Corrected Model	<0.01	0.041
Intercept	<0.05	0.019
Health Insurance for Child (HI)	<0.05	0.014
Functional Impairments (FI)	>0.05	0.008
HI*FI	<0.05	0.012

The above table suggested that the significant effects of interaction between assistive device supply and the total burden of care perceived by caregivers ($p<0.05$) could tell that provision of assistive devices could lessen the effects of overall caregiving burden on the anxiety scores.

There were significant effects of interaction between getting rehabilitation services for CP children and the overall burden of care, impact on self, and lack of family support on the variance of anxiety scores ($p<0.05$). It seems that access to rehabilitation services could ease the effects of the overall burden of care, especially the effects of impact on self and lack of family support on the anxiety scores.

The significant effects of interaction between CP children having health insurance and functional impairments of CP children on the change in GAD-7 scores with $p<0.05$ could explain that provision of health insurance for CP children could decrease the effects of functional impairments on caregivers' anxiety scores.

No statistically significant effects of interaction were found between monthly financial support from the government, getting special education services for CP children, providing information on how to care for CP children, joining activities of CPFAV, and the risk factors on the variance of GAD-7 scores ($p>0.05$). It could imply that those social supports did not influence the effects of risk factors on the anxiety scores of caregivers.

Main points on predictors for caregivers' anxiety

- Factors significantly related to caregivers' anxiety with $p<0.05$ identified as follows: caregivers with depression, their coping mechanisms, number of years and number of hours per day caregivers have to take care of CP child, their perceived burdens of care in total and specific forms (worry for the child, impact on self, lack of family support and lack of time), ages of CP child, number of year the child living with CP, total functional impairments and level of independence in daily living of CP child, total and some specific social support kinds including the use of special education, rehabilitation services, receiving information on how to care for CP child, family support, family incomes ($p<0.05$).

- The predictors having big effects on caregivers' anxiety were self-blame-focused coping and perceived caregiving burden, especially for insufficient time for enjoying their own lives. Of which 32.8% and 13.8% of the total variance on anxiety mean scores were attributable to the burden of care and self-blame respectively. It was noted that the burden kind "lack of family support" had very small effects, accounting for only 4.7% of the total variance in anxiety scores.
- Among the four coping styles, only self-blame had significant effects of interaction with some risk factors for anxiety. Self-blame could deepen the effects of the number of years caring for a CP child or could intensify the effects of functional impairments of a CP child on caregivers' anxiety.
- Our study found that some specific forms of social support such as provision of assistive devices for CP children, utilization of rehabilitation services, and delivering health insurance cards could ease the effects of caregiving burden or functional impairments on anxiety.

3.3.4. Key factors associated with the quality of life (QoL) of caregivers

3.3.4.1. Association between coping strategies and caregivers' QoL

Table 3.33: Effects of different coping strategies on QoL

Coping strategies	*p*	*Partial Eta Squared*
Total effects of each variable		
Self-support	*>0.05*	0.004
Self-blame	*<0.01*	0.071
Seeking external support	*>0.05*	0.006
Self-distraction	*>0.05*	0.003
Interaction effects among variables		
Corrected Model	*<0.01*	0.092
Intercept	*<0.01*	0.138
Self-support	*>0.05*	0.000
Self-blame	*<0.01*	0.044
Seeking external support	*>0.05*	0.000
Self-distraction	*>0.05*	0.000
Self-support*self-blame*external support*self-distraction	*>0.05*	0.004

Firstly, looking at the results of the simple total effects analysis of each coping response (self-support, self-blame, seeking external support, and self-distraction) on the QoL scores under the general linear model, we saw that there were no significant effects of self-support, seeking external support, and self-distraction coping styles on the QoL scores ($p>0.05$). It is interesting that only self-blame coping strategies made small effects on the variance of QoL scores, accounting for 7.1% of the total variance in QoL scores. The more caregivers used self-blame to cope with caregiving stress, the less likely quality of life they had (β=-1.5).

The finding also indicated that the effects of interaction among four coping styles on the changes in QoL scores were not significant ($p>0.05$). The effects of each coping strategy on the variance of caregivers' QoL scores did not depend on the effects of the other coping on QoL scores.

3.3.4.2. Effects of social support on caregivers' QoL

Table 3.34: Effects of social support on caregivers' QoL

Social support	QoL scores mean (SD)	*p*	*Partial Eta Squared*
Total social support		*<0.01*	0.034
CP child attending special education			
No	16.18 (3.58)	*<0.01*	0.034
Sometimes	17.00 (3.48)		
Often	17.89 (3.51)		
Getting information on caring CP child			
No	16.27 (3.72)	*<0.01*	0.033
Sometimes	16.61 (3.42)		
Often	18.54 (3.39)		
Interaction between special education and information support			
Corrected Model		*<0.01*	0.068
Intercept		*<0.01*	0.929
Special education support		*>0.05*	0.027
Information support		*>0.05*	0.026
Special Education*Information support		*>0.05*	0.008

The analysis results showed that there were significant small effects of total scores of all kinds of social support (government monthly financial support for CP child, for caregivers, provision of health insurance, assistive devices for CP child, giving information on how to care CP child, education and rehabilitation services were used by CP child, joining activities of the CP Family Association…) on the variance of QoL scores ($p<0.01$). The more social support received by caregivers the more likely the caregivers have better quality of life ($\beta=0.3$). However, the effect size was small and only accounted for 3.4% of the total variance in QoL scores.

Analyzing the effects of each specific type of social support on the changes in QoL scores pinpointed that only two groups of support including getting special education services for CP child and providing information on how to care for CP child made significant effects on caregivers' QoL scores ($p<0.05$).

The QoL scores of caregivers with CP often attending the special education centers, often receiving information on how to care for CP children were higher than those with CP children not attending the special education centers, not receiving information with $p<0.05$. Although the effect sizes of those mentioned social supports were small.

The effects of interaction between those two specific social supports were not significant with $p>0.05$. That means the effects of getting special education services for CP children on the variance of caregivers' QoL scores did not control the effects of getting information on how to care for the child and vice versa.

There were no statistically significant effects of monthly financial support from the government, health insurance provision, assistive device supply, getting rehabilitation services, legal support services, or joining activities of the CPFA on caregivers' QoL scores found ($p>0.05$).

3.3.4.3. Effects of family support and family income on caregivers' QoL

Table 3.35: Main effects of the family's support and incomes on QoL

Independent Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
Family support	*<0.01*	0.200
Monthly Incomes	*<0.01*	0.072
Interaction effects among variables		
Corrected Model	*<0.01*	0.249

Intercept	*<0.01*	0.820
Family support	*<0.01*	0.146
Monthly incomes	*>0.05*	0.000
Family support *family incomes	*<0.05*	0.018

Evaluation of the simple main effects analysis demonstrated that both family support and family income had positive significant effects on the variance of QoL scores ($p<0.01$), the more family support and incomes they get the better quality of life they may have. It was noted that family support made a big impact on caregivers' QoL, 20% of the total variance in QoL scores was attributable to the effects of family support while only 7.2% of the total variance on QoL scores was attributable to the effects of family incomes.

The effects of the interaction between family support and family incomes on QoL scores were statistically significant ($p<0.05$). The effects of family support on the changes in QoL scores could control the effects of family incomes on the QoL of caregivers. The family support, but not monthly incomes, had effects on the variance of GAD scores when both variables were put together in the model of interaction towards changes in QoL scores.

3.3.4.4. Effects of key risk factors on caregivers' QoL

*** Caregiving responsibilities**

Table 3.36: Effects of care responsibilities on QoL

Care responsibilities	*p*	*Partial Eta Squared*
Total effects of each variable		
#years caring for CP child	*>0.05*	0.003

#hours/day caring for CP child	*<0.05*	0.011
Interaction effects among variables		
Corrected Model	*>0.05*	0.013
Intercept	*<0.01*	0.512
#years caring for CP child	*>0.05*	0.000
#hours/day caring for CP child	*>0.05*	0.002
#years * #hours/day	*>0.05*	0.001

The above table revealed that the main effects of the number of years caregivers taking care of CP child on the QoL scores were not significant ($p<0.05$) while the number of hours per day caring for CP child had significant effects on caregivers’ QoL score ($p<0.05$) although the effect size was very small, accounted for only 1.1% of the total variance in QoL scores. The more hours per day caregivers spend for the CP child the lower quality of life they could have ($\beta=-.055$).

Effects of interaction between the number of years and the number of hours per day caregivers taking care of CP child on the caregivers’ QoL scores were not statistically significant ($p>0.05$). That means the effects of caring daily hours on caregivers’ QoL scores did not depend on the number of years taking care of CP child and vice versa.

*** Burden of care**

The effects of total caregiving burdens and the effects of different burden types on the variance of QoL scores were analyzed using the general linear model.

Table 3.37. Effects of caregiving burden on QoL

Burden of care	*p*	*Partial Eta Squared*
Total effects of each variable		

Burden of care	*p*	*Partial Eta Squared*
Total CDS	*<0.01*	0.333
Worry for the Child (WC)	*<0.01*	0.094
Impact on Self (IS)	*<0.01*	0.116
Lack of Family Support (FS)	*<0.01*	0.200
Lack of Time (LT)	*<0.01*	0.250
Interaction effects among variable		
Corrected Model	*<0.01*	0.401
Intercept	*<0.01*	0.626
Worry for the Child (WC)	*>0.05*	0.010
Impact on self (IS)	*<0.01*	0.021
Lack of Family Support (FS)	*<0.01*	0.112
Lack of Time (LT)	*<0.01*	0.096
WC*IS*FS*LT	*>0.05*	0.128

The same effects of caregiving burden on depression and anxiety scores, the burden of care made a very big impact on the variance of caregivers' QoL scores in which 33.3% of the total variance on QoL scores was attributable to the effects of general burden of care ($p<0.01$). The more burden of care caregivers held the less likely quality of life they had ($\beta=-.185$).

In a review of the main effects of each specific burden group on the variance of QoL mean scores, all of them had significant effects on QoL scores ($p<0.01$). Of which, burdens relating to lack of time created the largest impacts on QoL scores (25.0%), followed by lack of family support (20.0%), and impact on self (11.6%) while worrying for the child had smaller effects, accounted for 9.4% of the variance in QoL scores.

There were no statistically significant effects of interaction among four groups of caregiving burdens when putting them in one model ($p>0.05$). The effects of each burden pattern did not be interfered with by the effects of the others on the variance of caregivers' QoL scores.

*** CP child's disability conditions**

Table 3.38. Effects of CP child-related factors on QoL

Variables	*p*	*Partial Eta Squared*
Total effects of each variable		
Sex of CP child	*<0.05*	0.015
Functional impairments	*<0.01*	0.038
Independence in daily living	*<0.01*	0.034
Child CP prognosis	*<0.01*	0.052
Interaction effects among variables		
Corrected Model	*<0.01*	0.130
Intercept	*<0.01*	0.262
Sex of CP child (S)	*<0.01*	0.021
Functional impairments (FI)	*>0.05*	0.011
Independence in daily living (I)	*>0.05*	0.002
Child CP prognosis (P)	>0.05	0.002
S*FI*I*P	<0.05	0.055

The sex of the CP child, the level of functional impairments, the independent level of daily living of the CP child, and the level of CP prognosis had small significant effects on the variance of the caregivers' QoL scores. Of which effects of child CP prognosis had higher effects, accounting for 5.2% of the variance in QoL scores ($p<0.05$).

It was noted that caregivers of the male CP child had less QoL mean scores than those of the female CP child (*16.3 vs. 17.3*). Caregivers of the child with improved CP conditions were likely to have more QoL mean scores than those of the child with no improvement (*18.6 vs. 15.7*).

Caregivers of CP children with less functional impairments, and more independence in daily living were likely to have higher QoL than those of CP children with more functional impairments, and less independence in daily living ($\beta=-.108$ & $\beta=.028$).

No statistically significant interaction effects among the above-mentioned CP child-related factors on the variance of QoL scores ($p>0.05$). The effects of each above-mentioned independent variable on the change in QoL scores did not influence the effects of the other variables on QoL scores.

There were no significant effects on caregivers’ QoL scores of the following child-related features: CP child ages, number of years the child living with CP, children with different CP types (spastic, dyskinetic, ataxic, soft paralyzed, mixed CP); children with a level of motor functions impairments following GMFCS (*p>0.05*).

3.3.4.5. Interaction effects between moderators and the risk factors on QoL

Effects of interaction on caregivers’ QoL scores among moderators (coping strategies and social support) and risk factors (care responsibilities, burden of care, level of disabilities) were analyzed following the general linear model. The significant interaction effects were presented below.

*** Interaction between coping strategies and risk factors on QoL**

Table 3.39: Effects of interaction between coping strategies and risk factors on QoL

Variables	*p*	*Partial Eta Squared*
Interaction between self-support and CP prognosis		
Corrected Model	*<0.01*	0.072
Intercept	*<0.01*	0.136
self-support (SS)	*<0.01*	0.022
CP prognosis (P)	*<0.01*	0.040
SS*P	*<0.01*	0.029
Interaction between self-blame and impact on self		
Corrected Model	*<0.01*	0.157
Intercept	*<0.01*	0.483
Self-blame (SB)	*<0.01*	0.042
Impact on Self (IS)	*<0.01*	0.059
SB*IS	*<0.01*	0.025
Interaction between external support and total functional impairments		
Corrected Model	*<0.01*	0.056

Variables	*p*	*Partial Eta Squared*
Intercept	*<0.01*	0.155
External support (ES)	*>0.05*	0.008
Functional Impairments (FI)	*<0.01*	0.026
ES*FI	*<0.05*	0.013
Interaction between external support and worry for child		
Corrected Model	*<0.01*	0.123
Intercept	*<0.01*	0.072
External support (ES)	*<0.01*	0.023
Worry for Child (WC)	*>0.05*	0.001
ES*WC	*<0.05*	0.015
Interaction between self-distraction and CP prognosis		
Corrected Model	*<0.01*	0.056
Intercept	*<0.01*	0.163
self-distraction (SD)	*>0.05*	0.008
CP prognosis (P)	*<0.01*	0.024
SD*P	*<0.05*	0.013

In a review of self-support coping patterns, there were small significant effects of interaction among this coping type and the CP prognosis ($p<0.01$). Self-support coping could control the effects of the CP prognosis on the variance of caregivers' QoL.

