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The Caregiver of the Child with Cerebral Palsy: The Unnoticed Victim

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Abstract

The purpose of this study was to better understand the overall quality of life (QoL) in the primary caregiver who provides care to the child or adolescent, aged 0-17 with mild, moderate, or severe Cerebral Palsy (CP). This study aligned with a nonexperimental or observational design and examined the severity level of CP and the QoL in the mother and/or father.

For research question 1, regression results indicated that the overall model did not significantly predict the mother's and father's QoL [$R^2 = .000$, $R^2_{adj} = -.012$, $F(1,80) = .003$, $p = .957$]. Regression results indicated that the overall model did not significantly predict the mother's mental and physical QoL [$R^2 = .002$, $R^2_{adj} = -.007$, $F(1,111) = .268$, $p = .606$]. Regression results indicated that the overall model did not significantly predict the father's mental and physical QoL [$R^2 = .000$, $R^2_{adj} = -.011$, $F(1,86) = .024$, $p = .877$].

For research question 2, there was an association between the number of hours spent providing healthcare and the CP severity description, $x^2 (16) = 77.79$, $p <.001$. There was an association between harder to care for and the CP severity description, $x^2 (12) = 39.49$, $p<.001$. There was an association between stress and the CP severity description, $x^2 (4) = 25.20$, $p<.001$. There was an association between the job or work status and the CP severity description, $x^2 (4) = 11.08$, $p=.026$. Regression results indicated an overall model of two indicators (day-to-day emotional care and day-to-day emotional care from the health care provider) that significantly predicted the total score of the mother [$R^2 = .163$, $R^2_{adj} = .085$, $F(1, 9) = 2.081$, .039]. Regression results indicated an overall model of one indicator (caregiver(s) employment status) that significantly predicted the total score of the father [$R^2 = .145$, $R^2_{adj} = .042$, $F(1, 9) = 1.411$, .199].

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A. Chapter 1: Introduction

Cerebral palsy (CP), is a neuromotor disorder that affects the development of movement, muscle tone, and posture (Patel et al., 2020). The pathophysiology of CP consists of some type of injury that occurs to the developing brain during the prenatal through neonatal period (Patel et al., 2020). There has been disagreement on the definition of CP but, there has been a consensus on one that encompasses the whole disorder. With that said, CP is considered a group of permanent disorders of movement and posture, that can then lead to activity limitations (Patel et al., 2020). The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems (Patel et al., 2020).

CP can range dramatically from mild to moderate to severe leading to negative impacts on parents and/or primary caregivers. Through providing care to the child or adolescent with CP, parents or primary caregivers can be impacted through many facets of their life such as emotionally, physically, psychosocially, financially, and spiritually. If the parent or primary caregiver is affected in these instances within their daily life, then their overall quality of life (QoL) will decrease. Therefore, the research problem that was covered in this study explored how the severity of CP (i.e., mild, moderate, and severe) affected the overall QoL in the primary caregiver. The new findings from this study have specified where primary caregivers are affected the most in their life. Furthermore, the purpose of this study was to better understand the overall QoL in the primary caregiver that provides care to the child or adolescent, aged 0-17 with mild, moderate, or severe CP.

Background and Problem

It is well documented through data that caregivers of all different children and adults with disabilities face many obstacles when having to provide care for their child or adolescent. Parents or primary caregivers can be impacted emotionally, psychologically, and mentally, because they may be required to provide continual care to their child or adolescent. This can be immensely draining, especially if they have a job, other children, and other responsibilities. Parents or primary caregivers might also suffer physically because they must provide toileting and bathing care, which in turn can lead to neck and back pain. Their sleep schedule may also suffer due to the needs of the child or adolescent during the nighttime hours. Additionally, parents or primary caregivers may experience financial issues, as their child may require frequent doctors' appointments, hospital visits, equipment (e.g., wheelchair or diapers), and even multiple and expensive medications. In certain situations, primary caregivers may have to leave their job completely, cut back on hours, or even take a leave of absence due to the amount of care their child or adolescent requires.

Martin et al. (2021) stated that the prevalence and complexity of caregiving has been increasing across the US. For instance, from 2015 to 2020, the number of caregivers has grown from 10.2 million to 14.1 million (Martin et al., 2021). Forty percent of the 53 million caregivers in the US are in high-intensity care situations based on the number of care hours given and the number of activities of daily living (ADLs) for which they provide assistance (Martin et al., 2021). Caregiving is very stressful and can lead to depression, mood swings, and even resentment because of the time commitment that caregiving entails. It is even evident that caregivers will likely experience strain, an increased risk of mortality due to the strenuous physical demands, and a weakened immune system, and there is even a greater chance that they will battle chronic health conditions (Martin et al., 2021).

When investigating the QoL in the primary caregiver, factors that may increase caregiver vulnerability include cognitive disorders, traumatic brain injury, various forms of dementia, and end-of-life care (Martin et al., 2021). In addition, if the primary caregiver does not have access to social support, respite, or community services then the caregiver might have a poorer overall QoL. As will be shown, caregivers also report that assistance with financials is a big aspect that affects how they provide care. In the big picture, it is evident that primary caregivers deal with financial burdens in terms of the cost of equipment, treatments, therapies, insurance, and access to community services (Eloreidi et al., 2021). Overall, primary caregivers endure many struggles in providing care to their child or adolescent with CP, therefore, the results of this study will shed light on the complexities of caregiving.

Study

This study was a nonexperimental or observational design and was correlational because I investigated the relationships or associations among the variables identified in this study. The purpose of this study was to better understand the overall QoL in the primary caregiver that provides care to the child or adolescent, aged 0-17 with mild, moderate, or severe CP. Additionally, through using the provided database, I utilized secondary data analysis. The database that was used in accordance with this study was provided by the Data Resource Center for Child & Adolescent Health. Specifically, this database, *The National Survey of Children's Health (NSCH)*, provided current data on multiple aspects of the child's or adolescent's life in relation to their physical and mental health and access to healthcare (The Child & Adolescent Health Measurement Initiative, n.d.). As there are quite a few different databases provided, the most recent data was used, which was the *2020 National Survey of Children's Health (NSCH)*. This dataset was collected through the Census Bureau and was nationwide to include all 50 states and the District of Columbia (The Child & Adolescent Health Measurement Initiative, n.d.). Additionally, this dataset included a population of non-institutionalized children from the ages of 0-17 within the US and had a total sample size of 42,777, which equates to 644–3,039 per state (The Child & Adolescent Health Measurement Initiative, n.d., p. 1).

What is vital to know in this study is how the severity of CP and QoL in the primary caregiver was defined, as these are the most important variables in the study. The severity of CP can be observed using a few different tools, as mild, moderate, and severe are broad categories. Ultimately, healthcare professionals can utilize the Communication Function Classification System (CFCS), Gross Motor Function Classification System (GMFCS), and the Manual Ability Classification System (MACS). The CFCS is a tool that classifies everyday communication and there are five levels. Level I essentially means the child can communicate very well in most environments and a Level V means the child essentially does not communicate verbally at all. The GMFCS assesses gross motor function and movement in the child (i.e., walking and use of mobility devices) and has five levels. Level I means that the child can move around without hardly any limitations versus Level V means the child is in a wheelchair and cannot maintain posture or the movement of their arms or legs. The MACS examines how a child handles objects in an everyday setting; there are also five levels in this classification system. Level I means the child has no issues handling an object and Level V means they cannot handle an object or even complete simple movements with the use of their hands.

QoL can be viewed in many ways. One example was defined in 1984 by Zarit and colleagues, which states that QoL is perceived by each caregiver and potentially has an adverse effect on emotional, social, financial, physical, and spiritual functioning (Martin et al., 2021). Another definition of QoL entails the overall well-being of the caregiver. This includes personal health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, autonomy in decision-making, social-belonging, and their physical surroundings (Teoli & Bhardwaj, 2022). In contrast, The World Health Organization (WHO), defines QoL as a subjective evaluation of one's perception of their reality relative to their goals as observed through the lens of their culture and value system (Teoli & Bhardwaj, 2022). For this study's purpose, QoL was defined as the primary caregiver's subjective evaluation that impacts their physical health, mental health, psychological health, social health, emotional health, financial functioning, work environment, and their family function and relationships (Teoli & Bhardwaj, 2022; Martin et al., 2021).

The research questions in this study are the following. There were 3 research questions and 2 sub-research questions. The first research question to be examined was: Is there a difference between the primary caregivers' (mother/father) mental and physical health/QoL based on the degree of severity of CP? The sub-question for question 1 was: Can I predict the primary caregivers' (mother/father) QoL from the severity of CP? The second research question was: Is there an association between the CP severity level and the nine indicators (e.g., employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child) that represented the QoL of the primary caregiver? The third research question was: What variables can be a possible indicator to the primary caregivers' mental and physical QoL? The sub-question for question 3 was: How well does the combination of employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child predict the overall mental and physical QoL of the primary caregiver (mother/father)?

Significance of Problem

The identified problem was significant because primary caregivers are often "put on the backburner" or are forgotten. Primary caregivers put in a lot of time that often goes unnoticed. Ultimately, primary caregivers do not have time to juggle everything and also provide care to their children with CP. Through acknowledging the identified problem and focusing on the primary caregiver, healthcare providers can offer appropriate and tailored guidance and resources to caregivers to improve their QoL. Additionally, through bringing more attention to this area in research, communities can be better equipped to provide the needed resources to parents or primary caregivers. No existing quantitative research was found examining the severity of CP and the association with the primary caregivers' QoL. This study can help to begin closing this gap in research and bring more attention to the primary caregiver and CP.

Summary

In summary, through completing this study, healthcare providers and researchers can have a more thorough examination into the QoL in the primary caregivers of children and adolescents with CP. Additionally, I can assess whether the severity level of CP affects the QoL in primary caregivers. The results of this study can allow a conversation in this research area and hopefully can lay the groundwork for both the primary caregiver and the child or adolescent with CP as they begin to age. There is very limited research on the young adult and adult with CP and how life looks as these individuals age. Additionally, the research is also very limited in the QoL of the primary caregiver as he or she ages, therefore, this research can provide a basis of understanding on this topic and begin to close this gap in research.

B. Chapter 2: Literature Review

The exact definition or meaning of CP has evolved and been debated throughout history (Velde et al., 2019). CP, while the definition has evolved, is defined as a group of permanent, changing disorders that affect both movement and posture (Sadowska et al., 2020). There are many different causes that impact the diagnosis of CP such as problems that arise prenatally, perinatally, and during the neonatal or infant stages of life. CP has its origin in the mid-1800s. Dr. William John Little first initiated studying CP among his own disability and difficulties with CP (MyChild, 2023). Little made the argument that to promote “beneficial treatment, CP must be identified in the early stages” (Velde et al., 2019). Sir William Osler, another important contributor within the CP world, furthered modern medicine and wrote the first book on CP (MyChild, 2023, p. 1). During the mid-20th century, a female voice, Dr. Jean Macnamara, began questioning the diagnosis of CP and examined if we as a society are recognizing CP early enough (i.e., first few months of life) (Velde et al., 2019). Not until 1970 was CP examined systematically. Up until this point, it was believed that the signs of CP could not be recognized until the child was 12 months or older. Clinicians were taught that CP could not be diagnosed until the child was between the ages of 3–5. Then, during the 1970s and 1980s, the idea that there were risk factors for CP were introduced. This could exponentially help healthcare providers to identify babies with potential CP.

Our understanding of CP has come a long way. Tools have since been developed to better identify babies with signs and symptoms of CP. The biggest leap in predicting CP was the use of the general movements assessment (GMA) (Velde et al., 2019). This assessment, developed in the 1990s, was used to assess the spontaneous movement of an infant (Velde et al., 2019). In addition to the GMA, was the development of the Hammersmith Infant Neurological Examination (HINE). The HINE functions as a standardized neurological examination that can predict CP. For example, in Australia, only 21% of infants receive a diagnosis of CP by the age of 6 months and 52% have a diagnosis made after one year of age (Velde et al., 2019, p. 3).

Today, there is still no cure for the symptoms of CP (Cerebral Palsy Research Network, 2021). It is evident through research that there are some aspects that are not fully understandable with a diagnosis of CP. Additionally, the existing treatments for addressing pain and innovations in technology still appear to be inadequate (Cerebral Palsy Research Network, 2021), although there has been new identification of potential causes and risk factors that may lead to CP. For instance, there have been genetic studies, that have been funded by The National Institute of Neurological Disorders and Stroke (NINDS) that can link specific, individual genes with CP (National Institute of Neurological Disorders and Stroke, 2023). There have also been developments in the invention of drugs that can control both stiff and spastic muscles and advanced surgical techniques to correct irregularities in muscle and bone (National Institute of Neurological Disorders and Stroke, 2023).

This literature review has investigated the primary caregivers overall QoL in relation to providing care for their child or adolescent with CP within a continuum of severity of CP (i.e., mild, moderate, and severe). The primary caregiver has to dedicate more time in all aspects of their child's life resulting in mental, physical, emotional, psychological, financial, and social problems that may not have arised if their child was "typically developing". Through exploring and critiquing the literature, new findings can better acknowledge the primary caregiver’s impact and further identify what the needs are of primary caregivers when they are put in the situation of raising a child with CP. Within the population of CP, the focus is on the child and adolescent, although, to gain a broad perspective on this topic, some parts of this literature review have assessed the young adult and adult with CP.

The identified problem is significant because, primary caregivers are often “put on the backburner” or are forgotten. Through acknowledging the identified problem and focusing on the primary caregiver, healthcare professionals can offer appropriate and tailored guidance and resources to caregivers to improve their QoL. The first research question to be examined was: Is there a difference between the primary caregivers’ (mother/father) mental and physical health/QoL and degree of severity of CP? The sub-question for question 1 was: Can I predict the primary caregivers’ (mother/father) mental and physical QoL from the severity of CP? The second research question was: Is there an association between the CP severity level and the nine indicators (e.g., employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child) that represented the QoL of the primary caregiver? The third research question was: What variables can be a possible indicator to the primary caregivers’ mental and physical QoL? The sub-question for question 3 was: How well does the combination of employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child, predict overall mental and physical QoL of the primary caregiver (mother/father)?

Literature Review Search

To address the above research questions related to the child or adolescent with CP and the primary caregiver's QoL, a literature review was first conducted. The key search terms that were used were: cerebral palsy, caregiving, quality of life, severity of cerebral palsy, primary caregiver, family, and parent. The Boolean operators that were used were AND and OR. The search engines that were used were: CINAHL, Medline, Cochrane Library, Ovid Journals, and Wiley Online Library. The inclusion criteria were: children, adolescents, young adults, adults with CP, publications from 2018-2023, and published in English. The exclusion criteria were: publications earlier than 2018 and not published in English. The number of publications that met the inclusion criteria for this literature review was twenty-three. For a visual representation of the included and excluded articles for this study, refer to the PRISMA Flow Diagram in Figure 1.

Issues That Impact Study

Through familiarizing and staying updated on the current literature, there are a few major issues that impacted this study. First, in developing this study, it is evident that the current literature does not adequately cover data on the aging individual with CP. For example, there is a moderate amount of literature on the child and even adolescent with CP but, once this child develops into a young adult and adult what we know about CP declines. A second issue that impacted this study was the available secondary databases for all individuals with CP. The database that was used focused on the child and adolescent with CP. There are currently no databases or longitudinal studies that focus on the young adult or adult with CP. Third, while the current literature does not focus on the aging individual with CP, the current literature also does not concentrate on the caregiver, as the caregiver is also aging. Finally, another major issue that impacted this literature review and study was that the majority of studies have a solid response rate from mothers of children with CP, but the literature lacks responses from fathers of children with CP. It appears that the majority of caregivers of children with CP are mothers, therefore this could affect the results of the evaluation and analysis of this study. As a whole, what is available for the research and the academic community in relation to CP is scarce. Therefore, by pulling together the relevant variables in the provided and published database, these gaps can be addressed, and more attention can be brought to the forefront for the CP community.

Theory

While there are multiple theories related to caregiving, it is indeed difficult to search the literature and locate an exact discipline, theory, or model that fits the exact inclusions of the child with CP and the caregiver. While investigating for theories that fit these inclusions, one model does include some of the same parameters as this literature review. This theory is the *Role Strain Theory*. This theory is a sociological theory and proposes that caregiving can lead to role strain because, once the caregiver takes on new responsibilities and experiences, this will bring about many stresses (Sakwape et al., 2023). This theory suggests that the caregiver will experience both tension and stress as they try to balance being a caregiver and dealing with their other roles and responsibilities within their life (i.e., work, family, and personal life). This may then lead to feelings of burden, guilt, and burnout.

