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Relationship between Quality of life of Children with Cerebral Palsy and Psychosocial Burden of Mothers in Babylon Province

A Dissertation Submitted by

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Supervisor

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بسم الله الرحمن الرحيم

﴿ وَلَمّا بَلَغَ أَشُدَّهُ واستوى آتَيْنَاهُ حُكْمًا وَعِلْمًا

وكذلك نَجْزِي الْمُحْسِنِين ” ﴾

صدق الله العظيم

سورة القصص أية (14)

Supervisor Certification

This is to certify that this dissertation which is entitled (**Relationship Between Quality of life of Children with Cerebral Palsy and Psychosocial Burden of Mothers in Babylon Province**), submitted by **Raghad Nadhim Sahib Nasaif** to the University of Babylon, College of Nursing in partial fulfillment of the requirement for the Degree of Philosophy Doctorate in Nursing Science. The dissertation work is carried out by student under my supervision and guidance.

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Dedication

To

My Lady ***Fatima AL- Zahra*** *bless her*

To the……….. ***My dear mother***

My ideal in life, whose name I proudly bear……… ***my dear father***

To my beloved brothers and sisters….and my ***friends*** *with love and respect*

Raghad

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Finally, ….
I pray to Allah (the Great and Almighty)
To bless them all.

Abstract

Cerebral palsy is a chronic neurological disorder with movement abnormalities beginning from childhood facing society in general and the family in particular, and no family wants to infect one of their children with illness or disability in any way. Caregivers and especially mothers of children with cerebral palsy suffer from a large psychosocial burden.

The study aimed to assess the relationship between mother's psychosocial burden and quality of life for children with cerebral palsy.

A cross-sectional descriptive study design was accomplished from November/1st /2020 to April//2022.The study involving (150) mothers was selected using a non-probability convenient sampling technique. This sample was distributed among two hospitals according to the Babylon Health Directorate, including (Imam AL-Sadiq Hospital and Babylon Rehabilitation Centre).

The reliability of the questionnaire was achieved through a pilot study and then presented to (15) experts to prove its validity. The total number of items included in the questionnaire was (49) items for psychosocial burden and (23) items for quality of life for cerebral palsy children.

The results of the study indicated that (49.3%) of the mothers expressed a high level of psychological burden, and (68.7%) expressed a high level of social burden, a (92%) of mothers expressed a poor quality of life for cerebral palsy children. There are statistically relationship between psychosocial burden of cerebral children mothers and their socio-demographic characteristics at p-value <0.05. The study concluded that poor quality of life for cerebral palsy children depends psychosocial burden. The higher the psychosocial burden led to the lower the quality of life for children with cerebral palsy. The psychosocial burden has been influenced by mother's factors such as age, education level, occupation, income, housing area, number and type family.

The study recommends that the health professionals working in the field of cerebral palsy must also take into account the psychological state and quality of life of the mother when making treatment decisions, and prepare psychological care programs with the aim of helping them deal with the conditions of their children and meet their needs.

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List of Abbreviations

Item	Meaning
ADA	American with Disability Act
ADL	Activities Daily Living
AFO	ankle-foot orthosis
BAS	Beck Anxiety Scale
BDI	Beck depression Inventory
CB	Caregiver burden
CBI	caregiver burden inventory
CDS	Caregiver Difficulties Scale
CNS	Central Nerves System
CP	Cerebral Palsy
D.f	Degree of freedom
LBW	low Birth Weight
F	Frequency
FIM	Function Independence Measure
GMFCS	Gross Motor Function Classification System
HADS	hospital anxiety depression scale
HRQOL	health-related quality life

HS	Highly significant
ICF	International Classification of Functioning
IQ	intelligence quotient
K	Number of items
M.S	Mean of score
MRI	Magnetic resonance imaging
No.	Number
NS	Non-significant
PA	physical activity
PCAs	Personal Care Assistances
P-value	Probability value
QoL	Quality of Life
S	Significant
S.D	Standard Deviation
SPSS-XX	Statistical Package of Social Sciences 20

Symbol table

%	Percentage
E_i	Expected frequency
O_i	Observed frequency
σ_{ii}	Variance (not standard deviation) of item i
σ_{ij}	Estimated covariance between items i and j
$\sum$	Sum

Chapter one

Introduction

Chapter One

Introduction

1.1. Introduction

The nervous system is a complex network of nerves and cells that carry messages to and from the brain and spinal cord to various parts of the body. The proper functioning of these nerves ensures that each organ system, such as the cardiovascular, gastrointestinal, and immune systems, can adequately communicate with one another. The nervous system includes the central nervous system (CNS) and peripheral nervous system (PNS). The CNS is made up of the brain and spinal cord, whereas the PNS is made up of the somatic and autonomic nervous systems (Taoka & Naganawa, 2021).

Cerebral Palsy is a neurological disorder caused by anomalies in the brain's control centre for muscle movement affects most new-borns, yet it may go unnoticed for months or years. Symptoms of CP normally appear before a kid reaches the age of three. Ataxia is a loss of muscle coordination when performing voluntary movements; the most typical indications are stiff or tensed muscles and exacerbated. Cerebral Palsy refers to a range of disorders that impact a person's ability to move, balance, and maintain proper posture (Sheen, 2012).

The illness affects new-borns and children's central nervous system damage to the brain, particularly to the region of the brain responsible for motor function, is an incurable condition that affects movement and posture, limiting activity in a developing foetus or a child's brain. Spasticity is a symptom which is defined as increased muscle tension and tightness that hinders mobility affected body parts might range from a single limb to the entire body (Walde et al., 2021).

Cerebral palsy is the most frequent type of physical disability that impacts children's functional development among the several types of juvenile developmental disabilities (Zigmond et al., 2014).

The etiologic exact cause remains unknown, specifically caused by unknown prenatal factors particularly birth asphyxia as the first issue results from current prenatal brain deformities on the other hand, malnutrition, is usually an important and dangerous factor that may adversely affect the diagnosis of patients with CP (Rosello et al., 2021).

The disorders appear in the first few years of life. Usually, they do not get worse over time. Children with cerebral palsy may have difficulty walking. They may also have trouble with tasks such as writing or using scissors. Some have other medical conditions, including seizure disorders or mental impairment (Vitrikas et al., 2020).

The classification of CP varies depending on which brain regions are affected, spastic, dyskinesia, ataxia, and spastic kinaesthetic palsy all have impaired muscle tone and coordination as the predominant symptom (Hockenberry &Wilson, 2015; Issa & Mohammed, 2017).

Chronic discomfort, spastic paralysis, perceptual impairment, impaired eyesight, and speech impairments, as well as digestive issues and malnutrition, are all problems that a kid with CP faces. They are also restricted in self-care activities such as eating, changing clothes, moving, and bathing. This can result in the requirement for long-term care that is well beyond the usual needs of normal children (Nimbalkar et al., 2014).

People who have children feel that they have a stronger sense of purpose in life and a larger reason to exist. Children are the beauty of life for parent where they can see themselves through them; humans want to have off springs that are a deep desire to continue their descent, and leave a worthy memory of themselves (Abedinia, 2009).

During Pregnancy, a father or mother generally build up confident expectations of how their child will be and how they will be as parents up confident (Leeks & Burney, 2007).

The birth of a kid with a physical handicap that necessitates intensive care causes significant changes in family motivation; living with a disabled child can have far-reaching consequences for a family (National Research Council, 2010).

No parent anticipates a child who would require particular attention, shattering the family's expectations. It elicits strong feelings in both parents. It reorganizes the family's structure. In most circumstances, CP children are grouped alongside intellectually impaired children. Until now, there have been few research on the case load faced by mothers of children with CP is linked to a variety of disabilities, and as a result, it is linked to a variety of activity limitations and participation restrictions (Martini et al., 2005; Rosset & Oliveira, 2009; Muster et al., 2010; Sharan et al., 2012).

Even while motor dysfunction is the most important determinant of CP, the presence of sensitive, cognitive, and social failures also affects the severity of inability (Bottcher, 2010).

There is a consensus that gives care to how long that might affect the emotional health of mothers, physical, social of mothers, well-being, marital relations, work, and economic situation (Davis & Gaskell, 2009; Yilmaz et al., 2013).

Because caring for children is an important part of parenting, it can also be a big strain when the demands are excessive and long-term. Excessive accountability may have a negative influence on moms' physical and mental health. Their social, cultural, and professional lives are all affected as well as perhaps lowering their quality life (Brehaut, et al., 2009; Tucker et al., 2009; Davis et al., 2010).

It should also be noted that the presence of a disabled child affects not only the parents, but also siblings and relations between family members. The CP can take into account the specific type of disability that exists in children. In comparison to conventional children, these youngsters demand more attention and a longer duration of care. It puts a strain on parents and families (Issa & Mohammed, 2017).

The nursing examination includes a screening for new-born hazards associated with predisposing variations of CP. After continuing to evaluate newborns for aberrant muscle tone, failure to meet developmental goals, and persistent neonatal reflexes, the nurse is alerted for further investigation (Reddihough, 2016).

Cerebral Palsy is determined by parents' stories as a key role in identifying the late dynamic parameters, such as walking, pulling to stand, sitting, controlling the neck while position, deep tendon responses, and muscle strength determined by the doctor. A final diagnosis can only be established after the repeated test for it largely depends on neurological findings (Abdullahi et al., 2016; Dalvand et al., 2009).

As an individual's sense of where he or she is in life in terms of goals, expectations, standards, and interests, as well as the cultural and value systems in which they live. QOL is an umbrella term that encompasses all aspects of health (Nurani et al., 2015).

The level of happiness of an individual or a group of people is referred to as their quality of life. Quality of life, unlike standard of living, is an ethereal concept that cannot be quantified. It is made up of two parts: the body and the soul. Health, nutrition, pain management, and illness prevention are all included under the physical element. Stress, anxiety, pleasure, and other good or negative emotional states are examples of psychological factors (Costanza et al., 2008).

Quality of Living is a perspective on an individual's life circumstances in connection to his life's aspirations, expectations, standards, and worries, as well as the culture and value system in which he lives (QoL). In children, QoL has been defined subjectively and on a multidimensional basis, taking into account functional competence as well as the psychological link between the kid and the family. As a result, every child has a right to a good quality life and to have their fundamental needs met. It should be highlighted, however, that quality life standards are occasionally overlooked, highlighting the importance of analyzing a kid's QOL, especially if the child has a condition. Quality life refers to a person's perception of his or her place in life in terms of cultural characteristics and value system (QoL). On the other hand, health-related quality life is a subset of QoL that includes physical, social, and emotional well-being. It refers to a person's happiness and satisfaction in a variety of areas of their life that are influenced or influenced by their health (Dayapoglu &Tan, 2010; Frota & Mirna, et al., 2016).

The subjectively fellow human of people with physical disabilities is referred to as quality of life, and it focuses on health-related aspects of life satisfaction such as self-care, mobility, and community. Quality life assessments reflect subjective outcomes such as life satisfaction, a sense of belonging, and self-concept (Ozdemir & Tezcan, 2017).

One sign of good health is quality of life. When establishing an individual's health state, QoL, like traditional mortality and morbidity rates, is one of the most significant factors to consider. Cerebral Palsy is a non-progressive neurological illness that affects a person's capacity to move and coordinate their body, restricting their ability to do activities. Ataxia, spasticity, walking on toes or with a foot or leg pulled, a bent or scissor gait, and muscular tone are all signs that arise in the brains of persons aged foetal to early childhood (Yilmaz et al., 2013).

As a result, it's critical to differentiate between health-related quality of life, which measures happiness as a result of disease processes, conditions, and disorders, and overall quality of life, which measures happiness as a result of factors other than health, such as support, spirituality, and social and emotional well-being (Wippermann, 2013).

Majority of children with CP have difficulty walking and participating in other physical activities. The widespread consensus is that being subjected to such constraints lowers one's quality life (Wong & Lim 2009).

Due to motor limitations in terms of movement and self-care, children with CP are dependent on others, and these restrictions have an impact on their daily activity participation and quality life (Kerr et al., 2007).

Cerebral palsy children rely significantly on their mothers are the most common caretakers typically burdened with family duties, making a living, and caring for a child with CP in low- and middle-income conditions. Due to the interaction of gender norms, poverty, social shame, and caring for a disadvantaged child, this places a significant burden and stress on mothers. It has been proven that caring for a child reduces a mother's quality of life so prone to anxiety and depression (Marrón et al., 2013).

Due to the disorder's ambiguous and unclear projected results, it is causing family stress. Because CP impacts families differently based on coping methods, support systems, and the child's age and degree of functioning, among other things, it's critical to take an individualistic approach to care (Wippermann, 2013).

The mothers are difficulty involved in self-care performance which may collect an additional give notice and stress to the mother. Caregivers' levels of stress and depression are inversely connected to their levels of self-efficacy and social support (Pousada et al., 2013; Vayalil & premkumar, 2015).

The parents are socially isolated, unable to participate in social activities, stigmatized, and producing conflict in their family and community, in addition to the psychiatric. They are also affected by physical stress, such as sleep deprivation, musculoskeletal pain, and high blood pressure. As a result, the unimportant problem of maternal load must be acknowledged and effectively treated (Thrush & Hyder, 2014).

The problems that children with CP confront cause their mothers to be more stressed, which has a negative impact on their physical and social well-being (Parkes et al., 2009; Davis et al., 2010; Parkes et al., 2011).

The term psychosocial refers to the interaction between a person, the social environment, and the influence on their behaviour. Family members, friends, co-workers, employers, the compensation system, and health professionals are all part of the social environment. As a result, psychosocial issues are issues that affect a person's social environment. Understanding and addressing the psychological challenges faced by the mothers of the afflicted children is critical in developing a family-centred care practice. According to studies from western cultures, mothers of children with CP have been documented to suffer a variety of psychosocial issues (Ketelaar et al., 2008; Davis et al., 2010).

Depression, anger, reliance, lack of ambition, often feeling restricted, fatigue from their obligations, and forgetfulness are all linked to strong feelings of guilt, humiliation, despair, and self-pity, all of which can be overpowering for a mother with a disabled kid (Abdullahi et al., 2016).

Determined that long-term reliance on a mother entails difficult duties and care management experiences, particularly for mothers who must offer constant and undivided care and, as a result, neglect themselves, their children, and other family members (Alaee et al., 2015).

Early intervention treatment can assist people develop functional abilities that will allow them to be more independent and improve their quality of life. It includes specialized instruction and related rehabilitation services which minimize the disabling effects of CP and promote optimal development over time. Available treatments only address the signs and symptoms and are unable to cure the actual pathology underlying the disorder. For a long time, the treatment of CP has been based upon a biomedical model of health (Kurtuncu et al., 2015; Jindal, 2017).

Multidimensional interventions in different areas and time points of a child's life are required to make a change in the quality life for the child and his family. Increasing a child's job and participation in various age-appropriate activities, and healthcare professionals need a comprehensive understanding of all the areas influencing a child's development, activity, and participation (Lakhan, 2014).

1.2. Importance of Study

In a study conducted in the city of Baghdad, it is found that between (10 % - 15%) of children infected with the disease after birth due to traffic accidents and fall and infections such as meningitis. Epilepsy affects a significant number of children with CP (15 percent to 60%). Regardless of the causes, eighty per -cent of the total CP cases are associated with brain lesion or brain mal-development in the perinatal, or neonatal period. Several biochemical disorders may be cause motor abnormalities similar to those found in CP, and they can be misinterpreted as CP at first (Reddihough, 2016).