Relating to the second coping factor of self-blame& behavioral disengagement, we found the statistically significant effects of interaction between this coping type and impact on self-burden type ($p<0.01$). That means the effects of self-blame could deepen the effects of impact on self-burden on the caregivers' QoL scores.

As for seeking external support coping, significant effects of interaction were found among this type of coping and level functional impairments of CP child as well as burden type of worry for the child ($p<0.05$). Effects of seeking external support could reduce the effects of functional impairments and effects of caregiving burden type of worry for children on the variance of caregivers' QoL scores.

Concerning the fourth coping factor of self-distraction, there were small significant effects of interaction among this coping type and the CP prognosis ($p<0.05$). Self-distraction-based coping mechanisms could control the effects of the CP prognosis on the variance of caregivers' QoL.

*** Interaction between social support and the risk factors on QoL**

The results of significant effects of interaction among total social support and specific social support type and risk factors were presented below.

Table 3.40: Interaction between some social support and risk factors

Variables	p	*Partial Eta Squared*
Interaction between Government Monthly Financial Support for CP child and lack of time burden		
Corrected Model	*<0.01*	0.262
Intercept	*<0.01*	0.062
Government's Financial support (GS)	*<0.05*	0.017
Lack of Time burden (LT)	*>0.05*	0.000
GS*LT	*<0.05*	0.016
Interaction between Government Monthly Financial Support for caregivers and functional impairments of CP child		
Corrected Model	*<0.01*	0.056
Intercept	*<0.01*	0.205
Government's Financial support (GS)	*<0.05*	0.019

functional impairments (FI)	<*0.01*	0.034
GS*FI	<*0.05*	0.019

The significant effects of interaction between the government's financial support for CP child and the burden of care due to lack of time for caregivers' living and self-care ($p<0.05$) could tell that monthly financial support of government could lessen the effects of time lacking burden on the variance of QoL scores of caregivers.

Similarly, with significant interaction effects ($p<0.05$), it seems that the government's monthly financial support for caregivers could reduce the effects of functional impairments of CP children on the QoL scores of caregivers.

No statistically significant effects of interaction were found between assistive device provision, having health insurance, getting special education and rehabilitation services for CP child, providing information on how to care for CP child, joining activities of CPFAV, and the risk factors on the variance of QoL scores of caregivers ($p>0.05$).

Main points about predictors for caregivers' quality of life

- Only self-blame-based coping, but not self-support, self-distraction, or external support-focused coping strategies had significant effects on caregivers' QoL. However, the effect size was very small, accounting for only 7.1% of the total variance in QoL scores. The other factors significantly linked to caregivers' quality of life were: accessibility to special education services, getting information on caring for the CP child; family support and family incomes, number of hours per day caring for the CP child, caregiving burdens, sex of the child, functional impairments, independence in daily living, prognosis of CP child.

- Perceived burdens of care were the most important predictors of caregivers’ quality of life, accounting for 33.3% of the changes in QoL scores. Of these, burdens relating to lack of time for caregivers running their own lives created the largest impacts on QoL scores, making up 25.0% of QoL scores variance, followed by burdens caused by lack of family support (20.0%), impact on self (11.6%).
- All four coping styles had significant effects of interaction with some risk factors for QoL. In which self-support or self-distraction-based coping strategies could reduce the effects of CP prognosis on QoL, seeking external support coping could decrease the effects of functional impairments and perceived caregiving burdens on the variance of caregivers’ QoL scores. In the reverse, self-blame could deepen the effects of the caregiving burden on QoL.
- It is good to know that Government support in providing a monthly allowance for CP children and caregivers could control the effects of time lacking burdens as well as reduce the effects of functional impairments of CP children on the QoL of caregivers.

CHAPTER 4

DISCUSSION

This session discussed how this survey findings are similar or different from the other research in the same areas, the possible subjective explanations of the results, implications for policy, practice, further study, and the research limitations.

Literature review showed that burdens of care for children with cerebral palsy have heavily influenced the mental health of their caregivers, who are mostly informal and unpaid family members. The impact of the COVID-19 pandemic may add pressure on caregivers who were at high risk of mental health problems such as depression, anxiety, and poor quality of life.

The objectives of our research are to understand the mental health status of the primary caregivers of children with CP focusing on the common mental health problems of depression, anxiety, and general well-being, their coping strategies used to overcome stressful situations, and the relations between the identified mental health of the caregivers and coping mechanisms as well as other factors. The research findings could pave the way for further in-depth studies and for plans of action to enhance the mental health of the caregivers that lead to improved quality of care and quality of life for children with CP.

3.4.1. Mental health status among caregivers of children with CP

Our observational study on 340 caregivers within the network of the Cerebral Palsy Family Association from 47 provinces of Vietnam indicated that the prevalence of depression and anxiety among targeted participants, 37.1% and 67.8% respectively, seems to be higher than depression and anxiety rates in the general population globally and locally, especially for anxiety disorder.

Tianchen Wu and colleagues conducted a system review and meta-analysis on 66 studies with 221,970 participants to identify the prevalence of mental health problems during the COVID-19 pandemic. The results showed that the overall pooled proportion of depression and anxiety was 31.4% and 31.9% respectively (Wu, T et al., 2020). A meta-analysis of the prevalence of depression during the COVID-19 outbreak reported that the pooled prevalence of depression was about 25% (Bueno-Notivol, J. et al, 2020).

Another systematic review and meta-regression analysis on the prevalence of common mental disorders in South Asia including countries like India, Pakistan, Nepal, Sri Lanka, Bhutan, Bangladesh, Afghanistan, and the Maldives announced a depression rate from 23.6%-29.4%, and anxiety percentage of 19.4%-33.5% (Sadiq, et al., 2020).

We know from the literature review that the COVID-19 pandemic increased the mental health problems of the global population in which the prevalence of common mental disorders such as depression and anxiety was higher during the COVID-19 (Wu, et al., 2021). However, the caregivers of children with CP in our survey are even at higher risk of common mental health problems than other groups of Vietnamese people during the COVID-19 pandemic.

Quang Duc Tran and his colleagues conducted a system review and meta-analysis of 13 articles comprising 27,216 Vietnamese participants on depression prevalence in Vietnam during the Covid-19 pandemic. It was released that the overall prevalence of depression among studied Vietnamese using self-rated electronic assessment tools such as the self- rating depression scale (SDS) or the patient health questionnaire-9 (PHQ-9) was 14.6%. The highest rate of depression among health workers in one study was 34.7% (Tran.D.Q, et al., 2022).

Another web-based, cross-sectional survey on the psychological impacts of COVID-19 during the first nationwide lockdown in Vietnam implemented by Khanh Ngoc Cong Duong and colleagues in 2020 proclaimed that 23.5% of a total of 1,385 respondents experienced depression, 14.1% experienced anxiety (Duong.N.C.K. et al., 2020).

Reviewing a specific population of caregivers of children with disabilities, the rates of depression and anxiety vary from one to another study depending on lots of factors such as different kinds of disabilities the children have, different sample sizes as well as the different assessment tools used. For example, a cross-sectional survey on the prevalence of depression and anxiety among more than 300 caregivers of children with epilepsy in Western China reported that 5.3% of caregivers had depression and 25.7% of caregivers presented the symptom of anxiety (Yang, et al., 2021).

Park & Kim with their research in 2019 on depression among parents of children with developmental disabilities (CDD) in South Korea revealed that 22.3% of parents caring for CDDs got depression which was relatively higher than that of parents of children without the disability and behavioral problems (Park & Kim, 2019).

Another cross-sectional study on the prevalence of stress, anxiety, and depression among 146 parents of children with an autism spectrum disorder in Kazakhstan, a post-Soviet country in Central Asia, informed that the proportion of anxiety and depression among studied caregivers was 52.9%, and 53.7%, respectively (Alibekova, et al., 2022).

Regarding the common mental health problems among caregivers of children with CP, Farajzadeh and his colleagues through the online survey on predictors of mental health among 160 parents of children with CP during the COVID-19 pandemic in Iran reported that 40.6% of caregivers had signs of depression and 45.0% of caregivers had symptoms of anxiety (Farajzadeh, et al., 2021).

Another cross-sectional study among 232 mothers of CP children aged 5–18 years showed that 55.1% of mothers with CP had degrees of depression, and 69.0% of mothers with CP suffered from anxiety (Rasha, et al., 2019).

In comparison with the other investigations on caregivers' mental health situations in Vietnam, the prevalence of depression and anxiety also fluctuates depending on different kinds of care receivers, research locations, samples, and assessment measures.

A cross-sectional study on 117 mothers having children with CP going to Ninh Binh Rehabilitation Hospital for treatment and rehabilitation services in 2021 notified high rate of depression in which 49.6% of mothers had moderate depression and 50.4% of mothers had severe depression using the Beck Depression Inventory Scale-BDI (Tong, Duong & Nguyen, 2022).

Pham Thi Thu Cuc and her colleagues implemented a cross-sectional study on stress, depression, and anxiety among 157 parents of children with autism going for examination and treatment at Thai Binh Pediatric Hospital through an assessment scale of DASS-21. It was reported that 24.8% of parents had symptoms of depression in which 8.9% had moderate and severe depression. The rate of anxiety was 21.7%, and 13.9% had average and severe anxiety (Pham.T.T.C. et al., 2022).

Tran.T.Q, et al conducted a survey on 106 people caring for mentally ill people being treated at Mai Huong Daycare Psychiatric Hospital to identify depression using PHQ-9 and caregiver burdens. They reported that the rate of caregivers with depression assessed by the PHQ-9 tool was rather low, 7.5% (Tran.T.Q, Nguyen.T.T.Huong, Nguyen.M.H. 2023).

Vi Ngoc Tuan and Nguyen Thanh Binh investigated 100 caregivers of people with dementia coming to National Geriatrics Hospital for examination and treatment during the period from June 2020 to May 2021 to identify caregiver burdens and their consequences. They announced that the percentage of caregivers with depression and anxiety evaluated by the DASS-21 scale was 37.0% and 44.0% respectively (Vi.N.T & Nguyen.T.B, 2021).

A cross-sectional research on 150 mothers of children with disabilities going to the Lam Dong Province’s Social Protection Centers showed that 50%

of mothers of children with disabilities has psychological distress, 27% had mild, 18% had moderate and 5% had severe distress (Vu, 2019).

It was noticeable in our investigation that 17.0% of caregivers had moderate and severe levels of depression, and 27.6% had suicidal ideas. In addition to that, somatic symptoms such as sleep problems and feeling tired or having little energy appeared most frequently as compared to other symptoms of depression. Those findings could be taken into careful consideration for the selection of relevant therapeutic interventions.

Feeling anxious, and worrying too much about different things presented most frequently as compared to other signs of anxiety among our studied caregivers. The information collected through the caregiver difficulties scale suggested that caregivers had many worrying thoughts about their children's current state and futures, about comparison with other children, about sigma, and discrimination towards their children. Those results could be helpful inputs for the development of specific and practical psychological education and therapy if any.

Our survey identified that the caregivers perceived their general quality of life around the average level in which the mean score among 340 caregivers was 2.79 (0.89) out of a total of 5 scores. However, three fourth caregivers (77.1%) admitted they did not have or have little opportunity for leisure activities, more than half (57.6%) did not enjoy life, and one-third (34.7%) did not feel life was meaningful.

Some surveys also showed the consensus that giving care to children with CP has a negative impact on the quality of life of caregivers (Cankurtaran et al., 2021; Sonune et al., 2021). Tong Thi Hien and colleagues surveyed 117 mothers of children with CP admitted to Ninh Binh Rehabilitation Hospital and reported that caregivers' overall quality of life scores were relatively low with the scores of mental health indicators lower than those of physical health indicators (Tong.T.H. et al, 2022).

In addition to the universality of the caregivers’ mental health situations, it is also helpful to go into detail about mental health issues among caregivers in different groups. It was distinctive in mental health status by geography where caregivers live which caregivers living in rural areas, caregivers living in the central region of Vietnam were likely to be at higher risks of depression and anxiety and lower quality of life. On the reverse, those living in urban areas and Southern provinces seemed to be at lower risks of common mental health issues and higher quality of life.

Although there might be lots of factors attributable to that phenomenon, one immediate reason appearing in our mind is that the more disadvantages in social, economic, and environmental conditions as well as the less availability of services for CP children in those areas could put more hardships on caregivers’ life. Further investigation is needed to identify the risk and protected factors relating to those localities. Moreover, this information could be used for the development of a more culturally sensitive plan of action for the improvement of the mental well-being of those caregivers in that specific locality if any.

Several features relating to caregivers, CP children, and families were identified in our survey to associate with the differences in depression, anxiety, and quality of life among caregivers such as caregivers with jobs changed, caregivers working both inside and outside the house, caregivers living in poor economic and physical conditions, caregivers with male CP children, those with CP children without attending school, those without getting information on how to care for CP child are likely to be more vulnerable for mental health.

Those risk factors were also mentioned in some other studies (Marquis, 2019; Gugała et al., 2019; Power et al., 2018; Raina, 2003). The intervention programs for promoting the mental health and well-being of caregivers need to take a good look at how to mitigate the impacts of those risk factors.

Several researchers in the world emphasized the relationship between caregivers’ common mental health disorders and their educational background, occupation, and marital status (Farajzadeh, 2021; Power et al., 2018; Maridal et al., 2021; Mbugua et al., 2011) as well as the links between mental health issues of caregivers with disability status, kinds of CP, degree of disability in the child through measurement of Gross Motor Function Classification System-GMFCS (Marquis, 2019; Raina, 2003; Yilmaz, Erkin&Nalbant, 2013).

