DEVELOPMENT AND VALIDATION OF A QUALITY OF LIFE SCALE FOR PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN MALAYSIA

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by

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LIST OF ABBREVIATIONS

AAQ-II	Acceptance and Action Questionnaire (Revised)
CBRC	Community-based Rehabilitation Centre
CP	Cerebral Palsy
CWD	Children with Disabilities
DUREL	The Duke University Religion Index
EFA	Exploratory Factor Analysis
GERD	Gastroesophageal Reflux Disease
GMFCS	Gross Motor Function Classification System
HRQoL	Health-related Quality of Life
IR	Intrinsic Religiosity
KI	Key Informant
MLR	Multiple Linear Regression
PCQoL	Primary Caregiver Quality of Life
PEDSQL	Pediatric Quality of Life Inventory^{TM} Family Impact Module
PWD	People with Disabilities
QoL	Quality of Life
SD	Standard Deviation
SHS	Subjective Happiness Scale
SLR	Single Liner Regression
SPSS	Statistical Product and Service Solutions
SRC	Specialized Rehabilitation Centre
SWLS	Satisfaction with Life Scale

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PEMBANGUNAN DAN PENGESAHAN SKALA KUALITI HIDUP UNTUK PENJAGA UTAMA KANAK-KANAK DENGAN CEREBRAL PALSY DI MALAYSIA

ABSTRAK

Kualiti hidup (QoL) di kalangan penjaga utama kanak-kanak dengan Cerebral Palsy (CP) adalah kebimbangan kritikal, mempengaruhi kesejahteraan penjaga dan dinamik keluarga secara keseluruhan. Memahami faktor-faktor yang membentuk QoL penjaga utama adalah penting untuk membangunkan intervensi sokongan yang berkesan. Namun, kayu ukur yang sedia ada adalah amat terhad untuk menilai QoL penjaga dalam konteks tempatan. Kajian ini bertujuan untuk menghasilkan dan mengesahkan kayu ukur QoL yang relevan dari segi budaya untuk penjaga utama kanak-kanak dengan CP di Malaysia, yang dijalankan dalam tiga fasa. Fasa 1 melibatkan kajian kuantitatif asas yang menilai QoL penjaga utama, Fasa 2 tertumpu pada pembentukan skala, dan Fasa 3 mengesahkan skala melalui analisis faktor penerokaan (EFA). Peserta telah direkrut menggunakan persampelan pemberi maklumat utama dalam Fasa 1 dan persampelan bertujuan dalam Fasa 2 dan 3, dengan reka bentuk kajian keratan rentas digunakan. Dalam Fasa 1, 159 penjaga utama (Purata umur = 42.8 tahun, SD = 8.4) yang menghadiri kem pemeriksaan kesihatan di Kelantan, Johor dan Sarawak telah mengambil bahagian. QoL mereka dinilai menggunakan Modul Impak Keluarga Inventori™ Kualiti Hidup Pediatrik (PEDSQL FIM) dan dianalisis melalui analisis deskriptif, regresi linear tunggal dan regresi linear berbilang. Keputusan menunjukkan bahawa penjaga utama yang menghadiri kem pemeriksaan kesihatan secara amnya mempunyai QoL berkaitan kesihatan yang baik, fungsi keluarga, dan QoL keseluruhan, dengan tahap pendidikan ibu dan pendapatan bulanan keluarga dikenal pasti sebagai faktor utama yang mempengaruhi ketiga-tiganya. Dalam Fasa 2, skala QoL bahasa Melayu baharu telah dihasilkan melalui kajian literatur, cadangan pakar, dan temu bual mendalam dengan lapan belas penjaga utama tempatan (Purata umur = 39.3 tahun, SD = 7.28), mengenal pasti lapan tema utama: kekangan fizikal, tekanan emosi, kesulitan kewangan, tingkah laku sukar kanak-kanak, sokongan sosial, penerimaan, kepercayaan, dan inisiatif untuk perkembangan kanak-kanak. *Item* telah dijana dan disusun ke dalam draf skala, yang menjalani pengesahan kandungan oleh tujuh pakar dan pra-ujian dengan 15 penjaga utama. Dalam Fasa 3, seratus penjaga utama Malaysia (Purata umur = 44.9 tahun, SD = 11.1) mengambil bahagian dalam kajian ini. Skala yang baru dihasilkan, dinamakan skala Kualiti Hidup Penjaga Utama (PCQoL), telah diuji untuk kesahihan binaan melalui EFA, kesahihan serentak melalui korelasi dengan skala-skala lain yang berkaitan, dan kebolehpercayaan melalui alfa Cronbach. Versi akhir 28 *item*, meliputi lapan domain, menunjukkan kesahihan dan kebolehpercayaan yang kukuh dalam menilai QoL dalam konteks penjaga utama Malaysia. Kajian ini memberikan pandangan penting untuk pakar kesihatan untuk meningkatkan QoL penjaga utama kanak-kanak dengan CP.

