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Caregiver Burden in Caring for Children with Cerebral Palsy: A Concept Analysis

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Abstract

Purpose: To explore the concept of caregiver burden and clarify its meaning in caring for children with cerebral palsy.

Methodology The concept analysis used Walker and Avant's approach to develop a working definition of caregiver burden**.** Five electronic databases: Embase, Ovid Medline, Web of Science, Cochrane Library, and CINAHL were searched for articles written in English. Quantitative and qualitative studies related to caregiver burden in caring for children with cerebral palsy were included.

Findings: Of the 2986 articles yielded by the search, 24 articles were included in the analysis. The identified defining attributes of caregiver burden are heavy load, long-term care due to developmental disability, subjective experience, and multidimensional/complex phenomena. Case, borderline, and contrary models are provided to demonstrate caregiver burden in caring for children with cerebral palsy. Antecedents include the severity of the child's disability, lack of support, financial constraints, and confinement (restricted participation in social activities). Caregivers face consequences of caregiver burden such as lifestyle disruption, family function decline, decreased caregiver quality of life, and reduced care provision.

Unique Contribution to Theory, Policy, and Practice: The study explores the emotional, physical, social, and financial aspects of caregiver burden in children with cerebral palsy, highlighting its impact on various cultural contexts influencing theoretical caregiving stress and adaptation models**.** The analysis provides evidence for the need for inclusive policy changes that address caregiver burden, such as increased respite care, financial support, and specialized health services. It recommends that the healthcare sector can reduce caregiver burden by identifying and establishing supportive structures early, promoting caregivers' health, and improving the quality of care.

Keywords: *Caregiver Burden, Caregiving, Concept Analysis, Cerebral Palsy*

1.0 INTRODUCTION

With the growing number of people living with disabilities, caring is moving from a clinical area to a home setting to be done by caregivers who are sometimes referred to as informal caregivers reflecting a lack of compensation (Albayrak et al., 2019; Mohr et al., 2023). The caregiver burden (CB) encompasses all the challenges and feelings experienced by caregivers concerning their physical and emotional well-being, and family relations. The National Alliance for Caregiving and AARP reports that 36% of the 53 million United States of America caregivers experience a higher caregiver burden, while 23% experience a medium burden based on the degree of dependency and time spent providing care (Reinhard et al., 2019) . In caregiving research, burden is the commonly used variable both as an outcome and a predictor (Chou, 2000).

Caregivers are unpaid individuals providing self-care to individuals with developmental disabilities often struggling with social activities affecting their overall well-being (Bastawrous, 2013; Yilmaz & Küçük Alemdar, 2021). Caregiving involves providing holistic assistance to someone who cannot help utilizing knowledge, emotions, skills, character traits, and emotional connections with the care-receiver (Arasu & Shanbhag, 2021; Beydoun et al., 2019). Caregivers of children with developmental disabilities can improve care and functional recovery by providing emotional, physical, informational, and instrumental support (Çolak & Kahriman, 2023).

The concept of caregiver burden is a multifaceted issue in nursing research lacking consistency in definition as noted by (Bastawrous, 2013; Lee et al., 2019). This necessitates clarification and understanding of its relevant attributes for its usefulness in research and practice. Liu and colleagues conducted a concept analysis on caregiver burden, suggesting future research should focus on specific diseases or disabilities to understand the concept (Liu et al., 2020). Researchers undertook a concept analysis of the burden of care for people with schizophrenia (Gunawan et al., 2023) and on the caregiver burden of patients with advanced-stage cancer (Morgan et al., 2022). The literature on caregiver burden particularly in children with cerebral palsy (CP) is often overlooked due to clinicians' focus on the disabled child neglecting the burden borne by caregivers (Majumdar & Jain, 2020). Concept analysis is a method used to simplify complex ideas commonly used in nursing practice and research to identify key features and determine their clear meaning (Foley & Davis, 2017; Walker & Avant, 2019). The analysis explores the caregiver burden in caring for children with CP guided by Walker and Avant's framework (Walker & Avant, 2019).

1.1 Caregiver Burden in Caring for Children with Cerebral Palsy

CP is a disorder affecting posture and movement development resulting from non-progressive permanent injury to the developing fetal or infant brain (Liu et al., 2023), and a common cause of permanent motor impairment in children (Martinez de Zabarte Fernandez et al., 2021). CP occurs in three out of 1000 live births (Martinez de Zabarte Fernandez et al., 2021; Vitrikas et al., 2020) with variation between low to middle and high-income countries (Patel et al., 2020). CP's clinical features include various abnormalities affecting children's functional abilities

(Patel et al., 2020). Currently, no cure exists, but long-term therapies and medical treatments can reduce disability complications (Green & Gaebler-Spira, 2019; Honan et al., 2022).

Children with CP are managed by caregivers at home providing long-term care (Mwinbam et al., 2023; Yilmaz & Küçük Alemdar, 2021). Caregivers are often unprepared to bear significant caregiving burdens due to their daily tasks and child's dependency requiring support and resources (Martinez de Zabarte Fernandez et al., 2021; Menlah et al., 2020). Caring for children with CP involves addressing lifetime rehabilitation needs, medical consultations, and managing the child's comorbidities (Hewawitharana et al., 2023). The caring burden exceeds normal routine parenting and significantly impacts caregivers' quality of life (QoL) and ability to care for disabled children who rely on them for daily self-care and daily life activities (Yilmaz & Küçük Alemdar, 2021). This results in caregivers struggling to rest adequately due to the caregiving burden (Çolak & Kahriman, 2023; Kenis-Coskun et al., 2020; Liu et al., 2023; Tuncay & Sarman, 2023).