However, in our study, no significant differences in depression and anxiety scores among caregivers with the above-mentioned factors were found. The research samples of caregivers who are only within the Cerebral Palsy Family Association, not representative of all caregivers from the country could be one of the reasons. Further research with more representative samples could explain that phenomenon.

From the above overview of the epidemiological data on the mental health status of caregivers, we could feel that caregivers in general, and caregivers of children with CP are among groups substantially vulnerable to psychological distress and common mental health problems.

Besides, it is an emerging trend that the population of people with functional impairments/degradation such as adults/children with disability, people with chronic health conditions, people with injuries, and the elderly has increased that putting enormous demands on carers to assist the tasks of daily living of the dependent.

Given the essential roles of caregivers, health care support including mental health care for caregivers, mostly family caregivers, could have twofold impacts, on their health and well-being as well as on their care recipients’ life. Our survey data add evidence and can echo the high needs of this particular group to be met by society and by the public health sector.

It is commonly agreed that children with disabilities are a target group of social policies of Viet Nam that are designed to fulfill their human rights and eliminate disparities (UNICEF, 2018). Protecting and caring for children with disabilities including children with CP could not be efficient, effective, and sustainable if support for caregivers is put outside the agenda given almost children with disabilities/children with CP are dependent on their caregivers for activities of daily living, for their health and well-being.

3.4.2. Coping strategies used by caregivers of children with CP

Taking care of children is generally inherited and happy responsibility of the adults, mostly of the parents. However, caring for children with multiple disabilities like CP children is stressful, painful, and sometimes helpless and hopeless. The reasons revealed by caregivers in our survey included no time to relax (59.7% of them reported), no good health (52.6%), too much work to do (51.5%), difficulties in caring for CP child (44.1%), and unable to attend social activities (40.0%), much spending for CP child (35.9%), having no job or losing a job (30.6%), criticism, blaming by relatives (23.2%), conflict in the family (19.4%), maltreatment of CP child (15.9%), stigma and discrimination by others (14.1%), violence by the spouse (4.4%).

For caregivers to continue living life in the context of too much and continuous burdens and obstacles, they have to find ways to adjust and adapt to situations. Based on their assessment of situations, and their internal and external resources, caregivers use a broad range of coping strategies.

The Brief Coping Orientation to Problems Experienced Inventory (Brief-COPE) was applied in our investigation to understand how caregivers responded to adversity situations and mental distress. Studies in the world classified coping into three primary styles: problem-based, emotional based, and avoidant coping. Then 14 facets of coping were applied for analysis: active coping, planning, use of information support, positive reframing, venting, use of humor, acceptance, emotional support, religious practice, self-blame, self-distraction, denial, substance use, and behavioral disengagement (Carver, 1997; Kato, 2013; Fairfax, 2019; Obembe et al., 2019; Sharma & Subedi, 2022).

To fit our particular group of respondents, we conducted an exploratory factor analysis of Brief-COPE and identified four coping mechanisms employed by the studied caregivers: (i) self-support-focused coping style including acceptance, planning, positive reframing, problems solving, use of humor, and religion practice; (ii) self-blame and behavioral disengagement oriented coping way such as criticizing, blaming self for things that happened to CP child, giving up trying to deal with taking care of CP child, giving up the attempt to cope; (iii) seeking external support coping style comprising getting emotional support from others, getting help and advice from others, getting understanding and comfort from others; and (iv) self-distraction based coping including doing other things to take the mind off the situation, doing leisure activities to think less about the situation.

The results showed that caregivers in our survey used all possible ways of coping to deal with stressors. However, the frequency of using different coping strategies is different in which self-support coping ways were mostly frequently applied, followed by self-distraction, then seeking external support, and the least used self-blame and behavioral disengagement-directed coping.

Going deeply into specific coping instances, “acceptance” is a way of coping being used the most (3.6), followed by positive reframing, planning (3.2), problem-solving (3.1), use of humor (3.0), distraction (2.6), self-blame (2.4), getting support from others (2.3), denial (2.1), the practice of religion, expressing negative emotion (2.0), and behavioral disengagement were those caregivers used the least with the mean of 1.5.

Following Larazus and Folkman’s coping theory described in Chapter 1, assumptions to explain the above-coping responses employed by caregivers in our survey could be following: Firstly, the caregivers could appraise that cerebral palsy is a permanent disorder that their children have to live with that for his or her whole life. As a result, caring for a child with CP would be life-long tasks. They have been learning to live with and accept their CP child's situation. The coping way "acceptance" was therefore used the most.

The fact of living with a CP child and the fact of long-term caregiving responsibilities cannot be changed. What they can change is to see it in a different light, or to look for something positive in what is happening. Thus, positive reframing/cognitive restructuring-directed coping is used.

Taking care of CP children is challenging but they still can do some things within their capacities and resources to overcome situations for the better life of their beloved children and their own life. The majority of caregivers in our samples are better off and educated. They could be self-confident enough in their abilities. Caregivers have tried to come up with plans about what to do, and about what activities to take to make the situation better. Then coping ways "planning", and "problems solving" are applied.

Besides caring for CP children, caregivers still have other tasks in life to fulfill such as taking care of other family members, doing work for earning, maintaining social relationships with relatives, friends, and other important people, and so on. Keep thinking and focusing only on CP child caring shortcomings does not help them to achieve other goals. Sometimes they have been concentrating on other things or turning to other activities to take their minds off thinking about the CP child situation or thinking less about it. The coping mechanism "Self-distraction" seems to be beneficial and then be utilized.

Even caregivers rely on their capacities to deal with caregiving burdens, there are still a lot of things out of their abilities to handle such as how to treat

CP children’s health problems, how to improve CP children’s functions in learning, playing; how to know if there is something else better than what they are doing for their child. Therefore, support from others such as peer caregivers, health care providers, special educationists, authority, and other family members are in need. Based on their social resources, seeking support from relevant outsiders is seen as another coping strategy to apply.

It is inevitable during the interaction with others that the caregivers receive judgment, negative comments, and critiques about their situations. Even when CP conditions are up and down, conflicts within their family on caring work could happen. Comparison with other non-caregivers, or with caregivers of normal children could sometimes pop up in their minds. They could feel shameful about that.

As reported in the questionnaires, some caregivers could have physical and mental violence against their CP child that could make them feel guilty or regretful. Blaming themselves for things that happened, for things unlucky, for maladaptive behaviors, and life misery, could be a way caregivers respond to moral feelings. They also could choose to avoid doing things that make them feel bad. It is understandable that “self-blame”, and “behavioral disengagement” coping strategies could be beneficial sometimes in the short run to regulate impulsive and negative emotions and to find the subjective answers to their big and uneasy questions on why they have to live that life as it is.

It is beneficial to know how caregivers in other cultures and locations cope with caregiving stress. A cross-sectional study on coping strategies of caregivers of children with a disability including children with CP attending a special education center in Abakaliki, Southeast Nigeria in 2021 stated that problem-focused coping strategies appeared to be the most preferred coping strategies since they have a positive influence on reducing the stress associated with raising a child with a disability. Emotional coping strategies were the next utilized coping strategies and avoidant coping was the least used (Ezeonu, 2021).

Another study on stress and coping among 102 caregivers of children with disabilities in Nepal in 2021 revealed that the coping styles most frequently used by caregivers were also acceptance, self-distraction, positive reframing, active coping, use of informational support, planning, and emotional support. Humor, denial, substance use, and behavioral disengagement were less frequently used by the main caregivers (Sharma & Subedi, 2022).

Obembe and colleagues investigated the coping styles of 132 caregivers of children with cerebral palsy in Nigeria and reported that acceptance was the mechanism most used by caregivers of children with CP who have been facing for a long time of stressful caregiving responsibilities and knowing that CP is long-life conditions and that they have to accept the situation (Obembe et al., 2019).

In addition to learning about how caregivers cope with stressors, identifying the factors associated with coping strategies is also necessary for the development of appropriate interventions to promote adaptive and healthy coping styles.

Regarding the relationship between coping responses and geography, in our study, caregivers living in rural areas tend to use more self-blame and behavioral disengagement strategies than those living in urban areas. Krstic and colleagues within their research on coping with stress and adaptation in 60 mothers of children with CP aged from two to seven years old in Serbia reported that mothers of CP children from rural areas used passive appraisal (a style of behavioral or mental disengagement from a stressful situation such as escaping, avoiding, and denial of the stressor) more often than those in urban areas (Krstic et al., 2012).

As Larazus's coping theory, when people assess stressors that are out of their capacity to change, and their coping resources are limited, they tend to use emotion-based coping like self-blame or avoidance-based mechanisms like behavioral disengagement (Larazus.S, 1984, 1987). In consideration of this, we could assume that the social and economic conditions in rural areas are lower than those in urban areas which could lead to limited coping resources for rural caregivers. They have also fewer opportunities to access special education, social and rehabilitation services for CP children which could make them feel helpless and hopeless. Therefore, self-blame and giving up trying could be the ways the caregivers use to respond to such adversity.

It was interesting to know from our exploration that caregivers who told following Buddhism religion used the least acceptance-based coping as compared to those without religion or those with Christianity. This seems to be a paradox because following Buddhism teachings, acceptance is one of the main paths to gaining spiritual growth and ultimately awakening or enlightenment. It was not uncommon that Vietnamese Buddhism followers are more interested in ritual performance than well learning, understanding, and practicing Buddha teachings. There may be other underlying reasons that need to be further explored.

A remarked finding was about significant differences in using self-blame & behavioral disengagement coping types among caregivers having different jobs in which caregivers work as businessmen used the self-blame more than others. The self-blame, an emotional and moral coping mechanism, is about taking responsibility for a certain action, event, or outcome that has had negative consequences either for self or others (Jacobsen, 2022). Businessmen could perceive higher expectations from the society that they are successful people. Thus, when they saw children with CP with not much improvement, they could tend to blame themselves for that.

In our study, caregivers with primary school education used the most self-blame & behavioral disengagement, and those with college and university education used the least. Caregivers with low education qualifications could have low living conditions, low-paid work, and low social relationships that may result in feeling guilty, feeling helplessness, and self-criticism for their inability and incapability to provide sufficient assistance for their CP children. Low educational background might prevent them from gaining a broader sense and knowledge about what responsibilities towards their children are in and out of their control.

Additionally, self-blame coping used by caregivers was also found to have a significant association with the level of motor impairments, and the improvement level of the CP condition of the child. Caregivers of children with the most severity of motor impairments measured by GMFCS, and less improvement were likely to use the most self-blame and behavioral disengagement coping strategies than those of children with the less severity of motor impairments and more improved CP conditions. In the absence of a clear causal explanation for their child's situations, caregivers searched for an explanation and can attribute its cause to their responsibilities resulting in self-blame (e.g., not trying enough to help their children, not good enough to be a mother).

The results of the study on 60 mothers of 2 to 7-year-old children with CP to examine the coping strategies used by mothers of children with CP and the associated factors in Serbia showed that mothers of children with severe forms of CP seek the coping strategy of institutional support more often than those of children with less severe forms of CP (Krstic & Oros, 2012). In our study, no significant correlation between the coping type of seeking external support and the severity level of CP child’s functions.

The burden of care is seen as the most influential stressor for caregivers of children with CP. It is important to understand the relationship between caregiving burdens and how caregivers cope with those burdens. Results of our study showed the more hours per day caregivers spent taking care of CP child, the more general burden of care they got the more self-focused support and self-blame caregivers used.

This is in contrast with Wijesinghe and colleagues’ findings of the survey on factors associated with caregiver burden among 375 caregivers of children with CP in Sri Lanka in which the practice of seeking support, but not individual coping practice, is significantly related to caregiver burden. Following the explanation in their study, the collective nature of Sri Lankan society may lead to more benefits from interpersonal coping strategies rather than individual coping (Wijesinghe et al., 2014).

It was food for thought given Vietnam is also considered a collective culture where people value the collective whole rather than the individual. A deeper investigation needs to be done to have sound clarification for the above-mention conclusion.

Our study proclaimed the significant negative association between caregivers’ practice of self-blame with general social support, more specifically with the accessibility of CP children to education and rehabilitation services as well as the negative significant relationship between caregivers using self-blame and their involvement in CP Family Association’s activities. Thus, the provision of education and medical services for CP children as well as engagement in peer support groups could help caregivers delegate some caregiving responsibilities, could help keep hope for the CP child's improvement, and could lessen their maladaptive coping responses to the lifelong duties of caring for their CP children. This could be included in the intervention package to support caregivers of children with CP later.

Generally, the caregivers in our survey used more positive, confronting ways than negative and avoidant ones given most of our respondents are highly educated and better-off leading to better conditions and coping resources. It tends that caregivers with less internal and external coping resources, and those with more caregiving burdens use more self-blame and behavioral disengagement. Given our study samples cannot be generalized to all caregivers in Vietnam, the observed information needs to be further investigated within larger and representative sample sizes. The other studies reported the same or different coping strategies used by caregivers because of differences in life stressors, circumstances, individual characteristics, coping resources as well as the assessment coping measures and methodology.

There are things in common that life situations change over time, then coping strategies used by caregivers also do not stand still. Different coping mechanisms are used at different stages of caregiving. Some strategies are more successful in some situations than in others. All coping ways have their functions for fixing external and/or internal problems. Some coping strategies have negative impacts on mental health, and some have positive effects. It is more important to be aware of the consequences of different coping ways on mental health then we could decide to select wisely the more useful strategies for applying.

3.4.3. Factors associated with identified mental health of the caregivers

Theoretically, the biopsychosocial model by George L. Engel and Jon Romano and the model of the caregiving process and caregiver burden of Parminder Raina and colleagues, which are presented in Chapter 1, are fundamentally conceptual frameworks to guide our research in which multidimensional rather than unifactorial approach is applied.

Additionally, the literature review also proved that a variety of factors have a relationship with mental health among caregivers of children with disabilities including children with CP. They are the socio-economic issues, the characteristics of caregivers, the features of children with CP, the caregiving burden, and social support-related aspects.