DEVELOPMENT AND VALIDATION OF A QUALITY OF LIFE SCALE FOR PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN MALAYSIA

ABSTRACT

The quality of life (QoL) among primary caregivers of children with cerebral palsy (CP) is a critical concern, influencing both caregiver well-being and overall family dynamics. Understanding the factors that shape caregivers' QoL is essential for developing effective support interventions. Yet, there are limited validated tools to assess caregiver QoL in the local context. This study aimed to develop and validate a culturally relevant QoL measure for primary caregivers of children with CP in Malaysia, conducted in three phases. Phase 1 involved a baseline quantitative study assessing primary caregiver QoL, Phase 2 focused on scale development, and Phase 3 validated the scale through exploratory factor analysis (EFA). Participants were recruited using key informant sampling in Phase 1 and purposive sampling in Phases 2 and 3, with a cross-sectional study design applied. In Phase 1, 159 primary caregivers (Mean age = 42.8 years, SD = 8.4) who attended health screening camps in Kelantan, Johor, and Sarawak participated. Their QoL was assessed using the Pediatric Quality of Life Inventory™ Family Impact Module (PEDSQL FIM) and analysed through descriptive analysis, single linear regression, and multiple linear regression. Results indicated that primary caregivers who attending health screening camps generally had good health-related QoL, family functioning, and overall QoL, with maternal education level and family income identified as key factors influencing all three. In Phase 2, a new Malay-language QoL scale was developed through literature review, expert input, and in-depth interviews with eighteen local primary caregivers (Mean age = 39.3 years, SD = 7.28), identifying eight key themes: physical constraint, emotional distress, financial hardship, child's difficult behavior, social support, acceptance, beliefs, and initiative for the child's development. Items were generated and compiled into a draft scale, which underwent content validation by seven experts and pre-testing with 15 caregivers. In Phase 3, a hundred Malaysian primary caregivers (Mean age = 44.9 years, SD = 11.1) participated in the study. The newly developed scale, named the Primary Caregiver Quality of Life (PCQoL) scale, was tested for construct validity through EFA, concurrent validity through correlations with related constructs, and reliability via Cronbach's alpha. The final 28-item version, covering eight domains, demonstrated strong validity and reliability in assessing QoL in the Malaysian primary caregiver context. This study provides valuable insights for healthcare providers to improve the QoL of primary caregivers of children with CP.

CHAPTER 1
INTRODUCTION

1.1 Background

Cerebral Palsy (CP) represents a complex group of permanent movement disorders that caused by the non-progressive disruption occurred during the development stage or fetal or infant brain (Stavsky et al., 2017). These neurological impairments can occur before birth, during delivery, or in the early postnatal period, leading to a series of motor and sensory deficits that remain lifelong (Gulati & Sondhi, 2018). The clinical manifestations of CP are highly diverse, encompassing a wide range of motor impairments, from mild incoordination to severe spasticity and paralysis (Gilson et al., 2014). Multiple factors have been associated with the risk of congenital CP, including low birth weight, preterm birth, maternal infections during pregnancy, steroid use, and complications during delivery (Bakar, Samat & Yaacob, 2021). Despite the ongoing improvements in neonatal care, the management of conditions like dystocia and premature labour, as well as advancements in maternal health around the world, the overall prevalence of CP has remained constant in recent years (Finch-Edmondson et al., 2019). The estimate prevalence of pre-/perinatal CP in high-income countries was 1.5 per 1000 live births in high-income countries, 3.4 per 1000 live births in low- and middle-income countries (McIntyre et al., 2022).

In Malaysia, the latest available government statistics on persons with disabilities are quite up to date. As of 2023, there are 736,607 persons with disabilities in Malaysia, which represents approximately 2.2% of the total population in the country. However, the data on the number and prevalence of children with CP in

Malaysia remains scarce and limited. Azhariff and colleagues (2023) stated that the prevalence of CP in Malaysia is estimated at 2.6 per 1000 live births. The Department of Statistics Malaysia reported 5840 cases of CP in Malaysia in 2017 (Bakar, Samat & Yaacob, 2021). The Ministry of Health detected and registered 2766 children with special needs in the year 2012 and among them, 215 were children with CP (UNICEF Malaysia, 2014). In Kelantan (a state in the northeast of Peninsular Malaysia), until October 2015, 205 CP children were registered under Kelantan State Department of Social Welfare (JKM) and enrolled in Community-based Rehab Centre. There is a lack of explicit statistical data on children with CP in Malaysia, suggesting that this population has received limited attention from both researchers and the public. The absence of comprehensive epidemiological studies may indicate gaps in awareness, healthcare prioritization, and policy development, further highlighting the need for targeted research and support initiatives for these children and their caregivers.