In Erbil's Helena Centre for Disabled Children, 1700 children with CP under the age of 17 were registered. Though El-Tallawy stated Fifty-two of the 25,540 children in Egypt, Karajah area, had CP, resulting in a 2.04 (ninety-five per- cent from 1.48 to 2.59) / 1,000 live deliveries (Hasan et al., 2016; El-Tallawy et al., 2014)

The worldwide occurrence and frequency of the CP is not clearly known, but it is stable in some children who aged 3–10 years, with 2:4 per 1000 children. Different rates of boys and girls have been reported. The prevalence and ` of CP have increased in the previous 20 years, which may be useful in enhancing the documentation of cases given to national registries in new-born care, as well as other reasons (Almasri et al., 2011; Kurtuncu et al., 2015).

In the United States, CP affects two to three out of every 1000 live births and is the main cause of motor impairment in children. Perception, cognitive, communication, and/or behaviour impairments, as well as seizures, are frequently associated with motor abnormalities (Rosenbaum et al., 2007).

Cerebral Palsy is one of the utmost communal reasons for bodily incapacity in childhood, by a recounted occurrence of nearly 1.5–3\1,000 in spite of decreased perinatal and neonatal mortality rate (Gabr et al., 2016).

Al-Azzawi (2012) emphasized that degrees differ from one governorate and within governorates; that it is around 1-2/1000 live birth, with an occurrence of about 500/100000 population.

Gaber, et al (2016), specified that around forty to sixty per -cent of CP children have a percentage of mental disability and thirty to forty per-cent of them have epileptic seizures at the beginning of their lives. In general, the genetic predisposition of neurological disorders is determined by the family history of epilepsy ranging from seizure to CP and then mental disability.

Cerebral Palsy rates range from "2.0 to 2.5 per 1,000 live births, according to research from Western Australia, Sweden, the United Kingdom, and the United States. Despite this, the overall number of children with CP has remained constant or increased. The likelihood of CP in pre- and post-natal new-borns has progressively grown since 1970. Every year, between 8,000 and 10,000 babies and infants are diagnosed with CP, according to the United Centres for CP and the Centres for Disease Control and Prevention (Al-Azzawi, 2012; Ching & Khoo, 2017; Yaghmaie et al., 2018).

Mortality in CP is powerfully related to each level of functional disorder as well as the associated weakness of immobilizing disability.

However, among the non-motor impairments intellectual, disability is found to be a strong predictor of mortality (Abdullahi et al., 2016).

Cerebral palsy is a serious illness that has a substantial impact on the lives of those affected, their families, the broader public, and government policy. It refers to a long-term and expensive condition for children with CP who are referred to Children's Medical Centre, especially when complications emerge, such as hospitalization, accommodation, treatment, and para-clinic care (Lakhan, 2014; Issa & Mohammed, 2017).

In addition, direct and indirect costs for all children with CP, including those born in the second millennium, will exceed eleven and a half billion dollars. As long as caring for children with CP is tough and expensive for his family, the average cost of living for a person with CP is projected to be 921,000 dollars (Ching & Khoo, 2017; Yaghmaie et al., 2018).

Chronic diseases are afflicting an increasing number of individuals worldwide, posing serious health hazards. CP is an example of a chronic health disorder that manifests in childhood and has a significant influence on the family, as the responsibility for caring for a child with these conditions moves from health professionals to the family and, eventually, to the community (Klankaradi, 2008).

The presence of a child with disability at home puts challenges for the belongings so much so the whole nature and dynamics of family interactions change. Due to this, the family sometimes countenance multifarious challenges and adverse outcomes. The inability of any big baby in such CP not only his / her course of daily life but also does disrupt the social, psychological, and emotional areas of family life (Miller, 2005).

The family's challenges, which are commonly recognized in the care of children with CP, as well as the weight placed on main caregivers. Children's demands have an impact on the mental and physical health of parents, particularly the mother, who is the primary caregiver (Pimento et al., 2010; Rania et al., 2005; Ketelaar et al., 2008).

Parents with disabled children are more likely to see burdens, according to the study, when compared to parents of typical children (Barlow et al., 2006; Seguin et al., 2008).

Continuous increase in children inflicted with CP contribute to increased heavy burden on the mothers of these children: this burden represented by providing care for the child and help him to move and walk and require such care physical effort and financial as well as psychological and social burden. Hence, the importance of this study back to the few studies that focused on mother's burden a child inflicted with CP in Iraq. Therefore, we should focus on the study of this subject. During this study, the relationship between the quality life of children with CP and the mothers' psychosocial load is critical.

In general, caring for a child with a disabling ailment can put a mother under a lot of strain. CP has a significant influence on the lives of afflicted persons and their primary mothers because to its various comorbidities and interdisciplinary management.

1.3. Statement of a Study

Mothers s often suffer from stress and depression. The level of stress and depression suffered by the mothers is inversely proportional to their self-efficacy and level of social support. The burden of mothers for children with CP is a neglected phenomenon. In addition to the psychological problems the parents also feel socially isolated, unable to participate in social life, stigmatized and develop conflicts in their family and society. Besides, they also undergo physical stress including lack of sleep, musculoskeletal aches and pains, and hypertension (Vadivelan et al., 2020).

1.4. Objectives of a Study

1. Assess the psychosocial level of burden cerebral palsy children's mothers.
2. Assess the quality of life for children with cerebral palsy.
3. Investigate the differences in psychosocial burden of mothers with regards their demographical data.
4. Investigate the differences in cerebral palsy children quality of life with regards to their characteristics.
5. Find out the association between quality of life for the child with CP and psychosocial burden for mothers.

1.5. Research Questions

What is the relationship between the quality life of children with cerebral plays and their mothers' psychosocial burden?

1.6 Research Hypotheses:

H0: There is a non-significant relation between score quality of life of children with CP and Psychosocial Burden of Mothers.

H1: There is a significant relation between score quality life of children with CP and Psychosocial Burden of Mothers.

1.7. Definitions of Terms

1.7.1. Cerebral Palsy:

Theoretical:

It is a chronic condition defined as a set of limitation in functions arise because of harm to the development of the central nurse’s system (Jibril et al., 2020).

Operational:

Chronic condition that leads to a psychological, social, and financial burdens on the mother or family member.

1.7.2. Quality life

Theoretical:

Although rating systems exist to investigate physical and social dimensions, measuring an individual's general sense of well-being or contentment with life qualities is more difficult (Ali & Tawfiq, 2013).

Operational:

Refers to a state of wellbeing of children i.e., the ability to perform everyday activities that reflect their physical, psychological, environmental, and social wellbeing and parent’s satisfaction.

1.7.3. Children

Theoretical:

The child is a young boy or girl. Child is the legal term for a person under 18 years of age (Hanson, 2012).

Operational:

Any child aged between three years and puberty under 18 years of age that has CP.

1.7.4. Psychosocial Burden

Theoretical:

It is a worsened when the word related to the interaction of psychological and social factors and one of a homogenous group, for individuality is displaced in favour of a jaded (Hanson, 2012).

Operational:

The perception of stress, fatigue, social stigma, and withdrawal caused by the sustained effort required in caring for children with CP.

Chapter Two

Review of Literature

Chapter Two

Literature Review

2.1. Historical Background of Cerebral Palsy

Earliest years in the western region begin with many studies for detecting the disease and its process. William John Little, a British surgeon who began his first and serious efforts in the 1930 to study what will later become identified as CP. He was partly incapacitated due to polio and finished greatest of his professional medicinal life study various disabilities, including hemorrhagic spastic paralysis, which was later known as CP, in addition to William John little in 1853 who published his study entitled “On the Nature and Handling of the Abnormalities of the Humanoid”. He defined numerous newborn damages and inherited disabilities that disturb the musculature. Lengthways through his study on convulsive diplegia, as well as little inscribed the earliest explanation of pseudo-hypertrophic muscle atrophy (Rethlefsen et al., 2010).

William John Little in 1861 introduced his earliest description of CP by mentioning newborns with partial suffocation due to difficulties during labor. No one else has been identified or described for muscle fluctuation or convulsions. Little has written about the importance of early treatment and correct intervention for children “reinstated to considerable action and pleasure of life” (Baiee et al., 2019).

Furthermore, Sir William Osler put a book entitled "CP in Children" in 1889. Osler did not refer to Little's illness as incapacitated, but he depends on little’s study and addition his scientific findings. Osler built the term of the disease on Latin words instead of general English words and chose word brain and paralysis rather than CP (Panteliadis et al., 2013).

In 1897: Austrian neurologist and psychiatrist Sigmund Freud advised that CP is a disorder that affects children before birth at the stage of the fetus and not during or shortly after birth because it is a disease directly related to the brain. Freud linked this to various disorders such as mental retardation, fainting, visual disturbances and CP (Panteliadis et al., 2013).

While (Rethlefsen et al., 2010) reported that medical researchers in the eighties of the last century proved that paralysis can occur before birth and Freud's theory is true. Although it represents no less than 10% of diagnosed cases before delivery, clinical studies have subsequently confirmed that CP can occur due to birth injuries. A child with CP often suffers from other disorders like visual ad mental disturbances, said Sigmund Freud, adding that the disease may be present during the development of the brain in the womb early in life (Günel et al., 2014).

The US Congress passed the Americans with incapacitate Act (ADA) in 1990, barring workers from practicing discriminatory employment discrimination against individuals with disabilities. It is a federal law 1 (CP guidance, 2018) .

When they grew up, they did not get worse or better. Little did his best to classify all different types of CP that they called Little's Disease and this disorder is likely to result from suffocation at birth. Where he suggested that sensitive brain tissue responsible for movement had been damaged due to lack of oxygen (Mohammed, 2005).

2.2. Theoretical Framework

Rogers’ theory (Human-unitary human beings) is a grand theory as mean applicant in different fields in nursing science. Rogers’ theory defined Nursing as “an art and science that is humanistic and humanitarian. It is directed toward the unitary human and is concerned with the nature and direction of human development. The goal of nurses is to participate in the process of change. According to Rogers, the Science of Unitary Human Beings contains two dimensions: the science of nursing, which is the knowledge specific to the field of nursing that comes from scientific research; and the art of nursing, which involves using the science of nursing creatively to help better the lives of the patient (Smith & Parker, 2015).

2.2.1. Metaparadigm of Rogers Theory

1-Human beings

A person is defined as an indivisible, pan-dimensional energy field identified by a pattern and manifesting characteristics specific to the whole. That can't be predicted from knowledge of the parts. A person is also a unified whole, having its own distinct characteristics that can't be viewed by looking at, describing, or summarizing the parts (Smith & Parker, 2015)

2. Health

Rogers defines health as an expression of the life process. The characteristics and behavior coming from the mutual, simultaneous interaction of the human and environmental fields and health and illness are part of the same continuum. The multiple events occurring during the life process show how a person is achieving his or her maximum health potential. The events vary in their expressions from greatest health to those incompatible with the maintaining life process (Smith & Parker, 2015)

3.Nursing

It is the study of unitary, irreducible, indivisible human and environmental fields: people and their world. Rogers claims that nursing exists to serve people, and the safe practice of nursing depends on the nature and amount of scientific nursing knowledge the nurse brings to his or her practice (Smith & Parker, 2015)

4.. Environment

An irreducible, indivisible, pan-dimensional energy field identified by pattern and integral with the human field (Smith & Parker, 2015).

2.2.2. Principles of Martha Rogers Theory **as shown in Figure (2.1).**

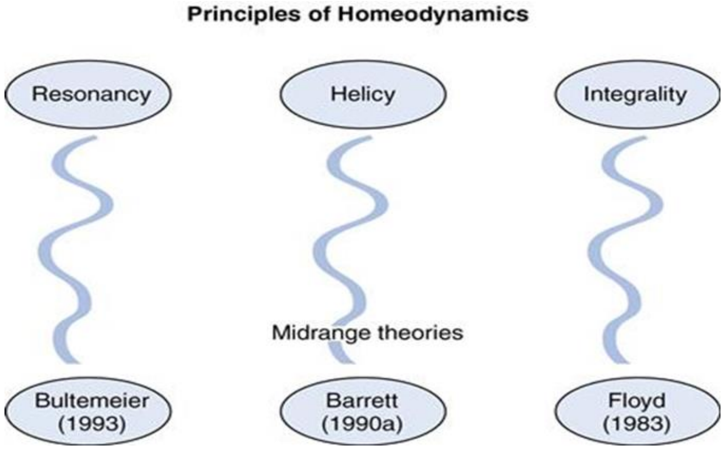

Figure 2. 1 Principles of Martha Rogers Theory (Unitary Human Beings) (Alligood, 2013)

2.2.3. Concepts of Martha Rogers Theory as shown in Figure (2.2).

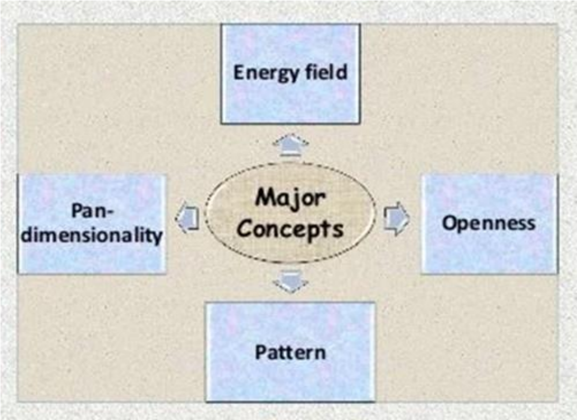

Figure 2. 2 Concepts of Martha Rogers Theory (Unitary Human Beings) (Alligood, 2013)

2.2.4. Assumption of Martha Rogers Theory as shown in Figure (2.3).

Assumptions

wholeness	• Human being is considered as united whole
openness	• A person and his environment are continuously exchanging energy with each other
Unidirectionality	• The life process of human being evolves irreversibly and unidirectional i.e from birth to death
Pattern and organization	• Pattern identifies individuals and reflects their innovative wholeness.
Sentence and thought	• Humans are the only organisms able to think, imagine, have language and emotions

Figure 2. 3 Assumption of Martha Rogers Theory (Unitary Human Beings) (Alligood, 2013).

The present study based on Martha roger's theory decreased burdens of disease for mothers of child lead to maintain quality of life of child with cerebral palsy as shown in **Figure (2.4)**.

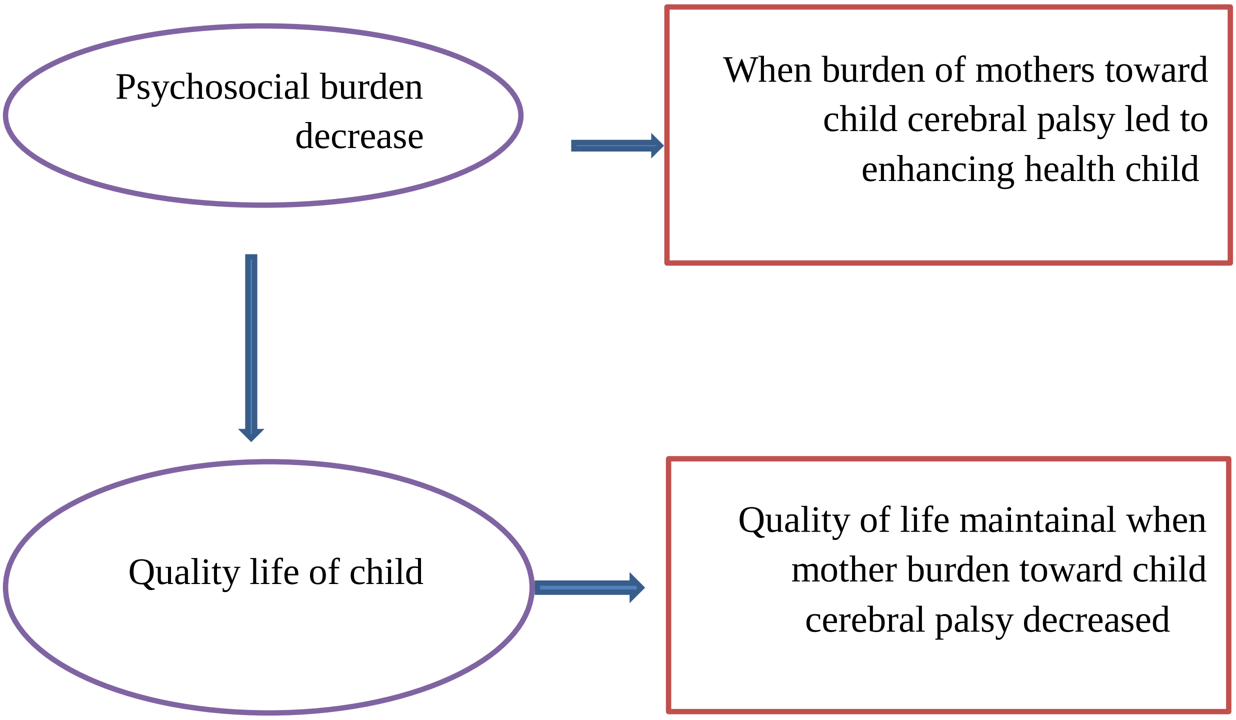

Figure 2. 4 Application of Rogers theory (designed by researcher).