Another theory that may shed some light on caregiving is the *Resilience Theory*. This theory is a psychological theory and indicates that some caregivers can adapt and cope with stress and hardship through their resilience and coping mechanisms. This theory states that a caregiver who is able to “bounce back” from a challenging situation and maintain their well-being is, resilient (Zimmerman, 2013). Resilience combines multiple aspects of personal characteristics such as: optimistic coping skills, a strong support system, and environmental factors (i.e., access to resources and opportunities). While both of the above theories provide a meaningful background to caregiving, with more research, enhanced and more inclusive theories or models can be identified to shine a light on all of the difficulties that a caregiver will face when caring for a child with different severities of CP.

While theory can greatly impact this study as well as other research within this field, the literature was searched intricately to identify an appropriate theory or model that can drive the work in this study. One specific model that encompasses many aspects of caregiving for this study is the *Conceptual Model of Caregiving Process and Caregiver Burden Among the Pediatric Population* (Raina et al., 2004). This is a multidimensional model that has made an advancement within caregiver theory, to focus on the “whole” caregiver over their lifespan.

What sets this model aside from others, is that this model investigates caregiving in both the pediatric and geriatric populations. This is beneficial to the researcher because, as the individual with CP ages, the diagnosis of CP may change. With this said, the caregiver might have to take on additional roles, which could be attending more doctors’ appointments or even grappling with new onset epilepsy. Additionally, what this model provides is a focus on both formal and informal caregiving and examining both physical and psychological health as outcomes (Raina et al., 2004). Between formal and informal caregiving, there is a dramatic difference between these two types of caregiving. In the big picture, the difference between formal and informal caregiving is the time commitment of providing care to the child with CP.

There are five constructs that make up this model and they are: background and context, child characteristics, caregiver strain, intrapsychic factors, coping factors, and outcomes (Raina et al., 2004). There are both and uni-directional and bi-directional arrows within this model that depict the relationships between the constructs and variables. For a visual representation of this model view Figure 2.

The first construct of background and context includes the socio-economic status variable. This variable includes the socio-economic characteristics of the entire family. To understand the socio-economic status variable, one must take into consideration parental education, occupation, and family income (Raina et al., 2004). The second construct which is child characteristics, includes the function and child behavior variables. These variables explore the severity of the disability of the child and if the child has behavior problems. When assessing the disability of the child, one must examine the motor severity and cognitive functioning, the extent of dependence in ADLs, and any other medical problems (Raina et al., 2004). When assessing the behavioral problems of the child, one must examine conduct disorders, hyperactivity, emotional disorders, and somatization. The third construct of caregiver strain/stress includes the caregiver demands and perception of formal care variables. Caregiver demands measure the day-to-day demands on the caregiver and examines the conflict between the role of the caregiver and the occupational roles of the primary caregiver (Raina et al., 2004, p.

9). The formal care variable assesses services and if they are family-centered (Raina et al., 2004).

The fourth construct of caregiver intrapsychic factors explores the variable of self-perception. This construct examined the caregiver's self-esteem and how the caregiver has taken on the new role of caregiver. The fifth construct of coping factors investigates the variables of social support, family function, and stress management. What these variables are considering are the resources the caregiver has and how the resources will ultimately lead to the health outcomes of the caregiver. Social support measures the informal support of the caregiver. This can include extended family, friends, and people within the community or neighborhood. Family function entails how the family works together. Stress management measures the amount of strategies and practices the caregiver has in response to a challenging situation (Raina et al., 2004). At the end of this model is the construct of outcomes. This construct contains the two variables psychological and physical health and ultimately assesses how the constructs above affect the outcomes. For a visual representation of this model view Figure 2.

Variables

Cerebral Palsy

CP is the most common severe motor disability in children, and its severity is demonstrated by the fact that 40% of children with the condition cannot walk independently, one-third have epilepsy, up to one-third are non-verbal, and about one-half have some degree of cognitive impairment (Korzeniewski et al., 2018). To reiterate, CP is a group of disorders that affects a person's ability to move and maintain balance and posture (Centers for Disease Control and Prevention, 2022). Due to injury to the developing brain of the child with CP, this child will have clinical findings that are permanent (Vitrikas et al., 2020). The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems (Patel et al., 2020).

CP can be divided into different types such as spastic, dyskinetic, ataxic, and mixed. Spastic CP is generally the most common, there is increased muscle tone, stiff muscles, and awkward movements, that may affect the body systemically or specifically (MedlinePlus, 2022). The second type is dyskinetic, which can cause difficulties controlling the movement of hands, arms, feet, and legs, leading to having problems sitting or walking (MedlinePlus, 2022). The third type is ataxic, which may lead to difficulties with balance and/or coordination (MedlinePlus, 2022). The fourth and last type is mixed, which means that the child will have symptoms of more than one type (MedlinePlus, 2022).

CP, as with other childhood diagnosed disabilities or disorders, can be viewed along a continuum of severity. On one end of the continuum, the child will have a mild form of CP. This child will be able to walk independently, not require 24 hours a day, 7 days a week care, and be able to function in a “typical” school day atmosphere. In the middle of the spectrum is a child with moderate CP, this child might need some assistance with daily activities, has a few comorbidities, and in general, is capable of some daily living tasks, but still does require some support and assistance. On the other end of the continuum is a child with severe CP. This child will be completely reliant on a full-time caretaker and will require complete support with each ADL. This child will likely need a wheelchair to move around, potentially suffer from epilepsy, need assistance with feeding, and may have many cognitive and communication deficits. While it is necessary to understand CP, it can certainly be helpful to understand how CP is evaluated pertaining to severity.

Evaluation of CP

For severity of CP, there was no specific measurement or tool used within the surveys. Parents or caregivers first marked whether or not their child had CP. Next, if the child had CP, the parents marked mild, moderate, or severe.

One way to evaluate the severity of CP is through the most widely used evidence-based tool, the GMFCS tool (Vitrikas et al., 2020). This is not a survey or instrument, rather a guide for how to diagnosis and for understanding the severity of motor function in a child with CP. The first level, GMFCS Level I, means that the child can walk and climb stairs but, their speed, balance, and coordination are limited. The second level, GMFCS Level II, means that the child needs a railing when walking. Walking long distances can cause difficulty; this is when a handheld mobility device or wheeled mobility device may come in handy. The third level, GMFCS III, means that the child probably uses a hand-held mobility device in most indoor settings and uses wheeled mobility when traveling long distances. The fourth level, GMFCS Level IV, means that the child uses methods of mobility that require physical assistance or powered mobility in most settings. This child at school, outdoors, and in the community are transported in a manual wheelchair or uses powered mobility. The fifth and last level, GMFCS Level V, means that the child is transported in a manual wheelchair in all settings. This child is limited in their ability to maintain head and trunk postures and control their leg and arm movements.

In addition to the GMFCS instrument, there are many other ways to classify and understand the severity of CP. Another classification system is the CFCS. It is estimated that 31% to 88% of individuals with CP have a communication disorder (Paulson & Vargus-Adams, 2017). This instrument is used to describe the ability of persons with CP for daily routine communication and provide healthcare providers with another way of understanding the severity of CP (Patel et al., 2020). This instrument assesses all methods of communication: vocalizations, manual signs, eye gaze, pictures, communication boards, and speech generating devices (Patel et al., 2020). The first level of this system, CFCS I, states that the child is completely able to communicate without any difficulties. The second level, CFCS II, means that the child is essentially the same as level one, although this child might be slower in a conversation. The third level, CFCS III, means that the child can normally communicate in a comfortable environment, where they might know the person but are unable to communicate in unfamiliar environments, where they do not know the individual. The fourth level, CFCS IV, means that the child is not always consistent when communicating with someone they are familiar with. The last level, CFCS V, means that the child is hardly able to communicate effectively, even when they are with a familiar face (Cerebral Palsy Alliance, 2018). The ability of the communication skills of the child with CP will dramatically affect how the primary caregiver carries out his or her everyday life and might affect the QoL of the primary caregiver.

While the tools highlighted above are not specifically used in or for the database, these classification systems are necessary to understand how the severity of CP can greatly impact the QoL in the caregiver. Furthermore, these instruments provide a standardized classification that is useful to determine the prognosis and treatment of children and enhance communication between clinicians, researchers, parents, and other caregivers (Piscitelli, 2021, p. 1252).

Quality of Life in Parents/Primary Caregivers

It is well documented through data that caregivers of all different children and adults with disabilities face many obstacles when providing care for their child. The prevalence and complexity of caregiving has been continually increasing across the US. For instance, from 2015 to 2020, the number of caregivers has grown from 10.2 million to 14.1 million (Martin et al., 2021). Forty percent of the 53 million caregivers in the US are in high-intensity care situations based on the number of care hours given and the number of ADLs for which they provide assistance (Martin et al., 2021). Caregiving is very stressful and can lead to depression, mood swings, and even resentment because of the time commitment that caregiving entails. It is even evident that caregivers will likely experience strain, an increased risk of mortality due to the strenuous physical demands, a weakened immune system, and even a greater chance that they will battle chronic health conditions (Martin et al., 2021).

When measuring the QoL in the primary caregiver, things that may increase caregiver vulnerability are cognitive disorders, traumatic brain injury, different forms of dementia, and end-of-life care (Martin et al., 2021). In addition, if the caregiver does not have access to things like social support, respite, or community services then, the caregiver might have a poorer QoL. QoL can be viewed in many ways. One example was defined in 1984 by Zarit and colleagues, which states that QoL is perceived by each caregiver and potentially has an adverse effect on emotional, social, financial, physical, and spiritual functioning (Martin et al., 2021, p. 1042). Another definition of QoL entails the overall well-being of the caregiver. This includes personal health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, autonomy in decision-making, social-belonging, and their physical surroundings (Teoli & Bhardwaj, 2022). In contrast, The World Health Organization (WHO) defines QoL as a subjective evaluation of one's perception of their reality relative to their goals as observed through the lens of their culture and value system (Teoli & Bhardwaj, 2022).

Caregivers also report that assistance with financials is a big aspect that affects how they provide care to their child or adolescent with CP. In the big picture, it is evident that caregivers deal with financial burden in terms of the cost of equipment, treatments, therapies, insurance, and access to community services (Eloreidi et al., 2021, p. 25). Having a child with CP can be exceptionally financially draining, which can lead to high levels of stress and a poorer QoL. Because of the amount of money it costs for medicine and equipment, the financial burden adds up quickly. Caregivers report financial burden from having to provide supplies, transportation, health facilities, and assistive devices (Sakwape et al., 2023). Even with grant money, parents still struggle to meet the financial needs of their child with CP. Caregivers ultimately could benefit from potential governmental assistance which could in turn, could benefit the child with medical expenses.

Parents also mention their experiences with healthcare and that they want above adequate healthcare to get the right services for their child. Caregivers also need individualized care, a plan of action, and for healthcare providers to treat them and the child as an equal. Additionally, mothers report it is difficult to navigate the healthcare system as the system is complex. There are differences in eligibility, accessibility, and availability and the raft of policies, procedures, and funding (Smith & Blamires, 2022).

When we examine what the caregivers deals with daily, we can have a better insight as to where the system fails the caregiver. First, caregivers feel that they lack basic knowledge of CP. Some parents find it is beneficial to be a part of a support group, therefore the caregiver can learn more about what others are going through and how they dealt with specific setbacks. Additionally, caregivers can gain useful knowledge and skills that can benefit them to provide care to their son or daughter. Caregivers must have social support to provide the best care to their child. As with informational needs, support groups can benefit the caregiver by knowing they are not alone. Although, research shows that some caregivers may feel that they are unable to discuss the health issues of their child with others due to their occupation or level of education. This can ultimately lead to ineffective decision making. This can also lead to further stress or depression because the caregiver feels that they cannot adequately or openly talk about their child’s disability.

It has also been reported that caregivers have high levels of psychological needs. This is due to fear, anxiety, and discomfort of their child’s disability (Eloreidi et al., 2021). To reduce psychological stressors, caregivers can benefit by learning coping strategies. These coping strategies (i.e., thoughts, emotions, and behaviors) can adjust how a caregiver reacts to certain difficult aspects in their life. When we examine coping strategies, some are positive and some are negative. Positive strategies include seeking support, exercising, watching movies, going on vacation, time management, and socializing (Eloreidi et al., 2021). Through using positive strategies, caregivers can work towards lower stress levels, optimism, a better time with acceptance, and an overall emotional well-being (Eloreidi et al., 2021). On the other hand, negative strategies include worrying, isolating oneself, not incorporating exercising into one's day, and hostile behavior (Eloreidi et al., 2021). These strategies can lead to feelings of hopelessness, depression, burden, and anxiety (Eloreidi et al., 2021). Ultimately, it is vital to have a good support system in place.

When examining the overall QoL in parents with children who have CP, parents describe that there is an immense physical toll that is thrust upon them. For example, fatigue, backaches, and wrist aches are all reported by parents. Furthermore, in response to endless fatigue and stress, parents experience a disturbed sleep pattern. Parents report that they have all over body pain. Parents also report that their mental health is affected when having to provide care to their child. They demonstrate that they do not have time for their own well-being, have low self-esteem, unending worry, crying, a feeling of being drained, and having to suppress their real feelings to pretend everything is fine (Sakwape et al., 2023). Overall, parents express that they are emotionally drained at the end of the day.

When beginning to raise their child with CP, many parents initially experience shock, denial, anger, and resentment which can greatly affect their QoL. Eventually and with time, caregivers reach acceptance. One mother discusses her "anger" as not anger toward her child but, now this child requires care, full-time care. She states "I have to halt my life and take care of him from dawn to dusk" (Kyeremateng et al., 2019). Kyeremateng et al. (2019) even comments on how mothers had to quit their job due to having to provide care for their child. As many other studies point out, parents deal with a great amount of depression. Kyeremateng et al., (2019) states that depression can both a combination of guilt and sadness. Other parents mention they can adjust and accept their child’s disability once they are able to understand the disability, their child’s capabilities, and what the future might look like for their child. Once the parent is also able to seek suitable treatments and educational programs for their child, their anxiety is somewhat reduced.

One mother reported that her husband showed little to no concern for their child’s disability. Another mother commented that her husband felt ashamed and embarrassed and forbade for their child to be seen in public. One mother expressed how others complain that they do not understand her child’s expressions. Therefore, this makes it difficult to understand if the child needs to use the bathroom or is hungry or is potentially unhappy about something. Another mother expressed that her mother was providing care to the child while the mother was at work but, the grandmother felt that it was too much to take care of the child. Therefore, this mother had to quit her job to provide care to her child. Among the fathers in this specific study, they reported it was difficult to obtain the medications and proper equipment for their child. Insurance did not cover the medicine their child needed therefore, the fathers would have to pay out of pocket costs. Pertaining to equipment, many participants reported that gaining access to a wheelchair was by far the hardest thing to accomplish. (Kyeremateng et al., 2019)

Many participants also reported how gaining access to specialists and even getting transportation to the hospital was a difficult task (Sakwape et al., 2023). In addition, once the family gets to the hospital that has the specialist, they would be required to get there very early in the morning to not be seen by the doctor until later in the afternoon. While the healthcare system was difficult to navigate, the educational system was also chaos. Finding a suitable day care and proper facilities that could accommodate the child with complex medical needs was another huge hurtle experienced by parents. The mainstream schools do not have the proper resources or personnel and some parents even ran into issues with getting their child into a special school setting. This was simply because the special school did not have the capacity. (Kyeremateng et al., 2019)

Other difficulties that parents face is being able to hold on to a full-time job. Some parents report that it is even difficult to be productive at work because, their child needs to be taken to multiple doctor appointments and requires frequent medical attention (Sakwape et al., 2023). Parents further report that they are unable to continue with their regular lives. They can no longer attend social events and must spend more time at home caring for their child with disabilities. Other parents report that they have guilt because, they also function as wives and have other children to take care of but, their child with a disability requires more care. As with other studies, what may benefit parents is the acceptance of their child’s disability. As highlighted earlier, parents report that having access to support groups and maintaining their religion helps to get them through each day. Being able to “speak the same language” in support groups is very valuable for caregivers. Additionally, being able to have conversations with family, fellow church members, and even work colleagues can provide a sounding board.

As evident, it appears that mothers tend to provide more care to their child with CP, which then leads to a greater burden (Smith & Blamires, 2022). Mothers experience significant changes that occur in their lives which require them to adapt, make adjustments, and sacrifices that they would not ordinarily have to make. Smith & Blamires (2022) states that this might include leaving their jobs, or reducing their hours at work, changes to their lifestyle, or an adaptation to a new daily routine that revolves around their child's life. Mothers additionally share their experiences of how routine things during the day even take extra time. One example is giving their child a bath. Something that should ordinarily not take a long amount of time, does when you have a child with CP, which can then impinge on other aspects during the day.