Several studies revealed that low education, unemployment, and low income were related to low levels of mental health in caregivers. Married caregivers had higher risks of anxiety and depression than those single, divorced, or separated. The important predictors of anxiety and depression of caregivers of children with CP included the poor economic status of the family, as well as difficult living conditions of the family (Farajzadeh et al., 2021; Gugała et al., 2019; Maridal et al., 2021; Marquis et al., 2021; Raina et al., 2003; Shin & Nhan 2009).

In our study, no statistically significant association between education, marital status of caregivers, and depression and anxiety has been found. It was similar in our research that the employment and economic status, and physical living conditions were associated with the mental health of the caregivers in which caregivers who had to quit their job for taking care of children with CP, caregivers with low incomes/living in the poor families, in poor physical living condition were at higher risks of depression and anxiety, and lower quality of life.

Concerning the child with CP-related factors, the association between age, sex, types of disability, the severity of disability in the child through measurement of GMFCS, level of independence in activities of daily living, comorbidities, behavioral disorders of children with disabilities were related to caregivers’ mental health were reported in some research (Maridal et al., 2021; Marquis et al., 2019; Power et al., 2019; Raina et al., 2004).

In our research, there were no significant effects of children’s CP types (spastic, dyskinetic, ataxic, soft paralyzed, mixed CP); level of motor functions following GMFCS, and level of CP prognosis on depression and anxiety of caregivers. However, the ages of the CP child, the number of years living with CP, the level of functional impairments, and the independence level in the daily living of the CP child had small significant effects on the variance of the caregivers’ depression and anxiety scores.

It was surprising that the caregivers of children with more years living with CP are less likely to have depression and anxiety than those of children with fewer years living with CP. May be more years the child living with CP more adapt to the stressful situation the caregivers had.

Our research also showed that the caregivers of CP children not attending school were at a higher risk of depression and lower quality of life than those of CP children attending the school, especially those of CP children attending the typical school. It could be explained that children with CP staying at home have put more caregiving burden on the caregivers.

Other factors relating to caregiving demands, and the burden of giving care for children with CP were announced in several studies as the most important factors influencing the mental health of caregivers. Longer duration of caregiving, higher caring intensity, activities of caring for a child with CP, and higher burden of care were those related to higher risks of mental health problems of caregivers (Barreto et al., 2019; Farajzadeh et al., 2021; Kiani et al., 2021; Maridal et al., 2021; Wijesinghe et al., 2014).

Our survey also found similar results in which the greater number of hours per day caregivers spend for the CP child the more likely risks of depression, anxiety, and lower quality of life they would have. It was remarkable that the burden of care had large effects on caregivers’ depression, anxiety, and quality of life, accounting for about 30% of the total variance of depression, anxiety, and QoL scores. The more caregiving burden they hold the more likely depression and anxiety the caregivers suffered from, and the less quality of life the caregivers had.

Some studies concluded the association between lower social support and poorer mental health of caregivers (Maridal et al., 2021; Marquis et al., 2019; Raina et al., 2004). The findings of our research were that caregivers receiving information on how to care for the CP child, and caregivers of children attending special education centers were at lower risk of depression, anxiety, and higher quality of life than those not receiving information, and those with the child has not received special education services. The caregiver of the child with CP without receiving rehabilitation services was likely to have more anxiety than those with CP children getting rehab services.

As for the factor relating to the caregivers' coping strategies, our study results showed that all studied coping strategies used by caregivers such as self-support based, self-distraction focused, self-blame directed, seeking external support oriented copings strategies had significant effects on caregivers' depression and anxiety in which healthy coping made small effects, and unhealthy coping styles of self-blame made biggest impacts, accounting to more or less 15% of the total variance in PHQ-9 and GAD-7 scores. Only self-blame-focused coping mechanisms made statistically significant effects on caregivers' quality of life.

Some other researchers also mentioned caregivers of children with CP used sometimes different strategies to cope with caregiving stress (Krstic et al., 2012; Guillamón et al., 2013). A study on the relationship between coping styles and depression among 132 caregivers in Nigeria found that planning, active coping, use of instrumental support, positive reframing, and humor had a negative relationship with depression in caregivers of children with CP. Whereas, denial, self-distraction, behavioral disengagement, and self-blame had a positive association with depression (Obembe et al., 2019).

A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability including children with CP revealed the significant associations between coping strategies used by caregivers and caregiver's quality of life. Poor coping strategies such as behavioral disengagement were negatively associated with the global QoL of caregivers (Fairfax et al., 2019).

Advanced statistical analyses were applied in our research to find the mediators and moderators that interacted with some risk factors for caregivers' depression, anxiety, and quality of life. Initial exploration of our research indicated that caregivers' coping styles of self-blame and behavior disengagement could deepen the negative effects of care demand (number of hours caring for the CP child). In the reverse, seeking external support including peer support from the Cerebral Palsy Family Association, provision of assistive devices, health insurance, and rehabilitation services for CP children could moderate the effects of the caregiving burden on caregivers' depression. While it is difficult to change the care demand and caregiving burden, intervention in reducing self-blame, and promoting the accessibility to assistive devices, rehab services, peer support groups, and health insurance could help mitigate the impact of care demand and burden of care on depression of caregivers.

As for anxiety, self-blame could intensify the effects of functional impairment of CP children on the level of anxiety of caregivers. The provision of assistive devices and rehabilitation services could decrease the bad impacts of caregiving burden on the level of anxiety. Among the possible support to help caregivers overcome their anxiety could be increasing the provision of rehab and assistive devices for CP children while assisting caregivers to find ways to reduce self-blame.

Concerning the caregivers' quality of life, practicing self-focused support coping strategies such as planning, active coping, positive reframing, using information support as well as actively seeking external support could moderate the negative effects of child disability conditions (functional impairments, low CP prognosis) on their quality of life. Less self-blame could reduce the bad influence of the caregiving burden relating to the impact on self on the quality of life. The study also suggested that the policy on monthly financial support for CP children and caregivers could lessen the effects of time lacking burden on the variance of QoL scores of caregivers, and reduce the effects of CP child functional disabilities on quality of life among caregivers.

In summary, our research results add the evidence in Vietnam to the international literature that the CP child caregivers' mental health focusing on depression, anxiety, and quality of life has been impacted by various factors in which coping strategy "self-blame and behavioral disengagement" and caregiving burdens (lack of time, impact on self) are the most important predictors that we could prioritize our efforts and limited resources for planning support to improve the mental health of the targeted beneficiaries.

Implications for policy and practice

It is necessary first to overview Vietnam's current policy context to support mental health care and support people with disability. Concerning policy on mental health care, the Vietnamese government has been aware of the importance of mental health and made a considerable effort and put mental health as a key task priority. The National Target Program on mental health was approved in 1999 and phased out in 2020 after 20 years of implementation of community-based mental health care focusing on schizophrenia, epilepsy, and depression.

Then, on January 1, 2022, the Prime Minister promulgated Decision Number 155/QD-TTg for approving the national program on non-communicable diseases and mental health disorders prevention and control for 2022-2025 executed by the Ministry of Health and delivered by the healthcare system. The goals of the program are to enhance the management of the risk factors of mental disorders, to strengthen mental health care services delivery including prevention, early detection, treatment, and management of some prioritized mental disorders including depression, to ensure at least 50% of people with depression are identified and managed.

The Government of Vietnam also issued Decision Number 1929/QD-TTg for approving the community-based program on social support and rehabilitation for people with mental illnesses, children with autism, and people with psychological problems for 2021-2030 executed by the Ministry of Labor, Invalid and Social Affairs and delivered by the social system. The specific objectives of the program are to ensure at least 70% of people with depression receive counseling, psychotherapy, and social services, at least 60% of families of people with mental health problems are provided with education and training to have skills on caring, and rehabilitation for their dependents.

Concerning the disability-related policy, Vietnam also has made strong commitments to supporting people with disability (PWD) including children with disability (CWD) by the endorsement of the National Assembly’s Law for PWDs in 2010, issuing the Government’s Decree on supporting PWDs in 2012, ratifying the United National Convention on the Rights of Persons with Disabilities (CRPD) in 2014, approving Government’s Decree on social welfare policies in 2021, and issuing the Decision Number 1190/QD-TTg for approving the program to support people with disability for 2021-2030 executed by Ministry of Labor, Invalid and Social Affairs.

Despite the achievements so far, there are continuing shortcomings in mental health care in Vietnam, including but not limited to very restricted availability of comprehensive interventions such as psychotherapy and psychosocial rehabilitation, scarcity of mental health service providers at all levels of the system, big gaps in policy making and implementation leading to very limited accessibilities to mental health care by people in needs. The mental health law has not been developed yet that results in the unmet needs of people with mental disorders (Minas, H., & Lewis, M. 2017).

Limitations of the disability support program are still observed in that the services are limited in both quantity and quality and the effective model of professional support services is still lacking. The majority of activities to assist people with disabilities are currently operated by the Government’s social affairs system with more emphasis on monthly financial allowance support rather than professional social service delivery in meeting a wide range of PWD’s needs in all aspects of life (Tran.K. 2016).

Our research findings in three areas could be one source of reference for the process of updating the policy in mental health care and disability support in the coming time. Firstly, the results of the high prevalence of common mental health problems among caregivers of children with CP could emphasize one more time the increased needs and the importance of mental health care for the population, more especially for the high-risk groups including caregivers. Prioritizing a component to support caregivers in the disability and/or mental health programs should be now taken into consideration.

Secondly, to meet the increased needs in mental health care within the context of a huge shortage of human and financial resources, a feasible and effective mechanism should be developed to mobilize all stakeholders, not only public, private sectors, and professional organizations, but also civil society’s organizations like the Cerebral Palsy Family Association in sharing the tasks of mental health care for different groups of users.

Thirdly, the multifaceted factors identified to be associated with mental health problems in our survey confirm that the biopsychosocial approach rather than the predominant medical model in mental health care as it is now in Vietnam is the advanced, effective, efficient direction that needs to be promoted. There should be effective procedures for enhancing the multisectoral collaboration across ministries, sectors, and organizations, and for ensuring the participation of people with mental disorders and their families in developing, implementing, and evaluating policies, legislation, and plans on mental health, and disability support programs.

Fourthly, it is needed to develop and implement strategies to empower individuals and families including caregivers in making useful and healthy choices for dealing with daily life obstacles, and for being responsible for their good health and well-being. The strategies could include but are not limited to awareness raising, psychoeducation, capacity building in different skills such as coping, self-care, inter-personal relations, parenting, and family building.

We can learn experiences on the best practice in caring for caregivers described by Strobel, N.A & Adams, C in which multi-faceted rather than single interventions had a more significant effect on caregivers' burdens and the importance of combining interventions for holistic health and well-being. They mentioned three main categories of intervention for caregivers including education programs to support caregiver mastery and preparedness; psychosocial support targeting coping, relationship issues, and problem-solving strategies; self-care programs to promote caregivers' health and well-being (Strobel NA, Adams C. 2015). Other specific support interventions such as respite care services, and technology-based support are recommended by WHO (WHO, 2017).

Following our specific results that the self-blame focused coping mechanism and caregiving burdens, especially for the burden types of "impact on self", "lack of the time for enjoy the life and for caring for self", "worry for the CP child", have made biggest effects on the mental health of caregivers, the psychological intervention could be developed and implemented to tackle the self-blame. A psychoeducation program could be of use to help caregivers to understand stress and coping, the consequences of coping strategies on mental health outcomes, and to know what and how self-blame impacts mental health. Empathetic listening without judgment should be applied throughout the whole process to provide caregivers with trust and safety to express their frustrations, anger, guilt, and hopelessness.

Then different psychotherapy techniques such as cognitive behavioral therapy (CBT) could be introduced. They include: (i) cognitive-based therapy to identify distorted thoughts and the belief and then restructure/reframe the more positive and useful thinking patterns; (ii) behavior-based therapy to build a more balanced life routine activities between responsible tasks and hobby tasks, to learn more effective problem-solving skills.

Even though it is normal and natural for caregivers to see life negatively due to daily caregiving stress, it is still helpful to support them to apply the positive psychology approach initiated by Martin Seligman. Instead of focusing on the negative signs of life events, caregivers should be encouraged to recognize even the smallest positive things in daily life, to find something they are grateful for. Emphasizing positive emotions, behaviors, and character strengths could help reduce the effects of exhaustion and unhappy things.

Many other specific psychological techniques could be considered such as mindfulness practice focusing on the present moment without judgment or distraction. It can assist in increasing concentration and decreasing mistakes, supporting better self-care, and reducing stress and anxiety in both caregivers and recipients. Building up unconditional self-acceptance and self-compassion could help caregivers to be kind and love themselves for whatever happens. Stefania Crisan and colleagues found the effect of self-compassion and unconditional self-acceptance training on reducing self-blame levels (Crisan, S., Canache, M., Buksa, D. et al 2023).

Research limitation and implication for further studies

Although it was the first time to have information in Vietnam about the mental health status of the primary caregivers of children with CP, the associated factors, and the strategies used by caregivers to cope with caregiving stress, there were some limitations observed in our study. The survey participants were members of the CP Family Association. Many of the participants with low educational status could not have proper access to online services to take part in the survey. Thus, the research results cannot be generalized to all caregivers of children with CP in Vietnam.

As the identified limitation of the cross-sectional study, our research does not allow us to find cause-effect relations between the mental health outcomes of the caregivers of children with CP and the associated factors. Further studies with different designs such as case-control, randomized control trial (RCT) or longitudinal studies are needed to better understand the cause and effect on mental health outcomes of the caregivers as well as to know better the process of adaptation and transitions of families with children with CP.

Given this cross-sectional survey was carried out during the COVID-19 pandemic without the control group consisting of caregivers of normally developing children, it was difficult to know whether the identified mental health problems of the caregivers may have been the results of the COVID-19 impact only or due to ongoing caregiving situations. To discover the exact difference in caregivers’ mental state before, during, and after the pandemic, retrospective surveys may clarify any differences.