2.3. Overview of Cerebral Palsy

As defined a series of irreversible developmental problems in mobility and posture that result in activity restriction and are linked to non-progressive disturbances of fetal or newborn brain development (CP). In addition to motor difficulties, the disease often includes sensory, perceptual, communicative, perceptual and behavioral disturbances, as well as secondary musculoskeletal problems and epilepsy (CP guidance, 2018).

Former civilizations such as the Greeks, Romans and Egyptians, diagnosed some cases of CP without knowing the reasons and how to treat. Till the 19th period, medicinal scientists in Europe did not begin to considerate, inherited or developed birth defects (Panteliadis et al., 2013).

2.4. Prevalence of Cerebral Palsy

About 2.0 to 2.5 persons per 1,000 live births are affected by CP. For the past 40 years, interest rates have remained unchanged. In many children, the cause of CP is unknown. "Preterm birth and low birth weight are known risk factors; for example, children born with a very low birth weight are 20-80 times more likely to suffer CP than children born weighing 2500g" (Baiee et al., 2019).

2.5. Causes of Cerebral Palsy

Cerebral palsy whether single or multiple, is influenced by antenatal, perinatal, and postnatal factors. During pregnancy and the first two years of life, the human brain develops. During this phase, brain damage or trauma can cause CP. Although it was often thought that CP was caused by perinatal problems, particularly birth asphyxia, it is now thought that prenatal brain abnormalities are the most common cause (Christopher & Reev, 2016).

Though the exact etiology of these defects is unknown, statistics reveal that70 to80percent of cases of CP are caused by unknown circumstances before birth. Intrauterine contact with parental chorioamnionitis he risks of CP in neonates is related to preterm infants and weight at birth; however, not all full-term infants with chorionic encephalopathy produce CP. Because of the consequences of the developing brain, babies exposed to maternal illness have a higher chance of CP. Despite the fact that CP can develop in preterm pregnancies, the most important risk factor for CP is premature birth of newborns with extremely low birth weight (ELBW) or very low birth weight (VLBW). However, there is no obvious justification in some situations (Reddihough, 2016).

In low-birth-weight new-borns, periventricular leukomalacia and intracerebral haemorrhage, as well as perinatal ischemic stroke, induce CP. According to one study, kids born at 42 weeks or more are more likely to develop CP than babies born at 37 or 38 weeks. Other factors contributing to CP, such as multiple concomitant births, around traffic accidents, brain injury because of a child's incorrect holding (infantile shaking syndrome) and postpartum infections such as bacterial meningitis (Eunson, 2012).

Cerebral palsy it can be caused by a number of factors, including congenital, genetic, inflammatory, hypoxic, traumatic, toxic, and metabolic. There are three types of causes: prenatal, perinatal, and postnatal. Cerebral palsy is linked to a variety of risk factors. Despite the fact that postpartum intraventricular haemorrhage may have neurological effects, the majority of hypoxic damage associated with cerebral palsy occurs before birth (Samar et al., 2020).

2. 5.1. Pre-natal

About 75% of children with CP are responsible for premenstrual events, toxin vascular events, cerebral artery failure, mean metabolic conditions, female infections (simplex virus, toxoplasmosis, cytomegalovirus, and German measles) (Reddihough ,2011).

2. 5.2. Infections During Pregnancy

Christopher & Reeve (2016) definite that some diseases that affect the mother during pregnancy or accidents that can lead to damage to the brain and thus infected CP, such as the German measles virus, the cytomegalovirus, rupture of the uterine wall before birth or lack of efficiency of the work of the placenta all this leads to insufficient access of the oxygen to the brain cells of the child and causing CP.

2. 5.3. Peri-natal

Ten to fifteen percentage of the cases are responsible for the surrounding causes as a result of problems during labor, like hemorrhage and umbilical cord prolapse or other problems during childbirth, which exposed the fetus to danger (Reddihough, 2011).

The period surrounding labor and childbirth, important events lead to brain dysfunction in newborns, manifest in the early days of the baby's age, a namely neurodevelopmental syndrome. like depress of tone and reactions, difficulty in starting and maintaining breathing, and level of subconscious awareness. Secondary events surrounding birth do not lead to CP as the child recovers quickly (Reddihough, 2016).

2. 5.4. Prematurity

Children who have a low birth weight and premature are more likely to develop CP 30 times compared to full-term infants. Doctors had thought until recently that the lack of oxygen and suffocation in difficult deliveries was the cause of most cases of CP, while recent studies showed that this caused only 10 per- cent of the total cases (Eunson, 2012).

2. 5.5. Other Birth Anomalies

The most at risk of CP are children with severe brain abnormalities, physical congenital defects, many genetic diseases, and chromosomal abnormalities (Nelson & Blair, 2015).

2.5.6. Post neonatal

10% of all cases of CP responsible for other causes occurring after 28 days and more of the child's age known as causes of postpartum. These include accidental accidents such as drowning, car accidents, falls and certain infections such as meningitis and others, and no accidental damages which could be early and clearly detected by exposing the baby to Magnetic resonance imaging (MRI) (Germany et al., 2013).

2.5.7. Acquired cerebral palsy

About 10% of a child with CP, acquires it after birth due to brain damages that happen through the earliest years of life. The most communal reasons for such damages are brain infections (like meningitis) and head injuries (Hockenberry &Wilson, 2015).

2.6. Pathophysiology:

There is a difficulty in distinguishing neural lesions accurately based on clinical reasons or clinical signs because there is no distinctive clinical picture. There may be serious abnormalities in the brain in some cases and in other cases, there is a sign of clogged blood vessels and degeneration of the lower back produces a narrower Jerry and wider adhesion of low brain weight and atrophy and loss of nerve cells. There is a little exception to oxygen, which has the main role of brain damage and which is secondary to other causes (Marret et al., 2013).

The pathogen is associated in some cases with the anatomy. For example, concomitant CP with early delivery is usually caused by haemorrhage in the area adjacent to the lateral ventricle caused by an oxygen-deficient infarction. Pastoral (extrapyramidal) CP is caused most usually by hypoxia at birth, although it can also be caused by jaundice and genetic and metabolic anomalies such mitochondrial and glutaric acid diseases (Christopher & Reeve, 2016).

Cerebral palsy is frequently related with intrauterine or perinatal thromboembolism, which is often caused by maternal thrombosis or an inherited coagulation abnormality (hemipleria). Ataxic CP is linked to cerebral hypoplasia and, in certain cases, severe neonatal hypoglycemia. In general, severe quadriparesis is associated with mental deficit and microcephaly due to cortical and cerebral atrophy. Cerebral palsy is a result of a still laceration of the cerebral motor cortex that happens before, during, or shortly after birth (Hockenberry & Wilson, 2015).

The clinical signs of lesion vary with the change in child growth and development, although the same lesion is not changing. Compared to children having CP with healthy children without paralysis, the motor skills of paralyzed children improve with their growth but, at a slower rate of (Reddihough, 2016).

Spasticity in people with CP can be brought on by musculoskeletal issues such as subluxation, spasms, or pain. Movement disorders such as athetosis, chorea, dystonia, and rigidity are caused by damage to the extrapyramidal systems. The degree and type of damage to the central nervous system (CNS), the location of the permanent harm, and the CNS ability to adapt or reorganize after the shock all influence clinical symptoms of neurological traumas (Miller, 2007; Reddihough, 2011).

2.7. Classification of Cerebral palsy

Cerebral Palsy has been categorized based on a number of factors. A variety of classifications have been proposed based on pathology findings, etiologic variables, and clinical symptoms. The Swedish classification is frequently used in clinical practice and is based on the distribution, tone, and number of wounded parties (Boyd et al., 2013).

2.7.1. Anatomical Site of the Brain Lesion Is Classified:

This is divided into three groups: (Inaloo et al., 2016).

1. **Pyramidal Tract Involvement:** Neurodevelopmental signs which characterize upper motor neuron lesion is spasticity weakness, increased muscular strength, pathological reactions, increased reflexes in deep tendons.
2. **Extrapyramidal Tract Involvement:** This includes primarily the participation of nuclear zones and their relations. Clinically patients suffer from motor abnormalities like sclerosis, anesthesia, shortness of breath, dizziness and tremors.
3. **Involvement of The Cerebellum:** includes CP in its ataxic form.

2.7.2. According to Clinical Symptoms:

This classification is divided into three groups based on clinical symptoms:

1. **Spastic Syndromes:** Clinical evidence of upper motor neuron lesions characterize this condition. Muscle contractions are more common in this type of CP than in other types. Convulsions and mental impairment are also more common than other symptoms (Bottcher, 2010).
2. **Dyskinesia's:** Usually, the distribution is the same among the four parties and is characterized by the movements of non-prominent or fluctuating muscles with choreoathetosis and it is the most common subtype (Monbaliu et al., 2012).
3. **Ataxia:** The outstanding symptom is Disturbance in the state of equilibrium and balance, and usually the tremors of the intention are present with past signs and indigestion (Schnekenberg et al., 2015).
4. **Mixed Type:** In some cases of CP, such as spastic CP, spastic sclerosis, and Parkinson's foot, clinical characteristics such as spastic dystrophy, spastic sclerosis, and spastic sclerosis coexist, typically due to serious brain injury (Kwon & Lee, 2014).

2.7.3. According to Topographic Involvement of the Extremities:

Topographic classification is only used for spastic types; other kinds do not use it because they include all four limbs and are categorized according to the nature of the movement condition (Panteliadis et al., 2013).

1. **Diplegia**: the lower limbs are more affected than the upper limbs (Hockenberry & Wilson, 2015).
2. **Quadriplegia:** which involves all four limbs, often with legs more affected than arms (Reddihough, 2016).
3. **Hemiplegia:** is lateral of the body partial (Ogoke et al., 2018).
4. **Tri-plegia**: this includes three limbs and usually, both legs are combined with one arm (Hewett & Newson, 2017).
5. **Monoplegia**: involves one limb (Hockenberry & Wilson, 2015).

2.7.4. Classification According to Functional Capacity:

Classification According to Functional Capacity: It is divided into grades as mentioned by (Kwon & Lee, 2014):

Type One: There is no restraint of movement.

Type Two: There is a minor to moderate restraint of movement.

Type Three: It is moderate to the excessive restraint of movement

2.8. Clinical Features:

Because it is the most widely used in clinical practice, this Swedish classification was chosen. It depends on the type of motor deficiency that has been identified (Agarwal & Verma, 2012).

1- **Spastic Cerebral Palsy:** This is the most prevalent sort of CP. Hyper-reflexes and diminished spontaneous movement are the first symptoms. Tonic neck reflexes are common and might last for a long period after the natural age for their elimination has passed. Scissoring of the legs occurs when hip adduction is prominent (Hockenberry & Wilson, 2015).

2- **Spastic Quadriplegia:** Each of the four limbs is involved. This is a form of CP that is more severe. The infant will be immobile, and the idea is that he or she will spend the rest of their lives in a chair with only a single passive movement. It's frequently linked to a mental health problem (Leung & Chau, 2010).

3- **Spastic Hemiplegia:** At a young age, these infants display less spontaneous movement and a drive to show their preferred hand. Limping and circumduction of the afflicted limb characterize the gait (Jelsma et al., 2013).

4- **Spastic Diplegia:** All four limbs are affected, but the legs are far worse than the arms (Calley et al., 2012).

5- **Spastic Paraplegia:** It's an unusual kind of CP that only affects the legs. The likelihood of a spinal cord injury must constantly be taken into account (De Bot et al., 2010).

6- **Spastic Monoplegia***:* Spastic weakness affecting only one limb is uncommon. An asymmetric diplegia or hemiplegia is usually discovered after a thorough examination. One limb is damaged more severely than the other (Baroff & George, 2014).

7- **Extrapyramidal CP:** Early on, this manifests as hypotonic, and later, choreoathetosis and dystonia (Al-Zwaini, 2018).

8- **Ataxic Cerebral Palsy:** Hypotonia and slow tendon reflexes are found in early infancy in this unusual kind of CP (Al-Mosawi, 2020).

9- **Associated Disabilities:** Although the neuromuscular impairment is the basis for the diagnosis of CP, brain injury is not limited to the motor system. As a result, related disabilities suggesting malfunction in areas other than the motor system are widespread (Schnekenberg et al., 2015)

10- **Mental Retardation:** Around 20% of children with CP have severe cognitive impairments, and mental retardation is a common occurrence (Thapa, 2017).

11- **Visual Problems:** In a youngster with CP, visual abnormalities are common. A significant visual impairment affects 11% of children with CP. In a child with CP, strabismus is common, followed by refractive errors in up to half of the cases (Fazzi et al., 2012).

12- **Auditory Problems:** It's a common link between CP and this condition. It's most commonly connected with choreoathetosis, and it's a form of high-frequency hearing loss (Hegde, 2018).

13- **Epilepsy**: Epilepsy affects 20 to 50 percent of children with CP. The most common type of spastic hemiplegia is spastic hemiplegia, followed by quadriplegia, and finally diplegia. Attacks began in the early years of life for the majority of children with CP (Sellier et al., 2012).

14- **Speech and Language Problems:** Any clinical kind of CP can cause slow or stuttering speech. Communication difficulties, whether linguistic or gestural, may exacerbate the child's behavior problems (Nordberg, 2013).

15- **Sensory Deficits:** Because CP is a specific posture and/or movement deficit, it is frequently referred to as sensory dysfunction due to the presence of sensory corticosteroids, but it is not a pure mobility problem, as finger agnosia and two-point discrimination are examples (Bleyenheuft & Gordon, 2013).

16- **Feeding and Dental Problems:** The inability to order food due to communication problems and the inability to feed himself due to a defect in the disk drive resulting in problems of nutrition and physical weakness in children with CP. In addition, a child with CP may suffer from coughing, choking or gastroesophageal reflux during eating, aggravating craving for food (Arvedson, 2013).

17- **Behavioral Problems:** emotional and Behavioral problems are common. At an early age (preschool age), a child with CP starts to consider himself different and may suffer a weak personality and lack of self-esteem with the development of growth (Whittingham, 2014).

18- Orthopaedic Problems: They're common in CP patients, particularly those with spastic CP (Miller& Bachrach, 2017).

2.9. Diagnostic Evaluation

According to CP-related causative factors, children at risk need a very accurate assessment during early childhood to distinguish functional muscular dystrophy as early as possible. The way of basic diagnosis is a family history and neurological examination. Neuroimaging is now recommended for a child with suspected cerebral anomaly and cerebral palsy, with MRI being a good predictor of cerebral palsy when done at the scheduled time (corrected age); the General Movements Assessment has also shown strong predictive value in children aged 2 to 5 years (Novak et al., 2017).