Mothers also share their issues within their marriage due to the huge time commitments of their child. The mothers being interviewed in one study share that they lose support from their husbands and then become the sole caregiver to their child. In several studies, mothers reported frequent fighting with their spouse, lack of support from their husbands, issues of substance abuse, domestic violence, and rejection by their partners (Smith & Blamires, 2022, p. 67). Other mothers share their experiences with shame, humiliation, and a sense of personal failure. Some mothers even feel that God is punishing them. They might view it as God's revenge for something they did in their life. Other mothers go on to discuss how they feel shamed by family or friends because, they have a disabled child. Even fathers feel embarrassed in having a child with CP and are unable to accept and adapt to their new situation.

While viewing the family and siblings is separate from understanding the caregivers QoL, mothers also consider their other children within this situation. Siblings must make huge adjustments to their lives. Having a sibling with CP can dramatically affect their sisters or brothers and how they live their childhood years. Families with a child with CP do not just have the luxury of being able to pick up and go. Everything must be planned out ahead of time to accommodate the child with CP. Siblings might even be expected to help with the caregiver responsibilities and required to help more around the house.

With the diagnosis of CP, mothers reveal that they feel unsupported, socially rejected, and discriminated against (Smith & Blamires, 2022, p. 67). Mothers report that there is a consistent lack of understanding and support from friends, families, and the community (Smith & Blamires, 2022). This leads to both psychological and physical stress. In terms of physical challenges, mothers report problems due to lifting and carrying their child. Generalized pain as well as shoulder and back pain has been reported from parents due to providing full-time care to their child with CP. What makes the pain even worse is when equipment (i.e., wheelchairs and hoists) is unavailable to parents. For the child with CP, things such as changing diapers, bathing, and dressing can be very physically demanding. As the individual ages, changing diapers, showering or bathing, and moving can greatly impact the caregiver. One thing that can aid the caregiver is a gait belt when moving their child, although this is a minor advantage. Other barriers that affect parents from maneuvering in society is the lack of ramps, lifts, and accessible sidewalks (Smith & Blamires, 2022). In addition, there are a total lack of inclusive spaces and disability friendly transport (Smith & Blamires, 2022, p. 70).

Pertaining to the QoL and the caregiver, there are many similarities found across many different studies. It is evident that caregivers endure many emotional, mental, physical, and financial struggles when providing care to their child with CP. Ultimately, parents need better and more access to resources that can benefit the caregiver during the course of caring for their child with CP. With further and better access to resources, parents can have a better QoL and be more involved in their family. With the utilization of the available database, there can be available data on the necessary variables related to the QoL in the caregiver in relation to the severity of CP in the child.

Literature on Combination of Variables

When examining the available literature among the topic of the caregiver and the child with CP, research shows that there is not a wealth of knowledge on this topic. We have many ideas why CP is caused but, there is not an exact answer. Overall, CP can vary widely from child to child. Each child's abilities will be different, and this can significantly impact the caregiver and their QoL. As shown in the literature, many parents are affected emotionally, physically, psychologically, mentally, and financially. When addressing all the variables that could affect the caregiver's QoL, there is not a perfect number of articles that gather exactly what's going on daily. What the research does show and what will be further proven is that as the child's CP is worsened, this will affect the caregivers QoL in a more negative way.

What the available research does also show is that parents feel financially impacted through having to care for their child with CP. Parents also are affected emotionally, mentally, and psychologically. Parents are affected physically by having generalized body aches. They can be affected physically through not getting adequate or proper sleep. Additionally, parents do feel that they do not have the adequate resources that they need to have their own life and still provide care to their child with CP. They feel neglected by their significant other as well as close family and friends. Overall, it is difficult for them to relate to other families when their family dynamic is very different.

When we examine the child forming into an adult, the research shows that their health is deteriorating, which can then lead to a worse QoL in their caregiver. The transition into adulthood is an exceptionally difficult time for the child with CP as well as the caregiver. The healthcare system as well as the educational system is not an easy transition. The parent or caregiver must commit a lot of their time to transition their child into an adult healthcare setting, as well as deciding what their child will do after they are taken out of the school system at age 21. With proper assistance from pediatric healthcare providers, the transition from the pediatric to adult healthcare can be an easy transition. With proper assistance from social workers and special school district teachers, the transition from post high school to adult life can also be an easy transition. With adequate planning and acknowledgement of resources for the caregiver, the caregiver can additionally feel less burdened and a reduction in anxiety about the next steps for their child can take place.

Overall, the caregiver needs a better social support system that can help them care for their child on a daily basis. It indeed does take a village to care for a child with a disability and often caregivers feel that they are the only ones caring for their child which can negatively affect their QoL. Caregivers truly need access to the right resources that can help them take care of their child financially and all the other aspects that come along with taking care of a child with CP. It is very evident that the caregiver is affected when providing care to their child with CP. With the knowledge from the analysis that took place in this study, we can have a better idea of the relationship between the caregiver's QoL and the severity of CP.

Summary

Strengths & Weaknesses in Methodology

There are many strengths and weaknesses of completing a secondary data analysis. Secondary data analysis can help a new investigator increase his/her clinical research expertise and avoid data collection challenges (e.g., recruiting study participants, obtaining large-enough sample sizes to yield convincing results, avoiding study dropout, and completing data collection within a reasonable time) (Wickham, 2019, p. 397). Another advantage, as already illustrated, is the timeline. Additionally, because of the effects of the COVID 19 pandemic, being able to carry out a survey may result in an inadequate response rate to have publishable results. Secondary data analyses may also allow for examining more variables than would be feasible in smaller studies, surveys of more diverse samples, and the ability to rethink data and use more advanced statistical techniques in analysis (Wickham, 2019, p. 397). Additionally, to carry out a secondary data analysis, it is vital that the researcher have a broad knowledge base on one's topic and be up to date on the state of science of the field of research (Wickham, 2019, p. 396). With the available dataset, this large sample size can allow for statistically significant results and may have added benefits. Ultimately, if the results from this study and analysis reveal significant results, this can "justify" means for carrying out further research on this topic.

With adequate investigation of secondary databases available to the researchers, one specific database was located and shares the same ideology of the presented research questions. While this may be a disadvantage to some researchers, this was not the case for this study. Response rates to surveys have decreased over time, calling into question how representative the responses might be, which must be considered in the interpretation of secondary analyses (Wickham, 2019). However, many well designed surveys include sampling weights to counter the biases that may occur from non-representative sampling (Wickham, 2019). It is evident that the response rate was adequate but, this knowledge is beneficial for potential future research in this area.

With the above knowledge, the available data was used to identify key factors that play a role in affecting the caregivers QoL. There are both advantages and disadvantages of conducting a secondary data analysis. Through using the dataset appropriately, the researchers can use a large dataset to reveal if the severity of CP plays a role in the caregivers QoL. While it appears that research in relation to the caregiver and child with CP may be scarce, the dataset has provided an overview for medical providers to bring these issues to the forefront of nursing and medicine.

Through understanding other studies strengths and weaknesses, this can be used as a tool to allow the best practices among the methodology used in this study. While there are not an abundant number of studies that precisely target the caregivers QoL, we can conclude what may or may not work in terms of analysis. As some studies evaluate their own strengths and weaknesses, the available database does have an adequate number of participants, therefore the results of this study did provide both valid and reliable results. For example, Ying et al., (2021) & Polack et al., (2018) used multiple linear regression to assess the caregivers QoL which in turn provided robust results. Multiple linear regression has been used in this study therefore, having this knowledge is beneficial.

In summary, there are many aspects that affect the caregivers QoL. Through exploring the variables within this literature review and study, we as researchers can provide better care to parents and caregivers through understanding the complexity of children with CP. The available database that has been used can provide a great wealth of knowledge on the multiple aspects of the caregivers' life. What truly provides a robust outlook on this topic is that I can explore the severity of CP within the database.

CP is a complex medical diagnosis and as I examined the severity, there are many aspects to take into consideration. For the child who has mild CP, this individual will probably be able to take care of themselves therefore, the caregivers QoL will not be as impacted. For the child who has moderate CP, this child will need a moderate amount of care therefore, these caregivers will be affected in their everyday life and their QoL will be impacted. For the child who has severe CP, this child will require a lot of care and guidance and essentially will not be able to do anything on his or her own.

As we examine the variables that were addressed in the beginning of this literature review, we can see where the caregiver is impacted the most and what severity level is impacted the most. Through understanding this knowledge, further research can be targeted at the adolescent, young adult, and adult with CP. We understand that as the individual with CP is aging so is their caregiver. The caregiver will also experience a shift in their health which, can affect how they are able to care for their child. If caregivers have the right resources and have access to the right resources their QoL can be improved dramatically. Additionally, through this research, researchers can formulate better transitions for the child with CP throughout all aspects of their life.

According to The National Alliance for Caregiving (2023), from 2015 to 2020, there has been an increase from 19% to 26% of caregivers reporting that they have difficulty coordinating care for the person they take care of. In addition, more family caregivers are reporting that their own health is fair to poor. This has increased from 17% in 2015 to 21% in 2020 (The National Alliance for Caregiving, 2023). These statistics are vital to understand as healthcare providers, as this gives us a better understanding that more and more individuals with disabilities are living longer. This can also give medical providers an understanding of the urgency that caregivers in America are struggling and require tailored care just as the child with CP does.

Caregiving in America in 2023 is continuing to evolve and change, shaped by various factors such as advancements in medical technology, demographic shifts, and changing societal attitudes. There has been an increased recognition of the important role that caregivers play, and the challenges and stress that they face. This has led to the development of new policies and programs aimed at supporting caregivers, such as respite care services, tax credits, and training and education programs. Although, caregivers do not always know where to go for resources or how to access them. Through this study, we as researchers, can bridge that gap and allow for caregivers to be better prepared in their role as a caregiver.

The increasing use of technology and telehealth services, can make it easier for caregivers to manage the health and well-being of their child with CP. While this sounds great in theory, it is apparent that most primary caregivers are older, therefore, the newest technological services can even make caregiving more complex. Finding ways to bridge the gap between technology and caregiving can benefit the caregiver to be successful.

Overall, caregiving in America in 2023 is likely to continue to be complex and challenging, but one that is essential to the health and well-being of individuals with CP, their families, and the caregiver. Efforts to support and empower caregivers is critical to ensure that they can provide the high-quality care that their child deserves.

C. Chapter 3: Methodology

The research questions in this study are the following. There are three research questions and two sub-research questions. The first research question to be examined was: Is there a difference between the primary caregivers' (mother/father) mental and physical health/QoL based on the degree of severity of CP? The sub-question for question 1 was: Can I predict the primary caregivers' (mother/father) QoL from the severity of CP? The second research question was: Is there an association between the CP severity level and the nine indicators (e.g., employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child) that represented the QoL of the primary caregiver? The third research question was: What variables can be a possible indicator to the primary caregivers' mental and physical QoL? The sub-question for question 3 was: How well does the combination of employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child, predict the overall mental and physical QoL of the primary caregiver (mother/father)?

The purpose of this study was to better understand the overall mental and physical QoL in the primary caregiver that provides care to the child or adolescent, aged 0-17 with mild, moderate, or severe CP. This study aligned with a nonexperimental or observational design because there was not an intervention or manipulation of the independent variable (Polit & Beck, 2017). Furthermore, from the developed research questions, this study was correlational because I examined the relationships or associations among the variables identified in this study.

To reiterate these were the following research questions for the study. The first research question to be examined was: Is there a difference between the primary caregivers' (mother/father) mental and physical health/QoL based on degree of severity of CP? The sub-question for question 1 is: Can I predict the primary caregivers' (mother/father) mental and physical QoL from the severity of CP? The second research question was: Is there an association between the CP severity level and the nine indicators (e.g., employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child) that represented the QoL of the primary caregiver? The third research question is: What variables can be a possible indicator of the primary caregivers' mental and physical QoL? The sub-question for question 3 was: How well does the combination of employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child, predict the overall mental and physical QoL of the primary caregiver (mother/father)?

Through examining the processes of this study, analysis of potential threats was completed. The first internal threat to internal validity is temporal ambiguity. This may be a problem if it is uncertain if the independent and dependent variables cause one another. Maturation may also have affected the data within the database. As this study collected data on children, adolescents, and caregivers, many aspects during the course of the study such as: physical progress, emotional maturity, and exhaustion might have affected the data that is available (Polit & Beck, 2017, p. 224).

The Database

The database that was used in accordance with this study was provided by the Data Resource Center for Child & Adolescent Health. Specifically, this database, *The National Survey of Children's Health (NSCH)*, provided current data on multiple aspects of the child's/adolescent's life in relation to their physical and mental health and access to healthcare (The Child & Adolescent Health Measurement Initiative, n.d.). This database also provided data on the child's/adolescent's family, neighborhood, school, and environment (The Child & Adolescent Health Measurement Initiative, n.d.). What this database also provided were aspects that relate to the parents and/or primary caregiver. Therefore, I could draw conclusions that allude to how the severity of CP affected the primary caregivers overall QoL.

As there were quite a few different databases provided, the most recent data was used which was the *2020 National Survey of Children's Health (NSCH)*. This dataset was collected through the Census Bureau and was nationwide to include all 50 states and the District of Columbia (The Child & Adolescent Health Measurement Initiative, n.d.). Additionally, this dataset included a population of non-institutionalized children from the ages of 0-17 within the US and had a total sample size of 42,777, which equates to 644–3,039 per state (The Child & Adolescent Health Measurement Initiative, n.d., p. 1). This database allowed a better understanding of how the primary caregiver of a child or adolescent with CP is affected emotionally, physically, mentally, physiologically, financially, and socially. This evaluation led to providing primary caregivers with the correct tools to successfully live their life and provide them with tools to know when to ask for help. Additionally, the findings also provided healthcare providers with ways to provide the right resources to caregivers.

Measurement

The operational definition of the QoL for the primary caregiver was the total score from the 16-item, five-point Likert-type Family Caregiver Quality of Life scale. The scale which contains 16 items in total can be used in part as physical (items 1, 5, 8 and 9), psychological (items 2, 3, 4 and 6), social (items 7, 10, 11 and 12) and spiritual (items 13, 14, 15 and 16) well-being subscales as well as general QoL (Dulgeroglu & Gurkan, 2018, p. 74). The total score of each subscale can be 4 at minimum and 20 at maximum, and the total score can be 16 at minimum and 80 at maximum (Dulgeroglu & Gurkan, 2018, p. 75). Higher scores are indicative of better QoL (Dulgeroglu & Gurkan, 2018, p. 75). The operational definition of degree of severity of CP was the total score from the 5 criteria GMFCS indicating severity (Cerebral Palsy Alliance, 2018). This classification system is ordinal in nature, as there were 5 classifications ranging from GMFCS Level I to GMFCS Level V.

During data collection, a screener questionnaire was used to identify households with children and roster children in the household (United States Census Bureau, 2020, p. 5). The screener questionnaire also included a battery of questions to identify children with special health care needs (United States Census Bureau, 2020, p. 5). One child was randomly selected from each eligible household, and that child was the subject of a more detailed topical questionnaire (United States Census Bureau, 2020, p. 5). Responses to the screener and topical questionnaires were collected, processed, and published in the

Screener Public Use File and Topical Public Use File (United States Census Bureau, 2020, p. 5).

For the data collection portion of this study, there was the first phase. This first phase included a screener that was sent to the household. This screener required basic demographic characteristics and the status if there was a child that lived in the home with special health care needs (United States Census Bureau, 2020). The second phase included a questionnaire that was completed by the parent or caregiver of the selected child (United States Census Bureau, 2020). The screener questionnaire entailed two sections. The first section contained four questions about the presence of children in the home, the primary language spoken, and home tenure (rent or own) (United States Census Bureau, 2020, p. 11). The next section contained detailed questions about the demographics and health of the children in the household (United States Census Bureau, 2020, p. 11). Depending on the age of the child, there were three different questionnaires tailored specifically to three different age groups. There were 11 sections included in the questionnaire: Section A–This Child's Health, Section B–This Child as an Infant, Section C-Health Care Services, Section D–Experience with This Child's Health Care Providers, Section E–This Child's Health Insurance Coverage, Section F–Providing for this Child's Health, Section G–This Child's Learning/Schooling and Activities, Section H–About You and This Child, Section I–About Your Family and Household, Section J–About You and Other Parent or Caregiver in the Household, and Section K–Household Information (United States Census Bureau, 2020, p. 11–12).

For the survey, respondents could use a web instrument or a paper instrument. For the web instrument, some response fields only accepted responses that represented legitimate values; other fields offered a “pick list” of response categories (United States Census Bureau, 2020, p. 14). There were soft edits for some questions that prompted respondents to provide an answer or revise an existing answer, but respondents were able to continue past these edits without changing their answers (United States Census Bureau, 2020, p. 14). For the paper instrument, the same instructions were given to respondents as with the web instrument.