The ability for self-care among children with CP is limited due to their physical and mental impairments. Among the complications experienced by children with CP, which requires special attention from parents include oral motor dysfunction such as feeding difficulties and drooling; gastrointestinal abnormalities including dysphagia, digestive problems, vomiting and constipation; poor dental hygiene; hip dislocation, osteopenia, osteoporosis, and scoliosis; epilepsy; respiratory inflammation; behavioural problems, learning and communication obstacles; sleep disturbance, autistic and depression, and more, resulting in long term care requirements and dependence on the parents or caregivers (Nimbalkar et al., 2014; Trabacca et al., 2016).

Primary caregivers of children with CP shoulder substantial responsibilities. These responsibilities involved not only the typical aspects of parenting, but also the intricate medical, therapeutic, and developmental needs that they must meticulously and diligently manage for their children with CP (Chiluba & Moyo, 2017). The challenges faced by families of children with CP begin with the confirmation and disclosure of the diagnosis. Upon receiving the diagnosis, parental expectations shift from those of raising a healthy child to adapting to the needs of a child with disabilities. The lifelong nature of the condition necessitates ongoing adjustments and increasing responsibilities for both the children and their families.

Primary caregivers of children with CP consistently face physical, emotional or even financial challenges. Physically, they face difficulties with lifting, transferring, and positioning their children, leading to musculoskeletal strain and fatigue (Smith & Blamires, 2022). Emotionally, caregiving to children with CP is highly demanding because they are burdened with concerns about their child's well-being, future prospects, and social integration, leading to feelings of stress, anxiety, depression, and social isolation (Liu et al., 2023). Financially, primary caregivers of children with CP must pay for medical fees, rehabilitation costs, and assistive devices to support their child's needs. While the government may provide some level of financial subsidies, these resources are often insufficient to adequately cover the long-term care required for children with CP (Dlamini, Chang & Nguyen, 2023). These real-life challenges have a significant and adverse impact on the caregivers' QoL (Tseng et al., 2016). Nonetheless, primary caregivers’ QOL is paramount as their personal health has direct impact on the level of care and support, they can provide to their children with CP (Raina et al., 2005). Therefore, it is crucial that primary caregiver attending to their own QoL.

1.2 Problem statement & study rationale

CP affects an estimated 2.6 per 1,000 births in Malaysia, impacting the lives of countless families and primary caregivers. While CP is a global condition, the experiences of primary caregivers differ significantly across countries due to differing healthcare systems, cultural beliefs and socio-economic conditions (Kakooza-Mwesige, 2018). In Malaysia, caregivers of children with CP face unique challenges, including limited access to information of child's CP information and specialised healthcare centres, financial constraints, and cultural expectations surrounding caregiving. However, existing QoL assessment tools, primarily developed in Western contexts, may fail to capture these culturally specific experiences (Collinge, Rüdell & Bhui, 2002). Most available instruments focus on physical, emotional, and financial burdens while overlooking critical aspects such as religious beliefs, impact of extended family support, acceptance, the sense of achievement from child's development, and external factors of child's behaviour.

There are studies in Malaysia that have examined caregivers of children with different disabilities such as autism (Asahar et al., 2021), CP (Ismail et al., 2022; Ghafar et al., 2023), Down Syndrome (Hussin et al., 2021), and epilepsy (Wo et al., 2015), with each condition presenting its own set of challenges. Most existing QoL tools, particularly generic ones or those adapted from overseas, do not fully capture the lived realities of Malaysian caregivers. For instance, while Wo et al. (2015) successfully adapted a tool for epilepsy, it illustrates the importance of cultural relevance in such measures. Moreover, studies such as Ismail et al. (2023) and Isa et al. (2013) show that QoL is shaped by a combination of factors including sociodemographic, financial issues, and family dynamics, yet many tools fail to address all the dimensions. Access to services, highlighted in Bakar et al. (2021) and Ismail et al. (2022), is also rarely included in mainstream QoL tools. These gaps suggest that a one-size-fits-all tool is insufficient, justifying the development of a local QoL scale to better reflect the real needs and lived experiences of Malaysia primary caregivers of children with CP in a more holistic and culturally grounded way.

Given the increasing recognition of caregiver burden, the development of a culturally relevant QoL measurement tool is essential to provide a more comprehensive understanding of caregiver well-being in Malaysia. Without an appropriate tool, policymakers, healthcare professionals, and support organizations lack accurate data to design targeted interventions that address caregivers' specific needs and challenges. This study aims to address this critical gap by developing and validating a QoL scale specifically designed for Malaysian primary caregivers of children with CP. To achieve this, the research will be conducted in three phases. Phase 1 will establish a baseline understanding of QoL levels and associated demographic factors among these caregivers. Phase 2 will delve into the specific barriers, challenges, coping mechanisms, and cultural understandings of QoL within this population, informing the development of the new scale. Finally, Phase 3 will rigorously evaluate the psychometric properties of the new scale.