Metabolic and genetic testing is recommended if no structural abnormality is identified by neuroimaging; laboratory tests are no longer recommended in the diagnostic process for CP. However, the nurse should display infants with known etiologic risk factors and evaluate them closely in the first 2 years of life. Because cortical control of movement does not occur until later in infancy, the motor impairment associated with voluntary control is usually not apparent until after 2 to 4 months of age at the earliest. More often the diagnosis cannot be confirmed until the age of 1 or 2 years because motor tone abnormalities may be indicative of another neuromuscular condition (Lungu et al., 2016; Novak, 2014).

In addition, some children who show signs consistent with CP before 2 years do not establish such signs after 2 years. Creating a diagnosis may be easier with the persistence of primitive reflexes: either the asymmetric tonic neck reflex or persistent Moro reflex (beyond 4 months of age), and the crossed extensor reflex. The tonic neck reflex normally disappears between 4 and 6 months of age, while the child with CP, when a crying infant is unable to move from the asymmetric posturing of the tonic neck reflex, it is considered obligatory and an abnormal response (Granild et al., 2015).

The modified Ashworth Scale is one of the assessment tools currently available to assess muscle spasm; functional independence in self-care, mobility, and cognition (Functional Independence Measure and WeeFIM [specify to children]); self-initiated movements with time (measuring the function of the total engine); and performance and ability of career activity in mobility, personal care and social function (Pediatric Assessment of Incapacity Record). Thoroughgoing understanding of standard differences of motor progress is necessary for discovering nonstandard development, and careful history is essential to distinguish probable etiologic factors. Detect the child's impulsive movements and behaviour, including tone; function; and muscle size, attitude, and posture. Because children with CP often have sensory deficits, it is appropriate to evaluate the child for hearing and vision deficits (Lungu et al., 2016; Novak, 2014).

2.10. Diagnosis: History:

It was focused by (Morris, 2007) that full family history and history of pregnancy could lead to a good diagnosis, aside from the medical records, information on the birth and perinatal period should be gathered. During pregnancy, medications, smoking, and alcohol intake should also be considered. Transient febrile sickness, especially in early infancy, may be significant.

2.10.1. General Examination:

It may reveal indicators such as congenital cataracts, retinitis (rubella), microphthalmia, microcephaly, cardiac lesion, hepatosplenomegaly (Lungu et al., 2016).

2.10.2. Neurological Examination:

The normal neurological examination on the couch can be challenging. Building the child's confidence in cooperation with the examination, as well as careful monitoring of the child's movement and posture during the history, are essential. CP patients have a stereotyped posture and limited range of motion. It's difficult to assess a person's tone and feelings (Novak, 2014).

2.11. Therapeutic Management: General Concepts

The goal of treating children with CP is to early discriminate the optimal developmental cycle and to strengthen it so that children can limit the imbalance of their function and achieve their potential. Treatment of symptoms in the first place protects them from permanent disorder (Hockenberry & Wilson, 2015).

The valuable effects of rehabilitation programs are based on parent and child as quickly as possible, recognizing disability and applying the treatment. The presence of parents in the treatment program is necessary and their confidence in management and cooperation and consideration of their goals and desires. Parents can also test the basic sensory experiences of cognitive development with the early diagnosis because maintaining the integrity of the central nervous system structure depends on stimulation. The objectives of the broad treatment are as follows: (Reddihough, 2016).

1. Self-care and create movement and communication.
2. Integrating the engine function and gaining the perfect appearance.
3. Possibility of repairing the defects associated with the fastest time and effectively.
4. Incorporate paralyzed children with healthy children to enhance their socialization experience.
5. Provide education for the child commensurate with his needs and abilities.

Each child with CP is assessed and treated individually, with a treatment plan that may include a combination of facilities, data, and training. The complexity of a child's needs necessitates comprehensive management and care coordination between specialists and the child's family. Because of their stability and predilection for self-care activities, children and parents with CP can attain their complete capacity (Reddihough, 2011).

2.12. Management:

Managing of CP includes these matters:

2.12.1. Reparation of Brain Damaged:

Yet, there is none significant clinical overlap which can repair damage to the brain regions responsible for successfully coordinating and moving muscles, as well the management of neuromuscular function impairments alteration with a growth period. Though the concept is that convulsion related to CP must be cured already child reaches the school age so that contractures do not take the casual to develop (Hockenberry & Wilson, 2015).

2.12.2. Physiotherapy:

The main goals are to produce muscle relaxation, improve controlled muscle activity, and develop a purposeful movement pattern. Physiotherapy is an important part of treatment (Dodd et al., 2010).

Physiotherapy can be done in a variety of ways:

1) Temple fay: This uses abnormal reflexes to facilitate movements.

2) Bopath treatment is based on a neurological understanding of the movement pattern of newborns.

3) Vojta: Improves postural control by inducing reflexes that cause movement using excitatory trigger regions.

4) Because hydrotherapy reduces the influence of gravity, the amount of medication required is reduced, and the young man becomes more mobile.

5) Hippo therapy (Horse Riding): When done properly and under supervision, it can help to improve posture and tone while also preventing aberrant movement patterns.

2.12.3. Device-assisted Modalities

Those in addition to the techniques used by the therapists have been developed to improve the function and reduce the vulnerability. These include biofeedback and therapeutic electrical stimulation (Hockenberry & Wilson, 2015).

2.12.4. Orthoses

Good orthoses are necessary in the treatment of CP. The use of an ankle-foot orthosis (AFO) worn within the shoe to control an equine's abnormality (Olawale et al., 2013).

2.12.5. Oral Pharmacotherapy and Parenteral Medication

To target focal problems or generalized convulsions drug therapy can be used. The most common oral agents to treat spasticity are gabapentin, baclofen, dantrolene, tizanidine and benzodiazepines (Morris et al., 2011).

2.13. Medication

Pain may also be experienced by children with CP as a result of painful procedures such as botulinum toxin type A (Botox) injections, surgical procedures for the relief of abdominal pain and systolic abnormalities associated with posture, pain, and gastroesophageal reflux associated with physical treatment. As a result, pain management is an essential component of care for children with CP (Berker & Yalçın, 2008).

Oral pharmacokinetics (Dantrium), Bacillus (Lioresal), and Diazepam [Valium] in children are not effective in improving muscle coordination. However, it is good at decreasing total cramping. Toxicity of the liver (dantrolene) is the most common side effect of these factors followed by weakness of the muscles, drowsiness and fatigue. Disorders of the diaphragm and constipation are less common. oral baclofen: other possible complications include hallucinations, mood changes, seizures, nausea, and urinary incontinence. Diazepam is used often but should be limited to school age and adolescents. Botulinum toxin A as well as used to decrease muscle spasm in the limbs (Buccino et al., 2018; Darrah et al., 2011).

A specific muscle is injected with botulinum toxin A. (commonly the quadriceps, gastrocnemius, or medial hamstrings). It prevents the release of acetylcholine in a specific set of muscles, thus preventing the movement of these muscles. This may prevent the cramps of the affected muscles and especially the lower extremities when administered early during the disease, and thus avoid potentially damaging effects with the surgical procedure. Its purpose is to approve the extension of the muscle as it relaxes and allows the blood to be inflamed with ankle-foot orthosis (AFO) (Buccino et al., 2018).

Surgical overlap and drugs are designed to regulate and manage the spasm associated with CP by placing the Baclofen pump in the tracheal space surrounding the spinal cord to relieve the spasm. High doses of oral baclofen have substantial adverse effects, such as tiredness and confusion, but they are typically ineffective at relieving spasticity (Haufs, 2015).

Intrathecal baclofen is particularly useful for enhancing comfort. Before the pump is placed, the patient is examined by pumping (test dose) of the Baclavin and is delivered via the lumbar puncture. Relieving convulsions and severe examination of side effects occurs for several hours after infusion such as problems related to catheterization or pump, tension, headaches, drowsiness, vomiting, nausea and seizures. If an optimistic effect occurs, and the patient may be considered a candidate to implant the pump. The pump is positioned in the center of the abdomen's subcutaneous layer. The pump is attached to an intrathecal catheter that runs from the lower back to the belly. Using a telemeter stick and a computer, the pump is filled with baclofen and programmed to give a specific dosage (Chung et al., 2011; Dudley et al., 2013).

The patient is admitted to the hospital for a few days in order to adjust the dose and ensure a complete recovery. Outpatient checkups to refill the pump and make dose changes are scheduled every 4 to 6 weeks, depending on the patient's response to treatment. Intrathecal baclofen has the advantages of dosage titration for optimal efficacy, therapeutic susceptibility, and the possibility to remove the pump without generating systemic side effects. Rebound spasm, pruritus, disseminated intravascular coagulation, hyperthermia, multiorgan failure, rhabdomyolysis, and death can occur when intrathecal baclofen is abruptly discontinued, especially at high dosages; in most cases, intrathecal baclofen withdrawal might mimic sepsis. The purpose of withdrawal treatment is to reinstate the medication, with noticeable results within 1-2 hours. Withdrawal may require hospitalization and surgery due to failure of the pump or catheter. (Berker &Yalçın, 2008).

Children who have seizures, such as carbamazepine (Tegretol), divalproex (sodium valproate and valproic acid; Depakote), oxcarbazepine (Trileptal), and lamotrigine (Lamictal) are frequently prescribed antiepileptic medications. Gabapentin (Neurontin) has been shown to relieve cramping in adults (Dudley et al., 2013).

There are no studies on the drug's effectiveness in children with CP, although one study of children with CP found that oral tizanidine combined with botulinum type A was more successful than oral baclofen and botulinum type A. All drugs should be closely monitored to avoid toxic or excessive doses and to maintain a therapeutic level (Chung et al., 2011; Hockenberry & Wilson, 2015).

2.14. Management of Associated Disabilities:

Associated disabilities, such as vision, seizures, hearing and speech, feeding, excessive salivation and drooling, and behavioral difficulties, can often be more severe than the motor disability itself, necessitating specialized care or just at home mentioned that severe cases required appropriate drugs that the treatment is right for a child with CP also depends on the stage of life and not just its symptoms. The youngster need direct treatment in order to help him develop suitable abilities for age or prepare for future educational pursuits (Nordberg et al., 2011; Arvedson 2013; Mu’ala, 2016).

2.15. Avoidance of Cerebral palsy

The best recommendation for a healthy child is to get regular carefulness before birth, a healthy food system, avoid smoking and alcohol intake, drug use before and during pregnancy. Additional tips include restraint CP: Use child safety seats in cars and a helmet when riding bikes, skateboards, and other similar activities to avoid skull injuries. Keep a close eye on young children when teaching them to swim. Child abuse should be avoided. Toxins should be kept out of reach of children, and phototherapy should be used to treat neonatal jaundice. In rare situations, blood transfusion may be required to establish the likelihood of Rh compatibility in expectant moms. Rh factor incompatible usually not a problem at the primary pregnancy, the mother's body normally products antibodies unnecessary just after birth. Special serum presented after every achievement can inhibit the production of antibodies Doubt antibodies appeared throughout the first gestation, or if it doesn't prevent the production of antibodies, the fetal monitor closely. If necessary, it can give a transfer to the baby in the womb or interchange transfusion can be given after birth, and the removal and replacement of a large amount of blood the baby (Doyle et al., 2009; Wolf et al., 2012; Nguyen, 2013; Stanley & Swierzewski, 2015).

2.16. Recreation

Growing up also necessitates participation in recreational activities. For youngsters who are unable to participate in fixed sports or other peer activities, fun openings and after-school activities must be an option. Many hobbies and pastimes are suited to their ability, and some can participate in athletic and artistic endeavours, recreational activities, for a child with CP, sports and physical fitness are encouraged, and early children should be exposed to all physical activities available to children without impairments. However, such programs require adequate supervision to avoid any harmful effects. To build self-confidence in children and improve their functional abilities, motivate children and their curiosity, and assist them in coping with their disabilities leisure activities that improve everything Children with impairments are increasingly able to participate in competitive sports, which adds a new dimension to physical activity (Kyle & Carmen, 2013).

2.17. Education

Learning requirements, like all elements of care, are decided by the child's needs and potential. This includes the sternness of a child’s illness and occurrence and degree of associated situations that disturb education and sharing, such as education impairment, anomalous activities, or behaviours, weakened vision or hearing, and seizures. In the regular seasons between period and time, children with mild problems can have an average of general involvement. To provide individual attention to the specific needs of the child, resource sections must be available in schools. The initial goal should be to integrate these youngsters into regular schools (Pillitteri, 2010).

Children who are unable to gain from formal education may benefit from a training program. Prevocational and professional counselling and guidance are arranged at adolescence in any setting. The nurse should support parents in obtaining the appropriate services for the child and should be familiar with child-related services, early intervention programs and special education items (Hockenberry & Wilson, 2015).

2.18. Prognosis

The prognosis of a kid is determined by the severity and extent of the child's motor impairment, as well as the related disability. Most children with hemiplegic CP can walk independently with the use of a circumduction gate. Only 63 percent of children with pure ataxia, 61 percent of children with diplegia, and 21% of children with dyskinetic CP can walk normally, while none of the tetraplegic children can (Berker & Yalçın, 2008).

Although CP is not a progressive condition (i.e., the brain injury does not worsen with time), the symptoms may worsen. If a child receives significant care, the child's condition may improve slightly during childhood, but after the bones and muscles have established themselves, orthopaedic surgery may be required. And, until the child begins school, the entire potential of an intellectual child born with CP is frequently unknown. Learning challenges are more common in people with CP, albeit these may be connected to IQ, including varied degrees of mental disability. As in the general population, the intellectual level of people with CP ranges from genius to cognitively handicapped. Experts have noted that it is vital not to underestimate a person with CP's ability and to provide them with every opportunity to learn, just as it is in the general population. Those with CP have a lower average life expectancy than the general population, but this has improved with the advancement of modern medicine (Jenks et al., 2007; John, 2013).

People with CP can live a variety of lives, depending on their vulnerability and capacity to self-determine and handle life's logistics. Some people with CP need a personal assistant to help them with all of their everyday duties. Others merely require support with specific tasks, while others may not require financial assistance. A person's ability to live freely is usually assessed by their ability to manage their life independently depending on their current circumstances, regardless of their level of physical handicap. CP patients can sometimes convert, manage, and hire others (PCAS). Personal care assists employers in maintaining their autonomy by assisting them in meeting their daily personal needs in a way that allows them to keep control of their lives. CP patients typically expect to live a normal life. Survival is tied to the ability to move, roll, and feed oneself. CP does not impair reproductive function, hence it can affect both children and parents (Panteliadis et al., 2018).

2.19. Prevention:

Kyle & Carmen (2013) Specified the preventive measures of certain influences such as, regular prenatal care, prenatal follow-up and immunization against rubella, child safety precautions, treatment right away for a baby who is jaundiced, and the last Labor room should be well equipped for fetal monitoring and neonatal resuscitation if needed.

2.20. Burdens

The disruption generated by dealing with the individual getting attention, the physical need for care, and the mental powerlessness is referred to as burden. It can also be defined as a collection of physical, mental, social, and economic issues that interfere with primary carers' everyday tasks, social contacts, and emotional equilibrium. The caregiver's view of the physical, psychological, emotional, social, and economic challenges that develop as a result of a family member's care has an impact (Vadivelan et al., 2020).

2.21. Type Burden

There are several types of burden, such as the economic burden, the burden as of its influences at the family habitual, and the burden as a result of the effects on family entertainment, a burden on the implications of family communication, the burden produced through the effects on physical health of other family organs and the burden of the effects on psychological health of the other family partners. Heavy responsibilities can be harmful to a person's physical, mental, and societal well-being. This also reflects on the statues mother's social, cultural, and professional life. Mothers of children with CP may experience psychological, social, and physical issues, such as difficulty maintaining social contacts, marital conflict, job rejection, insufficient support resources, and so on (Brehaut et al., 2004; Brehaut, et al., 2009; Grootenhuis et al., 2007; Davis et al., 2009; Ennis & Bunting, 2013).