Through assessing whether the presented and published survey was valid and reliable it is vital to take a further look. While there are many published studies that used the data from the National Survey of Children’s Health (NSCH), no studies specifically discuss the validity and reliability of the survey. Although, it is evident that the survey demonstrates construct validity because the survey has continued to be used from 2001 on. There have been updates and small changes throughout the years to stay updated with the times. Through examining the necessary variables related to CP and the caregiver, convergent validity was assessed. For content validity, there were many variables in this database and they assess all aspects of the child’s or adolescent’s life and even the caregiver’s life. Therefore, the “actual” content in these surveys does match the content that should be included in this test (Furr, 2018). When evaluating face validity, the surveys do have high validity, this can even be assessed as a nonexpert. The surveys used do have high face validity because, when evaluating the “face”, it is clear what the survey is assessing. Lastly, when considering the criterion validity of the surveys, through measuring the identified variables in the database, I was able to understand if the database does a suitable job of measuring the constructs.

Variables from Database

The main variables that were used in this study was the primary caregivers (mother or father) mental and physical QoL. With this said, to understand the QoL in the caregiver, the variables, physical health status of the mother and father were explored and the mental health status of the mother and father were explored. When examining the physical health status and the mental health status of the mother and father, both variables were an ordinal level of measurement and required a Likert-type scale response from the parent. Physical health status of the mother and father was indicated by 1, excellent or very good, 2, good, 3, fair or poor, 99, missing, or 95, no mother/father reported in the household as a primary caregiver of the child (Data Resource Center for Child & Adolescent Health, 2022, p. 211-213). Mental health status of the mother and father was indicated by 1, excellent or very good, 2, good, 3, fair or poor, 99, missing, or 95, no mother/father reported in the household as a primary caregiver of the child (Data Resource Center for Child & Adolescent Health, 2022, p. 215-217). Additionally, QoL was also examined by the following variables employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child.

Employment, within the database, was defined as the parent or caregiver's employment status, although this variable only takes into consideration the highest level of employment (Data Resource Center for Child & Adolescent Health, 2022). This variable was considered an ordinal level of measurement and required a Likert-type scale response from the parent. A 1, meant at least one caregiver was employed full-time, 2, meant at least one caregiver was employed part-time, 3, meant the caregiver(s) unemployed or working without pay, and a 99, meant missing (Data Resource Center for

Child & Adolescent Health, 2022, p. 226). Divorce or separation, within the database, was defined as an adverse childhood experience. This variable was represented by a simple yes or no response and was nominal in nature. Stress or parental aggravation, assessed the number of usually or always responses to three forms of stress reported by parents during the past month and children whose parents felt stress from parenting during the past month (Data Resource Center for Child & Adolescent Health, 2022, p. 243). This variable was represented by a nominal level of measurement. A 1 indicated parent usually/always felt aggravation from parenting, 2 indicated parent seldom feels aggravation from parenting, and a 99 indicated missing to all 3 items (Data Resource Center for Child & Adolescent Health, 2022, p. 244). Under the same indicator, I measured the variable that explored that the parent felt the child is much harder to care for than most children during the past month (Data Resource Center for Child & Adolescent Health, 2022, p. 242). This variable was represented by an ordinal level of measurement, as it required a Likert-type scale response from the parent. For this variable, a 1 indicated never, a 2 indicated rarely, a 3 indicated sometimes, a 4 indicated usually or always, and a 99 indicated missing (Data Resource Center for Child & Adolescent Health, 2022, p. 242).

Emotional care, within the database, designated whether the parent has day-to-day emotional support and if that parent had someone they can turn to for emotional support. In general, this variable was nominal in nature. The specific sources of emotional care I was interested in was the spouse or domestic partner and the healthcare provider, both were ordinal in nature and required a Likert-type response from the parent. For emotional care, this was a simple 1 indicating yes, 2 indicating no, and 99 indicating missing. For spouse or domestic partner and healthcare provider, a 1 meant received emotional support, a 2 meant received emotional support, but not from spouse, domestic partner, or healthcare provider, a 3 meant did not receive emotional support in the past 12 months, and 99 meant missing (Data Resource Center for Child & Adolescent Health, 2022, p. 246).

Next, was family health and activities. Within family health and activities, the database explored work and whether a parent had to leave a job, take a leave of absence, or cut back on hours due to their child's health (Data Resource Center for Child & Adolescent Health, 2022, p. 251). This variable was nominal in nature and a 1 meant that the family member left a job or took a leave of absence or both, a 2 meant employment was not affected and a leave of absence was not taken, and a 99 meant that both were missing (Data Resource Center for Child & Adolescent Health, 2022, p. 251). Pertaining to the needs of the healthcare of the child, this variable examined the number of hours spent providing health care at home for a child in an average week. This variable required a Likert-type response from the parent and was ordinal in nature. A 1 indicated less than 1 hour, a 2 indicated 1-4 hours, a 3 indicated 5-10 hours, a 4 indicated 11 or more hours, a 95 indicated the child did not need health care provided on a weekly basis, and a 99 indicated missing (Data Resource Center for Child & Adolescent Health, 2022, p. 253).

While the premise of this study was to investigate the QoL in the primary caregiver, I used the degree of severity of CP (i.e., mild, moderate, and severe) within this dataset to better understand if there was an association between the severity of CP and QoL in the primary caregiver. This variable was ordinal in nature.

Study Sample

To visualize an understanding of the sample for this study, a figure has been provided. Figure 3, depicts how the sample size went from 42,777 participants to 127 participants. Through running a frequency through IBM SPSS, I was able to identify participants that responded that their child had CP. The figure further shows that arriving at 127 meant excluding many other disorders or diseases, for example, Cystic Fibrosis or Autism. The inclusion criteria that encompassed this figure includes children and adolescents with mild, moderate, and severe CP. The exclusion criteria that aided in developing this figure meant excluding any child or adolescent with deafness, blindness, allergies, arthritis, asthma, diabetes, a heart condition, heart born, headaches, Tourette, anxiety, depression, Down Syndrome, blood disorder, sickle cell, Thalassemia, hemophilia, Cystic Fibrosis, a genetic condition, a behavior problem, a speech problem, a learning disability, Autism, or ADD/ADHD. Of the 127 study participants, 49 had mild CP, 27 had moderate CP, 33 had severe CP, 14 were a logical skip, and 4 were a no valid response. Through a further look, the race of the 127 participants with CP resulted in 91 of white alone, 16 of black or African American alone, and 20 of other. In addition, out of the 127 study participants with CP, 28 were 0-5 years old, 43 were 6-11 years old, and 56 were 12-17 years old. The gender of the 127 study participants with CP resulted in most males with 68 and 59 females.

The descriptive statistics of the caregiver and/or parent were discussed here. The surveys first asked for some basic information on the individual who was filling out the survey. Then, further asked some basic information about if there was a second adult or caregiver who lived in the household that provided care to a child or adolescent with CP.

In terms of investigating the caregivers that responded to the surveys of the 127 children or adolescents, the sex of adults was 39 male and 85 female with 3 not having a valid response. In terms of how this adult was related to the child, 116 of the 127 study participants were a biological or adoptive parent, with the next highest of 6 as a grandparent. For the sex of another adult within the household caring for this child or adolescent with CP, there were 60 male and 41 female with 24 as a logical skip and 2 with a not valid response. In terms of how this adult was related to the child, 79 of the 127 study participants were a biological or adoptive parent, with the next highest at 10 as a step-parent.

Data Analysis

To analyze the first research question, a Kruskal-Wallis test was run. The variables in this first research question did not meet normality when running a One-Way ANOVA, therefore the Kruskal-Wallis test was applied. Crosstabulations were also examined to better understand the difference between the mental and physical QoL in the caregiver and the severity of CP. The first sub-question was analyzed through simple linear regression. The rationale for using simple linear regression for the first sub-question was because there was one single independent and dependent variable. First, a total score was created, using the mother’s physical and mental health and the father’s physical and mental health. This total score was created because the variables were ordinal, and this was the reason for non-normality. Ultimately, I used the total score to make them a ratio scale. This total score was created to be used as the outcome. The severity of CP was used as the indicator. In response, we were able to achieve a linear equation so that we can predict the dependent variable on the independent variable (Mertler & Reinhart, 2017).

For the second research question, crosstabulations were examined as well as examining the results of the Chi-Square test. The second research question was examined by investigating the Chi-Square values. The third sub-question and research question, were examined through multiple linear regression. The rationale for using multiple linear regression was so that I could predict the value of the total mental and physical QoL in the primary caregiver on the value of two or more other variables available in the dataset (i.e., employment, divorce or separation, stress, emotional care, family health and activities, and the needs of the healthcare of the child) (Lund Research, 2018). All of the analyses provided answers to how the QoL in the primary caregiver was affected when caring for a child or adolescent with CP. Additionally, I was also able to find out what variables were statistically significant, which can allow us to know what was affecting the caregivers' QoL. To analyze the above research questions, IBM SPSS was used to assist in the analysis. In summary, with the use of the available database, the analysis brought to the forefront more understanding of the QoL in the primary caregiver.

In preparation for a multiple regression analysis examining the relationships between mother/father QoL and indicators of employment, divorce or separation, stress, emotional care, family health and activities, and the needs of the healthcare of the child, a sample size calculation was performed using G*Power. The desired level of statistical power was set at 80% ($1-\beta = 0.80$), and a significance level of 0.05 ($\alpha=0.05$) was chosen. The analysis included nine indicators ($k=9$) based on available indicators in the dataset.

An effect size (f^2) of 0.10 was assumed for the multiple regression analysis, and the calculated sample size required for the multiple regression analysis was N=81. Therefore, the study sample size was adequate for the multiple regression analysis. For reference, Appendix A has a visual of this G*Power assessment.

D. Chapter 4: Results and Discussion

Chapter 4 examined the results of the data analysis of the five research questions, three main and two sub-questions developed to better understand the QoL in the primary caregiver of the child or adolescent with CP.

The first research question: Is there a difference between the primary caregivers' (mother/father) mental and physical health/QoL based on the degree of severity of CP?

This first research question was examined by running a Kruskal-Wallis test in SPSS. Furthermore, the frequencies and the normality of the mother and father's mental and physical health were assessed. The frequencies of the mother's and father's physical and mental health status are presented in Table 1-4 below to illustrate where many of the responses aligned with the CP severity description. The mother's physical and mental health along with the father's physical and mental health did not meet normality, Kolmogorov-Smirnov test (significance, <.001) which is why a Kruskal-Wallis test was run instead of the originally anticipated one-way ANOVA.

There was a statistically non-significant difference between the mother's physical health and the CP severity description, (H(2) = 2.28, p = .321), with a mean rank of 53 for mild CP, 48 for moderate CP, and 44 for severe CP. There was a statistically non-significant difference between the father's physical health and the CP severity description, (H(2) = 3.22, p = .200), with a mean rank of 42 for mild CP, 38 for moderate CP, and 33 for severe CP. There was a statistically non-significant difference between the mother's mental health and the CP severity description, (H(2) = 4.16, p = .125), with a mean rank of 54 for mild CP, 46 for moderate CP, and 43 for severe CP. There was a statistically non-significant difference between the father's mental health and the CP severity description, (H(2) = 5.99, p = .050), with a mean rank of 43 for mild CP, 31 for moderate CP, and 38 for severe CP. Although, the relationship between the father's mental health and the CP severity description was non-significant, there was a close association between these two variables.

What stands out for the mother's physical health, is that regardless of the CP severity description, the mother reported that their physical health was fair or poor. This is similar to the crosstabulation of the father's physical health, which demonstrated that regardless of the CP severity description, the father reported that their physical health was fair or poor. As with all four variables, the crosstabulations show the same result and that is that both the mother and father report a fair or poor mental health. This aligns with the frequencies found earlier of each of the mother's and father's physical and mental health compared to the CP severity description.

What is most important in the analysis of this research question was to run and analyze the crosstabulations between the CP severity description and each of the four (mother's physical and mental health and father's physical and mental health). Table 1-4 will show the crosstabulations for the mother's physical health, the father's physical health, the mother's mental health, and the father's mental health. For reference, each of the crosstabulations will be for viewing under this paragraph with Table 1, Table 2, Table 3, and Table 4.

Table 1

Crosstabulation(s)

		CP Severity Description				
	Mild	Moderate	Severe	Logical Skip	No Valid Response	Total
Mother's Physical QoL						
Excellent/Very Good	32	13	18	8	2	73
Good	12	7	8	4	1	32
Fair/Poor	1	1	5	1	0	8
Total	45	21	31	13	3	113

Table 2

Crosstabulation(s)

		CP Severity Description				
	Mild	Moderate	Severe	Logical Skip	No Valid Response	Total
Father's Physical QoL						
Excellent/Very Good	29	13	10	6	2	60
Good	8	6	8	3	0	25
Fair/Poor	1	1	1	0	1	4
Total	38	20	19	9	3	89

Table 3

Crosstabulation(s)

		CP Severity Description				
	Mild	Moderate	Severe	Logical Skip	No Valid Response	Total
Mother's Mental QoL						
Excellent/Very Good	31	11	16	8	3	69
Good	13	8	9	5	0	35
Fair/Poor	1	2	6	0	0	9
Total	45	21	31	13	3	113

Table 4

Crosstabulation(s)

		CP Severity Description				
	Mild	Moderate	Severe	Logical Skip	No Valid Response	Total
Father's Mental QoL						
Excellent/Very Good	30	10	13	6	3	62
Good	6	8	5	3	0	22
Fair/Poor	1	2	1	0	0	4
Total	37	20	19	9	3	88

The next research question that was examined was the sub-question for research question #1: Can I predict the primary caregivers' (mother/father) mental and physical QoL from the severity of CP?

This research question was analyzed using simple linear regression. Standard simple linear regression was conducted to determine the accuracy of the independent variable(s) (mild, moderate, and severe CP) predicting the mother's and father's QoL. Regression results indicated that the overall model does not significantly predict the mother's and father's QoL [$R^2 = .000$, $R^2_{adj} = -.012$, $F(1,80) = .003$, $p = .957$]. This model accounts for 0% of variance in the mother's and father's QoL. A summary of regression coefficients is presented in Appendix B and indicates that the CP severity description non-significantly contributed to the model.

In addition, simple linear regression was run with the CP severity level and the total score of the mother. Regression results indicated that the overall model did not significantly predict the mother's mental and physical QoL [$R^2 = .002$, $R^2_{adj} = -.007$, $F(1,111) = .268$, $p = .606$].

Furthermore, simple linear regression was run with CP severity level and the total score of the father. Regression results indicated that the overall model did not significantly predict the father's mental and physical QoL [$R^2 = .000$, $R^2_{adj} = -.011$, $F(1,86) = .024$, $p = .877$]. Further visualization of these two simple linear regression results can be seen as a continuation in Appendix B. Considering these results, CP severity does not have a significant effect on the caregivers' QoL by itself. There must be other factors to affect the caregivers' QoL along with CP severity level.

The second research question: Is there an association between the CP severity level and the nine indicators (e.g., employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child) that represented the QoL of the primary caregiver?

To represent each of the nine indicators the Chi-Square test results are discussed below.

The first indicator variable that was examined was the number of hours that a primary caregiver spent providing health care to their child at home. In this case, when addressing the crosstabulation, it is evident that as the CP severity increased, so did the number of hours that the primary caregiver provided care. This is the same case for the mother's and father's physical and mental health in relation to the amount of hours spent providing care to their son or daughter. In fact, the mother's and father's physical and mental health were reported fair or poor almost tripled compared to excellent or even good. There was an association between the number of hours spent providing health care and the CP severity description, χ (16) = 77.79, p <.001. There was not an association between the number of hours spent providing health care and the mother's physical health, χ (8) = 5.76, p=.674. There was not an association between the number of hours spent providing health care and the father's physical health, χ (8) = 4.78, p=.783. There was not an association between the number of hours spent providing health care and the mother's mental health care, χ (8) = 12.58, p=.127. There was not an association between the numbers of hours spent providing health care and the father's mental health, χ (8) = 5.27, p=.728.

The second indicator variable that was examined was the employment status of the caregiver(s) in the child's household. When addressing the crosstabulations, regardless of the severity of CP, most caregiver(s) reported that at least one caregiver was employed full-time. This is also shown in the crosstabulations of the employment status and the mother’s and father’s physical and mental health status. There was not association between the employment status and the CP severity description, χ (8) = 10.08, p=.259. There was not association between the employment status and the mother’s physical health status, χ (4) = 8.59, p=.072. There was an association between the employment status and the mother’s mental health status, χ (4) = 16.35, p=.003. There was an association between the employment status and the father’s physical health status χ (4) = 10.15, p=.038. There was not an association between the employment status and the father’s mental health status χ (4) = 6.90, p=.141.