Current research contributes to evidence-based policies that enhance the QoL of caregivers, ultimately improving the care provided to children with CP and fostering a more inclusive and equitable healthcare system in Malaysia. By bridging this gap, this study aligns with the United Nations Sustainable Development Goals (SDGs), particularly SDG 3 (Good Health and Well-being) by promoting the well-being of caregivers and SDG 10 (Reduced Inequalities) by addressing disparities in healthcare accessibility and support services for families of children with CP.

1.3 Research questions

Phase 1:

1. What is the level of QoL among primary caregivers of children with CP in Malaysia?
2. What are the sociodemographic variables associated with QoL among primary caregivers of children with CP in Malaysia?

Phase 2:

3. What are the barriers and challenges faced by Malaysian primary caregivers when providing care to their children with CP?
4. What are the coping strategies Malaysian primary caregivers used to cope with the barriers and challenges faced when providing care to their children with CP?
5. What is the definition of QoL among Malaysian primary caregivers of children with CP?
6. What are the domains and items to be included in a new QoL scale for Malaysian primary caregivers of children with CP?
7. Are the domains and items to be included in the new QoL scale for Malaysian primary caregivers of children with CP valid in terms of content?

Phase 3:

8. What are the levels of HRQoL, life satisfaction, subjective happiness, intrinsic religiosity, and psychological flexibility among Malaysian primary caregivers of children with CP?
9. Is the Malay version of questionnaire internally reliable to assess well-being of Malaysian primary caregivers of children with CP?
    a. Is the Malay version of Health-related QoL (HRQoL) subscale of Pediatric Quality of Life Inventory^{TM} Family Impact Module (PEDSQL FIM) internally reliable to assess HRQoL among Malaysian primary caregivers of children with CP?
    b. Is the Malay version of the Satisfaction with Life Scale (SWLS) internally reliable to assess life satisfaction among Malaysian primary caregivers of children with CP?
    c. Is the Malay version of the Subjective Happiness Scale (SHS) internally reliable to assess subjective happiness among Malaysian primary caregivers of children with CP?
    d. Is the Malay version of the Intrinsic Religosity (IR) subscale of the Duke University Religion Index (DUREL) internally reliable to assess intrinsic religosity among Malaysian primary caregivers of children with CP?
    e. Is the Malay version of the Acceptance and Action Questionnaire – Revised (AAQ-II) internally reliable to assess psychological flexibility among Malaysian primary caregivers of children with CP?

10. Is the new QoL scale structurally valid to assess QOL among Malaysian primary caregivers of children with CP?
11. Is the new QoL scale internally reliable to assess QOL among Malaysian primary caregivers of children with CP?
12. Does the new QoL scale correlates with other scales in the questionnaire?

1.4 Research objectives

1.4.1 General objective

The main objective of this study is to develop a culturally specific QoL scale that is capable of capturing the multidimensional aspects of QoL among Malaysian primary caregivers of children with CP.

1.4.2 Specific objectives

Phase 1:

1. To examine the level of QoL among primary caregivers of children with CP in Malaysia.
2. To investigate the sociodemographic variables associated with QoL among primary caregivers of children with CP in Malaysia.

Phase 2:

3. To explore the barriers and challenges faced by Malaysian primary caregivers when providing care to their children with CP.
4. To explore the coping strategies Malaysian primary caregivers used to cope with the barriers and challenges faced when providing care to their children with CP.

5. To explore the definition of QoL among Malaysian primary caregivers of children with CP.
6. To develop a new QoL scale for Malaysian primary caregivers of children with CP.
7. To assess the content validity of the new QoL scale for Malaysian primary caregivers of children with CP.

Phase 3:

8. To examine the levels of HRQoL, life satisfaction, subjective happiness, intrinsic religiosity, and psychological flexibility among Malaysian primary caregivers of children with CP.
9. To examine the internal reliability of Malay version of PEDSQL FIM, SWLS, SHS, IR subscale of DUREL, and AAQ-II among Malaysian primary caregivers of children with CP.
10. To examine the structural validity of the new QoL scale among Malaysian primary caregivers of children with CP.
11. To examine the internally reliability of the new QoL scale among Malaysian primary caregivers of children with CP.
12. To examine the concurrent validity of the new QoL scale among Malaysian primary caregivers of children with CP.

1.5 Research hypotheses

Phase 1:

1. The sociodemographic variables of interest are significantly associated with the QoL among primary caregivers of children with CP in Malaysia.

   a. There is a significant association between sociodemographic variables of interest and overall QoL of primary caregivers.
   b. There is a significant association between sociodemographic variables of interest and HRQoL of primary caregivers.
   c. There is a significant association between sociodemographic variables of interest and family functioning of primary caregivers.

Phase 2:

Not applicable

Phase 3:

2. The Malay version of HRQoL subscale of PEDSQL FIM, SWLS, SHS, IR subscale of DUREL, and AAQ-II are reliable to be used among Malaysian primary caregivers of children with CP.
3. The new QoL scale is structurally valid to be used among Malaysian primary caregivers of children with CP.
4. The new QoL scale is reliable to be used among Malaysian primary caregivers of children with CP.
5. The new QoL scale significantly correlates with HRQoL of PEDSQL FIM, SWLS, SHS, IR subscale of DUREL, and AAQ-II, which inform concurrent validity.