In addition, research in this area could consider possible differences between male and female caregivers’ coping responses and adaptation to their child’s difficulties. In our study, the sample size of male caregivers was too small so we could not analyze the differences. Additionally, given the research samples are not representative of all caregivers of children with CP in the country, that could be one of the reasons that we could not find significant differences in depression, anxiety, and quality of life of caregivers with different demographic features such as ethnicity, religion, educational background, occupation.

The online data collection method used by our study could lead to some degree of inaccuracy in the information filled in by the participants. Some research measurements used in this study have not been culturally validated in Vietnam and in the community among caregivers of children with disabilities. Therefore, the accuracy of the results could be affected.

Given the information on symptoms of mental health problems like depression and anxiety was collected based on the self-report of participants who could for some reason, not tell the truth. The tools used for identifying depression and anxiety are the screening tool, not the diagnosis tools. Thus, the prevalence of depression and anxiety among caregivers of children with cerebral palsy in our study may not reflect exactly and completely the real situation of mental health problems of this population.

Despite the limitation, this study is still important to help understand the burden of mental health problems and to know the needs for mental health care of the caregivers of children with CP. The protective and risk factors related to those identified mental health issues, and how caregivers be adaptive to the stressful situation by choosing different coping strategies. That information could be useful in informing the planning and allocation of resources for the development of appropriate interventions to improve the mental health and quality of life of caregivers.

By learning more about what is going on in a specific population of caregivers of children with cerebral palsy, researchers can understand the relationships that might exist between certain variables relating to mental health problems and other variables considered the mental health determinants so that the development of further studies that explore these conditions in greater depth could be made.

Implications for further studies

Given this dissertation could be seen as the first exploratory survey to learn about the mental health and coping strategies used by caregivers of children with cerebral palsy, further analytical and/or empirical studies in this area are needed based on the goals as well as the resources.

For example, another observational study with a bigger samples size representative of caregivers all over the country and with mixed quantitative and qualitative methods could be helpful to determine whether caregivers from different demographic groups could have different mental health status, and whether they could employ more typical ways to cope with caregiving difficulties. We could understand more deeply the issues underlying the phenomenon identified and know more about the decision-making process that caregiver experience in response to life adversities. We could be in better position to analyze the roles of social support variables in mediating or moderating the interaction between caregivers' coping strategies and their mental health problems.

The analytical and longitudinal research could be conducted to know how caregivers cope with caregiving hardships over time, how different coping strategies could change their mental health outcomes, how caregivers' behaviors could impact the life of children with cerebral palsy, and the relationship between caregivers and care recipients.

The empirical research with a case-control design could help confirm the cause-effect relations between caregivers' mental health outcomes and the possible predictors identified in this study such as care demands, caregiving burdens, coping strategies, and social support services.

Given we have no opportunity to validate some main measures used in this study like Brief-COPE for assessment of coping strategies or the Caregiver Difficulties Scale for evaluation of caregiving burden, there could be a topic for another study on validation of those tools in the Vietnamese context.

CONCLUSION

This dissertation contributes to the existing literature about the mental health status of the Vietnamese primary caregivers of children with cerebral palsy focusing on depression, anxiety, and quality of life, their coping strategies to respond to the caregiving stress, and the relations between identified mental health problems and coping as well as other associated factors.

Our observational online-based study on 340 caregivers within the network of the Cerebral Palsy Family Association from 47 provinces of Vietnam showed that the prevalence of depression and anxiety among targeted participants, 37.1% and 67.8% respectively, seems to be higher than depression and anxiety rates in general population globally and locally, especially for anxiety disorder. In comparison with the other investigations on caregivers' mental health situations in Vietnam and in other countries, the prevalence of depression and anxiety also fluctuates depending on different kinds of care receivers, research locations, samples, and assessment measures.

The caregivers perceived their quality of life around the average level. However, 77.1% of them admitted they did not have or have little opportunity for leisure activities, 57.6% did not enjoy life, and 34.7% did not feel life was meaningful. Rather than external factors, the internal factors of caregivers such as no time to relax, no good health, too much work to do, unable to attend social activities were reasons reported by most caregivers for their emotional problems. This implies the high need for mental health care for this group.

To overcome life hardships, caregivers in our investigation used all possible ways of coping to deal with stressors. However, the frequency of using different coping strategies is different in which self-support coping ways were mostly frequently applied, followed by self-distraction, then seeking external support, and the least used self-blame and behavioral disengagement-directed coping. Among the specific coping instances, acceptance used the most (3.6) and self-blame and behavioral disengagement were those caregivers used the least (1.97). The other research also reported acceptance was the mechanism most used by caregivers of children with CP who have been facing for a long time of stressful caregiving responsibilities and know that CP is a long-life condition that they have to accept the situation.

Like the literature review, our research identified a variety of factors that have a significant relationship with mental health among caregivers of children with CP. They are the socioeconomic issues, the characteristics of caregivers, the features of children with CP, the caregiving burden, and social support-related aspects. This implies that the approach to support improving the mental health of caregivers should be multi-dimensional and comprehensive.

It was remarkable that the burden of care had large effects on caregivers' depression, anxiety, and quality of life, accounting for about 30% of the total variance of depression, anxiety, and QoL scores. The more caregiving burden they hold the more likely depression and anxiety the caregivers suffered from, and the less quality of life the caregivers had.

Our study also generates the insights that self-blame has made biggest effects on the mental health of caregivers. The caregivers’ coping style of self-blame and behavior disengagement could intensify the effects of the caregiving burden on the mental health of caregivers.

Seeking external support including peer support from the Cerebral Palsy Family Association, provision of assistive devices, health insurance, and rehabilitation services for CP children could moderate the effects of the caregiving burden on their mental health.

In addition to other solutions, psychological intervention could be developed and implemented to help caregivers to detach from the self-blame coping pattern and to practice more positive and effective coping ways.

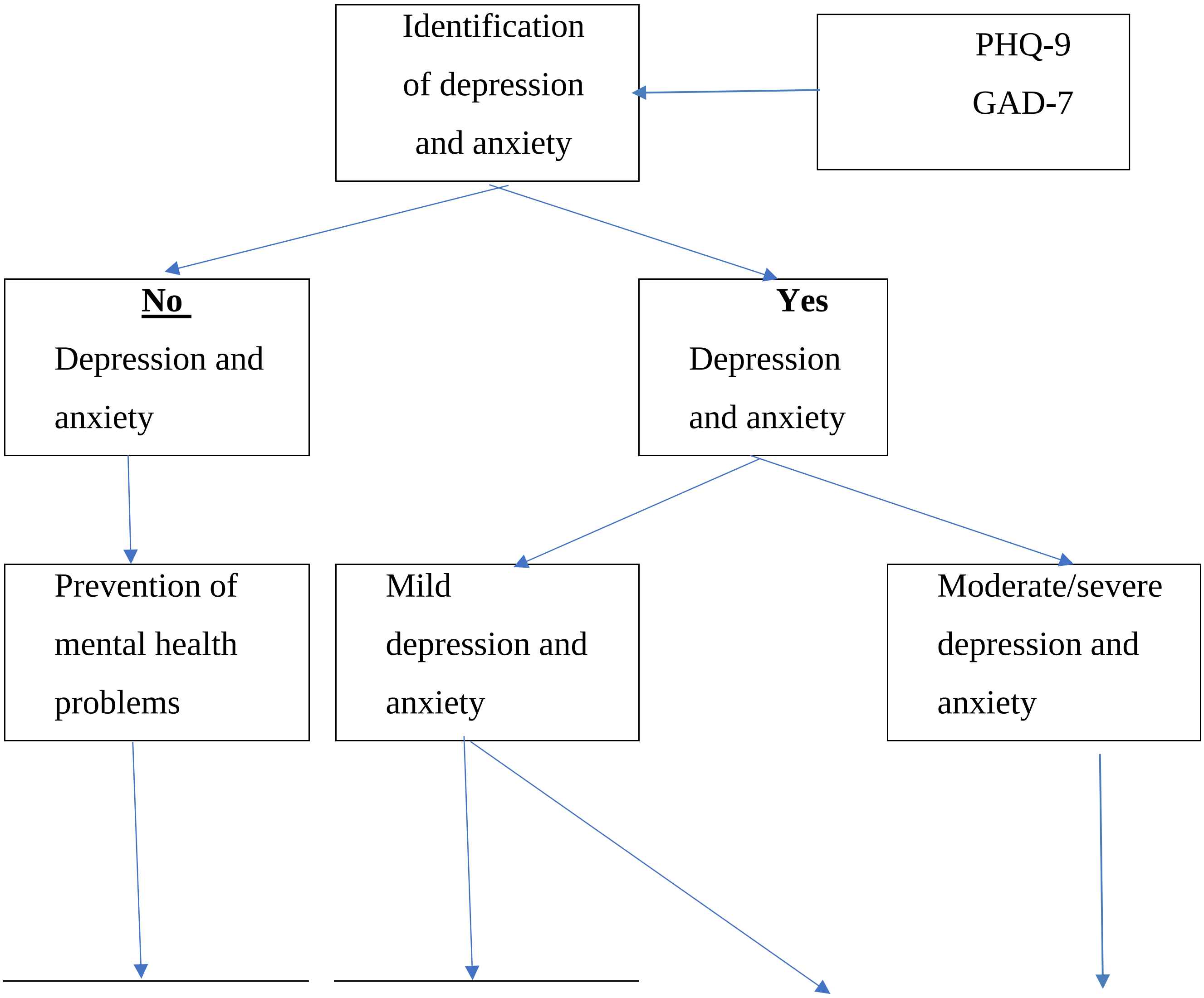
Recommendation

Following the results of this research, literature reviews on proposed interventions to improve the mental health of caregivers in general and caregivers of children with CP in particular, review of Vietnam’s context, we suggest some ideas for consideration by different stakeholders.

As for policymakers, a component to support caregivers should be prioritized and integrated into disability and/or mental health programs. A mechanism to mobilize the active and effective participation of all stakeholders including civil society organizations like the Cerebral Palsy Family Association in sharing the tasks of mental health care for caregivers should be promoted.

As for scientists, professionals, and researchers, a comprehensive model of multi-faceted intervention to improve the mental health of caregivers should be developed, implemented, and evaluated. The link between scientists and policymakers should be tightened so that scientific evidence from research could be transformed into policy actions.

To Cerebral Palsy Family Association and caregivers, it is of need to develop strategies to empower individuals and families in making choices for better dealing with caregiving and daily life obstacles. The specific plan of action could be designed and implemented based on the approach (i) to enhance self-care by caregivers such as maximizing healthy coping of self-support, seeking external support, and minimizing the unhealthy way of self-blame and behavioral disengagement; (ii) to promote different ways of peer support through the Cerebral Palsy Family Association Vietnam (CPFAV); (iii) set-up referral channels of caregivers with moderate and severe depression and anxiety to specialized mental health services.



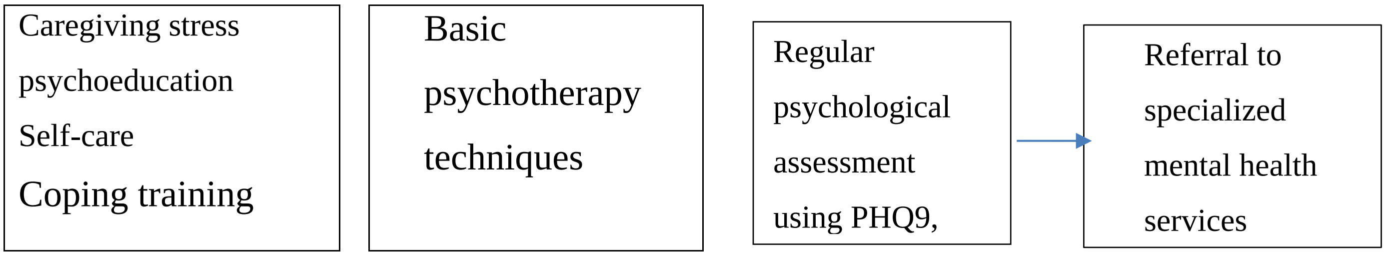


Figure 3.9. Proposed diagram of mental health care applied by CPFAV

Proposed activities

- Setting up the core self-help group within CPFAV
- Training for core self-help group about screening depression and anxiety, basic self-care, psychoeducation, and basic psychotherapy techniques including how to deal with self-blame
- Providing web-based psychoeducation and BA delivery

LIST OF RESEARCH PAPERS RELATED TO THE DISSERTATION

[1] Nguyen Thi Mai Hien, Nguyen Thu Huyen, Tran Van Cong (2019), “Mental health and associated factors among people with mobility disabilities in central provinces of Vietnam”, *Proceedings of the 5th International Conference in Child Mental Health in Vietnam, ISBN: 978-604-9870-57-6,* October 2019, p.173-184. Vietnam National University Press, Hanoi.

[2] Nguyen Thi Mai Hien, Tran Van Cong (2022), "Why can’t children with cerebral palsy attend schools? An exploratory research in Vietnam", *Proceedings of 2nd Hanoi Forum on Pedagogical and Educational Sciences, ISBN: 978-604-384-936-3,* November 2022, p.413-419. Vietnam National University Press, Hanoi.

[3] Nguyen Thi Mai Hien (2022), "Emotional health of caregivers of children with cerebral palsy after the COVID-19 pandemic in Vietnam: An online cross-sectional study", *Proceedings of International Conference “The World in Crisis: The Contribution of Psychology”, ISBN: 978-604-999-272-8,* December 2022, p.79-92. Vietnam National University Press, Hanoi.

[4] Nguyen Thi Mai Hien, Bahr Weiss, Tran Van Cong (2022), "Stress coping strategies among mothers of children with disabilities: Implication for support", *Proceedings of International Conference “The World in Crisis: The Contribution of Psychology”, ISBN: 978-604-999-272-8,* December 2022, p.391-406. Vietnam National University Press, Hanoi.