2.22. Psychological Burden of Mothers

When a crippled child is born, the parents' suffering can be intense, with feelings of guilt, shame, misery, and depression. A caregiver who is caring for a disabled child may experience sad, anger, and be under a lot of stress. Mothers of children inflicted with CP might be on danger of depression and interferences be considered the impacts of moderate social assistance might raise the adaptability of mothers (Marrón, et al., 2013; Thompson & Sherwood, 2014).

Mothers of children with CP are put under physical and mental pressure, which must be linked to a reduction in quality of life. Mothers of children with CP have been linked to an increased incidence of depression due to stress from caring for a challenged child, a lack of social support, and a low level of parental approval. Furthermore, the level of social support and the severity of the child's sickness are associated to the high risk for anxiety and depression, among moms of children with CP. So mothers are experiencing a variety of mental and behavioral changes, including forgetfulness, sadness, dependency, lack of motivation, a sense of being trapped, and fatigue from their duties. The family, has a handicapped child born into it and who grows into adulthood, is one of the most stressful experiences a family can tolerate. Parenting high-risk infant's additional challenges and pressure on families that are struggling to deal with child-rearing. The level of stress that parents possess many determinants, involving the difficulty of the child's health problems, imagine the parents of the child's abilities, and situational factors, such as social and economic settings poor or inadequate social assistance (Ketelaar et al., 2008; Dervishaliaj, 2013; Chowdhury, 2018; Masulani et al., 2018; Asa et al., 2020).

Mothers frequently experience social isolation and physical stress, such as sleep deprivation, musculoskeletal pain, and hypertension. A kid with CP primary caregiver is responsible for assisting the youngster in becoming more self-sufficient in their everyday activities. In order to have enough time for patient care, he must risk his safety. For many parents, the age of childhood can be challenging; however, parents of children with disabilities may face additional difficulties due to their child's handicap and their family's concern. Parents of impaired children face a lot of stress, which can be linked to the child's features, such as behavioral issues, insufficient assistance, and long-term care. Parental conflict over caring for a disabled kid, a lack of financial and social support, and changes in family lifestyle and recreational activities as a result of caregiving responsibilities are all possible sources of stress (Shyam et al., 2014; Klosi et al., 2019).

Mothers of children who suffer from CP showed the extreme levels of strain were those who perceived their children as poor and unable to adjust. They too sensed severe social separation and obtained little support from a spouse.The severity of the child's health problems, as well as the treatments available, have little impact on the mother's anxiety; instead, a perceived lack of partner support and an external position of control are important mediating elements of parental stress(Glenn et al., 2009).

The connected somatic and mental condition of primary care providers, usually mothers, and strongly demands behavior and the time it requires the child. Within several situations, mothers and the changing dynamics of their life's and end the performance of its social role given to children suffering from CP. Thus, the responsibilities that enhance this function leads to fatigue, separation, and pressure on the portion of mothers. Caring for children with CP is an unavoidable part of parenting, but it can increase the mother's effort and stress. Living with a chronic disease like CP has an impact on the entire family, particularly the caregiver, who is usually the child's father or mother (Glinac et al., 2017; Barros et al., 2019; Vadivelan et al., 2020).

Parents, caregivers, and other family members may face a variety of obstacles when caring for a disabled child or children. Stress, guilt, low self-confidence, and negative attitudes and behaviors are some of the psychological and social obstacles that parents and caregivers of children with disabilities encounter. Concerns for the children's future cause anxiety and despair, as well as mental fatigue (Asa et al., 2020).

2.23. Social Burden

Living with a disabled person can have an impact on a family's psychological and social well-being as well as cause conflict. However, because families with disabled children must engage with the outside world, the difficulties caused by extend beyond the household. Another constant challenge for mothers with impaired children is society's unfavourable attitude toward their children. Despite the fact that society's attitude toward and treatment of people with disabilities has improved through time, some parents still feel uneasy around their children and choose to avoid contact with them or their children, many disabled mothers isolate themselves and their children from outside social engagement, and the social life that families manage to maintain is confined to their extended family and a few acquaintances who can deal with their child's condition. (Linda, 2012; Andrea et al., 2014; Stuart & Gail, 2014).

Mothers of challenged children face social withdrawal, "lower involvement with extended family, changes in acquaintances, fewer husband-wife activities, decreased occasions attendance, and fewer contacts with neighbours" .The CP child's chaotic behaviour may make taking him or her out in public difficult, limiting family outings, parents of impaired children are more prone to withdraw into the home and use less social supports and outside activities to reduce stress because they have strong ideas about their children's undesirable features(Morgan et al., 2009; Cadman et al., 2012; Andrea et al., 2014).

Marital animosity, loneliness, stigma, and a lack of social engagement with other members of society all have an impact on the family. Low family income, large financial demands, and limited access to materials and services are all financial repercussions of having children with disabilities, which affect not only parents but also extended family members who help with the child's care, such as siblings and grandparents (Asa et al., 2020).

Having a child with impairments can deplete a family's resources due to costs such as tests, educational programs, and many therapies. Due to the care-taking demands of nurturing a child with disabilities, financial strains may be exacerbated by only having one income to support all of the families' needs. Mothers express concern about the financial challenges of raising a disabled child, as well as whether the family's income will be enough to meet the child's current and future needs, such as special education, therapy, and medical care. Unlike children who develop normally and become financially self-sufficient, most impaired children require long-term financial assistance. For the remainder of their lives, the majority of handicapped children will rely on others (Adrianne, 2008; Andrea et al., 2014).

Social burden of the CP child itself feeding, toileting, and transporting the child to and from appointments may take longer for the child with special needs. Balancing the expectations of the kid and the family's normal life against the demands of the handicap is one of the most difficult challenges parents confront. In addition to the everyday costs of caring for a kid, mothers of special-needs children face the additional challenge of locating special clothing, adaptive equipment, and making housing adjustments (Thompson, 2010; Linda, 2012).

2.24. Quality life child with Cerebral palsy:

The term "quality of life" refers to a general sense of well-being that includes objective and subjective assessments of physical, material, social, and emotional well-being, as well as personal growth and meaningful activities, all of which are assessed against a set of personal values. Whether crippled or not, everyone has the same level of quality of life. Second, people's perspectives on the world differ, affecting how they define happiness (Kotzampopoulou, 2015).

The concepts of quality life and quality life as it relates to health are inextricably linked. Children with CP who strive to improve their HRQOL are extremely valuable. The functional impairment that develops in children with CP as a result of concomitant physical, cognitive, sensory, emotional, and social disabilities prevents these children from carrying out the social responsibilities that have been assigned to them, resulting in a significant decrease in HRQOL. Children with CP face a variety of functional limitations, depending on the severity of the effect, and these functional limitations have a negative impact on HRQOL. Furthermore, there is a variable amount of HRQOL effect even among children with similar functional limitations (Ozdemir & Tezcan, 2017).

It emphasizes the importance of quality of life and well-being as one of the initiative's four fundamental goals. The following are the goals: The first goal is to live longer, higher-quality lives that are free of preventable illness, impairment, damage, and death. The second goal is to achieve health justice, reduce inequities, and improve everyone's health. The third objective is to create social and physical conditions that encourage everyone's health. At all phases of life, the fourth purpose is to encourage quality of life, healthy growth, and healthy behaviors (U.S. Department of Health and Human Services, 2019).

Quality life reflects people's impressions of how their health and functional status affects their ability to participate in society. QoL is not directly equivalent to health or functional status as assessed by participation; rather, it reflects the level of community participation based on an individual's level of participation considering their health or occupational status and surroundings. This participation measure is based on the principle that a person with functional limitations, such as vision loss, mobility difficulties, or intellectual disability, can live a long, productive life with a good quality of life; Lower functional status cannot and should not be equivalent to poorer QoL (Hays et al., 2009).

Wellness is emphasized by community health practitioners, which includes this notion of health as well as the ability to develop a person's potential to live a full and productive life—a life that can be assessed in terms of quality of life. Healthy communities have characteristics that enable individuals to maintain a good quality life and productivity through improving health and reducing disease, as well as health disparities and health care delivery inequities. Furthermore, one of the environmental health aspects is quality of life, which is influenced by environmental physical, chemical, biological, social, and psychological issues. It also refers to the concept and practice of identifying, correcting, managing, and preventing environmental features that may have a negative impact on the health of current and future generations. There are two methods for measuring QoL are available. One may use common measures that are designed to take advantage sides of health related influences of care through a wide-ranging of population, the second may seek for the indications that process the components which will distress the lives of individuals with a particular condition. In this situation the investigators search for a measure of QoL that specifically address the burdens which is produced by a possible social disturbance condition (Allender et al., 2014; Caruso et al., 2016).

Despite the fact that CP is caused by a non-progressive lesion, some children's motor abilities have been demonstrated to deteriorate as they get older. Sensory, cognitive, communication, and behavioral problems, as well as neuromuscular and musculoskeletal abnormalities, are all signs of CP involving persistent reflexes and altered muscular tone and strength (Costigan & Light, 2011; Shariat et al., 2014; Wely et al., 2014).

Individuals with CP are currently divided into groups based on function, which links to their clinical presentation and level of activity limitation , this CP classification is particularly essential since it helps tell healthcare providers about a patient's current and future needs, allows them to distinguish between different types of CP, and allows them to observe the same person over time , because everyone's skills change over time, functional classification of CP is age-dependent .The Gross Motor Function Classification System is used to classify children with CP .This is based on self-initiated movement as well as usual performance, particularly in the areas of sitting, transfers, and mobility(Rosenbaum et al., 2007; Rosenbaum et al., 2008).

There are five levels of classification, with the following details:

Level I – walk without restrictions.

Level II – walk with limitations (difficulty with long distances and balance).

Level III – walk with limitations (difficulty with long distances and balance with the aid of a hand-held mobility device).

Level IV – walk with limitations or limited self-mobility (either use of wheelchair or hand-held mobility device).

Level V - a manual wheelchair is required for transportation. It should be noted, however, that there are some classification differences based on the child's age. Multiple physical restrictions, such as muscle weakness, decreased cardiovascular and muscular endurance, poor circulation, systemic difficulties, lower bone density, and higher fractures, are all common in children with CP (Russell et al., 2011).

Children with CP face a variety of challenges in order to improve their quality of life, including cognitive deficiencies and functional difficulties. Over half of children with CP report experiencing moderate to severe pain on a daily basis in many parts of the body, and this self-reported pain is thought to impair emotional, social, and physical aspects of health-related quality life (HRQOL) (DeFazio & Porter, 2016; Patel et al., 2020).

Lack of energy, fear of damage, lack of body control, and the existence of cognitive impairment all affect children with CP capacity to engage. Participation is essential for the development of a kid since it allows them to form relationships, acquire social skills, and create an environment conducive to physical activity (DeFazio & Porter, 2016).

As a result of people's desires, the concept of quality life is evolving. Quality life is defined as the enrichment of one's daily life. Furthermore, while the focus is on the individual's choices and aspirations, environmental factors have an impact on life quality as well. Subjective and objective measurement, life domains, and the impact of personal values are the three essential components of the framework (Shearer, 2010).

2.25. Physical Functioning (problems with child CP)

Physical activity is defined as any movement of the body involving the use of skeletal muscles and resulting in an energy expenditure (consistently varying between low and high levels). Physical activity performed during normal daily activities over a period of time (day, week, etc.) Children and adolescents with CP (CP) have lower hypothalamic-pituitary-adrenal levels than their typically developing peers. Impaired physical health and loss of function will both result in a decrease in QOL (Reedman et al., 2017).

Despite the existence of suggestive signs and symptoms much earlier, clinical aspects of this entity grow with time, and a distinct CP syndrome may not be identified until 3-5 years of age (Gulati & Sondhi, 2018).

Children with CP engage in 30 percent less physical activity than children who are usually developing, because their neuromuscular and musculoskeletal systems are weakened, children with CP are more prone to sedentary behaviours and are less physically active than their peers. Children with CP have fatigue, pain, and mobility difficulties, which prevent them from participating in physical activity as much as they could. Environmental elements like as transportation, government policy, and community services play a crucial mediating role in the involvement of disabled children (Furtado et al., 2015; DeFazio & Porter, 2016; O'neil et al., 2016; Gorter et al., 2017).

Interference with brain impulses that either wrongly raise or diminish muscular tension causes poor coordination, abnormal balance, and irregular movement patterns in people with CP. The most prevalent symptoms of brain injury are high degrees of motor dysfunction and difficulty with gait quality. Gait is a complex capacity that includes not just keeping the body's center of gravity in a standing position, but also preparing the body to move, maintaining movement, and stopping movement (Verschuren et al., 2012).

Abnormal muscle tone, the presence of a movement disorder, poor balance, decreased range of motion, lower muscle force, decreased endurance, less motivation, and a lack of family support are all barriers to improving motor skills in children with CP. Almost all children with CP require long-term traditional physical therapy, which is frequently provided in schools (Mccoy et al., 2018).

The location and severity of brain injury dictate the type of current tone, the degree to which selective motor control and balance are compromised, and the extent of the subsequent developmental distortion. An abnormal gait is caused by three factors: defective selective motor control, poor balance, and abnormal muscle tone. The inability to activate specific muscles selectively in order to produce a movement pattern is referred to as impaired selective motor control (Gage, 2004; Gage & Schwartz, 2009).

People with CP often have poor balance, which impacts their step quality "Balance or postural stability is a fundamental component of movement, including the ability to recover from instability as well as predict and act in ways to minimize instability, "delayed initiation of muscle contractions, alteration of muscle response time, and greater co-activation of antagonist muscles with agonists are all aspects of the neuromuscular response that contribute to these balance deficits in CP patients.". Increased muscular tone (hypertonia) or decreased muscle tone (hypotonia), unstable muscle tone (dystonia), and muscle spasms are all examples of abnormal muscle tone (Levitt, 2004; Miller & Bachrach, 2006; Donker et al., 2008; Clifford & Holder-Powell, 2010; Hsue et al., 2009; Eek et al., 2011).

Two prevalent CP-related abnormal gait patterns are stiff knee gait and crouch gait, though current patterns may alter. The most typical pattern, which can be seen in both hemiplegic and diplegic CP, is a stiff knee gait. Insufficient knee flexion occurs during the swing phase in people who walk with a stiff knee gait. Excessive hip and knee flexion occurs during the gait cycle in a crouch gait pattern. It can happen to people with hemiplegia, but it's more common in people with diplegia (Krogt et al., 2010).

Balance and gait quality continue to be the most difficult everyday challenges for people with a variety of physical limitations. For young children, they are more difficult to stabilize, and once impaired, individuals identified with CP require more rigorous recovery efforts (Law & Pennington, 2021).

2.26. Emotional and Social Functioning (problems with child CP)

Children and adolescents with CP are in danger of having their activities and participation restricted, particularly during adolescence; studies have indicated that restrictions on activity participation and the risk of social isolation are more common in older children. The amount of activities and participation were determined in part by the prevalence of epilepsy and intellectual ability. Children with CP have a lower capacity to participate in childhood activities such as sports, play, mobility, and daily living abilities in areas such as social functioning and communication. Interpersonal interactions and relationships, as well as communal, social, and public life, are all characterized as social function by the International Classification of Functioning, Disability, and Health (ICF).Communication is defined as a separate but clearly connected area in which a person sends and receives messages in a range of settings through a number of communication modalities such as listening, speaking, reading, and writing .Individuals with CP may have a lower quality life in terms of sociability and reaching their potential than the general population (Miller &Bachrach, 2006; Voorman et al., 2010; Usuba, 2014).