1.6 Operational definition

1.6.1 Quality of Life (QoL)

In Phase 1 of this study, QoL among primary caregivers of children with CP is measured by using the Pediatric Quality of Life Inventory^{TM} Family Impact Module

(PEDSQL FIM). PEDSQL FIM was developed by Varni et al. (2004). It measures parent self-reported physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, family daily activities and family relationships.

In Phase 3 of the study, a new 28-item QoL scale was developed to measure the QoL among Malaysian primary caregivers of children with CP. This new scale measures QoL from eight aspects: physical well-being, emotional well-being, social support, financial stability, belief, acceptance, initiative to child's development, and child's behaviour.

1.6.2 Health-related quality of life (HRQoL)

In this study, HRQoL among primary caregivers of children with CP is measured using the Parent HRQoL Summary Score of PEDSQL FIM. It consists of 20 items, measuring parent self-reported physical functioning, emotional functioning, social functioning, and cognitive functioning.

1.6.3 Life satisfaction

In this study, life satisfaction among primary caregivers of children with CP is measured using the SWLS. This 5-item brief survey was developed by Diener et al. (1985) to assess subjective well-being and overall life satisfaction.

1.6.4 Subjective happiness

In this study, subjective happiness among primary caregivers of children with CP is measured using the SHS. This 4-item self-report scale was developed by Lyubomirsky and Lepper (1999) to capture both absolute and relative happiness levels.

1.6.5 Intrinsic religiosity (IR)

In this study, intrinsic religiosity among primary caregivers of children with CP is measured using the IR subscale of the DUREL. The whole scale was developed by Koenig, MacCullough & Larson (2001) to measure religiosity through 3 dimensions: organizational religious activity, non-organizational religious activity, and intrinsic religiosity. The IR subscale is a 3-item subscale assessing the extent to which religious beliefs influence different aspects of personal life.

1.6.6 Psychological flexibility

In this study, psychological flexibility among primary caregivers of children with CP is measured using the AAQ-II. It was revised by Bond and colleagues (2011) into a 7-item scale, aiming to measure psychological flexibility by assessing one's ability to accept unwanted thoughts and feelings without avoidance.

1.7 Chapter summary

This chapter outlines the study's background and problem statement, which then have guided the research direction through the formulation of research questions, general and specific research objectives, research hypothesis. Additionally, the operationalized definitions are presented to clarify key terminology used throughout the research. The subsequent chapter, Chapter 2, presents a review of relevant literature related to this study.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This chapter offers the current issues and knowledge related to CP and QoL of primary caregivers from previous studies. This chapter covers search terms, overview of CP, role of primary caregivers, QoL, existing QoL scales, development for new QoL scale, and gaps in the literature. This chapter ends with the conceptual framework of the present study.

2.2 Databases and search terms

The search engines that were used include Science Direct, Google Scholar, ProQuest, Web of Science, Scopus and other database sources. A systematic approach was employed to identify peer-reviewed articles, systematic reviews, meta-analyses, and relevant studies that contribute to the understanding of QoL among primary caregivers of children with CP. The search strategy involved the use of key terms such as “cerebral palsy (CP)”, quality of life (QoL)”, “caregivers”, “parents”, “barriers and challenges”, “physical”, “emotional”, “social support”, “spirituality”, “economic burden”, “scale validation”, “questionnaire development”. Boolean operators "AND" and "OR" were utilized to refine and expand search results. Other than that, there was also an overview on the various theories that inform QoL in general population as well as caregiver population, such as WHOQOL framework, Ferrans and Powers QOL model, Wilson and Cleary’s Model of Health-Related QoL, and Maslow’s Hierarchy of Needs.

Filters were applied where necessary, such as selecting QoL related studies published in the last 20 years, prioritizing articles in English and those relevant to the Malaysian or Southeast Asian context. However, foundational theories that remain widely cited and applicable were included to provide a comprehensive theoretical framework for understanding QoL among caregivers. Additionally, reference lists of key articles were manually screened to identify additional relevant studies. Grey literature, including reports from international health organizations (e.g., WHO, UNICEF) and local disability advocacy groups, was also considered to provide contextual insights into the lived experiences of caregivers.

2.3 The overview of Cerebral Palsy (CP)

2.3.1 Definition of CP

CP is a group of disorders that affect a person's ability to move and maintain balance and posture (Patel et al., 2020). The term "cerebral" refers to the brain, and "palsy" refers to weakness or problems with using the muscles. CP is caused by abnormal brain development or damage to the developing brain that affects the ability to control muscles. This damage usually happens before a child is born, during birth, or within the first few years of life (Gulati & Sondhi, 2018). Kurt (2016) emphasizes this developmental aspect, highlighting that CP is not a progressive disease, indicating the brain damage doesn't worsen over time. However, the symptoms can change over time as the child grows and develops (Sadowska, Sarecka-Hujar & Kopyta, 2020).