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APPENDICES

Annex 1: QUESTIONNAIRE

PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

INTRODUCTION

Caring for children with cerebral palsy is hard work, requires much effort, will, persistence, encouragement, and support from family, relatives, and the surrounding community. However, intensive, and longer-term care for children with cerebral palsy could lead to stress and impact the health and quality of life of caregivers.

We would like to learn about the mental health situation of caregivers in order to develop with your collaboration the effective strategies to improve the mental health of caregivers, to increase the productivity, and quality of life of both caregivers and children with cerebral palsy.

We develop this questionnaire to collect relevant information on children with cerebral palsy and on their caregivers. You are cordially requested to read carefully and provide accurate and sufficient information for each of the following questions. Your participation in this survey is voluntary.

All information you provided is confidential. The names, addresses, telephones, and private information of participants will not be included in any report. Only the people conducting this research will have access the provided information for the aforementioned purposes. If you have any questions relating to this study or this questionnaire, please feel free to contact Dr. Nguyen Thi Mai Hien, email: maihiennguyen2010@gmail.com.

I. INFORMATION ABOUT PRIMARY CAREGIVER

1.1. GENERAL INFORMATION

No.	QUESTION	ANSWER	
a1	Your full name?	---------------------	
a2	Your permanent address?	Which province?............... Which district?.................. Which commune?.............	
a3	Your telephone number?	…………………	
a4	Your email?	…………………	
a5	Your sex?	Male Female	1 2
a6	Your year of birth?	[__|__][__|__]	
a7	Your ethnicity?	Kinh Others (specify pls)...……..	1 2
a8	Your religion?	None Buddhism Christian Others (specify pls)..........	1 2 3 99
a9	Your marital status?	Married Divorced Separated Widowed Not married Others (specify pls.)...…	1 2 3 4 5 99
a10	Your highest education qualification?	Don’t go to school Primary (Cấp 1)	0 1

No.	QUESTION	ANSWER	
		Secondary (Cấp 2) High school (Cấp 3) Vocational, colleage, university and post university	2 3 4
a11	Your main job?	Farmer Worker Business Buôn bán Odd job Office staff Housework Others (specify pls)………	1 2 3 4 5 6 7 99
a12	Do you work at home ot outside your house?	At home Both at home and outside Outside the house	1 2 3
a13	Do you have to quit or change the job for caring the CP child?	Yes No	1 2
a14	Your relation with CP child?	Mother Father Siblings Grant parent Caretaker Others (specify pls)……	1 2 3 4 5 99
a15	Which tasks in your family are you responsible for? (multiple choices)	Housework Caring for CP child Caring for other children Caring for the old parents Main earning for living Subordinate earning for living	1 2 3 4 5 6

No.	QUESTION	ANSWER	
		Others (specify pls)……	99
a16	Duration of caring for CP child?	(number of years) [__|__] (years)	
a17	An average number of hours per day for taking care of a CP child?	(number of hours) [__|__] (hours)	
a18	How many people do you have to care for every day (such as old parents, disable child or other young child)	(number of persons) [__|__] (persons)	
a19	Have you ever had COVID-19?	Yes No	1 0
a20	If yes, how the severity of disease it was?	Very severe Severe Moderate Mild No symtom	1 2 3 4 5

1.2. MENTAL HEALTH INFORMATION OF PRIMARY CAREGIVER (Applying PHQ 9 and GAD 7)

<u>Over the last two weeks</u>, how often have you been bothered by any of the following problems? Please read each sentence carefully and chose the most appropriate answer to your status in the last two weeks

No	PHQ-9 content	0. Not at all	1. Several days	2. More than half the days	3. Nearly every day
b1	Little interest or pleasure in doing				

Over the last two weeks, how often have you been bothered by any of the following problems? Please read each sentence carefully and chose the most appropriate answer to your status in the last two weeks

No	PHQ-9 content	0. Not at all	1. Several days	2. More than half the days	3. Nearly every day
	things				
b2	Feeling down, depressed, or hopeless				
b3	Trouble falling or staying asleep, or sleeping too much				
b4	Feeling tired or having little energy				
b5	Poor appetite or overeating				
b6	Feeling bad about yourself – or that you are a failure or have let yourself or your family down				
b7	Trouble concentrating on things, such as reading the newspaper or watching television.				
b8	Moving or speaking so				

Over the last two weeks, how often have you been bothered by any of the following problems? Please read each sentence carefully and chose the most appropriate answer to your status in the last two weeks					
No	**PHQ-9 content**	**0. Not at all**	**1. Several days**	**2. More than half the days**	**3. Nearly every day**
	slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual				
b9	Thoughts that you would be better off dead, or of hurting yourself in some way				
b10	If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?	0.Not difficult at all	1. Somewhat difficult	2. Very Difficult	3. Extremely Difficult

<table>
<tr><td colspan="6">**Over the last two weeks**, how often have you been bothered by any of the following problems? Please read each sentence carefully and chose the most appropriate answer to you status in the last two weeks</td></tr>
<tr><th>No</th><th>GAD-7 content</th><th>0. Not at all</th><th>1. Several days</th><th>2. More than half the days</th><th>3. Nearly every day</th></tr>
<tr><td>b11</td><td>Feeling nervous, anxious, or on edge</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b12</td><td>Not being able to stop or control worrying</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b13</td><td>Worrying too much about different things</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b14</td><td>Trouble relaxing</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b15</td><td>Being so restless that it’s hard to sit still</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b16</td><td>Becoming easily annoyed or irritable</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b17</td><td>Feeling afraid as if something awful might happen</td><td></td><td></td><td></td><td></td></tr>
<tr><td>b18</td><td>If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other</td><td>0. Not difficult at all</td><td>1. Somewhat difficult</td><td>2. Very Difficult</td><td>3. Extremely Difficult</td></tr>
</table>

	people?				

b19..In this question, please select all of the reasons that have caused the problems that you selected above? *(you can choose as many problems as is appropriate)*	No good health No job/lose the job No time to relax Unable to attend the social activities Difficult to care for CP child Two much work to do Pressure (criticism, blaming) by relative Conflict in family Violence by spouse Scold and bite CP child Much spending for CP child (learning, treatment) Stigma, discrimination by others Others (specify pls)…………………….………………..	1 2 3 4 5 6 7 8 9 10 11 12 99

1.3. BURDEN OF CARE FOR CP CHILD

(Following Caregiver Difficulties Scale: CDS)

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.					
Content					
c1. How often does your child become physically ill (such as having a cold, having headaches, etc.)?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.					
Content					
c2. Are you satisfied about the improvement in your child’s CP condition after receiving treatment / therapy for the CP?	5. Not at all	4. To a lesser extent	3. To some extent	2. To a greater extent	1. Completely
c3. How often do you worry about what your child’s future might be?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c4. How often do you worry about your child’s present state?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c5. How often do you worry that your child cannot function like other children (e.g., going to school, playing)?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c6. How often do you feel sad that your child cannot do anything by	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.					
Content					
himself/herself?					
c7. How often do you worry that your child gets insulted and/or ridiculed by others?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c8. How often do you fear that your child will have accidents as a result of his/her disability?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c9. How often does caring for the child make you feel tired and exhausted?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c10. How often does the child's condition prevent you from being relaxed?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c11. How much do you have enough time to look after your own health?	5. Not at all	4. Small amount	3. Moderate amount	2. A great deal	1. An extreme amount
c12. How much do	5.	4.	3.	2.	1.

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.					
Content					
you have enough time for your basic daily needs such as having meals, sleeping, bathing etc.?	Not at all	Small amount	Moderate amount	A great deal	An extreme amount
c13. How frequently do you feel that you will never have enough time to get everything done?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c14. How much do you think that your health has been affected because of your child's condition?	1. Not at all	2. Small amount	3. Moderate amount	4. A great deal	5. An extreme amount
c15. How often does the child's condition prevent you from attending to the needs of other family members?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c16. How often does	5.	4.	3.	2.	1.

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.					
Content					
your spouse help you with the care of this child?	Never	Rarely	Sometimes	Often	Always
c17. How often does your spouse support you in other family responsibilities?	5. Never	4. Rarely	3. Sometimes	2. Often	1. Always
c18. How often are you able to discuss your child’s problems with other family members?	5. Never	4. Rarely	3. Sometimes	2. Often	1. Always
c19. How much are the other family members well aware about the child’s CP condition?	5. Not at all	4. To a lesser extent	3. To some extent	2. To a greater extent	1. Completely
c20. How often do your relatives/neighbours help your with caring for the child?	5. Never	4. Rarely	3. Sometimes	2. Often	1. Always
c21. How often do you have to restrict	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.

Content					
your social visits and relationships due to the child's illness?					
c22. How often do you have to face embarrassing situations when you are traveling with the child (such as when the child screams)?	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
c23. How much are your family expenses increased due to the child's condition?	1. Not at all	2. Small amount	3. Moderate amount	4. A great deal	5. An extreme amount
c24. To what extent is your income adequate to provide the necessities for the child?	5. Not at all	4. To a lesser extent	3. To some extent	2. To a greater extent	1. Completely
c25. How often do you worry that you	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always

Read each sentence and select the most suitable response for each item which best describes your experience in caring for CP child.					
Content					
are unable to provide special facilities (CP wheelchair, commode…) needed by your child?					

1.4. STRESS COPING STRATEGIES WHEN CARING FOR CP CHILD

(Following Brief COPE Inventory)

Read each sentence and select the most suitable response that best describes your strategy for **coping with stress due to caring for CP child**				
Content	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
	1	2	3	4
d1. I've been turning to work or other activities to take my mind off things				
d2. I've been concentrating my efforts on doing something about my child's situation				
d3. I've been saying to myself "this isn't real".				

Read each sentence and select the most suitable response that best describes your strategy for **coping with stress due to caring for CP child**				
Content	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
	1	2	3	4
d4. I've been using alcohol or other drugs to make myself feel better				
d5. I've been getting emotional support from other people				
d6. I've been giving up trying to deal with taking care of my child				
d7. I've been taking action to try to make the situation better				
d8. I've been refusing to believe that it has happened				
d9. I've been saying things to let my unpleasant feeling escape.				
d10. I've been getting help and advice from other people.				

<table>
<tr><td colspan="5">Read each sentence and select the most suitable response that best describes your strategy for **coping with stress due to caring for CP child**</td></tr>
<tr><td>Content</td><td>I haven’t been doing this at all</td><td>I’ve been doing this a little bit</td><td>I’ve been doing this a medium amount</td><td>I’ve been doing this a lot</td></tr>
<tr><td></td><td>1</td><td>2</td><td>3</td><td>4</td></tr>
<tr><td>11. I’ve been using alcohol or other drugs to help me get through it</td><td></td><td></td><td></td><td></td></tr>
<tr><td>d12. I’ve been trying to see it in a different light, to make it seem more positive</td><td></td><td></td><td></td><td></td></tr>
<tr><td>d13. I’ve been criticizing myself</td><td></td><td></td><td></td><td></td></tr>
<tr><td>d14. I’ve been trying to come up with a strategy about what to do</td><td></td><td></td><td></td><td></td></tr>
<tr><td>d15. I’ve been getting comfort and understanding from someone</td><td></td><td></td><td></td><td></td></tr>
<tr><td>d16. I’ve been giving up the attempt to cope</td><td></td><td></td><td></td><td></td></tr>
<tr><td>d17. I’ve been looking for something good in what is happening</td><td></td><td></td><td></td><td></td></tr>
</table>

Read each sentence and select the most suitable response that best describes your strategy for **coping with stress due to caring for CP child**

Content	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
	1	2	3	4
d18. I've been making jokes about it				
d19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping				
d20. I've been accepting the reality of my child's and my situation				
d21. I've been expressing my negative feelings				
d22. I've been trying to find comfort in my religion or spiritual beliefs				
d23. I've been trying to get advice or help from other people about what to do				
d24. I've been learning				

Read each sentence and select the most suitable response that best describes your strategy for **coping with stress due to caring for CP child**				
Content	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
	1	2	3	4
to live with and accept my child's situation.				
d25. I've been thinking hard about what steps to take to make our situation better.				
d26. I've been blaming myself for things that happened				
d27. I've been praying or meditating				
d28. I've been making fun of my child				
d29. I have found the joy from caring for the other healthy child				

1.5. QUALITY OF LIFE OF THE PRIMARY CARE GIVER

(*Following selected items of QoL BREF of WHO*)

e1.	How would you rate	1. Very poor	2. Poor	3. Neither poor nor	4. Good	5.Very good

	your quality of life?			good		
e2.	How would you rate your health?	1. Very poor	2. Poor	3. Neither poor nor good	4. Good	5. Very good
e3.	How much do you enjoy life?	1. Not at all	2. Small amount	3.Moderate amount	4.A great deal	5.An extreme amount
e4.	To what extent do you feel your life to be meaningful?	1. Not at all	2.Small amount	3.Moderate amount	4.A great deal	5.An extreme amount
e5.	To what extent do you have the opportunity for leisure activities?	1.Not at all	2. Slightly	3.Somewhat	4.To a great extent	5.Completely
e6.	How satisfied are you with your spouse	1. Very dissatisfied	2.Fairly dissatisfied	3.Neither satisfied or dissatisfied	4.Satisfied	5.Very satisfied

	relationships					
e7.	How often do you have negative feelings such as blue mood, despair, anxiety or depression?	5.Never	4.Infrequently	3.Sometimes	2.Freqquently	1.Always

II - FAMILY INFORMATION

No	QUESTION	ANSWER	
f1	How many people do you live with? (# persons)?	[__|__]	
f2	With whom do you live? Select as many as is appropriate.	Parents Spouse Children Siblings Relatives Other, specify:………	1 2 3 4 5 99
f3	Of which, how many children under 18 yo	[__|__]	
f4	How many children under 18 yo	[__|__]	