Daily activities are difficult for people with CP because of their motor deficits, such as gait quality. Individuals may experience emotional and social challenges as a result of their physical difficulties, decreasing their quality of life. Despite the fact that CP is primarily a mobility disorder, many children with it are restricted in their participation in play and social activities due to a variety of motor deficits and other difficulties (Heide et al., 2004; Woollacott et al., 2005; O'Shea, 2008)

Miller and Bachrach (2006) Children with CP may have limited access to other children due to their parents' protectiveness and other parents' beliefs about allowing their child to play with a child with a disability.

Physical, psychological, and environmental barriers limit access to school-based and extracurricular activities. Because of their limited mobility, children with CP have less opportunity to participate in group play and other activities. Lack of drive, imagination and creativity, sociability, and aggressiveness are also common secondary issues. Social and emotional development and maturity are hampered by CP physical limitations. The disease's motor weakness limits, and in some cases eliminates, these fundamental, life-changing human experiences for children with CP. The inability to move might have a negative impact on a child's life and cause them to become isolated (Turkcan, 2016).

2.27. School Functioning (problems with child CP)

Basic intellectual works are focused with the educational work in which children learn to read, write, and execute basic arithmetic during their school years. At this age, children learn to accept and follow rules both in and out of the classroom (school friendship, relationship to authority). Basic school knowledge can be inhibited by CP at any level, and at varying intensities. The ability of a youngster to learn is related to his or her intellectual capacity. It's often difficult to assess a child's intellectual ability, especially when they have more difficulties in certain areas, have physical problems, or have a restricted vocabulary (Pereira et al., 2019).

Many children are afflicted with illnesses that make determining what a youngster can do, how much he or she can learn, and what to expect from them challenging. It's crucial to distinguish between a child's ability to learn and his or her ability to present information in the classroom. Despite their eventual and typical intellectual powers, children struggle to absorb school abilities like reading, writing, math, and speech, as well as other skills required for successful study. Perceptual or processing anomalies typically result in a lack in the interaction process on higher mental processes (Reid, 2005).

Listening, thinking, concentrating, speaking, reanalyzing and writing, analyzing, learning, realizing, expressing, and math are all areas where children struggle. Children with CP have both motor and non-motor deficits: Low intellectual ability affects 25% to 30% of children; epilepsy affects 25% to 45 percent of children; sensory deficits affect 18% of children; hearing difficulties affect 5% to 15% of children; behavioral problems affect 25% of children; ADHD affects 25% of children (Žgur & Erna, 2012).

2.28. Nursing Care Management:

To improve the quality of life child's psychological and physical development, a care plan should be developed that includes a wide range of inputs to assess the child's capacities and accommodations that help to expand these capacities and limitations and develop the treatment (Pillitteri, 2010).

Because each child's situation and circumstances are unique of their kind, their needs will be as well. Therefore, the services provided by the therapists depend on Nature accepts the situation by the family, their need for these services, and the level of support they receive (Almasri et al., 2011).

The care plan identifies the various aspects that parents wish to explore during their child's journey with CP. Access to effective education plans, health care facilities, community support, government assistance, health insurance, financial stability and appropriate shelter can be very useful (Kyle & Carmen, 2013).

2.28.1. Assessment

The risk recording of a kid with etiologic reasons connected to CP is part of the nursing assessment. The nurse was alerted to examine further after continuing to screen infants for failure to meet developmental milestones, the persistence of neonatal reflexes, and aberrant muscular tone (Berker &Yalçın, 2008).

2.28.2. Reinforce Therapeutic Plan and Assist in Normalization

Mothers participate in the treatment of their disabled children at an early age, so they need to have programmed steps for home care and proper handling of their children with CP and to be able to do so that their expanded parental role can be melded into the established relationship. Nurses help parents develop and adjust their child's activities and Modification of equipment and enhance their plan to continue treatment at home (Berker &Yalçın, 2008).

Encouraging parents to recognize and identify their concerns and ask them what approaches they have tried and for how long. In this way, the nurse is able to find out what works, what does not work, and what the parents would like to try next. Give the parents positive feedback for their observations of the infant, the progress they note, and how they differentiate the child's needs (Pillitteri, 2010).

2.28.3. Address Health Maintenance Needs

Because a kid with CP expends so much energy in attempting to perform ADLs, more frequent break intervals should be scheduled to avoid fatigue, which could exacerbate their limited abilities (Almasri et al., 2011).

Because of his or her incapacity to self-feed or gastroesophageal reflux, loss of appetite, swallowing and nutritional issues, and chronic constipation, meeting the child's food demands is a challenge for him. As a result of being extremely low birth weight (LBW) in combination with these feeding problems, children with CP are at danger for letdown to grow well, and the nurse must ensure an adequate caloric intake (Milbrath et al., 2012).

After the kid has reached the age of one year, nutritional supplements such as high-calorie milk products (e.g., Pedi-sure) may be required to ensure optimal caloric intake. Additional nutritional concerns include providing adequate intake of fruits and fire to enhance gastrointestinal motility, routinely monitoring child's growth on a standardized growth chart, and avoiding overfeeding and obesity (Mazumder et al., 2015).

Repetitive valuation of skin status is imperative in a child with CP who are narrow in movement or who must remain in assistive devices. Care must be taken to ensure that adequate objective skin assessments are routinely performed. If skin breakdown does occur, consult a skin and wound specialist for management and additional prevention. Oral motor skills can be maintained by continuing oral feedings (Pillitteri, 2010).

Vaccines should be given to children to prevent illnesses and protect against respiratory infections like influenza. Depending on their degree of engagement, oral disorders may be more common in children with CP, demanding extra attention to all aspects of dental care (Milbrath et al., 2012).

2.28.4. Support the Family

Supporting the family is important to reduce psychosocial burden and a critical nursing task is to manage the child's and parent's care for the child and parent with CP. In other circumstances, the family assumes complete responsibility for the child and gains a thorough grasp of his or her wants and requirements. The home health nurse or case manager's involvement in providing support and encouragement to the families who are responsible for the child's primary care is crucial (Matthews et al., 2011).

Having a child with CP entails many challenges in everyday management and changes in family life, and the nurse can emphasize the need of normalization principles. The nurse can help parents by recognizing and speaking about their fears and concerns, as well as observing and raising their problem-solving abilities and techniques of aiding the child. The impaired child's brothers and sisters may be affected as well, with public conduct issues or ambiguous behaviour (Peplow et al., 2013).

Mothers may need assistance and advice with Giving treatment to prevent blockage by tube gastric bypass. It can also grind the grains and mix them with a small amount of water and not just other liquids, such as alkaline and herbal medicines, which can be sludge that interferes with the work of gastrectomy tube. When crushed pills or tablets administered, flesh the feeding tube with more water after instilling the dissolved pill in water (Olawale et al., 2013).

Throughout the rehabilitative process, the family requires a relationship with nurses who can give regular connection, care, and encouragement. Parents can also find comfort and practical counsel in parent groups, where they can share their daily routines, activities, problems, and concerns while receiving support and advice. mothers, for example, can learn what it's like to have a child with CP from others (Matthews et al., 2011).

2.29. Parental Roles

Parenting a kid with a complicated chronic condition includes balancing the regular obligations of parenting with the added responsibility of providing complex technical care, symptom management, support, and seeking and organizing health and social resources for their sick or disabled child. These new responsibilities must be managed with the needs of other family members, extended family, and friends, as well as personal health and obligations, to avoid negative consequences for the family's overall functioning (James et al., 2014).

One parent or spouse frequently stays at home to take care of other household responsibilities while the other stays with the ill child. The partner who is not active in the caregiving activities may feel ignored and resentful that he or she is not fully informed to be competent in the care because all of the attention is focused on the child. If the parent is not actively involved in the child's care, they have little appreciation for the time and energy spent on these activities. When this spouse tries to help, the other parent may be dismissive of his or her inexperienced efforts (Judie, 2018).

Differences in Mother–Father Relationships: Mothers and fathers of children with complex medical conditions frequently adjust and cope in various ways. Mothers are frequently the primary caregivers, and they are more likely than males to leave their employment to care for their children, which can lead to social isolation (Coffey, 2006).

The nurse can assist parents avoid role conflicts by providing anticipatory guidance early on. The weight of care at home, the financial burden, the dread of the kid dying, the pressure from relatives, the hereditary character of the condition (if relevant), and the fear of pregnancy are all stresses that are widely cited as influencing marriages. Inconveniences of care, such as long wait times for appointments, a lack of parking near care facilities, or a lack of overnight hotels, could all be sources of stress (Hockenberry et al., 2021).

Mothers may require more social support and a favorable assessment of their circumstances than fathers. Fathers of disabled children face challenges that differ from those faced by their mothers (Swallow et al., 2012).

Because they don't know how to help and can't defend their families from the seemingly insurmountable repeating difficulties, fathers may believe that their job as protector is being tested. Fathers may feel unhappy, weak, guilty, powerless, alienated, embarrassed, and angry as a result of the family's severe pressures (Davies et al., 2004).

Fathers often hide their sentiments and project an external assurance that may make others to assume that everything is alright, fearful of losing control or being perceived as weak or ineffective. Fathers are concerned about their children's future, their capacity to manage a rising financial load, and the everyday disturbances that their families face (Swallow et al, 2012).

2.30. Educate About the Disorder and General Health Care

Daily Living Activities mothers also want to know how the illness affects or interferes with daily activities including eating, dressing, sleeping, and going to the bathroom. One area frequently affected is nutrition. Common problems are undernutrition resulting from food being inappropriately restricted or loss of appetite, vomiting, or motor deficits that interfere with feeding; over nutrition may also occur, usually because of a caloric intake in excess of energy expenditure because of boredom and lack of stimulation in other areas. Although the child requires the same basic nutrients as other children, the daily requirements may differ. Special nutritional considerations are discussed as appropriate throughout the text (Speedie et al., 2021).

2.31. Safe Transportation

Modifications may also be needed regarding car safety. Children with conditions such as low birth weight or orthopaedic, neuromuscular, or respiratory impairments often cannot safely use conventional car limits. Modifications can be made to some commercial models, and for older children, a special vest is available that secures the child to the back seat in a lying-down position. If a child requires a wheelchair, the family should consult the wheelchair manufacturer for specific instructions regarding safe car transportation. Considerations for wheelchairs used with vehicle transportation must address securing both the wheelchair and the occupant in the wheelchair. Wheelchairs should be secured facing forward with tie downs at four points. The tie down system should be dynamically crash tested, as should the occupant securement system that secures the child in the wheelchair (El-Morsy et al., 2020).

2.32. Primary Health Care

Quality of life can be enhanced by primary health care in which children with special needs require the same level of health care as any other youngster. Injury prevention, vaccines, dental hygiene, and regular physical check-ups are all important. Nurses can play a vital role in reminding parents about these components of care, which are frequently overlooked when the attention is on the child's chronic illness. Specific discussions of nutrition, sleep and activity, dental health, and injury prevention are presented in the chapters on health promotion for specific age groups. In the event of a medical emergency, parents should be aware of the necessity of reporting their child's condition. Young children are unable to provide information about their ailments, while older children may be unable to communicate after an accident owing to physical constraints, despite being valuable sources. As a result, any child with a chronic illness that could affect medical treatment should wear a Medic Alert bracelet or carry a wallet card that identifies the medical condition, includes a phone number for emergency medical records, and other personal information (Wilson et al., 2014).

2.33. Previous Studies

1. A study of (**Comparison of the caregiver burden of the mothers of children with cerebral palsy and healthy children hospital Physical Medicine and Rehabilitation Service in Turkey**) conducted by **Kaydok et al. 2020**. The goal of the study is to compare caregiver burden levels of mothers of children with cerebral palsy (CP) to mothers with healthy children. Methods: Participants comprised 40 mothers of children with CP (Group 1), and controls comprised 40 mothers with healthy children (Group 2). Caregiver burden inventory (CBI), hospital anxiety depression scale (HADS) were applied. The functional status of children with CP was evaluated by the Gross Motor Function Classification System (GMFCS). Secondary problems accompanying CP were also noted. Results: A secondary problem was seen in 75% of children with CP. The caregiver burden (CB) and the frequency of depression among Group 1 mothers were significantly higher than Group 2 mothers ($p<0.05$).

2. A study of **(Relationship between quality of life of children with cerebral palsy and their mothers' depression and anxiety)** carried out by **Soliman et al. 2019**.The purpose of this study was to see if there was a link between maternal anxiety and depression and the children's perceived quality life (QOL) (CP). A cross-sectional study was conducted on 232 mothers of children with CP aged 5 to 18. The Pediatric Inventory Parent Version (PedsQL-P), Beck Anxiety Scale (BAS), and Beck Sadness Inventory were used to assess children's QOL as well as their mothers' depression and anxiety (BDI). showed that 55.5 percent of moms were depressed in some fashion, with 47.4 percent reporting moderate anxiety and 21.6 percent reporting severe anxiety, respectively. PedsQL-P scores ranged from 69.35 to 18.18. PedsQL-P was found to have a high negative connection with both BAS and BDI scores.CP Sadness and worry were common among the mothers of the children, which had a negative impact on the children's quality of life.

3. The study of **(Child’s quality of life and mother’s burden in spastic cerebral palsy: a topographical classification perspective)** conducted by **Ozkan, 2018**.The goal of this research was to find out about the child's quality life (QoL), the mother's burden, and the relationship between the two.On the basis of topographical classification, children with spastic CP (n = 120; mean age: 8.64 3.45 years; range: 2–17 years) were divided into three groups: diplegia, hemiplegia, and quadriplegia. The child's QoL and the mother's burden scores were determined using the Pediatric Quality Life Inventory and the Zarit Burden Interview, respectively**.** Quadriplegic children had lower quality life scores than hemiplegic and diplegic children (except for emotional functioning). The quadriplegia group was lighter than the other groups, but the diplegia group was lighter than the hemiplegia group. Lower burden scores among mothers were linked to improvements in children's QoL. In spastic CP, children's QoL is connected to the mother's load, with quadriplegic children and moms being the most affected. The quadriplegia group had the most mothers, followed by the diplegia and hemiplegia groups. In children with spastic CP, topographical classification is an excellent indicator of the children's quality life and the mother's burden.

4.A study of **(Impact of spastic cerebral palsy upon the quality of life of children under the age of 12 years in Erbil City: parents’ reports)** done by **Hasan & Shukir (2016).** Amide will analyze the quality life of children with CP under the age of 12 who have been reported by their parents in Erbil, Iraq. A descriptive study was conducted on the quality life of children with CP. A total of 100 mothers of children with CP participated in this study. Helena Center for Handicapped Children in Erbil conducted the study. A two-part questionnaire was used to collect the information. The first section is separated into two sections:

one examines the demographic characteristics of mothers, and the other defines the demographic characteristics of CP children. In the second phase of the questionnaire, the Inventory brand (Parent's reports) was employed. The moms were mostly from low-income families who resided in cities and were between the ages of 28 and 37. The majority of children with CP were males between the ages of 2 and 4, and had spastic type CP. Significant associations were found between kinds of CP and everyday activities, pain and hurt, speech and communication, and eating and activities, with p-values of 0.032, 0.000, 0.011, and 0.014, respectively.