While the core understanding of CP as a non-progressive motor disorder stemming from brain damage early in life remains, the specifics of how we define and categorize it have been refined over the years to improve diagnostic accuracy, clinical management, and research efforts.

Early definitions often focused solely on the motor aspects of CP, while more recent definitions incorporate a broader perspective. For instance, Bax et al. (2005) describes discussions around updating the definition and classification of CP to address the needs of clinicians, researchers, and health officials, hinting at an ongoing evolution of understanding. Similarly, Smithers-Sheedy et al. (2014) explicitly discusses the challenges in defining CP in the 21st century, emphasizing the need for clearer inclusion/exclusion criteria for surveillance and research. Kurt (2016) clarifies that CP is not a single disease entity but rather an “umbrella term”, which encompasses a wide range of motor impairments.

Rosenbaum (2006) raises several key questions about the definition and classification of CP, including how to define the age of diagnosis and address the associated developmental disability aspects. Te Velde et al. (2019) reinforces this by highlighting the historical perspective and the challenges in early diagnosis, noting that neurological signs can emerge and change over the first two years of life. The way CP manifests can also shift as a child develops, making a definitive early diagnosis difficult and highlighting the evolving nature of our understanding. Goldsmith et al. (2023) further underscores that the epidemiology of CP is complex and “continually changing.” The ongoing research and advancements in our understanding of brain development and its impact on motor function continue to shape the definition and classification of CP.

It's important to know that each person with CP experiences the condition differently depending on which areas of their brain were affected and to what extent.

Miller (2005) states that the complication originate in the brain, not the muscles or nerves themselves. While the term “CP” is widely used and understood by medical professionals and most parents, it sometimes carries a stigma. There can be a misconception that CP is associated with intellectual disability (Miller, 2005). It's important to clarify that while some individuals with CP may have cognitive impairments, many have average or above-average intelligence. The severity of motor impairment doesn't necessarily correlate with cognitive abilities.

2.3.2 Types of CP and The Gross Motor Function Classification System (GMFCS)

CP is classified based on the type of movement disorder it causes, with four primary subtypes:

1. Spastic CP

Spastic CP is the most common form of CP, accounting for approximately 70–80% of cases. It is characterized by muscle stiffness (spasticity), exaggerated reflexes, and difficulty in movement control, often leading to jerky and awkward motions. Spastic CP can be further classified based on the affected limbs:

a) Spastic Hemiplegia: One side of the body is affected (e.g., one arm and one leg).

b) Spastic Diplegia: Both legs are more affected than the arms.

c) Spastic Quadriplegia: All four limbs are significantly impaired, often accompanied by severe motor and cognitive impairments.

2. Dyskinetic CP

Dyskinetic CP is characterized by involuntary, uncontrolled movements, which can manifest as slow, writhing motions (athetosis) or sudden, jerky movements (chorea). The muscle tone in individuals with dyskinetic CP fluctuates between stiffness and hypotonia, making voluntary movements difficult to control.

3. Ataxic CP

Ataxic CP is the least common subtype, affecting balance and coordination. Individuals with ataxic CP may experience tremors, difficulty with fine motor skills, and challenges in walking and maintaining posture. Tasks requiring precise hand movements, such as writing or grasping small objects, can be significantly impaired.

4. Mixed CP

Some individuals exhibit symptoms of multiple types of CP, often combining features of spastic and dyskinetic CP. The severity and manifestation of symptoms vary based on the extent of brain damage (Patel et al., 2020; Sadowska, Sarecka-Hujar & Kopyta, 2020).

The Gross Motor Function Classification System is a widely used five-level framework that categorizes the gross motor capabilities of children with CP. This system focuses on self-initiated movement, with particular emphasis on sitting, transfers, and mobility.

The GMFCS levels are as follows:

- Level I: Children can walk without limitations, though their speed, balance, and coordination may be somewhat restricted when performing gross motor skills like running and jumping.
- Level II: Children can walk, but with some limitations. They may require assistive devices for longer distances or uneven terrain, and they exhibit restrictions in running and jumping.

- Level III: Children use a hand-held mobility device to ambulate. They may rely on wheeled mobility for longer distances and may need assistance with stairs or uneven surfaces.
- Level IV: Children utilize mobility methods that necessitate physical assistance or powered mobility. They may walk short distances with physical help or use powered mobility, and they may require adaptive seating to support their trunk.
- Level V: Children are transported in a manual wheelchair. They have limited capacity to maintain antigravity head and trunk postures, as well as limited control over their leg and arm movements.

The GMFCS is an invaluable tool for classifying the gross motor function of children with CP, supporting treatment planning, predicting future equipment needs, and facilitating research efforts (Rosenbaum et al., 2014).