No	QUESTION	ANSWER	
	with disability/CP?		
f5	Is your family in urban or rural area?	Urban Rural	1 2
f6	Following the Government criteria of the poverty, which kind of your household?	Poor Near poor Better-off	1 2 3
f7	What is total monthly income of your family (million VND)	[__|__][__| (Mill.)	
f8	Who is mainly responsible for earning money?	Husband Wife Other, specify…………	1 2 99
f9	How convenient is your living environment for taking care of CP child (sufficient space, separate room, accessible toilet)?	Very convenient Convenient Normal inconvenient Very inconvenient	1 2 3 4 5

III - INFORMATION OF CHILDREN WITH CEREBRAL PALSY

3.1. GENERAL INFORMATION

No	QUESTION	ANSWER	
g1	Sex	Male Female	1 2
g2	Year your child was born	[__|__][__|__]	
g3	Does a CP child go to	No	1

No	QUESTION	ANSWER	
	school?	To special education school To typical school Other, specify……	2 3 99
g4	How many years does the child live with CP? (*number of years*)? Under 1 year -> rounded 1 year	[__|__]	
g5	Which kind of CP does the child have? *(Multiple choices)*	Spastic CP Dyskinetic CP Ataxic CP Soft paralized Mixed CP No classified Don't know/remember	1 2 3 4 5 6 98
g6	Following the GMFCS- Gross Motor Function Classification System, which level of function is the child in?	**Level I** : can walk, climb, need support for balance **Level II** : can walk, climb stairs holding onto a railing. **Level III**: Can sit dependently and need a little support for sitting **Level IV** : Can control head and neck but need more support. **Level V** : Need 100% support for all trong tất cả các tư thế, no control of head and neck Don't know/no answer	1 2 3 4 5 98

No	QUESTION	ANSWER	
g7	How has your child’s CP changed over time, up until now?	Very much improved	1
		Much improved	2
		Little improved	3
		Keep the same	4
		Get worse	5
g8	Has the CP child had COVID-19?	Yes	1
		No	0
g9	If yes, how the severity of disease it was?	Very severe	1
		Severe	2
		Moderate	3
		Mild	4
		No symtom	5

3.2. FUNCTIONS IMPAIRMENTs OF CP CHILD

No	QUESTION	HOW DIFFICULT IT IS?	
h1	Does the child have difficulty in movement? (Crawl, walk, stand, change in positions)	No difficulty at all	0
		A little difficult	1
		Rather difficult	2
		Much difficult	3
		Can not move	4
h2	Does the child have difficulty in seeing?	No difficulty at all	0
		A little difficult	1
		Rather difficult	2
		Much difficult	3
		Can not see	4
h3	Does the child have difficulty in speaking?	No difficulty at all	0
		A little difficult	1

No	**QUESTION**	**HOW DIFFICULT IT IS?**	
		Rather difficult Much difficult Can not speak	2 3 4
h4	Does the child have difficulty in hearing?	No difficulty at all A little difficult Rather difficult Much difficult Can not hear	0 1 2 3 4
h5	Does the child have difficulty in communicating with other?	No difficulty at all A little difficult Rather difficult Much difficult Can not communicate	0 1 2 3 4
h6	Does the child have difficulty in studying or learning the new skills?	No difficulty at all A little difficult Rather difficult Much difficult Can not learn	0 1 2 3 4
h7	Does the child have difficulty in self-care (eating, drinking, Bowels, Bladder?	No difficulty at all A little difficult Rather difficult Much difficult Can not do	0 1 2 3 4
h8	Does the child have behavioral or emotional problems, such as getting	No problem at all A little bit problem Rather problem	0 1 2

No	QUESTION	HOW DIFFICULT IT IS?	
	angry and hitting people, becoming very anxious, etc.?	Much problem Very much problem	3 4
h9	Does the CP child have epilepsy?	Yes No	1 2
h10	Does the CP child have other health conditions (heart, lung, liver related problems)?	Yes No	1 2

3.3. LEVEL OF INDEPENDENCE IN DAILY LIVING ACTIVITIES

(Following Barthel Index)

No	QUESTION	ANSWER	
i1	Feeding	Unable Needs help Independent	0 5 10
i2	Bathing	Dependent Independent	0 5
i3	Grooming	Needs help Independent	0 5
i4	Dressing	Dependent needs help but can do about	0 5

No	QUESTION	ANSWER	
		half unaided independent (including buttons, zips, laces, etc.)	10
i5	Bowels	incontinent occasional accident continent	0 5 10
i6	Bladder	incontinent occasional accident continent	0 5 10
i7	Toilet use	Dependent needs some help, but can do something alone independent (on and off, dressing, wiping)	0 5 10
i8	Transfers (bed to chair and back)	unable, no sitting balance major help (one or two people, physical), can sit minor help (verbal or physical) independent	0 5 10 15
i9	Ability to move (on level surfaces)	immobile or < 50 m wheelchair independent, including corners, > 50 m walks with help of one person (verbal or physical) > 50 m	0 5 10

No	QUESTION	ANSWER	
		independent (but may use any aid; for example, stick) > 50 m	15
i10	Stairs	unable needs help (verbal, physical, carrying aid) independent	0 5 10

IV. SERVICES ACCESIBILITY AND SOCIAL SUPPORT

No	QUESTION	ANSWER	
k1.	Do you receive the monthly allowance from the government to support for CP child?	No Yes	1 2
k2.	Do you receive the monthly allowance from the government to support for caregiver of CP child?	No Yes	1 2
k3	Do you recceive assistive devices (CP wheelchair, commode…) for CP child?	No Yes	1 2
k4	Is the CP child sent to the special care education center?	No Sometimes Often	0 1 2
k5	Is the CP child sent to the rehabilitation facility?	No Sometimes Often	0 1 2
k6	Does the CP child have health	No	1

No	QUESTION	ANSWER	
	insurance?	Yes	2
k7	Do you have health insurance?	No Yes	1 2
k8	Do you get information you need for caring CP child (guidelines on caring for the child, government support…)	No Sometimes Often	0 1 2
k9	Do you get the legal support service?	No Sometimes Often	0 1 2
k10	Do you get the mental health services?	No Sometimes Often	0 1 2
k11	Do you get psychological counseling?	No Sometimes Often	0 1 2
k12	How often have you joined the activities of the Cerebral Palsy Family Association (CPFA)	No Sometimes Often	0 1 2
k13	How helpful are the CPFA's activities for helping you in taking care of CP child?	Not helpful et all A bit helpful Moderate helpful Much helpful Very much helpful	0 1 2 3 4
k14	Which benefits do you get when joining CPFA?	No benefit To be heard,	1 2

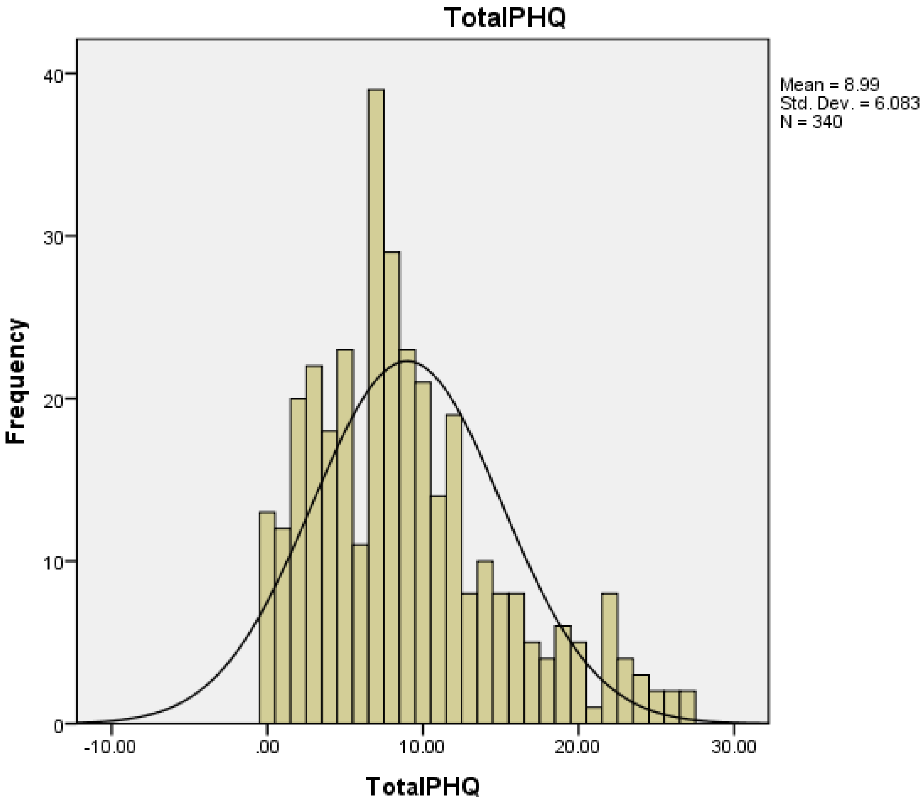
No	QUESTION	ANSWER	
	(Please select all benefits you have got)	understood for stress release	
		Sharing information and experiences in caring for CP child	3
		Get more friends	4
		Get materialized support (Gift for Tet, studying scholarship, Rehabilitation devices)	5
		Free accommodation when going to examination for the CP child	6
		Better understanding on CP	7
		Getting information on studying, school for CP child	8
		Orientation for CP child occupation	9
		Other, pls specify…	99
k15	Who could help to take care of the CP child for you? (Multiple choices)	No one	0
		Wife/husband	1
		House worker	2

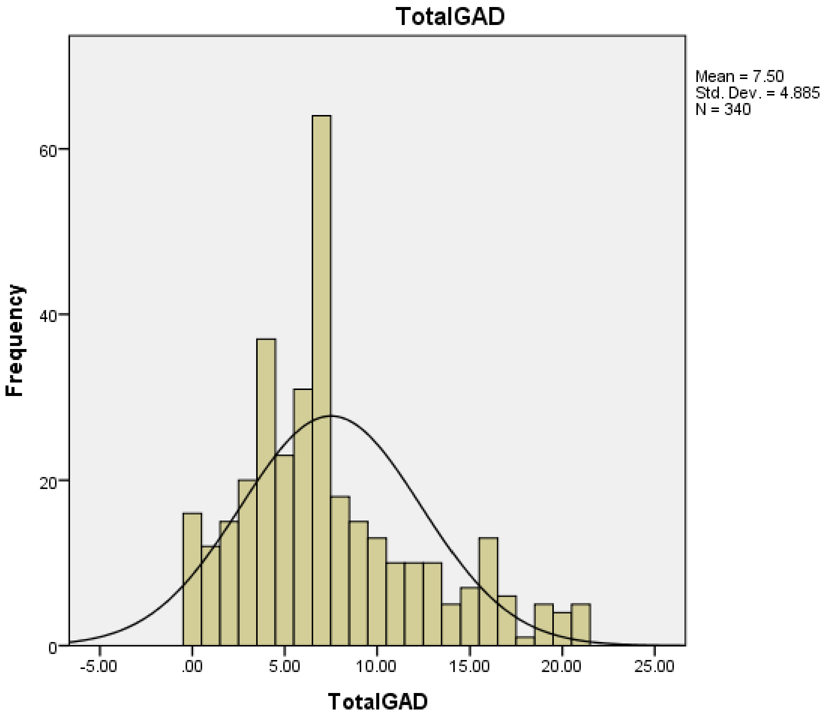
No	QUESTION	ANSWER	
		Other family member	3
		Relatives	4
		CP support center	5
		Other, specify………	99

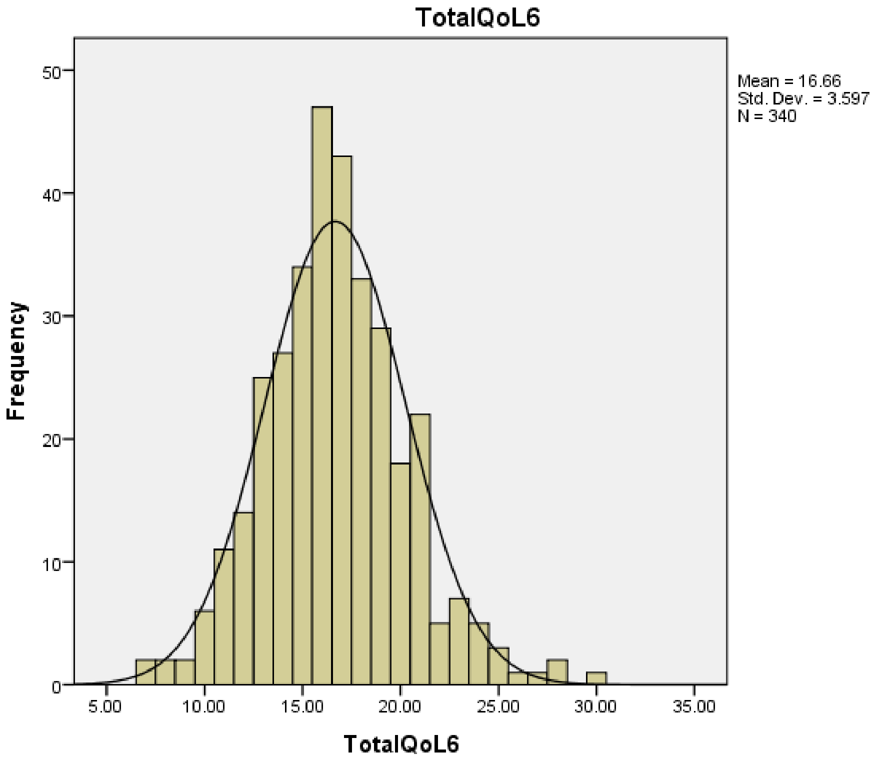
Annex 2: Normal distribution tests results