5. The study of **(The caregiver's burden of caring for children with cerebral palsy in India)** conducted by **Vayalil & Premkumar (2015)**; the purpose of the study was to assess the concern burden amongst caregivers of kids inflicted with cerebral palsy. Conducted in selected rehabilitation centers in Kerala. The research designing utilized was semi experimental Pertest and post-test; The design of the control group. The research sample comprised 100 care givers of children inflicted with cerebral palsy. Subjects were selected with total enumeration sampling process. The care giver-child social and emotional relationship was assessed by structured observation. The care burden was assessed by care burden assessment tool. It was a self-rating five-point scale. The reliability of the tools was developed by interclass correlation coefficient (0.90) and Crunch's alpha (0.82) respectively. Majority of caregivers had weak bonding, (82%) and (84%) in experimental and comparison group respectively. None of the subjects had strong social and emotional relationship with their children. There is significant association between care burden of caregivers of children with cerebral palsy and selected back ground variables of child, birth order (2-11.64, p=0.020) and ability to walk independently (2=6.93, p-0.031). Two weeks after the intervention there is significant difference in the care burden level between the experimental and comparison group. (Z score-2.9, p-0.004). Two weeks after the intervention the mean score is (33.2) and (47.8) in experimental group and comparison group respectively with (Z score=7.62, p=D0.001). Three months after the intervention the mean. score becomes (20.3) and (47.4) in experimental group and comparison group respectively with (Z score=8.29, p-0.001). The study highlights the broad range of societal and mental problems practiced by caregivers of kids through cerebral palsy. While planning for a program that focuses on the family for these children, and should be considered in these problems and address them in order to make child care more effective.

6. The study of (**Family Burden on Parents of the Children with Cerebral Palsy: Effectiveness of the Family Centered Psycho-Social Intervention Programme)** done by **Kumari & Joseph (2014).** The purpose of this study was to see how effective family-oriented and psychological interference was at reducing family stress among parents of encephalic palsy children. The employment of a non-control group in a semi-experimental research approach. Using a simple random technique, parents select their child for therapy from a file of children with CP ages 1 to 12 years at a tertiary care center. Between June and November of 2013, the research was presented. The data was collected in two methods. It also included the following information: a variety of initiatives.

In interactive group meetings, family stress avoidance and coping mechanisms are discussed. Second, individual and family psychotherapy sessions may be open to parents and family members. SPSS version 17 was used to calculate the frequency of variables, mean, and standard deviation. To determine the application's outcome, "paired" tests are used. Mothers make up the bulk of the population when compared to fathers (88.6 percent). In the 26-30-year-old age group, it was 37.1 percent of parentages. The majority of parents live with their children in the same house (91.4 percent). The majority of the time, 91.4 percent of the time Parents who are inbreeding account for 65.7 percent of all parents. He noted that over half of low-income parents (48.6%) had a living guide. After the intervention on a sample of parents, there was only a minor positive effect (d =

0.08). It was revealed that a family-centered psychosocial intervention was beneficial in reducing family hardship among parents of children with CP. To prove the usefulness of this strategy, more research is needed.

7. A study of **(A Qualitative Study of Psychosocial Problems among Parents of Children with Cerebral Palsy Attending Two Tertiary Care Hospitals in Western India)** done of **Nimbalkar et al., 2014.** Examine the psychological and social challenges that parents of children with CP (CP) experience in both rural and urban areas. Design research and qualitative focus group talks will be used to perform the study (with a caveat). Two reservations were made, one in a rural clinic with a higher education level and the other in an urban clinic with a higher education level. At the focus group meetings, a total of 13 parents looked at two significant findings. It looked examined the social and psychological challenges faced by parents of children with CP. Common challenges such as strained societal connections, health issues, financial difficulties, moments of pleasure, worry for the child's future, the need for more support services, and a sufficient number of qualified physiotherapists are linked to the concerns of mothers. Parents of CP children face a variety of psychological and social challenges. This type of research can help with the establishment of a family-centered program for children with CP.

8. The study of **(Psychological impact of cerebral palsy on families: The African perspective)** conducted by **Olajide et al., 2013. The** study's purpose was to detect and explain the emotional impact of CP on households based on Africans' assessments, as well as to identify strategies that were authorized by families in the handling. The design of the study was descriptive cross-sectional design study at the University Hospital's Department of Physiotherapy. 52 of the contributors were parents of children with CP. They filled out a questionnaire to find out how much psychological stress the families were dealing with and what coping techniques they employed to deal with it. In the study, descriptive statistics were used to illustrate the responses. Having enough CP, according to the majority of respondents, can help them manage with the obligations of caring for children with CP. According to the poll, 38.5 percent of respondents felt that community members suspect them of committing some of the mistakes that led to their children being diagnosed with CP. It comprises personal loss of function issues, as well as an inability to concentrate at work, as well as a loss of family joy and financial perplexity. To prepare their children, 50% of them utilize spiritual religious interference as a replacement or balancing treatment, while 28% use a larger family system as a support system. Families that care for children with CP are typically optimistic about their children. However, the general public has to be educated about the causes of CP and the treatment choices accessible to families.

9. A study of the **(Burden on caregivers of children with cerebral palsy: predictors and related factors)** conducted by **Maroon et al., 2013 .**The study's main purpose was to figure out what characteristics are most likely to put a strain on primary care physicians when it comes to children with CP. Being aware of these characteristics can aid in the identification of carers who are at risk of harming their physical and mental health, as well as the implementation of programs to lessen the negative impact of care on the parentages of children with chronic illnesses. The study included 62 caregivers (89 percent of whom were women) ranging in age from 30 to 54 years. The average degree of disability and age of children with CP (CP) aged 1 to 17 years (mean = 7.69, SD = 4.18) were used to evaluate the load of a model concentrating on multiple linear regressions. The model took into account the degree of disability, depression (as measured by the Beck Katia- II), and self-efficacy (as measured by the revised measure to provide care self-efficacy). 40.9 percent of the total variation was explained by the regression model. Self-efficacy and load had a negative linear association, whereas disability and gloominess had a positive linear link. Gloominess and ego-efficiency load are the most important predictors of the level of care insufficiency. Creating therapies to reduce unhappiness and promote self-efficacy in parents of children with CP is one of the most important goals for minimizing the burden on caregivers of children with special needs.

Chapter Three

Methodology

Chapter Three

Methodology

3.1. Design of the Study:

A correlational descriptive study design approach is done by interrogating members of the study population, with the aim of describing the studied phenomenon in terms of its nature and degree of existence only.The subject of the study was limited to psychosocial burden and quality of life.The spatial boundaries of the study were limited to rehabilitation centres/ Babylon Province.The study was conducted for the period of 1 November/ 2020 to 24 April/2022. The study was conducted on mothers of cerebral palsy children.

3.2. Administrative Arrangements

The official permissions were obtained from relevant authorities before collecting the study data as follow:

1) Approval from the University of Babylon/ College of Nursing Council for the study as shown in the appendix (A1)

2) Official permissions were also obtained from the Babylon Health Directorate (Training and Development Division) in order to formally access the Rehabilitation Centres as shown in the appendix (A2)

3) Official permission have been obtained from administer rehabilitation centres which include Imam Al-Sadiq hospital and Babylon centre for rehabilitation as shown in the appendix (A2).

3.3. Setting of the Study

The study was carried out in Babylon Province, at two centres for Rehabilitation of children with disabilities. These centres are Babylon for rehabilitation and Imam AL-Sadiq Teaching Hospital.

3.3.1. Imam AL-Sadiq Hospital

It is one of the governorate's hospitals. The hospital adheres to the Iraqi Ministry of Health's guidelines. The hospital has (492) narrow-bed beds, as well as a number of clinics and specialty centers, as well as (18) operating theaters. To a hospital with (400) beds on 40 dunums of land, and six floors dedicated to providing citizens with preventive, consultative, medical, and therapeutic services.

3.3.2. Babylon Rehabilitation Centre

It belongs to the Babylon Health Department, the Physiotherapy Division of the Babylon Centre for the Rehabilitation of the Disabled, which is affiliated with the department.

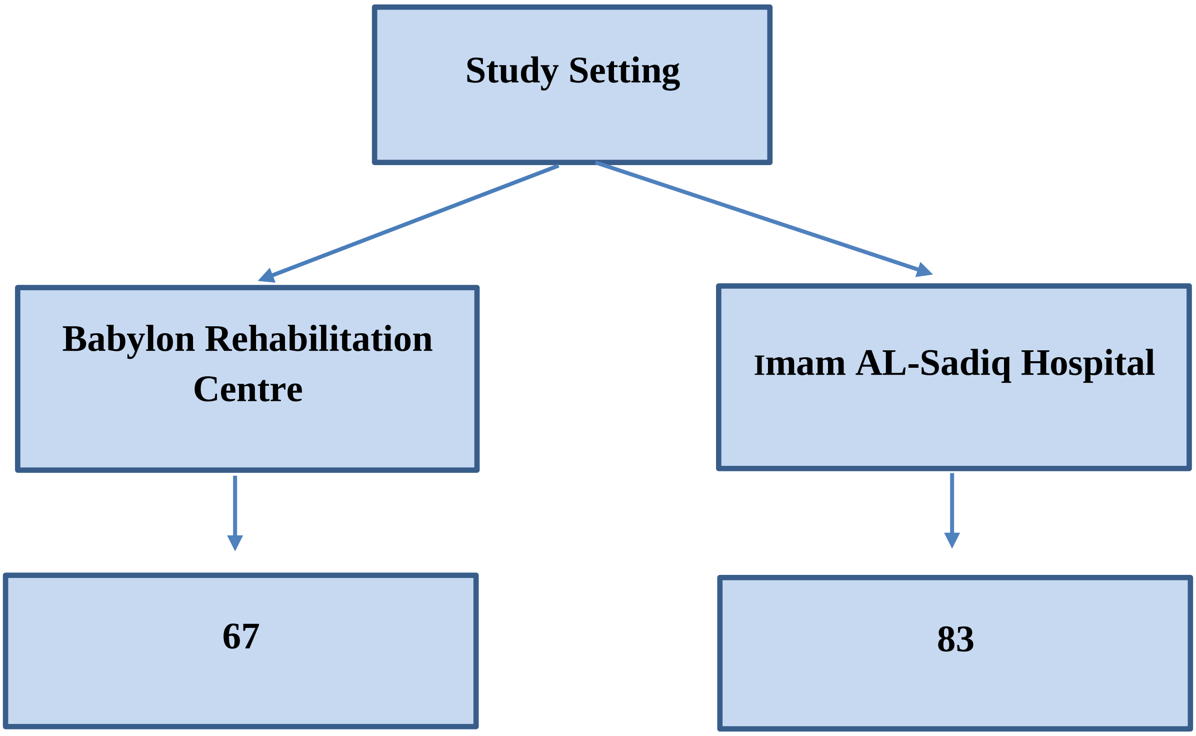

Figure 3. 1 Distribution of study setting for data collection.

3.4. Sample of the Study

The non-probability (convenient) sample was selected to carry out the study which consists of (150) mothers who have children with cerebral palsy in Babylon Province. These sample is selected according to the criteria which are include the following:

Inclusions criteria:

1) Mothers with children who have cerebral palsy.

2) Mothers with children ranging in age from 2 to 12 years.

3) Mothers who agree to take part in the research.

3.5. Study Instruments

A questionnaire is one of the means to help collect data that contribute to achieving the objectives expected by the study, so the researcher designed this questionnaire, which aims to clarify the study’s objectives and significance by obtaining answers to the study’s questions.

So the questionnaire items was constructed by the researcher for the present study. The questionnaire based on extensive review of related studies and available literatures.

The study instrument consists of three parts; sociodemographic data (*for mother's and child's*), psychosocial burden and children quality of life. as shown in the appendix (B)

Part I: This section composed of socio-demographic data which include:

- Age, education, occupation, monthly income, housing area, number of family members, and kind of family are among the details provided by mothers.

- Age, gender, number of siblings, order, age at diagnosis, kind of birth, type of feeding, risk factors, and type of cerebral palsy are some of the details about a cerebral palsy child (*this information described as mother's feedback*).

Part II: This section deals with psychosocial burden, an assessment tool was developed by the researcher to measure the psychosocial burden among mothers of child with CP.The following are some of the tools available:

1) Psychological burden: This consisted of (31) items that were

2) rated and scored 1 for always, 2 for some time, and 3 for never on a three-level Likert rating scale.

3) The social burden is made up of 18 things that are measured on three levels. They have been rating and scoring 1 for always, 2 for some time, and 3 for never using a Likert rating scale.

Part III: The quality of life for children with cerebral palsy developed by Frota. et al. 2016, which measures problems associated with quality of life. QoL questionnaire include the following:

1) Physical function: Which composed of (8) items measured on 5-point such as (never, almost never, sometime, often, almost always).

2) Emotional function: Which composed of (5) items measured on 5-point such as (never, almost never, sometime, often, almost always).

3) Social function: Which composed of (5) items measured on 5-point such as (never, almost never, sometime, often, almost always).

4) School function: Which composed of (5) items measured on 5-point such as (never, almost never, sometime, often, almost always).

The researcher adhered to the rules of writing the questionnaire due to the importance of the type of information that the researcher is keen to be sufficient and comprehensive for all aspects of the problem and can be relied upon and trusted. To vague and complex answers. The type of questions was of the closed type, which required answering with reference to what was appropriate.

3.6. Validity

The validity of the questionnaire means making sure that it will measure what it was prepared to measure, as is meant by honesty (the questionnaire’s inclusion of all the elements that must be included in the analysis on the one hand, and the clarity of its paragraphs and vocabulary on the other, so that it is understandable to everyone who uses it).

In order to test the validity of the questionnaire, the instrument was presented to 15 experts in different fields to make it more valid. Experts were requested to provide their views and suggestions on each of the items of the study questionnaire in term of its linguistic appropriateness, its association with the dimension of study variables it was assigned to and its suitability for the study population context as shown in appendix (C).

The experts responses indicated that minor changes should be done to some items and it's were made according to their suggestions , then the final draft was completed to be ready for conducting the study .

3.7. Pilot Study

This preliminarily study was conducted to determine the stability and credibility of the study tool, clarity and its efficiency which confirmed, and standard time required to collect data for each subject which can estimated during the interview procedures and to difficulties identification that may encounter.

The pilot study aimed to achieve the following objectives.

1) Developing and testing adequacy of research instruments.
2) Assessing the feasibility of instrument.
3) Identifying logistical problems which might occur using proposed methods.
4) Assessing the proposed data analysis techniques to uncover potential problems.
5) Estimate the time during collected data by the researcher.

3.7.1. Results of pilot study

1) The questionnaire is reliable.
2) The time required for answering the questionnaire ranged from (20-25) minutes.
3) The instrument items were clarify and understood the phenomenon of relationship between mothers psychosocial burden and its relation to quality of life for children with cerebral palsy (Table 3.1).

Before the questionnaire reached its final form, it went through the following stages:

1) Determining the data that will be collected through the questionnaire according to the study questions.
2) Determining the method and format of the questionnaire.
3) Determining the type of criterion that determines the type of answer in the questionnaire.
4) Presenting the questionnaire to the supervising to express his opinion and observations in developing the questionnaire and modifying it based on his observations.

5) Presenting the questionnaire to a number of panel of experts to express their opinion and observations in developing the questionnaire and modifying it based on what they submitted.

6) Conducting a reliability test on it by distributing the questionnaire to a sample of 15 mothers.

7) Writing the questionnaire in its final form, then printing, reviewing and distributing it.

3.7.2. Reliability of the Questionnaire:

The reliability of the study instruments entails ensuring that the result will be almost identical if it is administered to the same person's multiple times at different times. The same people the second time, after confirming the apparent validity of the study tool, the researcher applied it to a random exploratory sample of 15 mothers, using the test method, where each mothers from the sample was given a number from 1 to 15 and the questionnaire was distributed to them without prior known of them that they are a sample to measure the stability of the tool, and after an interval of about two weeks, 15 questionnaires were reallocated to the same exploratory sample, which was later eliminated from the final study's original sample. As illustrated below, the reliability coefficient is calculated using the Alpha Cronbach sample coefficient.