CP-related impairments negatively impact children's growth, development, and participation in age-appropriate activities causing physical and psychological burdens on caregivers who often face exhaustion, distress, and societal rejection (Albayrak et al., 2019; Arasu & Shanbhag, 2021; Dlamini et al., 2023). Caregiver burden predictors are self-efficacy, distress, emotional trauma, and disability severity, necessitating interventions to support and enhance the self-efficacy of caregivers of disabled children (Liu et al., 2023; Marrón et al., 2013).

1.2 Selecting the Concept

Caregiver burden is a crucial aspect of nursing practice and a widely used term in nursing literature, referring to the long-term stressors experienced by caregivers (Liu et al., 2020). Scholars point out inconsistency surrounding the operational and conceptualization definition of the concept (Gunawan et al., 2023; Liu et al., 2020). According to the literature, the caregiver burden of children with CP is a neglected issue with significant global negative impacts on the healthcare system (Gugała, 2021; Vadivelan et al., 2020). The concept of caregiver burden was chosen for analysis due to its urgency, significance in healthcare, and ambiguity in definition, aiming to improve its practical application.

2. Aims of Concept Analysis

The second step of concept analysis is determining the aims. The analysis aims to clarify the meaning of caregiver burden providing a clear understanding of its use in nursing practice and future research. To understand the defining attributes, antecedents, and consequences of caregiver burden in children with CP.

2.1. METHODS

2.1.1. Concept Analysis Method

The paper followed Walker and Avant's method as the framework for this concept analysis of caregiver burden (Walker & Avant, 2019).The analysis focused on studies addressing caregiver burden for caregivers of children with CP excluding those focusing on caregivers of children without CP. The method includes eight steps: 1. Select a concept, 2. Determine the aims of the analysis, 3. Identify all uses of the concept 4. Determine the defining attributes, 5. Identify a model case, 6. Construct additional cases, 7. Identify antecedents and consequences and 8. Define empirical referents.

2.1.2 Data Sources

A professional librarian assisted in conducting a literature search on caregiver burden in caring for children with CP identifying uses of terms from various disciplines. The search was not limited to only nursing literature to fully understand the nature of the concept (Walker & Avant, 2011). Five electronic databases were searched for articles written in English. The databases were Embase (n=1182), Ovid Medline (n=502), Web of Science (n=744), Cochrane Library (n=169), and Cumulative Index to Nursing and Allied Health Literature (CINAHL) (n=389). The Emtree and Mesh search terms such as "caregivers", "caregiver burden", "fatigue", "caregiver burnout", "caregiver stress", "exhaustion", "psychological stress", "children", "child", "adolescent", "adolescence", "cerebral palsy" and "muscle spasticity" were used to search for literature from electronic databases and were used in various combinations with Boolean operators “OR” and “AND”. The database search yielded 2986 articles, duplicates (n=1311) were removed, literature screened through titles and abstracts (n=1622) irrelevant articles were removed and reviewed selected full texts (n=53) for the relevance of which (n=29) were further removed. The analysis included 24 articles, and a hand search was conducted to identify missing papers revealing nonrelevant articles. The screening process is presented in *Figure* 1