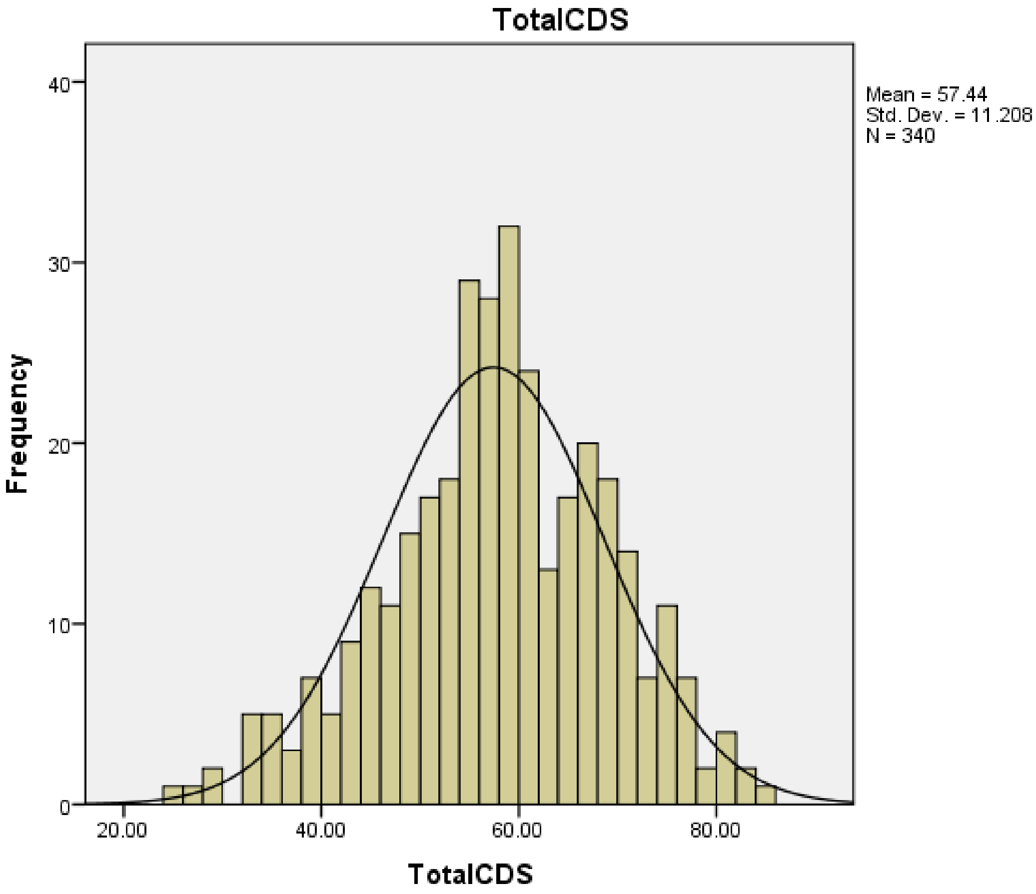
Descriptive Statistics

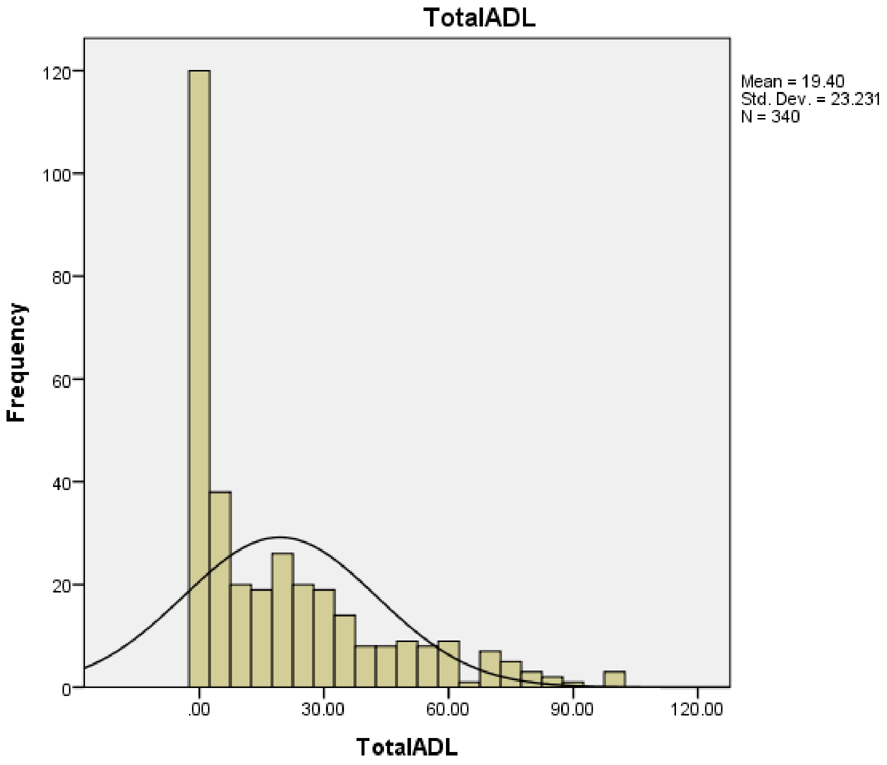
	N	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
Total PHQ	340	.00	27.00	8.9853	6.08274	.845	.132	.298	.264
Total GAD	340	.00	21.00	7.5029	4.88481	.843	.132	.278	.264
Total QoL	340	7.00	30.00	16.6618	3.59699	.337	.132	.749	.264
Total CDS	340	25.00	84.00	57.4353	11.20809	-.232	.132	-.096	.264
Total ADL	340	.00	100.00	19.3971	23.23101	1.305	.132	1.066	.264
Functional Impairments	340	11.00	40.00	27.3235	6.46397	-.297	.132	-.469	.264
Valid N (listwise)	335								

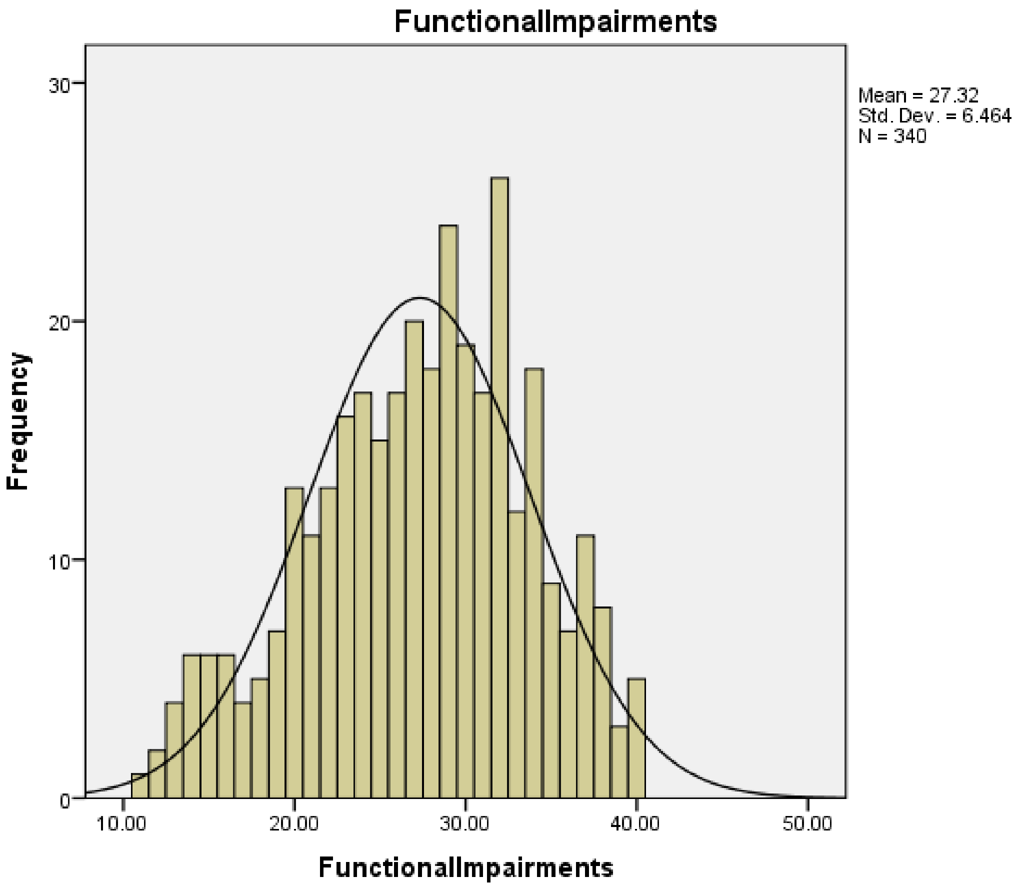

TotalPHQ
Mean = 8.99
Std. Dev. = 6.083
N = 340
Frequency
40
30
20
10
0
-10.00
.00
10.00
20.00
30.00
TotalPHQ


TotalGAD
Mean = 7.50
Std. Dev. = 4.885
N = 340
Frequency
60
40
20
0
-5.00
.00
5.00
10.00
15.00
20.00
25.00
TotalGAD


TotalQoL6
Mean = 16.66
Std. Dev. = 3.597
N = 340
Frequency
0
10
20
30
40
50
5.00
10.00
15.00
20.00
25.00
30.00
35.00
TotalQoL6


TotalCDS
Mean = 57.44
Std. Dev. = 11.208
N = 340
Frequency
0
10
20
30
40
20.00
40.00
60.00
80.00
TotalCDS


TotalADL
Mean = 19.40
Std. Dev. = 23.231
N = 340
Frequency
120
100
80
60
40
20
0
.00
30.00
60.00
90.00
120.00
TotalADL


FunctionalImpairments
Mean = 27.32
Std. Dev. = 6.464
N = 340
Frequency
30
20
10
0
10.00
20.00
30.00
40.00
50.00
FunctionalImpairments

Annex 3
Exploratory Factor Analysis of Brief-COPE

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.795
Bartlett's Test of Sphericity	Approx. Chi-Square	2151.803
	df	325
	Sig.	.000

Pattern Matrix[a]

Brief-COPE Items	Factor			
	1	2	3	4
d25.COPE. I’ve been thinking hard about what steps to take to make our situation better (Planning)	.664			
d24.COPE. I’ve been learning to live with and accept my child’s situation (Acceptance).	.643			
d17.COPE. I’ve been looking for something good in what is happening (Positive reframing)	.597			
d14.COPE. I’ve been trying to come up with a strategy about what to do (Planning)	.524			
d12.COPE. I’ve been trying to see it in a different light, to make it seem more positive (Positive reframing)	.494			
d20.COPE.I’ve been accepting the reality of my child’s and my situation (Acceptance).	.478			
d23.COPE.I’ve been trying to get advice or help from other people about what to do (Use of information)	.477			
d28.COPE.I've been making fun of my child situation (Humor)	.421			
d7.COPE.I’ve been taking action to try to make the situation better (Active coping)	.396			
d27.COPE.I’ve been praying or meditating (Religion)	.328			
d26.COPE.I’ve been blaming myself for things that happened (Self-blame)		793		
d13.COPE.I’ve been criticizing myself (Self-blame)		701		

d16.COPE.I’ve been giving up the attempt to cope (Behaviour disengagement)		381		
d6.COPE.I’ve been giving up trying to deal with taking care of my child (Behaviour disengagement)		329		
d10.COPE. I’ve been getting help and advice from other people (seeking social support)			696	
d9.COPE.I've been saying things to let my unpleasant feeling escape (Venting)			514	
d5.COPE.I’ve been getting emotional support from other people (Seeking emotional support from other)			511	
d15.COPE.I’ve been getting comfort and understanding from someone (Seeking emotional support from other)			398	
d1.COPE.I’ve been turning to work or other activities to take my mind off things (Self-Distraction)				577
d2.COPE.I’ve been concentrating my efforts on doing something about my child’s situation (Active coping)				535
d19.COPE.I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping (Self-Distraction)				404
d3.COPE.I’ve been saying to myself “this isn’t real” (Denial)				362
d18.COPE.I’ve been making jokes about situation (Humor)				314

Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.

Reliability Statistics

Coping Factor	Cronbach’s Alpha	N of Items
1	0.796	10
2	0.616	4
3	0.630	4
4	0.614	5

Annex 4

Exploratory Factor Analysis of Care Difficulties Scale (CDS)

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.844
Bartlett's Test of Sphericity	Approx. Chi-Square	3260.312
	df	300
	Sig.	.000

Items	**Factor**			
	1	**2**	**3**	**4**
c3.CDS.How often do you worry about CP child's future	.927			
c8.CDS.How often do you fear that your child will have accidents as a result of his/her disability	.813			
c5.CDS.How often do you worry that your child cannot function like other children (e.g., going to school, playing)	.790			
c4.CDS.How often do you worry about your child's present state	.782			
c6.CDS.How often do you feel sad that your child cannot do anything by himself/herself	.614			
c7.CDS.How often do you worry that your child gets insulted and/or ridiculed by others	.610			
c17.CDS.How often does your spouse support you in other family responsibilities		.806		
c16.CDS.How often does your spouse help you with the care of this child		.799		
c18.CDS.How often are you able to discuss your child's problems with other family members		.653		
c19.CDS.How much are the other family members well aware about the child's CP condition		.527		

Items	**Factor**			
	1	**2**	**3**	**4**
c9.CDS.How often does caring for the child make you feel tired and exhausted			.767	
c14.CDS.How much do you think that your health has been affected because of your child's condition			.679	
c10.CDS.How often does the child's condition prevent you from being relaxed			.655	
c15.CDS.How often does the child's condition prevent you from attending to the needs of other family member			.484	
c22.CDS. How often do you have to face embarrassing situations when you are traveling with the child (such as when the child screams)			.421	
c12.CDS.How much do you have enough time for your basic daily needs such as having meals, sleeping, bathing etc.?				-.689
c11.CDS.How much do you have enough time to look after your own health				-.610
c13.CDS.How frequently do you feel that you will never have enough time to get everything done				-.429
c1.CDS.child become physically ill				-.379
c25.CDS.How often do you worry that you are unable to provide special facilities (CP wheelchair, commode…) needed by your child				-.315

Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.

Reliability Statistics

CDS Factor	**Cronbach's Alpha**	**N of Items**
1	0.891	6
2	0.781	4
3	0.751	5
4	0.657	5