The third indicator variable that was examined was whether the primary caregivers were divorced or separated. When addressing the crosstabulations, severity of the CP, the majority of caregivers were not divorced or separated. This also holds true for the mother’s and father’s physical and mental health in relation to separation or divorce. There was not an association between whether the caregivers were separated or divorced and the CP severity description, χ (4) = 7.07, p=.132. There was not an association between whether the caregivers were separated or divorced and the mother’s physical health, χ (2) = 5.29, p=.071. There was not an association between whether the caregivers were separated or divorced and the father’s physical health, χ (2) = 0.36, p=.834. There was not an association between whether the caregivers were separated or divorced and the mother’s mental health, χ (2) = 5.20, p=.074. There was not an association between whether the caregivers were separated or divorced and the father’s mental health, χ (2) = 2.21, p=.330.

The fourth indicator variable that was examined was that the parent felt that the child is much harder to care for than most children during the past month. When examining this variable through the crosstabulations in relation to the CP severity description, most caregivers reported that they usually or always feel that their child is much harder to care for. When investigating the mother's physical health, the majority responded their physical health was fair or poor (73 out of 113 total responses, which equivalents to 65%) in relation to "being harder to care for". This was similar to the results for the father's physical health, mother's mental health, and the father's mental health. There was an association between harder to care for and the CP severity description, χ (12) = 39.49, p<.001. There was not an association between harder to care for and the mother's physical health, χ (6) = 6.93, p=.327. There was not an association between harder to care for and the father's physical health, χ (6) = 6.78, p=.341. There was not an association between harder to care for and the mother's mental health, χ (6) = 9.80, p=.133. There was not an association between harder to care for and the father's mental health, χ (6) = 3.44, p=.751.

The fifth indicator variable that was examined was the children whose parents who felt stress from parenting during the past month. When examining this variable through the crosstabulations in relation to the CP severity description, the caregivers reported equally on that they usually/always feel aggravation or seldom feels aggravation from parenting. In regard to the mother's and father's physical and mental health, the majority of the reported responses were fair or poor health status. There was an association between stress and the CP severity description, χ (4) = 25.20, p<.001. There was not an association between stress and the mother's physical health, χ (2) = 1.85, p=.395. There was not an association between stress and the father's physical health, χ (2) = 2.13, p=.343. There was an association between stress and the mother's mental health, χ (2) = 7.27, p=.026. There was not an association between stress and the father's mental health, χ (2) = 1.07, p=.584.

The sixth indicator variable that was examined regarded if the primary caregiver(s) have day-to-day emotional support. When examining this variable through crosstabulations in relation to the CP severity description, the majority reported that they did have emotional support. This is the same result for the physical health of the mother and the father and the mental health of the mother and father. There was not an association between day-to-day emotional support and the CP severity description, χ (4) = 5.23, p=.264. There was not an association between day-to-day emotional support and the mother's physical health, χ (2) = .041, p=.980. There was not an association between day-to-day emotional support and the father's physical health, χ (2) = 2.36, p=.306. There was not an association between day-to-day emotional support and the mother's mental health, χ (2) = 3.11, p=.211. There was not an association between day-to-day emotional support and the father's mental health, χ (2) = 1.43, p=.488.

The seventh indicator variable that was examined was whether the primary caregiver received day-to-day emotional support from their spouse or domestic partner. Most of the responses from the primary caregiver stated that they did receive emotional support and it was from their spouse or domestic partner. For receiving emotional day-to-day support from a spouse or domestic partner and the mother's physical health, results showed that the majority reported their physical health to be fair or poor in relation to receiving emotional support from their spouse or domestic partner. This is the same for the father's physical health, the mother's mental health, and the father's mental health. There was not an association between the emotional support from spouse/domestic partner and the CP severity description, χ (8) = 7.85, p=.448. There was not an association between emotional support from the spouse/domestic partner and the mother's physical health, χ (4) = 6.87, p=.143. There was not an association between emotional support from the spouse/domestic partner and the father's physical health, χ (4) = 2.66, p=.616. There was not an association between emotional support from the spouse/domestic partner and the mother's mental health, χ (4) = 5.34, p=.254. There was not an association between emotional support from the spouse/domestic partner and the father's mental health, χ (4) = 6.21, p=.183.

The eighth indicator variable that was examined was whether the primary caregiver received day-to-day emotional support from their health care provider. The majority of responses in relation to the CP severity description stated that they did receive emotional support from the healthcare provider or they did receive emotional support but, it was not from their health care provider. Results were similar for the mother's physical health, and most mothers reported that their physical health was fair or poor even with receiving this emotional support. This was the same for the father's physical health, the mother's mental health, and the father's mental health. There was not an association between the emotional support from the health care provider and the CP severity description, χ (8) = 15.43, p=.051. There was not an association between the emotional support from the health care provider and the mother's physical health, χ (4) = .674, p=.954. There was not an association between the emotional support from the health care provider and the father's physical health, χ (4) = .110, p=.110. There was not an association between the emotional support from the health care provider and the mother's physical health, χ (4) = 5.16, p=.271. There was not an association between the emotional support from the health care provider and the father's mental health, χ (4) = 1.79, p=.773.

The ninth and last indicator variable that was examined was children whose family members left a job, took a leave of absence, or cut back hours due to their child's health. For the CP severity description, the majority of responses were from parents caring for a child with severe CP and the majority responded that their job was not affected. This is similar for the mother's physical health, father's physical health, mother's mental health, and the father's mental health. There was an association between the job or work status and the CP severity description, χ (4) = 11.08, p=.026. There was not an association between the job or work status and the mother's physical health, χ (2) = .289, p=.865. There was not an association between the job or work status and the father's physical health, χ (2) = 2.32, p=.312. There was an association between the job or work status and the mother's mental health, χ (2) = 6.54, p=.038. Lastly, there was not an association between the job or work status and the father's mental health, χ (2) = 1.07, p=.585.

Enter multiple regression was conducted to determine which independent variables (caregiver(s) employment status, divorce or separation, harder to care for, stress, day-to-day emotional care, emotional care from spouse/domestic partner, emotional care from health care provider, cutting hours or stopping work, and number of hours spent providing health care) were indicators of the total score of the mother (mother's physical and mental health). Regression results indicated an overall model of two indicators (day-to-day emotional care and day-to-day emotional care from the health care provider) that significantly predicted the total score of the mother [$R^2 = .163$, $R^2_{adj} = .085$, $F(1, 9) = 2.081$, .039]. Table 5 below, represented significant indicator slope values and p values. This model accounted for 16.3% of variance in the total score of the mother. A summary of the regression model and the coefficients are presented in Appendix C.

Table 5

Regression Results: Total Score of the Mother

Variable	Standardized Coefficients Beta	*p*
Day-to-day emotional care*	.613	.029
Day-to-day emotional care HCP*	-.367	.046
Caregiver(s) employment status	-.156	.118
Divorce/ separation	.143	.158
Harder to care for	-.010	.954
Stress	.120	.487
Day-to-day emotional care spouse/ domestic partner	-.375	.122
Left a job, took leave of absence, cut back on hours	.052	.615
Time spent providing care	-.105	.402

*Note. Day-to-day emotional care and day-to-day emotional care HCP was significant**

Enter multiple regression was conducted to determine which independent variables (caregiver(s) employment status, divorce or separation, harder to care for, stress, day-to-day emotional care, emotional care from spouse/domestic partner, emotional care from health care provider, cutting hours or stopping work, and number of hours spent providing health care) were indicators of the total score of the father (father's physical and mental health). Regression results indicated an overall model of one indicator (caregiver(s) employment status) that significantly predicted the total score of the father [$R^2 = .145$, $R^2_{adj} = .042$, $F(1, 9) = 1.411$, .199]. Table 6 below, represented significant indicator slope values and p values. This model accounted for 14.5% of variance in the total score of the father. A summary of the regression model and the coefficients are presented in Appendix D.

Table 6

Regression Results: Total Score of Father

Variable	Standardized Coefficients Beta	*p*
Caregiver(s) employment status*	-.265	.022
Divorce/ separation	.105	.352
Harder to care for	-.299	.113
Stress	-.141	.437
Day-to-day emotional care	.563	.168
Day-to-day emotional care spouse/domestic partner	-.645	.111
Day-to-day emotional care HCP	.031	.883
Left a job, took a leave of absence, cut back on hours	-.012	.921
Time spent providing care	.012	.931

*Note. Caregiver(s) employment status was significant**

The third research question was: What variables can be a possible indicator to the primary caregivers' mental and physical QoL? The sub-question for research question 3 was: How well does the combination of employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child, predict the overall mental and physical QoL of the primary caregiver (mother/father)?

In order to monitor potential indicators to answer the research question, first the relationship of each variable with the child's CP severity level was examined by using the crosstabulations and through examining the Chi-Square test. This analysis helped to monitor how each indicator affected CP severity level. Additionally, for the sub-question for the research question 3, multiple regression was run to monitor the prediction of employment, divorce or separation, stress, emotional care, family health and activities, and needs of the healthcare of the child on the overall QoL of the primary caregiver (mother/father). This gave us a better understanding of the caregivers QoL. The results from SPSS were presented in Appendix E.

To answer the third research question, the number of hours spent providing health care at home for a child in an average week, parents felt the child is much harder to care for than most children during the past month, children whose parents who felt stress from parenting during the past month, and children whose family members left a job, took a leave of absence, or cut back hours due to child's health all predicted the CP severity level. In addition, children whose parents who felt stress from parenting during the past month and children whose family members left a job, took a leave of absence, or cut back hours due to child's health, and the caregiver(s) employment status all predicted the mother's mental health. The caregiver(s) employment status also predicted the father's physical health.

Discussion and Summary

To examine the first research question, it is evident that regardless of how severe the child's or adolescent's CP, the mother and father both report that both their physical and mental health status are fair/poor. This supports the literature review that was done in Chapter 2. When assessing the sub-question for research question number 1, the results show that the QoL cannot solely be predicted by the child's or adolescent's severity of CP.

What might provide a more detailed examination into the QoL of the primary caregiver is to better understand the results of research question 2 and 3 and the sub-question for research question 3. These three questions dive deeper into what could have more of an effect on the day-to-day aspect of the caregivers overall QoL. It is evident when measuring the number of hours spent providing care, as the CP severity is increasing so are the hours spent providing care. In addition, as the number of hours spent providing care increased, the overall QoL decreased.

When examining the second indicator variable, the primary caregiver's employment status, the only aspect that was prominent was the association between the employment status and the mother's mental health and the employment status and the father's physical health. The third indicator variable, whether the primary caregivers were divorced or separated showed no association. This is a little different from what the literature shows but, this is a promising finding. For the fourth indicator variable, "harder to care for", the results did show that primary caregivers reported that as their child's CP severity increased, the primary caregiver reported that their child was harder to care for. For the fifth indicator variable, “parents felt stress”, caregivers did report that as their child’s CP severity increased, so did the stress level of the caregiver.

The sixth indicator variable, “parents receiving day-to-day emotional support”, nothing specifically stood out and the caregivers that responded stated that they did have day-to-day emotional support. When examining the seventh and eighth indicator variable, “receiving emotional care from spouse/domestic partner or health care provider”, the results showed similar responses as with the sixth indicator variable. Overall, primary caregivers did receive the emotional support they needed. The ninth and last indicator variable, showed the same results as indicator variable number 2, and that is that the primary caregivers’ job was not affected due to their child’s health. Overall, all five research questions provided a better insight into the primary caregivers QoL and their child’s CP severity. Lastly, the ninth indicator variable also supported the literature that was examined in Chapter 2 and can perhaps give us a look as this child or adolescent with CP and the primary caregiver ages.

E: Chapter 5: Summary and Conclusions

This study was a nonexperimental or observational design and was correlational because, I examined the relationships or associations among the variables identified in this study. The purpose of this study was to better understand the overall QoL in the primary caregiver that provides care to the child or adolescent, aged 0-17 with mild, moderate, or severe CP. This study aligned with using the provided database: the *2020 National Survey of Children's Health*. Furthermore, this study used the theory framework from the *Conceptual Model of Caregiving Process and Caregiver Burden Among the Pediatric Population*. This theory guided the variables that were investigated such as: having to leave a job, take a leave of absence, cutting back on hours at work, the caregiver(s) employment status, whether the caregiver(s) are separated or divorced, time spent caring for the child/adolescent with health care needs, "feeling their child is much harder to care for", caregiver(s) who feel stress, and day-to-day emotional support. All of these indicator variables that align with the theory can and did highly impact the outcomes, that being the mother's and father's physical and mental health.

When examining the results of this study, the severity of CP did impact the mother's and father's physical and mental health. Among all the variables investigated in all five research questions, it is also evident that the primary caregiver reported their physical and mental health to be fair/poor in many instances. What ultimately stood out was, when examining the number of hours spent providing care, as the CP severity increased so did the hours spent providing care. Additionally, as the number of hours spent providing care increased, the overall QoL decreased. Furthermore, caregivers reported that as their child's CP severity increased, the primary caregiver reported that their child was harder to care for and the caregivers stress level was higher.

Pertaining to the first research question, there was a statistically non-significant difference between the mother's physical health and the CP severity description, (H(2) = 2.28, p = .321), with a mean rank of 53 for mild CP, 48 for moderate CP, and 44 for severe CP. There was a statistically non-significant difference between the father's physical health and the CP severity description, (H(2) = 3.22, p = .200), with a mean rank of 42 for mild CP, 38 for moderate CP, and 33 for severe CP. There was a statistically non-significant difference between the mother's mental health and the CP severity description, (H(2) = 4.16, p = .125), with a mean rank of 54 for mild CP, 46 for moderate CP, and 43 for severe CP. There was a statistically non-significant difference between the father's mental health and the CP severity description, (H(2) = 5.99, p = .050), with a mean rank of 43 for mild CP, 31 for moderate CP, and 38 for severe CP. Although, the relationship between the father's mental health and the CP severity description was non-significant, there was a close association between these two variables.

Furthermore, results indicated for the mother's physical health, showed that regardless of the CP severity description, the mother reported that their physical health was fair or poor. This is similar to the crosstabulation of the father's physical health, which demonstrated that regardless of the CP severity description, the father reported that their physical health was fair or poor. As with all four variables, the crosstabulations show the same result and that is that both the mother and father report a fair or poor mental health. This aligns with the frequencies found earlier of each of the mother's and father's physical and mental health compared to the CP severity description.

For the first sub-question, the regression results indicated that the overall model does not significantly predict the mother's and father's QoL [$R^2 = .000$, $R^2_{adj} = -.012$, $F(1,80) = .003$, $p = .957$]. In addition, simple linear regression was run with the CP severity level and the total score of the mother. Regression results indicated that the overall model did not significantly predict the mother's mental and physical QoL [$R^2 = .002$, $R^2_{adj} = -.007$, $F(1,111) = .268$, $p = .606$]. Furthermore, simple linear regression was run with CP severity level and the total score of the father. Regression results indicated that the overall model did not significantly predict the father's mental and physical QoL [$R^2 = .000$, $R^2_{adj} = -.011$, $F(1,86) = .024$, $p = .877$]. Considering these results, it is safe to say that the CP severity does not have a significant effect on the caregivers' QoL by itself. There must be other factors to affect the caregivers' QoL along with the CP severity level. Ultimately, there could many other factors or variables that were not examined specifically in this study that can affect the mother and the father's overall QoL. Future studies could expand on this knowledge to better understand how the primary caregiver is impacted on an everyday basis, since these specific results were found to have no impact on the overall QoL in the primary caregiver.

To answer the third research question, the number of hours spent providing health care at home for a child in an average week, parents felt the child is much harder to care for than most children during the past month, children whose parents who felt stress from parenting during the past month, and children whose family members left a job, took a leave of absence, or cut back hours due to their child's health all predicted the CP severity level. In addition, children whose parents who felt stress from parenting during the past month and children whose family members left a job, took a leave of absence, or cut back hours due to child’s health, and the caregiver(s) employment status all predicted the mother’s mental health. The caregiver(s) employment status also predicted the father’s physical health.

Furthermore, regression results indicated an overall model of two indicators (day-to-day emotional care and day-to-day emotional care from the health care provider) that significantly predicted the total score of the mother [$R^2 = .163$, $R^2_{adj} = .085$, $F(1, 9) = 2.081$, .039]. Regression results also indicated an overall model of one indicator (caregiver(s) employment status) that significantly predicted the total score of the father [$R^2 = .145$, $R^2_{adj} = .042$, $F(1, 9) = 1.411$, .199]. Overall, it is evident when examining the number of hours spent providing care, as the CP severity is increasing so are the hours spent providing care. In addition, as the number of hours spent providing care increased, the overall QoL decreased.