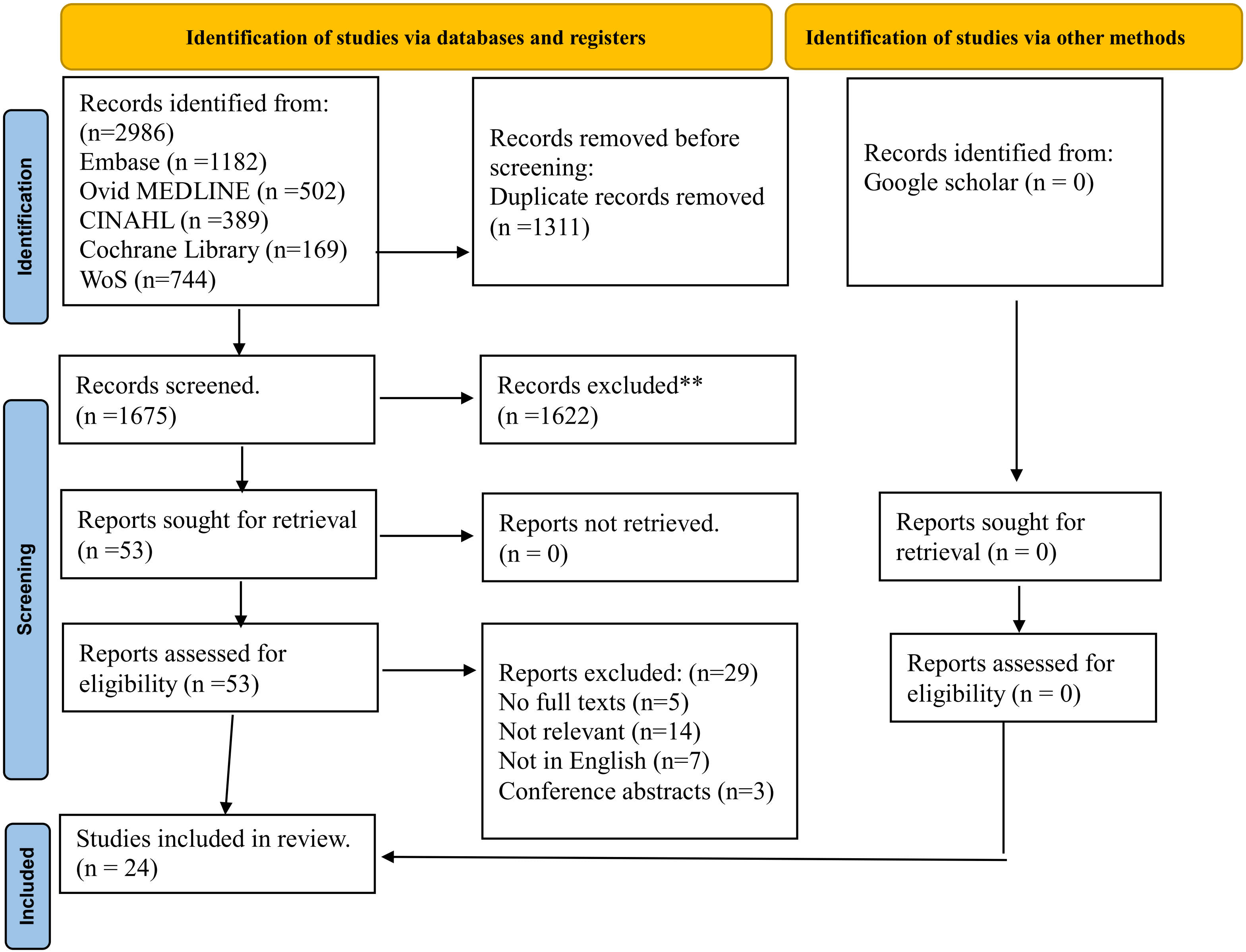

Figure 1: Flow chart describing literature search and exclusion process using PRISMA model retrieved from(Page et al., 2021)

2.1.3 Related Concepts

Related concepts are terms that are usually used interchangeably as distinguished from the conceptual analysis (Thoun, 2022). This concept analysis uses caregiver stress and fatigue as related terms to represent caregiver burden. Caregiver stress refers to the unjust distribution of assistance among closely related individuals causing fatigue and tension, particularly when caring for a disabled or chronically ill person (Llanque et al., 2016). Caregiver fatigue is the caregiver's extreme physical experience as a result of performing caregiving tasks to a chronically ill or disabled family member (Beydoun et al., 2019). Caregiver burden refers to the stress that caregivers experience when taking care of chronically ill family members (Llanque et al., 2016).

Caregivers often take on caregiving roles due to personal responsibility, which may be overtime (Beydoun et al., 2019).

3. USES OF THE CONCEPT

This is the third step of concept analysis which identifies the uses of caregiver burden in literature sources (Walker & Avant, 2019). Dictionary definitions were sought from numerous health-related and English dictionaries to understand how the concept is conceived and used. Caregiver burden is a two-word concept hence caregiver and burden were explored individually and then jointly. Caregiving is a common practice among children with CP-related disabilities. It was explored in nursing and healthcare literature making its understanding crucial due to its historical origins.

The legal definition of a caregiver is "someone older than 18 years who is responsible for providing direct care, protection, or assistance to someone who cannot perform critical tasks for daily survival" (Legal., 2023). Beydoun et al. (2019) defined a caregiver as "someone who provides physical, and emotional support to an individual on an unpaid basis". The Cambridge Dictionary defines a caregiver as "someone who provides direct care to people who are ill or cannot help or care for themselves" (Dictionary, 2023). The caregiver is defined as a "person who informally provides unpaid care to someone having a personal relationship and maybe a parent to pediatric patients" (Kenis-Coskun et al., 2020). This becomes more challenging when a child's disability is added (Bastawrous, 2013) and has no special training (Atar et al., 2022). Caregivers, who can be family, friends, relatives, and neighbors, excluding clinicians bear significant emotional, physical, social, and financial burdens while caring for disabled children (Arasu & Shanbhag, 2021; Beydoun et al., 2019; Gunawan et al., 2023).

Merriam-Webster dictionary defines a burden as a "load or responsibility that is worrisome" (Merriam-Webster, 2023). The burden is “the impact that caregiving has on the primary caregiver" (Boztepe et al., 2019). A burden is defined as a "responsibility or duty that is hard to bear and causes worry" (Miller, 2017). The burden is a subjective and objective aspect of caregiving caused by emotional and physical factors which may lead to negative effects on the caregivers' mind and body (Bastawrous, 2013; Chou, 2000; Wolkowitz et al., 2022).

Caregiving is “a process of helping a person who is unable to help herself holistically” (Hermanns & Mastel-Smith, 2012). Caregiving is an “unpaid act of providing direct care to someone with physical, developmental or intellectual impairment” (Beydoun et al., 2019). Caregiving for children with CP intensifies caregiver burden, influenced by impairment severity, symptoms, financial status, and child's caregiving demands (Arasu & Shanbhag, 2021; Davis et al., 2021; Garcia-Ptacek et al., 2019). The literature identified 3 types of caregiving: instrumental, informational, and emotional (Beydoun et al., 2019). Instrumental caregiving involves providing basic support to a disabled person, while informational caregiving focuses on learning how to care for them, and emotional caregiving involves counseling and companionship (Beydoun et al., 2019).