2.3.3 Prevalence of CP

The global prevalence of CP has been the subject of systematic analyses. A 2013 study estimated the global prevalence at 2.1 per 1,000 live births. However, more recent data suggests this figure may be an overestimation. Regional variations in CP prevalence have also been observed. In high-income countries, recent evidence indicates a declining trend, with the current birth prevalence estimated at 1.5 per 1,000 live births. This improvement is attributed to advancements in neonatal care, particularly for premature infants. Conversely, the prevalence is thought to be higher in low- and middle-income countries, estimated at 3.4 per 1,000 live births. However, the limited availability of data in these regions makes it challenging to establish precise figures and track trends (Finch-Edmondson et al., 2019; McIntyre et al., 2022).

Regarding the prevalence in Malaysia, accurate data are limited due to underreporting and diagnostic challenges. Nevertheless, available statistics provide some insights. In 2017, the Department of Social Welfare Malaysia registered a cumulative total of 5,840 children diagnosed with CP between 2011 and 2017. Notably, the state of Johor accounted for 568 cases, representing approximately 9.7% of the national total. Within Johor, 503 cases were analyzed, constituting 88.6% of the state's reported instances (Bakar, Samat & Yaacob, 2021). These figures suggest a prevalence rate of approximately 2.6 per 1,000 live births in Malaysia, aligning with data from developed countries, which report rates ranging from 2 to 2.5 per 1,000 live births (Azhariff et al., 2023). However, the actual number of children with CP in Malaysia may be higher, considering potential underreporting and the lack of comprehensive nationwide surveillance. The discrepancy between the reported data and the estimated prevalence highlights the need for improved reporting mechanisms and more comprehensive data collection efforts to better understand the true burden of CP in Malaysia.

2.3.4 Risk factor of CP

Understanding the risk factors associated with CP is crucial, as these factors can increase the likelihood of a child developing the condition. It is essential to recognize that the presence of one or more risk factors does not guarantee a CP diagnosis, and conversely, the absence of these factors does not rule out the possibility. CP is a complex condition, and its causes are often multifactorial in nature. The risk factors can be broadly categorised into prenatal, perinatal, and postnatal factors.

Prenatal risk factors significantly contribute to the development of CP. Prematurity, especially births occurring before 32 weeks of gestation, is a notable risk factor due to the association with low birth weight and underdeveloped brains that are more susceptible to injury (Başaran et al., 2023). Infants weighing less than 2,500 grams at birth face an increased risk of CP, as low birth weight often correlates with preterm delivery and intrauterine growth restrictions (Van Naarden Braun et al., 2016). Multiple gestations, such as twins, triplets, or higher-order multiples, have a higher incidence of CP compared to single births, partly because of the elevated likelihood of preterm birth and related complications (Eunson, 2012). Maternal infections during pregnancy, including cytomegalovirus, rubella, toxoplasmosis, and certain sexually transmitted infections, can adversely affect foetal brain development, increasing the risk of CP (Eunson, 2012). Additionally, maternal health conditions like thyroid disorders, intellectual disabilities, and seizure disorders may contribute to the risk of CP in offspring. Recent research has also identified maternal overweight and obesity as significant antenatal risk factors for CP, suggesting that maternal health and nutrition play a crucial role in foetal neurodevelopment (Strøm et al., 2021). These findings underscore the importance of comprehensive prenatal care, early detection, and management of maternal health issues to mitigate the risk of CP.

One major perinatal risk factor is birth asphyxia, a condition where the baby experiences a lack of oxygen during delivery, leading to brain injury and an increased likelihood of CP (Albrecht et al., 2019). This deprivation of oxygen can result in long-term neurological impairments, especially if resuscitation efforts are delayed or insufficient. Another critical perinatal risk is stroke in the foetal or infant brain, which occurs when there is an interruption in blood supply, causing localized brain damage. These strokes may result from blood clotting disorders, maternal infections, or complications with the placenta, and they significantly increase the risk of CP by affecting areas of the brain responsible for motor control (Paul et al., 2022). Additionally, severe or untreated neonatal jaundice can contribute to CP development. Jaundice occurs when excess bilirubin (a yellow pigment produced by the breakdown of red blood cells) accumulates in the baby’s bloodstream. If left untreated, extreme levels of bilirubin can lead to kernicterus, a form of brain damage that specifically affects movement and hearing, ultimately leading to CP (Tegegne, 2023).

Postnatal risk factors for CP include brain infections and traumatic injuries that cause lasting damage to the developing brain. Severe infections such as meningitis or encephalitis can lead to widespread brain inflammation, reduced oxygen supply, and neuronal death, increasing the risk of motor impairments (Norova, 2024). Traumatic brain injuries from accidents, falls, or abuse, such as shaken baby syndrome, can also disrupt neural connections and damage the brain’s white matter, leading to motor and cognitive deficits (Rosenbaum et al., 2014). Additionally, hypoxic-ischemic injuries resulting from near-drowning incidents or cardiac arrest can further deprive the brain of oxygen, worsening neurological outcomes (Novak et al., 2012).