When examining the second indicator variable, the primary caregiver’s employment status, the only thing that stuck out was the association between the employment status and the mother’s mental health and the employment status and the father’s physical health. The third indicator variable, discussed whether the primary caregivers were divorced or separated showed no association. This is a little different from what the literature showed but, this is a promising finding. For the fourth indicator variable, “harder to care for”, the results did show that primary caregivers reported that as their child’s CP severity increased, the primary caregiver reported that their child was harder to care for. For the fifth indicator variable, “parents felt stress”, caregivers did report that as their child’s CP severity increased, so did the stress level of the caregiver.

The sixth indicator variable, “parents receiving day-to-day emotional support”, nothing specifically was significant and the caregivers that responded stated that they did have day-to-day emotional support. When examining the seventh and eighth indicator variable, “receiving emotional care from spouse/domestic partner or health care provider”, the results showed similar responses as with the sixth indicator variable. Overall, primary caregivers did receive the emotional support they needed. The ninth and last indicator variable, showed the same results as the indicator variable number 2, and that is that the primary caregivers’ job was not affected due to their child’s health. Overall, all five research questions provided a better insight into the primary caregivers QoL and their child’s CP severity. Lastly, the ninth indicator variable also supported the literature that was examined in Chapter 2 and can perhaps give us a look as this child or adolescent with CP and the primary caregiver ages.

This study has shown that both mothers and fathers report their mental and their physical health status to be either fair or poor in relation to their child or adolescent having CP. This is significant especially for future studies that examine the mother and father's overall QoL. This is also significant because it tells us that mothers and fathers of children or adolescents with CP are struggling. Unfortunately, this study was not able to exactly pinpoint what the reasons are that the parent or primary caregiver reports their physical and mental health status to be fair or poor. This effects the results of this study because we do not exactly know what is affecting the mother or father's overall QoL which then impacts the results of this study. Although this can benefit how future research in this topic is studied. We as researchers understand that something is impacting the QoL in the primary caregiver unfortunately, we do not know exactly what.

This can aid us to study this topic in perhaps terms of a qualitative study, in which primary caregivers are interviewed to better pinpoint what is significantly impacting their QoL.

This study has laid the groundwork for future research in this topic especially as the child or adolescent with CP is aging as well as the primary caregiver. Although this study did not allow for groundbreaking results, we as researchers and healthcare providers can understand that primary caregivers ultimately deal with many emotional, physical, spiritual, and psychological issues that go unnoticed. With the results that were found in this study I can have a better idea of how to focus on the needs of the primary caregiver. Ultimately, what may further benefit primary caregivers is to better understand what resources and tools they need to survive every day and then make those supports more tailored and easier to access. On the flip side, healthcare providers can be better prepared and equipped to aid the primary caregiver by giving them the resources and tools they need.

Implications

The implications of this study explain that the severity of CP can drastically affect how the primary caregiver carries out his or her everyday life. For researchers, the implications about this population can continue to develop better ways of connecting primary caregivers with resources so that caregivers can provide better care for their child as well as their other children. The implications of this study also provided a basis that this issue is a problem in our society and that often the primary caregiver is forgotten about. What also is vital to understand about this study is that there is a great amount of research on the child with CP but, as this child ages the caregiver is also aging. A huge aspect that is missing in research is understanding the severity of CP in the adolescent, young adult, and adult and then how this affects the primary caregiver as they are also aging. While not every variable that was examined showed an association with the primary caregivers physical or mental health, it is vital to know that the variables that did stand out were aspects that can not easily be addressed.

Ultimately, results indicated from what was found in this study was fairly similar to what was covered in Chapter 2. What does align is that the degree of severity of CP really does in fact affect the QoL in the primary caregiver. One aspect that was not identified or studied was the financial impact that CP brings. This is widely identified in the literature, unfortunately there were no specific variables that were identified in the survey that could take a better look into the financial burden of caring for a child with CP. Further literature on this could add to the physical and mental strain of the caregiver in the future. Another aspect that was different is that in the literature, it seems that primary caregivers felt that they potentially do not have the emotional support that they need, although this study found that the primary caregiver does feel that they have the appropriate amount of emotional support day-to-day. Additionally, in previous literature it seems that caregivers felt that it might be hard to hold on to a full-time job, this was not the case in this study. Although, previous literature that was measured examined a single mother or a single father dealing with their child or adolescent with CP. One aspect that was touched on a little bit in Chapter 2 was the siblings and how the siblings deal with having a brother or sister with CP. While this study did not examine that, this is another aspect that impacts the whole family and, in the future, could be further examined.

Recommendations for Future Research

Recommendations for future research on this topic are vital to understand how the QoL will change in the primary caregiver that is caring for their child or adolescent with CP. Further research can also examine other variables that could strongly affect or impact the QoL in the primary caregiver aside from the nine indicator variables that were examined in this study. Through measuring other variables, we as researchers can gain a better understanding of how to support and prepare caregivers for caring for their child or adolescent with CP.

One aspect that is huge that has been briefly talked about in this study is the fact that research does not focus on how the child or adolescent with CP ages and how that impacts the primary caregiver. For instance, an individual with CP can no longer stay in a public school district after they have turned 21 and depending on the severity of CP a primary caregiver must make a decision on where their child or adolescent will go as they will not be able to stay in a school district daily setting. This can be a stressful transition for the primary caregiver as they must weigh their options. This can then impact the primary caregiver's QoL. In addition, as the individual with CP is aging, most likely their physical health will decline. Through examining further research in this transition, researchers and healthcare providers can be better equipped to provide the needed resources to the caregiver.

In conclusion, this study provided a basis for understanding the severity of CP in a child or adolescent and how that impacts the caregiver's life. What is most important to take away from this study is that the caregiver is often forgotten about because their child with CP is probably dealing with multiple health issues themselves. Without the caregiver having the proper resources and support, their issues will continue to go unnoticed in the healthcare field. Ultimately, this study allowed to better understand the primary caregivers QoL in relation to the severity of CP. The major takeaway is that this study did accomplish that and through future research, I can investigate other variables that can impact the QoL in the primary caregiver and perhaps increase the QoL in the individual with CP and their caregiver.

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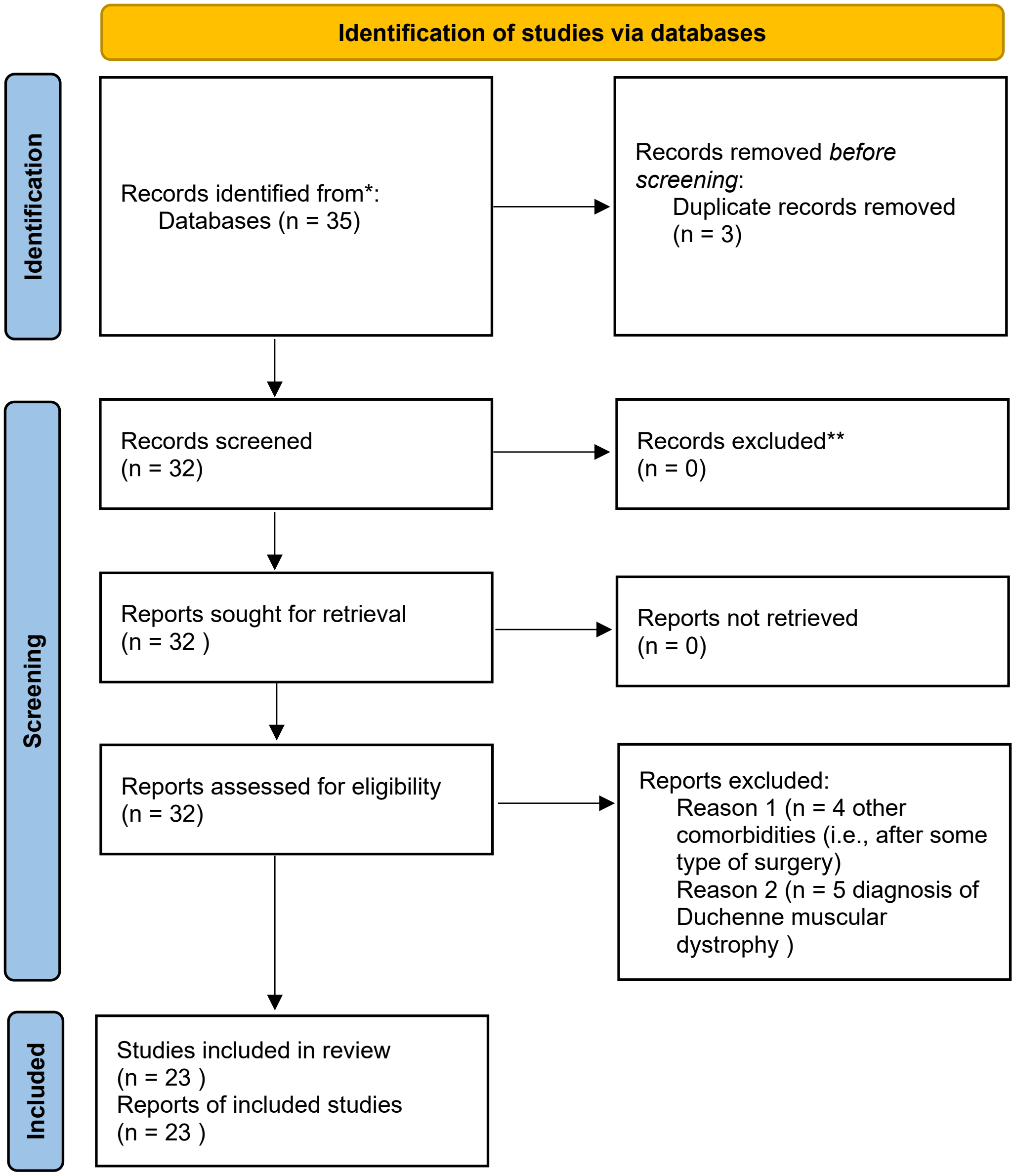
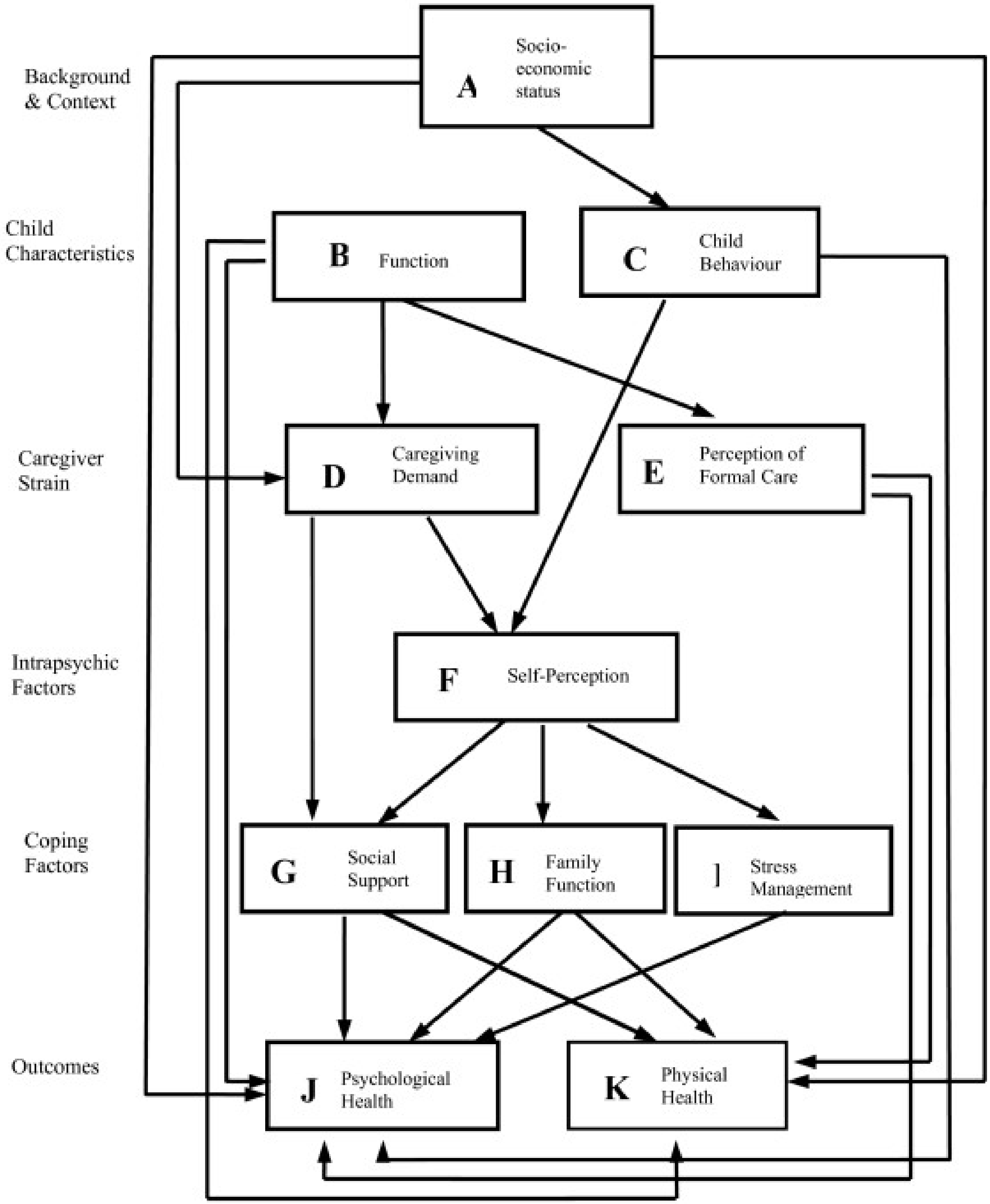


Figure 1

PRISMA Flow Diagram

Figure 2

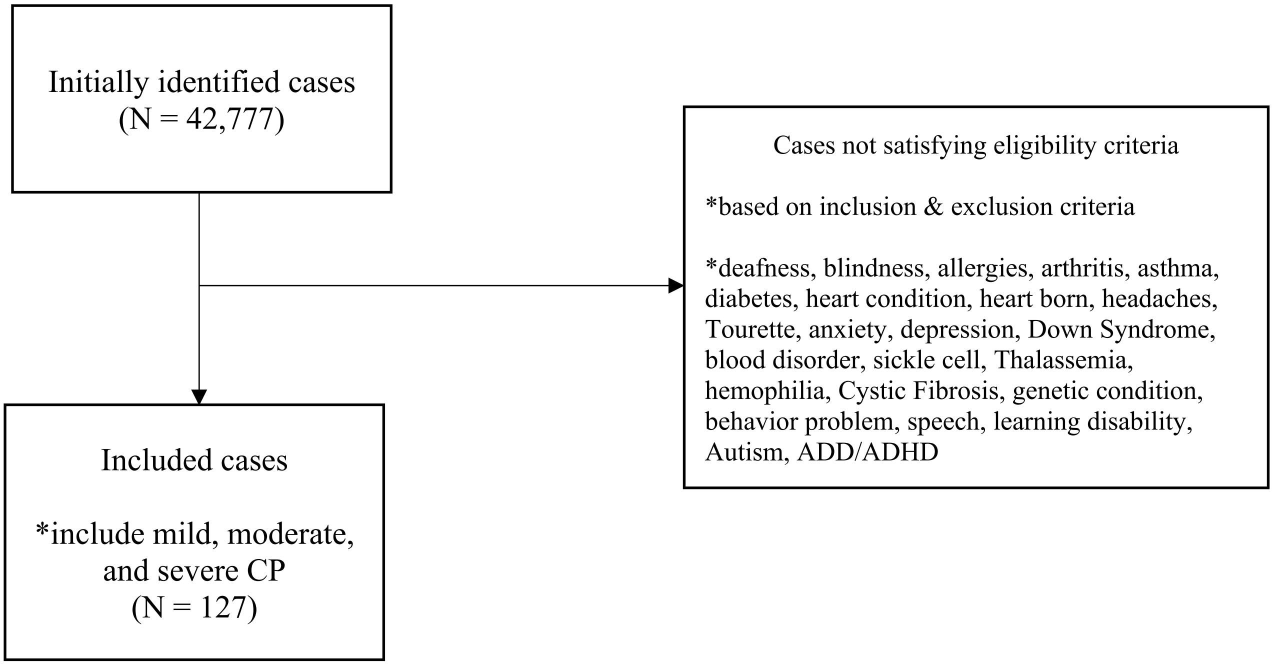
Conceptual Model of Caregiving and Caregiver Burden Among Pediatric Population



Note. From Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., &Wood, E. (2004). Caregiving Process and Caregiver Burden: Conceptual Models to Guide Research and Practice. https://doi.org/10.1186/1471-2431-4-1