Now the caregiver burden is jointly explored and defined. Caregiver burden is the "level of multifaceted strain perceived by a caregiver from caring for an ill family member" (Liu et al., 2020). Caregiver burden means "heavy load or strain borne by an individual who cares for a disabled chronically ill, elderly family member" (Atar et al., 2022; Hiseman & Fackrell, 2017). Caregiver burden is a "subjective perception of overload in physical, emotional, social and financial and includes carers self-efficacy, emotional and problems focused coping"(Beydoun et al., 2019). Caregiver burden is the "subjective stress perceived by caregivers due to the home care situation" (Gräßel & Adabbo, 2011). Caregiver burden is defined as "negative costs that disabled children cause to their caregivers" (Çolak & Kahriman, 2023). Caregiver burden is the "multidimensional response for physical, psychological, emotional, social and financial stressors associated with caregiving experience" (Gugała, 2021; Hewawitharana et al., 2023; Liu et al., 2023; Wijesinghe et al., 2015; Yigman et al., 2020).

The caregiver burden can be familial, emotional, and economic. Family burden refers to the challenges faced by the entire family due to a disabled child, while emotional burden refers to the chronic distress experienced by caregivers (Çolak & Kahriman, 2023). The family faces financial strain due to the child's education and private health expenses as primary caregivers handle complex care and advanced medical procedures (Yotani et al., 2014). Long-term care for disabled children places significant pressure on caregivers but effective interventions can improve care and help them adapt to their roles (Çolak & Kahriman, 2023).

Caregiver burden is a complex interplay of caregiver compassion, resources, and care demands for a child with CP, encompassing both physical and emotional costs (Hewawitharana et al., 2023). Caregiver burden negatively impacts the disabled child and caregiver, disrupting family functioning and social interaction (Wijesinghe et al., 2015) resulting in unmet patient needs and a decline in caregivers' QoL (Liu et al., 2023). Caregiver burden is influenced by the child's disability severity and is characterized by increased subjective strain, limited social life and financial outlays (Seliner et al., 2016). Its reduction can improve caregivers' mental health and care for disabled children.

4. DEFINING ATTRIBUTES

Attributes are common characteristics in literature that enhance understanding of a concept, as they are consistently existing in its description (Walker & Avant, 2019). Caregiver burden incorporates the following defining attributes: heavy load, long-term care due to permanent developmental disability, subjective experience, and multidimensional/complex phenomena**.**

4.1. Heavy Load.

The caregiver burden is a significant challenge in caring for children with moderate and severe CP who rely on them for their daily self-care needs (Albayrak et al., 2019; Çolak & Kahriman, 2023). Caregivers provide comprehensive primary care for disabled children including bathing, medication administration, feeding, dressing, undressing, ambulation, managing seizures, and medical and therapy reviews (Albayrak et al., 2019; Dalvand et al., 2015). Caregivers often deal with additional health challenges for disabled children like non-oral feeding, behavioral, and sleeping disorders (Omole et al., 2019). (Dlamini et al., 2023; Vadivelan et al., 2020; Yildirim et al., 2022).

4.2. Long-term Care due to Permanent Developmental Disability.

Caregiver burden refers to the lifetime care children with CP require due to their lifelong permanent neurological disability, which currently has no cure (Albayrak et al., 2019; Green & Gaebler-Spira, 2019). CP is foreseen as the phototype of chronic pediatric disability that requires lifetime extensive care for children to meet their daily self-care activities (Dambi et al., 2016). Caregiver burden can arise from long-term care for children with CP who rely heavily on their caregivers for daily basic needs (Trabacca et al., 2016). The literature emphasizes the significance of lifelong multidisciplinary care, comorbidity management, therapies for managing CP, and promoting child growth and development (Zhong et al., 2023).

4.3. Subjective Experience

Caregivers' burden depends on sharing personal experiences and feelings during child caregiving with varying degrees of care burden based on the child's impairment severity. Caregiver burden refers to the feelings and experiences of caregivers due to the increasing long-term care demands (Lindt et al., 2020). Global healthcare issues involving caregiver burden negatively impact caregivers' QoL, daily lives, and emotional and physical health, leading to chronic distress and psychiatric disorder risk (Del-Pino-Casado et al., 2021). Caregivers often experience emotions like guilt, grief, disappointments, and shame but some accept their roles and view themselves as skilled and effective (Dlamini et al., 2023; Tuncay & Sarman, 2023).

4.4. Multidimensional/complex Phenomena

Current studies reveal that caregiver burden is multifaceted, encompassing various facets: physical, psychological, social, and financial stressors (Çolak & Kahriman, 2023). Long-term care of CP often leads to caregivers neglecting their health, and prioritizing child care, resulting in numerous health issues such as psychological problems, and social isolation (Yigman et al., 2020), generalized body pains (Yilmaz et al., 2013), fatigue and sleep disturbances (Jawed & Mowry, 2023). Caring for a child with CP is a complex, dynamic, and potentially devastating task necessitating a multidisciplinary team approach (Tuncay & Sarman, 2023; Vadivelan et al., 2020).