It is crucial to consult with a healthcare professional for any concerns about CP risk factors, diagnosis, or management. They can provide personalized advice based on individual circumstances (Kurt, 2016). Understanding the epidemiology and etiology of CP is essential for early diagnosis and prevention (Eunson, 2012), allowing healthcare providers to take proactive measures to mitigate the risk and support

2.3.5 Complications arising from CP

CP often presents various complications that can significantly impact an individual's QoL. These complications can be manifested across different body systems and vary in severity depending on the type and extent of brain damage.

Motor complications are a defining feature of CP, affecting movement, muscle control, and coordination due to damage to the developing brain. One of the most common issues is muscle spasticity, where increased muscle tone and stiffness lead to involuntary contractions, making voluntary movements difficult and often causing discomfort or pain. Prolonged spasticity can cause a condition where muscles and tendons permanently shorten, restricting joint movement and potentially leading to deformities that impair mobility. Additionally, skeletal deformities such as scoliosis, hip dislocation, and foot abnormalities may arise due to muscle imbalances and prolonged abnormal postures, further affecting mobility and requiring orthopedic interventions. Individuals with CP also frequently experience fine motor skill impairments, which hinder precise movements like writing or buttoning clothes, affecting their ability to perform daily tasks independently. Moreover, balance and coordination difficulties are common, increasing the risk of falls and limiting participation in physical activities, though physical therapy and adaptive strategies can help manage these challenges (Graham et al., 2021).

Cognitive and communication impairments are frequently associated with CP, significantly impacting an individual's ability to learn, communicate, and interact with their environment (Fluss & Lidzba, 2020). While CP primarily affects motor control, the brain damage that causes CP can also affect cognitive functions, ranging from mild learning difficulties to intellectual disability. These difficulties can manifest in various ways, including challenges with attention, memory, problem-solving, and executive functions like planning and organisation (Wotherspoon et al., 2023). The severity of cognitive impairment varies widely among individuals with CP and is not always directly correlated with the severity of motor impairment. For instance, a child with severe motor limitations may have relatively intact cognitive abilities, while a child with milder motor impairments might experience significant cognitive challenges. Communication difficulties are also prevalent in CP, stemming from both motor and cognitive impairments (Pennington, Goldbart & Marshall, 2005). Children with CP may have difficulties with speech production due to impaired control of the muscles involved in articulation. This can lead to difficulties with pronunciation, volume, and clarity of speech (Mei et al., 2020). Language impairments can also occur, affecting a child's ability to understand and use language effectively. These impairments may involve difficulties with vocabulary, grammar, and comprehension. Furthermore, the motor impairments associated with CP can hinder a child's ability to use augmentative and alternative communication devices, such as communication boards or speech-generating devices. As a result, some children with CP may have limited expressive communication abilities (Molinaro et al., 2020). Children with CP experience a range of communication impairments. Some are non-verbal but can understand language and communicate through gestures or assistive devices. Others have difficulty producing speech but have intact receptive language skills.

Sensory impairments include vision problems such as strabismus (misalignment of the eyes), nystagmus (involuntary eye movements), and refractive errors, can impair visual perception, making it difficult for individuals with CP to interact with their surroundings (Park et al., 2016). Similarly, hearing impairments, ranging from mild to profound loss, can disrupt communication, learning, and social engagement, further complicating developmental progress (Reid et al., 2011). Seizures are another common complication, with epilepsy affecting a significant proportion of individuals with CP, often leading to additional cognitive and motor challenges while increasing the risk of injury and neurological decline (Cooper et al., 2023). Beyond sensory and neurological complications, swallowing difficulties (dysphagia) frequently occur due to poor muscle coordination, leading to malnutrition, dehydration, and a heightened risk of aspiration pneumonia, which can be life-threatening without proper management (Speyer et al., 2019). Bladder and bowel dysfunctions, such as urinary incontinence and chronic constipation, further add to daily challenges, affecting hygiene, independence, and overall well-being (Baram et al., 2023). Chronic pain, stemming from spasticity, joint deformities, muscle contractures, and gastrointestinal discomfort, is another significant issue, often leading to sleep disturbances, reduced mobility, and diminished participation in daily activities (Harvey et al., 2024).

The cumulative burden of these complications not only affects individuals with CP but also extends to their families and caregivers, highlighting the need for a holistic approach to care. As caregivers play a crucial role in providing long-term support, their well-being must be prioritized to ensure sustainable and effective care. Recognizing and addressing their needs through appropriate resources, support systems, and policies can help improve their QoL, ultimately benefiting both caregivers and the individuals with CP under their care.

2.4 Role of primary caregivers

2.4.1 Who are the primary caregivers?

Primary caregivers are individuals who provide most care and support for a dependent person, typically within the home setting. In the context of CP, primary caregivers are most often parents, particularly mothers, but may also include fathers,