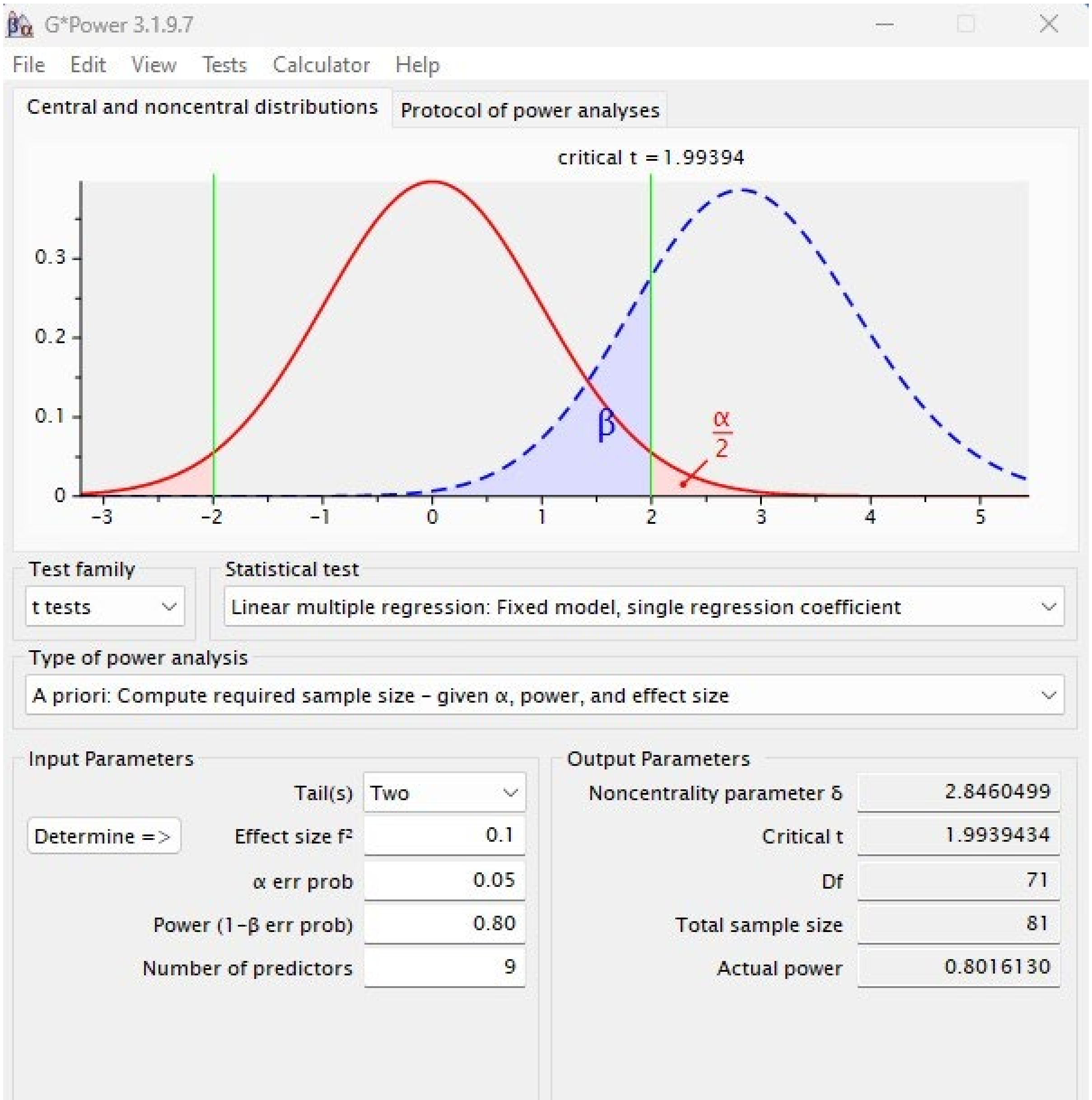
Figure 3

Flowchart: Mild, Moderate, & Severe CP Sample



Appendix A

*G*Power*



Test family: t tests

Statistical test: Linear multiple regression: Fixed model, single regression coefficient

Type of power analysis: A priori: Compute required sample size – given α, power, and effect size

Input Parameters

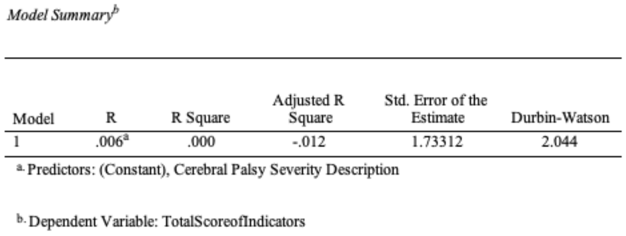
Tail(s)	Two
Effect size f²	0.1
α err prob	0.05
Power (1−β err prob)	0.80
Number of predictors	9

Output Parameters

Noncentrality parameter δ	2.8460499
Critical t	1.9939434
Df	71
Total sample size	81
Actual power	0.8016130

Appendix B

Results from Sub-Question #1

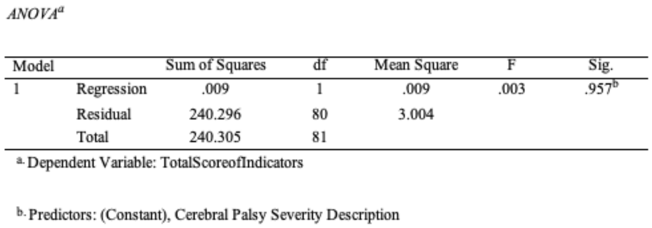


Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.006[a]	.000	-.012	1.73312	2.044

[a] Predictors: (Constant), Cerebral Palsy Severity Description

[b] Dependent Variable: TotalScoreofIndicators

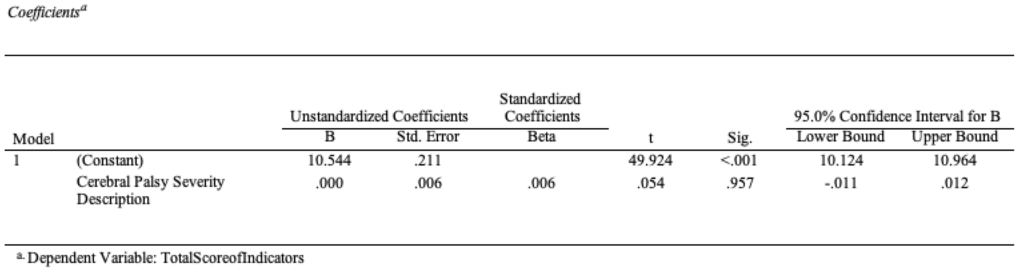


ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.009	1	.009	.003	.957[b]
	Residual	240.296	80	3.004		
	Total	240.305	81			

[a] Dependent Variable: TotalScoreofIndicators

[b] Predictors: (Constant), Cerebral Palsy Severity Description



Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B	
Model		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound
1	(Constant)	10.544	.211		49.924	<.001	10.124	10.964
	Cerebral Palsy Severity Description	.000	.006	.006	.054	.957	-.011	.012

[a] Dependent Variable: TotalScoreofIndicators

Appendix B

Simple Linear Regression Results- Mother

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.049[a]	.002	-.007	1.10037

[a] Predictors: (Constant), Cerebral Palsy Severity Description

[b] Dependent Variable: TotalScoreMother

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.324	1	.324	.268	.606[b]
	Residual	134.402	111	1.211		
	Total	134.726	112			

[a] Dependent Variable: TotalScoreMother

[b] Predictors: (Constant), Cerebral Palsy Severity Description

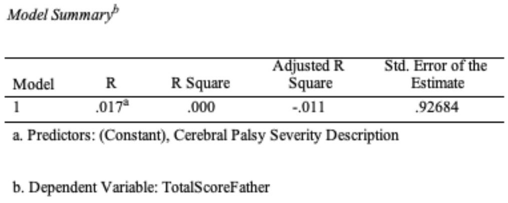
Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	5.081	.114		44.553	<.001
	Cerebral Palsy Severity Description	.002	.003	.049	.517	.606

[a] Dependent Variable: TotalScoreMother

Appendix B

Simple Linear Regression Results- Father

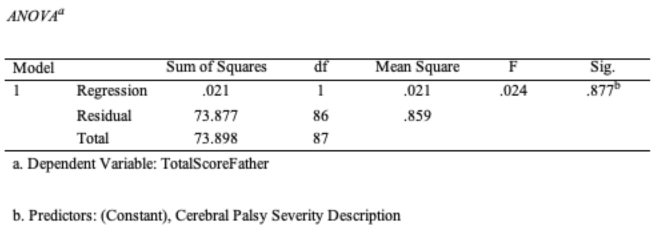


Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.017^a	.000	-.011	.92684

a. Predictors: (Constant), Cerebral Palsy Severity Description

b. Dependent Variable: TotalScoreFather

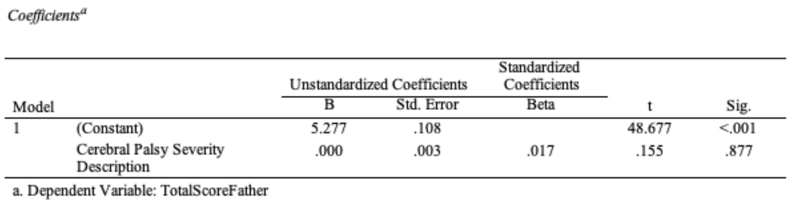


ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.021	1	.021	.024	.877^b
	Residual	73.877	86	.859		
	Total	73.898	87			

a. Dependent Variable: TotalScoreFather

b. Predictors: (Constant), Cerebral Palsy Severity Description



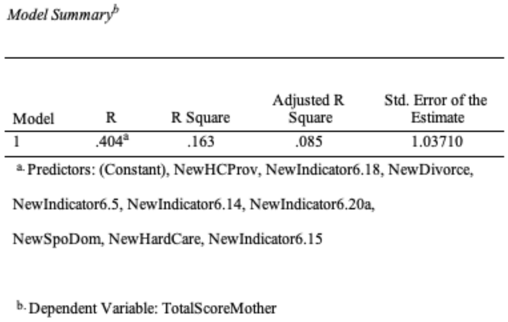
Coefficients^a

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	5.277	.108		48.677	<.001
	Cerebral Palsy Severity Description	.000	.003	.017	.155	.877

a. Dependent Variable: TotalScoreFather

Appendix C

Regression Results for Mother

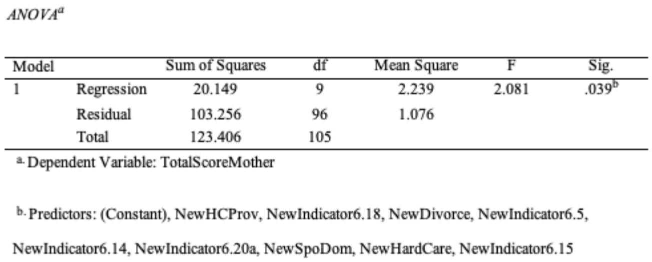


Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.404[a]	.163	.085	1.03710

[a] Predictors: (Constant), NewHCProv, NewIndicator6.18, NewDivorce, NewIndicator6.5, NewIndicator6.14, NewIndicator6.20a, NewSpoDom, NewHardCare, NewIndicator6.15

[b] Dependent Variable: TotalScoreMother

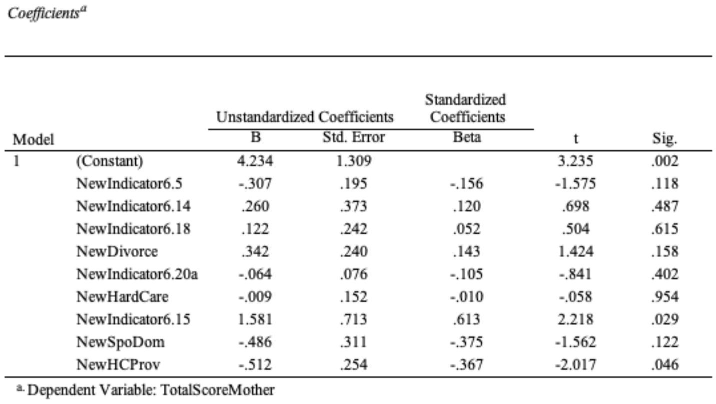


ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	20.149	9	2.239	2.081	.039[b]
	Residual	103.256	96	1.076		
	Total	123.406	105			

[a] Dependent Variable: TotalScoreMother

[b] Predictors: (Constant), NewHCProv, NewIndicator6.18, NewDivorce, NewIndicator6.5, NewIndicator6.14, NewIndicator6.20a, NewSpoDom, NewHardCare, NewIndicator6.15



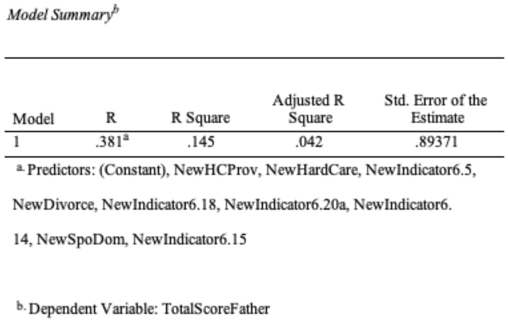
Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	4.234	1.309		3.235	.002
	NewIndicator6.5	-.307	.195	-.156	-1.575	.118
	NewIndicator6.14	.260	.373	.120	.698	.487
	NewIndicator6.18	.122	.242	.052	.504	.615
	NewDivorce	.342	.240	.143	1.424	.158
	NewIndicator6.20a	-.064	.076	-.105	-.841	.402
	NewHardCare	-.009	.152	-.010	-.058	.954
	NewIndicator6.15	1.581	.713	.613	2.218	.029
	NewSpoDom	-.486	.311	-.375	-1.562	.122
	NewHCProv	-.512	.254	-.367	-2.017	.046

[a] Dependent Variable: TotalScoreMother

Appendix D

Regression Results for Father

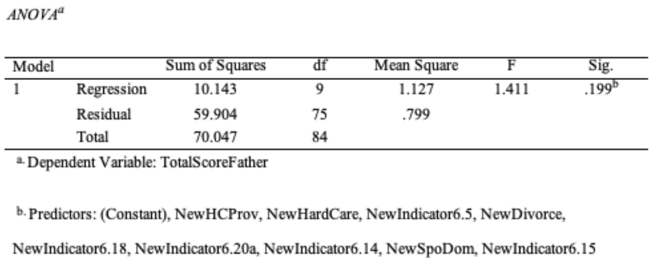


Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.381[a]	.145	.042	.89371

[a] Predictors: (Constant), NewHCProv, NewHardCare, NewIndicator6.5, NewDivorce, NewIndicator6.18, NewIndicator6.20a, NewIndicator6.14, NewSpoDom, NewIndicator6.15

[b] Dependent Variable: TotalScoreFather

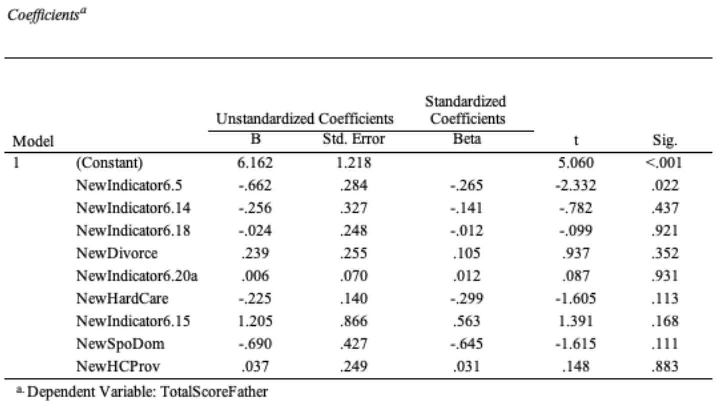


ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	10.143	9	1.127	1.411	.199[b]
	Residual	59.904	75	.799		
	Total	70.047	84			

[a] Dependent Variable: TotalScoreFather

[b] Predictors: (Constant), NewHCProv, NewHardCare, NewIndicator6.5, NewDivorce, NewIndicator6.18, NewIndicator6.20a, NewIndicator6.14, NewSpoDom, NewIndicator6.15