5. IDENTIFY MODEL CASES

5.1. Model Case

A model case is a structured approach that exemplifies the concept and its defining attributes (Walker & Avant, 2019). Debby*, a 37-year-old mother, is the primary caregiver of Mandy*, her third-born daughter diagnosed with spasticity CP during infancy period and classified as GMFCS level V. Mandy is now 5-year-old, with no self-care abilities due to severe muscle stiffness in both upper and lower limbs. Mandy is fully dependent on her mother for self-care activities. Mandy cannot maintain head and trunk posture with sluggish speech, and epileptic seizures requiring weekly physical, occupational, and speech therapies. She continues with physical exercises at home to ease muscle stiffness and improve her speech.

Debby and Sam*, parents of Mandy have two other normal children attending school aged 9 and 7 respectively. They are living in an extended family with grandparents and aunts. Sam, a small-scale farmer spends most of his time on the farm and returns home exhausted in the evening. Debby is the sole primary caregiver for Mandy assisting with weekly therapies, home exercises, and complete self-care activities **(Heavy load).** Debby is aware that there is no cure for CP. She is overwhelmed by the lifelong care Mandy needs and views herself as a lifetime caregiver **(Long-term care due to permanent developmental disability).**

Debby expresses concern about Mandy's future feeling trapped in caring roles, overwhelmed, and frustrated describing her days and nights as endless and lacking rest. She is worried about who will care for Mandy as she ages and becomes tired. The woman is facing challenges such as lack of support, concerns about her husband's low farming income, and experiencing social discrimination, often blamed for her child's disability **(Subjective experience)**. Debby struggles financially with Mandy's caregiving, causing backache and physical pain, restricting her social activities, and confining her in one place. Societal rejection results in depression, anxiety, and chronic sorrow. **(Multidimensional phenomena)**. The model case highlights the caregiver burden of a child with CP, highlighting the lack of family support, overwhelming long-term care responsibilities, distress, future worries, and financial constraints.

6. Construct Additional Cases.

6.1 Borderline Case

The borderline case contains the central attribute of the concept of caregiver burden in caring for children with CP with few attributes compared to the case model (Walker & Avant, 2011). Debby* is a 37-year-old mother and the primary caregiver of Mandy*, her third-born daughter diagnosed with spasticity CP during infancy period and classified as GMFCS level V. Mandy is now 5 years old with no self-care abilities due to severe muscle stiffness in both upper and lower limbs. Mandy is fully dependent on her family for self-care activities. Mandy cannot maintain head and trunk posture with sluggish speech, and epileptic seizures requiring weekly physical, occupational, and speech therapies. She continues with physical exercises at home to ease muscle stiffness and improve her speech. Debby and Sam* are Mandy's parents and have two other normal children attending school aged 9 and 7 respectively. They live in an extended family with grandparents and aunts. Sam is a small-scale farmer spending most of his time on the farm and returns home exhausted in the evening.

Debby provides partial care to Mandy due to her grandmother's assistance with weekly therapies and self-care activities. Debby is aware that there is currently no cure for CP. **Long-term care due to permanent developmental disability.** Debby is grateful for family support, supportive treatments, and therapies for Mandy's motor and speech improvement. She expresses happiness with her grandmother's partial support and occasional rest. **Subjective experience**. The siblings play with Mandy, receiving financial and emotional support from aunts and the father. The grandmother physically cares for her. Despite the heavy workload of Mandy's caregiving, Debby has accepted the role and is committed to doing everything she can to support her. The case highlights the significant attributes in the caregiver burden of children with CP characterized by long-term care and subjective experience, despite minimal family support their caring responsibilities are manageable.

6.2 Contrary Case

A contrary case is when most of the negative attributes defining the concept of caregiver burden are absent. Debby* is 37 years old mother and primary caregiver of Mandy* her third-born daughter who was diagnosed with spasticity CP during infancy period and classified as GMFCS level 11. Mandy is a 5-year-old with some self-care abilities and mild stiff muscles in her lower extremities. Mandy is on epileptic treatments to manage seizures and participating in weekly physical therapy and home exercises to alleviate muscle stiffness. Mandy is responding well to the therapies and antiepileptic treatments. Debby and Sam* are Mandy's parents and have two other normal children attending school aged 9 and 7 respectively living in an extended family with grandparents and aunts. Sam works as a small-scale farmer with the assistance of the family members.

Debby receives full family support in caring for Mandy, including assistance with weekly therapies, home exercises, and self-care activities she cannot perform independently. Debby is optimistic about Mandy's motor skills improvement despite CP being incurable. She appreciates family support, supportive treatments, and therapies that allow time for herself and the other children. Mandy's healthcare is a family affair safeguarding her from social stigma and mockery allowing her to interact with other children in social activities. The family provides financial, emotional, and physical support for Debby, demonstrating a normal caring load and optimism for her condition improvement through continuous therapies and supportive treatments. Debby has a strong support system including her in-laws, husband, and children.

7. ANTECEDENTS

Antecedents are preexisting events that precede the occurrence of the concept which should be considered when assessing the risk of caregiver burden (Walker & Avant, 2019). The caregiver must be aware of the disabled child's behavior, recognize their need for assistance, and know when to provide it (Foley & Davis, 2017). The reviewed studies revealed the following antecedents: the severity of the child's disability, lack of support, financial constraints, and confinement (restricted participation in social activities).

7.1. The Severity of the Child's Disability

CP is a prevalent cause of pediatric disability, significantly impacting children's growth, self-care, and social participation, necessitating lifetime care and rehabilitation, and imposing significant family burdens (Liu et al., 2023). Severely disabled children rely on caregivers for complete self-care activities due to their muscle spasticity and uncoordinated motor control (Ni et al., 2022; Vadivelan et al., 2020) resulting in an emotional and overwhelming caring burden (Dlamini et al., 2023). Caregivers face significant caregiving burdens, managing daily self-care activities and a child's changing health condition disrupting lifestyle and family functioning resulting in a decline in QoL (Ozkan, 2018).

7.2. Lack of Support

Caring for a disabled child can be emotionally demanding, necessitating support from family members to manage the responsibilities (Dezoti et al., 2015). Literature reveals that caregivers do not get the much-needed support (Ni et al., 2022) most family members are unsupportive and all they get is blame and discrimination (Smith & Blamires, 2022; Vadivelan et al., 2020). Lack of support increases the burden of care which negatively impact the caregiver's QoL and results in depressive symptoms (Davis et al., 2021).

7.3. Financial Constraints

Care cost for children with CP is one of the significant caregiver burden indicators (Smith & Blamires, 2022). Caregivers often leave their jobs due to overwhelming full-time care demands causing financial constraints for disabled children's families, increasing stress, and straining their ability to meet their financial needs (Muller-Kluits & Slabbert, 2018). Children with CP-related disabilities require continuous therapies for managing their condition and heavy health expenses they often self-funded (Muller-Kluits & Slabbert, 2018; Vadivelan et al., 2020). Wijesinghe et al. (2015) reported a significant association between caregiver burden and huge finances.

7.4. Confinement (restricted participation in social activities).

Caregiver burden is common in providing care to children with CP requiring long-term care (Liu et al., 2023). Caregivers of children with CP often experience limited social participation due to their full-time caregiving roles leading to feelings of immense burden (Dlamini et al., 2023; Elangkovan & Shorey, 2020; Vadivelan et al., 2020). Caregivers must care for children with CP confining them to one place with limited family support (Mwinbam et al., 2023). Caregivers often feel isolated, spending time alone and neglecting their hobbies due to the lack of support from others (Madzhie et al., 2022; Ni et al., 2022).

8. CONSEQUENCES OF CAREGIVER BURDEN

Consequences are factors resulting from the concept and review of the literature (Walker & Avant, 2011). The concept analysis revealed the following consequences of caregiver burden: disruption of caregiver lifestyle and family function, decline in caregiver quality of life, and decrease in care provision. The consequences of caregiver burden negatively impact caregivers and care receivers. Literature lacks positive outcomes for caring for children with CP.

8.1. Disruption of Caregiver Lifestyle and Family Function

The high caregiving demand for children with CP has led to job losses and financial difficulties (Mwinbam et al., 2023) further disrupting their desired lifestyle (Wijesinghe et al., 2015) and exposing entire families to lots of psychological turmoil (Vadivelan et al., 2020). The caregivers are enclosed in a single space disrupting their daily routines and isolating them from society (Arasu & Shanbhag, 2021; Vadivelan et al., 2020). Caregivers must make significant changes in their plans, social lives, life expectancies, and family functions to provide care for disabled children resulting to a caregiver burden (Yildirim et al., 2022).

8.2. Decline in Caregiver Quality of Life (QoL).

QoL is a subjective and objective measure of one's life due to the caregiver's burden (Arasu & Shanbhag, 2021). Caregivers of children with CP face chronic generalized body pain, depression, and anxiety limiting their time for self-care (Dambi et al., 2016; Yilmaz et al., 2013). Caregivers' lack of awareness about proper maneuvering for disabled children results in adopting the wrong postures leading to a decline in their QoL (Arasu & Shanbhag, 2021; DiFazio et al., 2022; Tuncay & Sarman, 2023).

8.3. Decrease in Care Provision.

A decrease in care provision is one of the consequences of caregiver burden due to insufficient family support and resources (Bastawrous, 2013). Yilmaz and Küçük Alemdar (2021) assert that quality of care provision is compromised when the caregiver is burdened and overwhelmed. Vadivelan et al. (2020) claim that caregivers care for the entire family not just the disabled child thus compromising quality care provision. Caregivers face challenges in meeting disabled children's basic needs and limiting physical activities due to exhaustion, anxiety, and lack of emotional support (Yilmaz & Küçük Alemdar, 2021).

9. EMPIRICAL REFERENTS

Empirical referents are crucial in concept analysis serving as measurable means to demonstrate the reality of the concept's occurrences (Walker & Avant, 2011). Several measurements are used in literature to measure this concept and have similar domains related to the defining attributes. The most widely used measurements are The Zarit Burden Interview (ZBI), the Burden Scale for Family Caregivers – short version, and The Caregiver Reaction Assessment Scale (CRA).

9.1. The Zarit Burden Interview (ZBI)

The ZBI also known as the Zarit burden scale (ZBS) is a widely used reliable instrument to measure caregiver burden (Atar et al., 2022; Wijesinghe et al., 2015; Zarit et al., 1980). ZBI contains 22 items and has high internal and test-retest consistency with Cronbach alpha of 0.93, and intraclass correlation coefficient of 0.89 respectively (Barutcu et al., 2021) . ZBI questions comprise 5 domains: (1) burden in the relationship (6 items), (2) emotional well-being (7 items), (3) social and family life (4 items), (4) finances (1 item), and (5) loss of control over one's life (4 items) (Zarit et al., 1980). The items explore either personal strain or role strain and record the caregiver's feelings on an ordinal Likert-type scale, (0: never; 1: rarely; 2: sometimes, 3: quite frequently; and 4: nearly always).