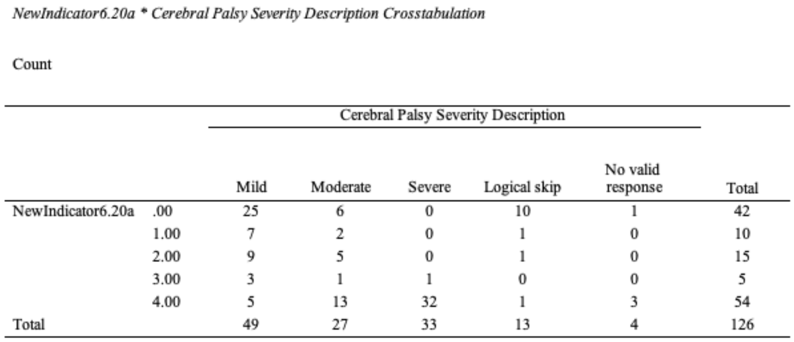
Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	6.162	1.218		5.060	<.001
	NewIndicator6.5	-.662	.284	-.265	-2.332	.022
	NewIndicator6.14	-.256	.327	-.141	-.782	.437
	NewIndicator6.18	-.024	.248	-.012	-.099	.921
	NewDivorce	.239	.255	.105	.937	.352
	NewIndicator6.20a	.006	.070	.012	.087	.931
	NewHardCare	-.225	.140	-.299	-1.605	.113
	NewIndicator6.15	1.205	.866	.563	1.391	.168
	NewSpoDom	-.690	.427	-.645	-1.615	.111
	NewHCProv	.037	.249	.031	.148	.883

[a] Dependent Variable: TotalScoreFather

Appendix E

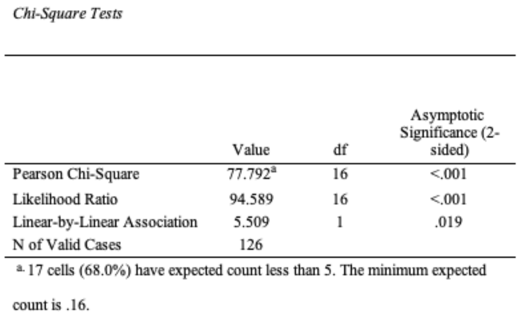
Hours of Health Care Spent Providing Healthcare



*NewIndicator6.20a * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewIndicator6.20a	.00	25	6	0	10	1	42
	1.00	7	2	0	1	0	10
	2.00	9	5	0	1	0	15
	3.00	3	1	1	0	0	5
	4.00	5	13	32	1	3	54
Total		49	27	33	13	4	126



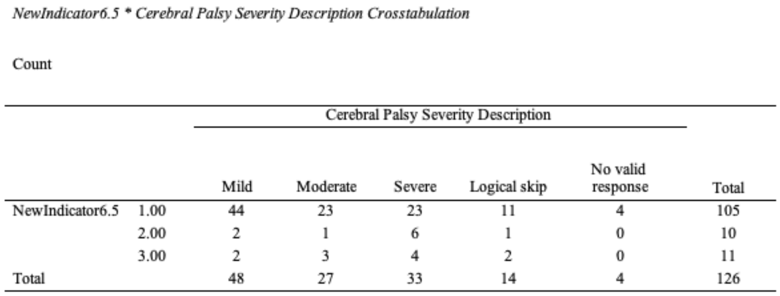
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	77.792[a]	16	<.001
Likelihood Ratio	94.589	16	<.001
Linear-by-Linear Association	5.509	1	.019
N of Valid Cases	126		

[a] 17 cells (68.0%) have expected count less than 5. The minimum expected count is .16.

Appendix E

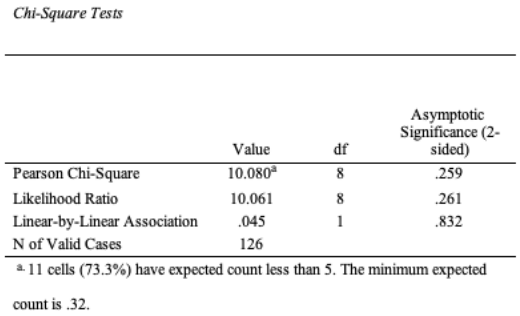
Caregiver(s) Employment Status



*NewIndicator6.5 * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewIndicator6.5	1.00	44	23	23	11	4	105
	2.00	2	1	6	1	0	10
	3.00	2	3	4	2	0	11
Total		48	27	33	14	4	126



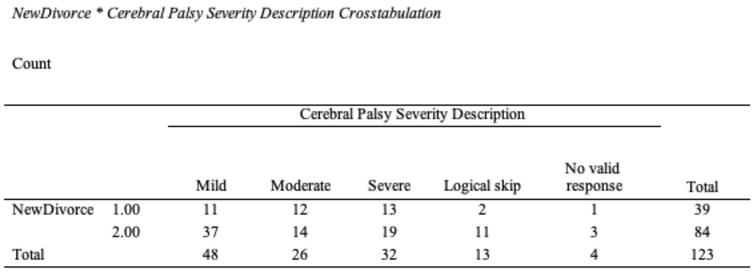
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	10.080[a]	8	.259
Likelihood Ratio	10.061	8	.261
Linear-by-Linear Association	.045	1	.832
N of Valid Cases	126		

[a] 11 cells (73.3%) have expected count less than 5. The minimum expected count is .32.

Appendix E

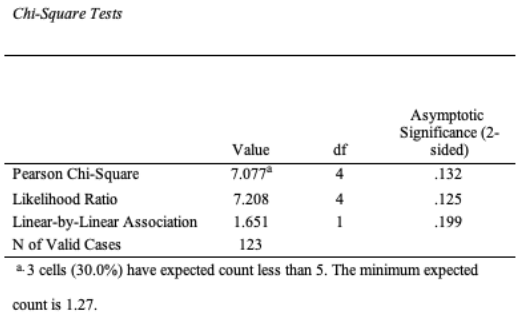
Parent Divorced or Separated



*NewDivorce * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewDivorce	1.00	11	12	13	2	1	39
	2.00	37	14	19	11	3	84
Total		48	26	32	13	4	123



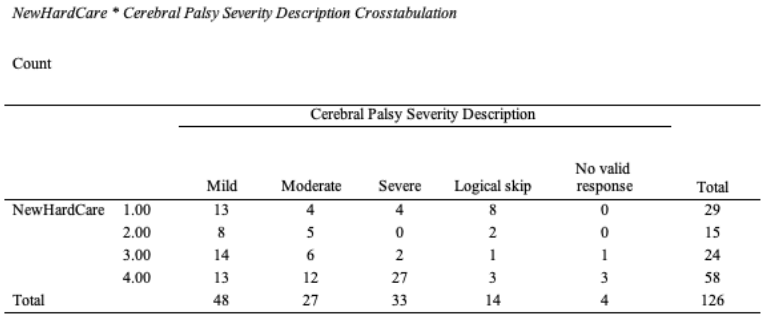
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	7.077[a]	4	.132
Likelihood Ratio	7.208	4	.125
Linear-by-Linear Association	1.651	1	.199
N of Valid Cases	123		

[a] 3 cells (30.0%) have expected count less than 5. The minimum expected count is 1.27.

Appendix E

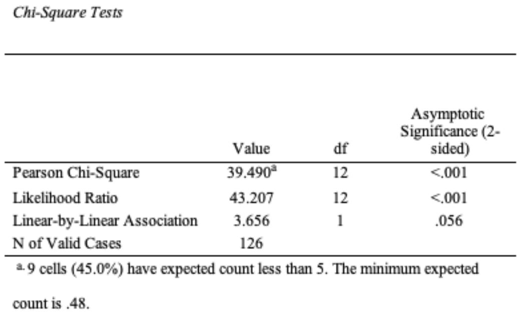
Child Harder to Care For



*NewHardCare * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewHardCare	1.00	13	4	4	8	0	29
	2.00	8	5	0	2	0	15
	3.00	14	6	2	1	1	24
	4.00	13	12	27	3	3	58
Total		48	27	33	14	4	126



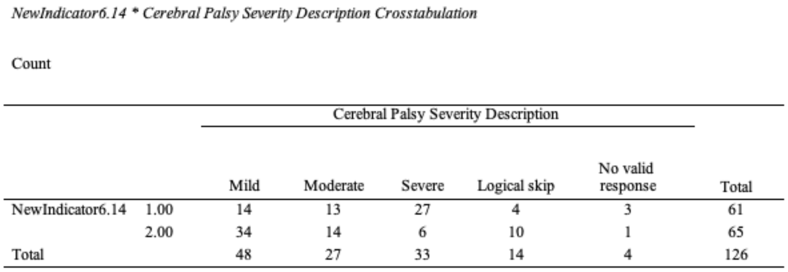
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	39.490[a]	12	<.001
Likelihood Ratio	43.207	12	<.001
Linear-by-Linear Association	3.656	1	.056
N of Valid Cases	126		

[a] 9 cells (45.0%) have expected count less than 5. The minimum expected count is .48.

Appendix E

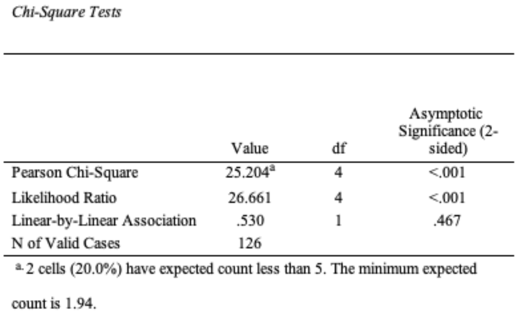
Stress



*NewIndicator6.14 * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewIndicator6.14	1.00	14	13	27	4	3	61
	2.00	34	14	6	10	1	65
Total		48	27	33	14	4	126



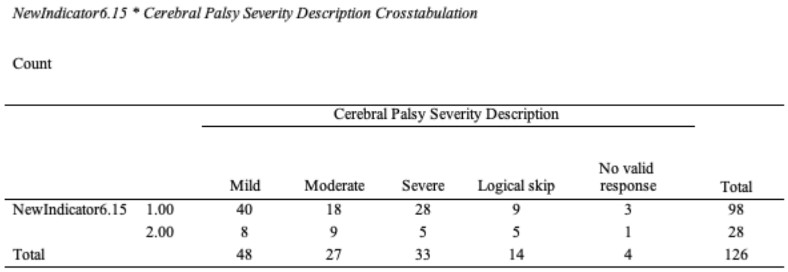
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	25.204[a]	4	<.001
Likelihood Ratio	26.661	4	<.001
Linear-by-Linear Association	.530	1	.467
N of Valid Cases	126		

[a] 2 cells (20.0%) have expected count less than 5. The minimum expected count is 1.94.

Appendix E

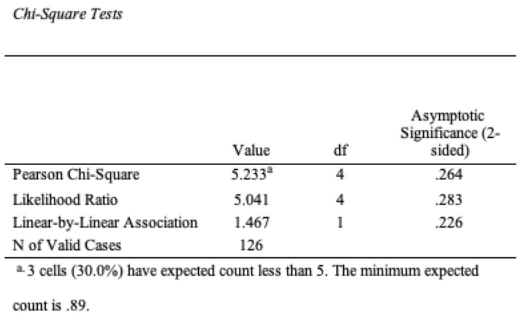
Day-to-Day Emotional Support



*NewIndicator6.15 * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewIndicator6.15	1.00	40	18	28	9	3	98
	2.00	8	9	5	5	1	28
Total		48	27	33	14	4	126



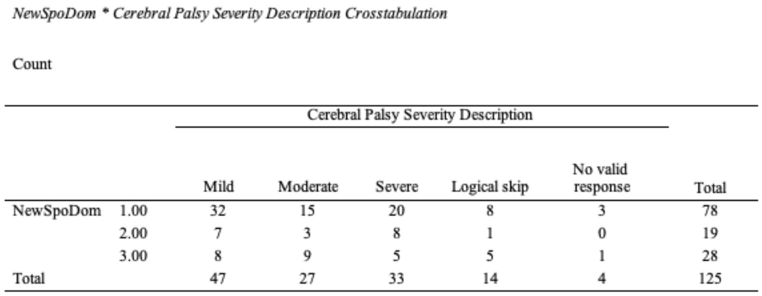
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	5.233[a]	4	.264
Likelihood Ratio	5.041	4	.283
Linear-by-Linear Association	1.467	1	.226
N of Valid Cases	126		

[a] 3 cells (30.0%) have expected count less than 5. The minimum expected count is .89.

Appendix E

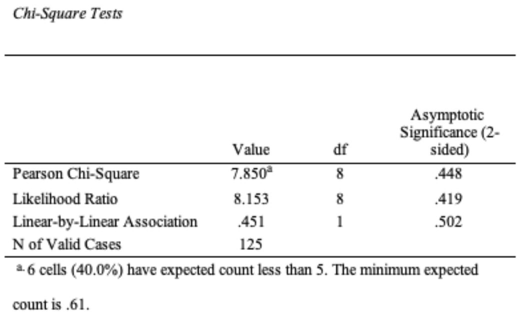
Emotional Support/Spouse/Domestic Partner



*NewSpoDom * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewSpoDom	1.00	32	15	20	8	3	78
	2.00	7	3	8	1	0	19
	3.00	8	9	5	5	1	28
Total		47	27	33	14	4	125



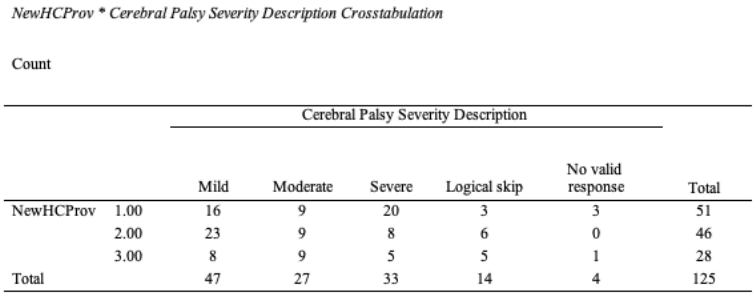
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	7.850[a]	8	.448
Likelihood Ratio	8.153	8	.419
Linear-by-Linear Association	.451	1	.502
N of Valid Cases	125		

[a] 6 cells (40.0%) have expected count less than 5. The minimum expected count is .61.

Appendix E

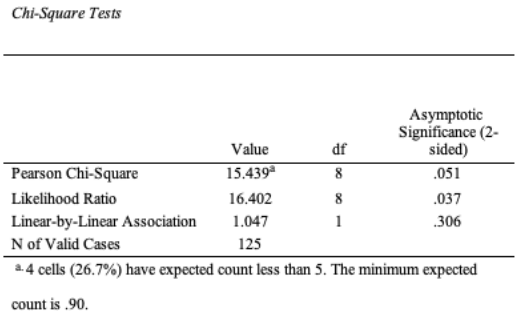
Emotional Support/Health Care Provider



*NewHCProv * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewHCProv	1.00	16	9	20	3	3	51
	2.00	23	9	8	6	0	46
	3.00	8	9	5	5	1	28
Total		47	27	33	14	4	125



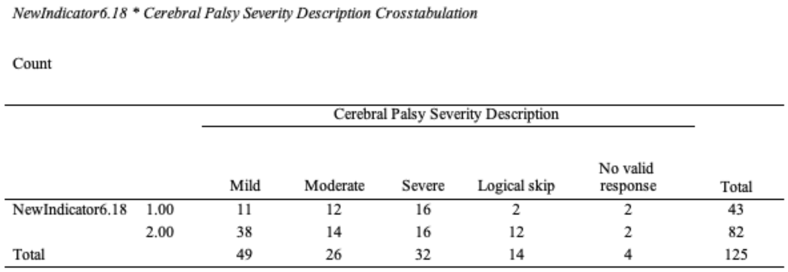
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	15.439[a]	8	.051
Likelihood Ratio	16.402	8	.037
Linear-by-Linear Association	1.047	1	.306
N of Valid Cases	125		

[a] 4 cells (26.7%) have expected count less than 5. The minimum expected count is .90.

Appendix E

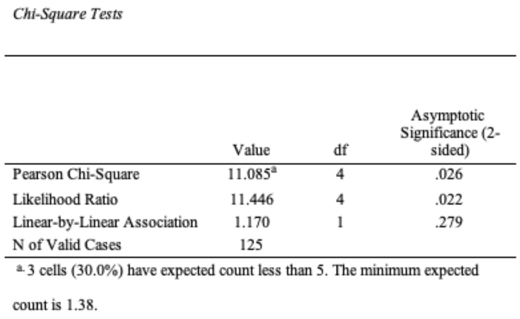
Left a Job, Took Leave, or Cut Back Hours



*NewIndicator6.18 * Cerebral Palsy Severity Description Crosstabulation*

Count

		Cerebral Palsy Severity Description					
		Mild	Moderate	Severe	Logical skip	No valid response	Total
NewIndicator6.18	1.00	11	12	16	2	2	43
	2.00	38	14	16	12	2	82
Total		49	26	32	14	4	125



Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	11.085[a]	4	.026
Likelihood Ratio	11.446	4	.022
Linear-by-Linear Association	1.170	1	.279
N of Valid Cases	125		

[a] 3 cells (30.0%) have expected count less than 5. The minimum expected count is 1.38.