9.2. Burden Scale for Family Caregivers (BSFC)– short version

The BSFC is a global measure of perceived burden from home care, suitable for clinical practice and research studies (Pendergrass et al., 2018). BSFC measures informal family caregivers' subjective burden in the care of chronically disabled and ill people at home. It is a 10-item scale rated from 0 (strongly disagree) to 3 (strongly agree) which comprises several domains: physical, financial, and psychological well-being, environment, and relationships (Graessel et al., 2014). The tool has a Cronbach's alpha of 0.91 and a split half coefficient of 0.9. It measures caregiver burden from 0 to 30 points with higher scores indicating greater caregiver burden.(Graessel et al., 2014).

9.3. The Caregiver Reaction Assessment Scale (CRA)

CRA is a well-developed 24-item measure of the multidimensional burden informal caregivers of people with multiple long-term conditions (Kudra et al., 2017). CRA assesses one positive (carer self-esteem) and four negatives: financial problems, family support (relationships), disrupted daily schedules, and physical health problems (Kudra et al., 2017) . CRA has Cronbach's Alpha ranging from 0.71 to 0.83 across different domains (Chang et al., 2016).

10. THE PROPOSED DEFINITION OF CAREGIVER BURDEN

Based on the literature review and concept analysis, caregiver burden can be defined as a "subjective long-term multifaceted heavy caring load borne by caregivers from caring for individuals with a permanent developmental disability". Caregivers bear the burden of caring for their disabled children, as a personal responsibility that may last for a long time. The proposed definition of caregiver burden for children with CP incorporates all defining attributes, focusing on all aspects due to the permanent developmental disability. The conceptual model for caregiver burden is shown in Figure 2

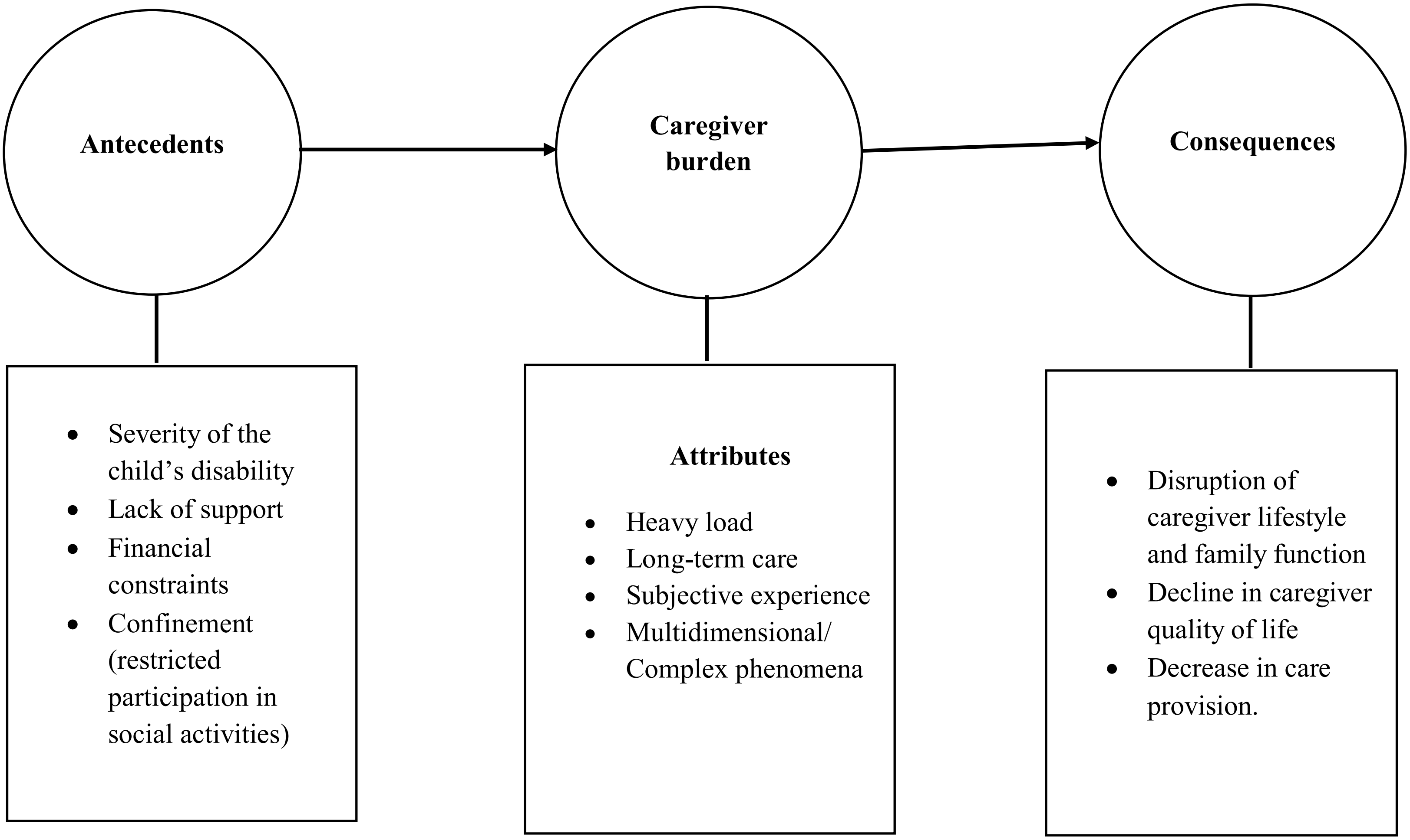

Figure 2. Conceptual model of caregiver burden

DISCUSSION

Caregiver burden is a complex and multifaceted phenomenon (Liu et al., 2023) involving both subjective and objective aspects (Chou, 2000) and includes negative responses to physical, social, psychological, and emotional stressors resulting from caregiving experiences (Gugała, 2021; Hewawitharana et al., 2023; Yigman et al., 2020). The study examined the caregiver burden for children with CP-related disabilities who are typically managed at home by primary caregivers (Mwinbam et al., 2023). The caregiver burden is a multifaceted issue that is expected to intensify as the child with a disability grows older. The analysis reveals that caregivers of children with CP face a higher caring burden compared to other chronic diseases and have to deal with stigma, discrimination and lack of family's emotional and physical support which is increasing as the child's disability worsens.

This study presents one attribute of caregiver burden as subjective experience which is similar to subjective perception (Chou, 2000) and self-perception (Liu et al., 2020). Chou's study identifies caregiver burden as a personal assessment of a caregiving situation based on the level of difficulties experienced by caregivers (Chou, 2000). Liu and colleagues claim perception is the way caregivers personally regard, understand, and interpret burdens from caregiving roles (Liu et al., 2020). The analysis reveals that caregiver burden for children with CP is subjective and long-term, influenced by caregivers' personal experiences and feelings, especially in the absence of a cure. Caregiver burden is an unequal distribution of responsibilities, with female caregivers being more burdened than males, traditionally viewed as a woman's moral responsibility (Gunawan et al., 2023).

The analysis reveals that the caregiver burden on children with CP is influenced by the severity of their disability, lack of support, financial constraints, and confinement. Of all the antecedents, the severity of the child's disability determines the amount of caregiving required and the significant predictor of caregiver burden. Children with severe gross motor impairment rely heavily on caregivers for self-care activities as they cannot achieve independence (Kim et al., 2017). Financial constraints and lack of support significantly contribute to caregiver burden in children with CP whose management is costly and self-funded. Some countries provide insufficient disability funds (Dlamini et al., 2023; Vadivelan et al., 2020). The analysis of caregiver burden in advanced cancer patients revealed that lack of economic resources is a precursor to caregiver burden (Morgan et al., 2022). Lack of support can exacerbate the burden on caregivers, who must care for not only a disabled child but also the entire family. Family support and family-centered caregiving help to reduce caregiver burden (Aydin & Nur, 2012; Marrón et al., 2013). Restricted participation in social activities such as family gatherings, visiting friends, and weddings adds more stress and burden on caregivers (Madzhie et al., 2022).

The caregiver burden is a serious issue that requires comprehensive support from family, society, and healthcare providers to ensure the well-being of caregivers and disabled children. The analysis highlights the severe impact of unattended caregiver burden, which leads to disruption of caregiver lifestyle, and family function, decreased caregiver QoL, and reduced care provision. Piran et al. (2017) indicates that long-term dependency of children with functional limitations can negatively impact family functioning, leading to high divorce rates and reduced caregiver efficacy.

Liu and colleagues conducted a concept analysis and also showed that a decline in QoL and care provision is significantly related to caregiver burden (Liu et al., 2020) and that can be attributed to lack of resources and support. Quality of care is reduced when the caregiver is burdened with caring responsibilities (Çolak & Kahriman, 2023). The child's reliance on caregivers disrupts family functions, as they are constantly present and forced to miss family holidays (Martinez de Zabarte Fernandez et al., 2021). Early identification and support of caregivers in a patient's caregiving journey is crucial for promoting positive care outcomes and improving their QoL (Kwame & Petrucka, 2021).

Implications for Practice and Research

The concept of caregiver burden in children with CP is clarified and redefined to include emotional, physical, social, and financial dimensions. It highlights how caregiver burden manifests in diverse cultural contexts, influencing theoretical caregiving stress and adaptation models. The analysis of caregiver burden will enable clinicians to develop effective interventions and a comprehensive family-centered care approach to alleviate the burden of care. The healthcare sector can reduce caregiver burden by identifying and establishing supportive structures early, promoting caregivers' health, and improving the quality of care. The concept analysis recommends developing caregiver burden assessment tools specific to CP caregiving, improving early identification and intervention, and developing caregiver education programs for stress management and health promotion.

Conclusion

This analysis explores the concept of caregiver burden, identifying its attributes, antecedents, and consequences in caring for children with CP. This analysis was conducted to formulate a working definition of the concept. It is essential to simplify the concept of caregiver burden for healthcare providers and the general populace to obtain a clear understanding of the meaning of caregiver burden in the context of children with CP-related disabilities from the caregiver perspective. The case models provided accurate use of the caregiver burden concept and demonstrated all its defining attributes. Furthermore, healthcare providers can identify caregivers early, assess their caring burden using reliable tools, and develop appropriate interventions to support caregivers. The analysis reveals that caregivers of disabled children face significant physical and emotional strain due to their responsibility in caring for them.

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