Table 3. 1 Reliability of the Studied Questionnaire

Reliability Cronbach's Alpha			
No. of items	**Cronbach's Alpha**	**Standard value**	**Result**
Psychosocial burden =49 items	**0.83**	**0.70**	**pass**

Quality of life =23 items	**0.78**	**0.70**	**pass**

3.8. Ethical Considerations

Ethical obligations are one of the most important things that the researcher must follow and abide it when doing the study. Before the starting of collect the data from the sample that has been identified for the study, the researcher should clarify the main purpose and desired goal of conducting this study for the sample to be including in the study, as well as adhere to the strict confidentiality of the data taken from the study sample and pledge to use it for scientific purposes related to the study only.

Before the starting of gathering the data from the sample who are participating in the study, the researcher given a brief explanation about the scientific background of the research and the purpose of conducting. Mothers of cerebral palsy children were verbally informed about the study aims and were asked to participate and this participation were voluntary. After they agreed to participate in the study, anonymous questionnaire was handed to them to maintain a complete confidentiality for the participants.

3.9. Methods of Data Collection

The data was carried out from (May/16th to September/15th / 2021).The questionnaire has been administered personally by the researcher to the mothers of children.

After obtaining the approval of the Babylon Health Directorate and verifying the validity and reliability of the questionnaire. The researcher interviewed himself (face to face) to the mothers of children with cerebral palsy, explained the instructions, answered their questions regarding the form, urged them to participate and thanked them for the cooperation.

Questionnaire collection: Determining the method that the researcher will follow in collecting data after taking the important steps that must be included in the study design.

3.10.Rating Score

For psychosocial burden

The assessment tool measures on 3-level of Liker's scale scored as the following:

Score 1× Always

Score 2×Sometime

Score 3× Never

For quality of life

All items of the quality of life scale measured on 5-poitn of Liker's Sale as

(1) × Almost Always.

(2) × Often.

(3) × Sometime.

(4) × Almost Never.

(5) × Never.

Whenever, the low statistical mean which indicated negative results.

Whenever, the high statistical mean which indicated positive results.

3.11. Methods of Statistics Data Analysis

In order to statistically analyze the data collected from the study sample to arrive at the results, the researcher used the SPSS version (24) and Microsoft Excel (2010) program to analyze this data and deal with it statistically, to find the relationships between the variables, and obtain the final results of the research based on a set of statistical tests.

3.11.1.Descriptive approach

Descriptive statistics includes a set of mathematical and statistical methods that are adopted to describe the main features of a data quantitatively by using tables and charts. Descriptive statistics always aim to present and describe the data which is required to be processed, organized, summarized and categorized, as well as presenting them in a simple and clear manner that makes it easier for the recipient to recognize and understand its content. The analysis performed through use:

A. Statistical tables "Frequencies and percent" which are:

$$\% = \frac{\boldsymbol{Frequency}}{\boldsymbol{Sample\ Size}}\ x100$$

B. Mean of scores "MS".

The average score can be calculated by using the following:

$$M.S = \frac{\sum \mathrm{ri} = 1\mathrm{Fi}\ \mathrm{x}\ \mathrm{Si}}{\sum \mathrm{ri} = \ 1\mathrm{Fi}}\ x100$$

<u>For Psychosocial Domains</u>

∑xi=sum of the (***1x Always+2x Sometime+3x Never***) for items.

(1)(M.s= 1-1.66) is considered ***Always***.

(2)(M.s= 1.67-2.33) is considered ***Sometime***.

(3)(M.s≥2.34) is considered ***Never***.

The overall responses according to total mean of score which follow:

49-81 refers to high burden

82-114 refers to moderate burden

115-147 refers to low burden

For Quality of Life Domains

$\sum xi$ = sum ***(1x Almost Always + 2x Often +3x Sometime + 4x Almost Never +5x Never)***

1. Almost Always [M=1-1.79].
2. Often[M=1.80-2.59].
3. Sometime [M= 2.60-3.39].
4. Almost Never [M=3.40-4.19].
5. Never [M=4.20-5].

The overall responses according to total mean of score which follow:

23-53 Poor quality of life

54-84 Moderate quality of life

85-115 Good quality of life

C. The test of standard deviation SD.

$$SD = \sqrt{\frac{1}{n-1}\sum_{i=1}^{n}(Xi - \tilde{\chi})^2}$$

D. It uses a correlational coefficient "Cronbach alpha" used in estimating the internal consistency of the study tool, which can be calculated by using the following:

$$\alpha = \frac{K}{K-1}\left[1 - \frac{\sum_{i=1}^{K}\sigma_{ii}}{\sum_{i=1}^{K}\sum_{j=1}^{K}\sigma_{ij}}\right]$$

K is the items number questions and σ_{ij} is the investigate covariance between the items i and j. Note the σ_{ii} is the variance not standard deviation of item I.

3.11.2. Inferential approach

1. **Chi-Squared Test(x^2):** As in crosstab, is used to test hypotheses regarding proportional differences (Polit & Beck, 2018).

$$\chi^2 = \frac{\sum_{all\ i}(O_i - E_i)^2}{E_i}$$

- Chi-Squared= " X2 "
- Sum =∑

“Where O_i is the observed frequency of group I”

E_i is the expected frequency.

$$\left.\begin{array}{l} \textit{They } x^2\textbf{obs.} < x^2\ \textbf{crit.} = \textit{insignificantly} \\ \textit{They } x^2\textbf{obs.} > x^2\ \textbf{crit.} = \textit{significantly} \end{array}\right\}$$

As compared with df

1. **Spearman's Correlation Coefficient**

This test is used for qualitative variables

$$\text{Ƥ} = 1 - \frac{6\sum \text{ɗ}2\ \text{ị}}{\text{ɳ}\,(\text{ɳ}2 - 1)}$$

Ƥ =Spearman's rank correlation coefficient

∑ ɗ2 ị =difference between the two ranks of each observation

ɳ =number of observations

Shortcuts for measuring important compared to the level, are used as follows:

(1) **NS** : *Non significantly at probability-value>0.05.*

(2) **S** : *Significantly at probability-value <0.05.*

(3) **HS** : *Highly significantly at probability-value <0.01.*

3.12. Study limitations

This study faces some limitations during its process:

1) The study sample is distributed in wide geographical area (centre, suburbs, rural).

2) The mothers feeling about behavior their children, some difficulties are experienced through data collection.

3) Mothers feel hopeless when they are asked about their child due to the lack of information toward child situation, therefore they don’t speak about some burdens.

4) Much time needed to some mothers due to their low education to clarify and explain the questionnaire for them.

Chapter Four

Results of the Study

Chapter Four

Results of the Study

Table 4. 1 Distribution of Study Sample by their Socio-demographic Characteristics

Age/years	**Classification**	**Freq.**	**%**
(*M + SD= 28.79+7.661*)	<20 years old	11	**7.3**
	20-24 years old	43	**28.7**
	25-29years old	30	**20.0**
	30-34years old	30	**20.0**
	35-39 years old	21	**14.0**
	≥40 years old	15	**10.0**
	Total	150	**100.0**
Education Level	Do not read or write	28	**18.7**
	Read and write	**82**	**54.7**
	Secondary	21	**14.0**
	Institutes and more	19	**12.7**
	Total	150	**100.0**
Occupation	Employ	34	**22.7**
	Unemployed	**116**	**77.3**
	Total	150	**100.0**
Monthly income	Enough	47	**31.3**
	Certain limit enough	33	**22.0**
	Is not enough	70	**46.7**
	Total	150	**100.0**
Housing area	**Countryside**	**68**	**45.3**
	Outskirts	35	**23.3**
	City	47	**31.3**
	Total	150	**100.0**
Number of family member	<4	28	**18.7**
	4-5	**67**	**44.7**
	>5	55	**36.7**
	Total	150	**100.0**
Type of family	Nuclear	58	**38.7**
	Extended	**92**	**61.3**
	Total	**150**	**100.0**

Table (4.1) show participants age, the mean age is 28.79+7.661, at age group 20-24 years old (*n=43*; 28.7 %), followed by those who were at age group 25-34 years old (*n=30*; 20 %), followed by those who were at age group 35-39 years and old (*n=21*; 14%), followed by those who were at age group ≥ 40 years old (*n=15*; 10%) and those who were at age group <20 years old (*n=11*; 7.3%). Respect to the education, findings show the read and write was predominated (*n=82*; 54.7 %), followed by those who are do not read and write (*n=28*; 18.7 %), followed by those who are secondary school (*n=21*; 14%), and those who are graduated of institute and above (*n=19*; 12.7%). In regards with occupation, findings show that the unemployed mothers were records the highest percentage (*n=116*; 77.3 %), as compared with those who are employed (*n=34*; 22.7 %). In terms of monthly income, the mothers express is not enough income (*n=70*; 46.7 %), followed by those who enough income that is (*n=47*; 31.3 %), and those who are mention is sufficient to certain limit (*n=33*; 22%). Housing area related findings, most of mother's countryside residents (*n=68*; 45.7 %), followed by those who are city residents (*n=47*; 31.3 %), and those who are outskirts (*n=35*; 23.3%). Number of family member, most of families constituted from 4 to 5 member (*n=67*; 44.7 %), followed by those who are >5 member (*n=55*; 36.7 %), and those who are <4 member (*n=28*; 18.7%). Type of family, the extended families were recording the highest percentage (*n=92*; 61.3 %), as compared with those who are nuclear families (*n=58*; 38.7 %).

Table 4. 2 Distribution of Cerebral Palsy Children Characteristics

Children Age	Classification	Freq.	%
	<5 years	**95**	**63.3**
	5-10 years	46	**30.7**
	>10 years	9	**6.0**
	Total	150	**100.0**
Child gender	**Male**	**81**	**54.0**
	Female	69	**46.0**
	Total	150	**100.0**
Children Number of Siblings	**<3**	**109**	**72.7**
	3-5	35	**23.3**
	>5	6	**4.0**
	Total	150	**100.0**
Children order	First	31	**20.7**
	Second	38	**25.3**
	Third	**43**	**28.7**
	Beyond that	38	**25.3**
	Total	150	**100.0**
Children age at diagnosis	Before birth	5	**3.3**
	Newborn	**73**	**48.7**
	Infant	72	**48.0**
	Total	**150**	**100.0**

Table (4.2) findings show the age of cerebral palsy children, most of children aged less than 5 years (*n=95*; 63.3 %), followed by those who were at age group 5-10 years old (*n=46*; 30.7%), and followed by those who were aged more than 10 years and old (*n=9*; 6%). In terms of child gender, most of cerebral palsy were male gender (*n=81*; 54 %), while the female (*n=69*; 46%). Number of siblings related findings, most of them had a less than 3 siblings (*n=109*; 72.7 %), followed by those who had 3-5 siblings (*n=35*; 23.3 %), and those who had more than 5 siblings (*n=6*; 4%). Child order in the family, most of cerebral palsy children their sequence third one *(n=43*; 28.7%), followed by those who its sequence second and beyond it (*n=38*; 25.3 %), and those who sequence the first older (*n=31*; 20.7 %). In regards with age at diagnosis of cerebral palsy, most of children diagnosed at newborn period (*n=73*; 48.7 %), followed by those who were diagnosed at infancy period (*n=72*; 48%), and followed by those who were diagnosed before birth (*n=5*; 3.3%).

Table 4. 3 Distribution of Clinical Information for Cerebral Palsy Children

Family history	Classification	Freq.	%
	Yes	12	**8.0**
	No	**138**	**92.0**
	Total	150	**100.0**
Type of birth	**Normal delivery**	**98**	**65.3**
	Caesarean Section	52	**35.7**
	Total	150	**100.0**
Type of feeding	Breast feeding	43	**28.7**
	Artificial feeding	**67**	**44.7**
	Mixed feeding	40	**26.7**
	Total	150	**100.0**
Risk factors of cerebral palsy	Suffocation	29	**19.3**
	Meningitis	**60**	**40.0**
	Jaundice	55	**36.7**
	Twins pregnancy	6	**4.0**
	Total	150	**100.0**
Classification of cerebral palsy	Hemiplegia	25	**16.7**
	Monoplegia	**64**	**42.7**
	Triplegia	4	**2.7**
	Tetraplegia	57	**38.0**
	Total	**150**	**100.0**

Table (4.3) it is clear from findings the most of mother's express there is no role for family history in these cases (*n=138*; 92%), compared to those who confirmed that there is a family history play a role in these cases (*n=12*; 8%). Most of children normally delivered (*n=98*; 65.3%), compared with those who are Caesarean section delivered (*n=52*; 35.7%). Artificial feedings were the most common among cerebral palsy children (*n=67*; 44.7%), followed by those who are breast feeding (*n=43*; 28.7%), and followed by those who are mixed feeding (*n=40*; 26.7%). Mothers express that the meningitis was considered the most common risk factors for their cerebral palsy children (*n=60*; 40%), followed by those who are jaundice (*n=55*; 36.7%), followed by those who are suffocation (*n=29*; 19.3%), and those who are twin's pregnancy (*n=6*; 4%). Monoplegia were the most common class among cerebral palsy children (*n=64*; 42.7%), followed by those who are Tetraplegia (*n=57*; 38%), followed by those who are hemiplegia (*n=25*; 16.7%), and followed by those who are Triplegia (*n=4*; 2.7%).

Table 4. 4 Psychosocial Burden of Mothers

Table 4.4. 1 Psychological Burden of Mothers

List	Psychological Burden Items	Weighted	Freq.	%	M.s. ± SD	Ass.
1	You find it difficult to balance caring for your child with your family responsibilities.	Always	58	38.7	1.85±0.780	**Moderate**
		Sometime	56	37.3		
		Never	36	24.0		
2	You feel embarrassed by your child's behavior	Always	76	50.7	1.64±0.726	**High**
		Sometime	52	34.7		
		Never	22	14.7		
3	You feel angry when you are around your child	Always	91	60.7	1.46±0.619	**High**
		Sometime	49	32.7		
		Never	10	6.7		
4	You feel afraid for your child from the future	Always	86	57.3	1.8±0.955	**High**
		Sometime	8	5.3		
		Never	56	37.3		
5	You feel nervous when you are close to your baby	Always	105	70.0	1.36±0.593	**High**
		Sometime	36	24.0		
		Never	9	6.0		
6	You feel that your mental health has been affected because of your care (or care) for your child	Always	88	58.7	1.48±0.620	**High**
		Sometime	52	34.7		
		Never	10	6.7		
7	You feel that you will be unable to take care of your child much longer	Always	105	70.0	1.35±0.580	**High**
		Sometime	37	24.7		
		Never	8	5.3		
8	You wish to leave someone else's care for your baby	Always	136	90.7	1.13±0.443	**High**
		Sometime	8	5.3		
		Never	6	4.0		
9	You feel you must do more for your baby	Always	58	38.7	2.18±0.965	**Moderate**
		Sometime	6	4.0		
		Never	86	57.3		
10	I feel fear and panic for no good reason	Always	49	32.7	2.24±0.919	**Moderate**
		Sometime	15	10.0		
		Never	86	57.3		
11	I worry that people close to me will leave me because of my child	Always	52	34.7	1.84±0.714	**Moderate**
		Sometime	70	46.7		
		Never	28	18.7		
12	I am afraid of what the future holds for	Always	50	33.3	2.28±0.936	**Moderate**
		Someti	7	4.7		

	my child	me				
		Never	93	62.0		
13	I feel very sensitive to the behavior of others	Always	80	53.3	1.74±0.868	**Moderate**
		Sometime	28	18.7		
		Never	42	28.0		
14	I find it difficult to concentrate in my work	Always	58	38.7	2.08±0.926	**Moderate**
		Sometime	21	14.0		
		Never	71	47.3		
15	I feel tired and overwork as a result of caring for my child	Always	83	55.3	1.56±0.699	**High**
		Sometime	49	32.7		
		Never	18	12.0		
16	I have lost control of my life since my child's illness	Always	94	62.7	1.48±0.682	**High**
		Sometime	40	26.7		
		Never	16	10.7		
17	I feel the loss of time to rest and take care of myself	Always	81	54.0	1.55±0.660	**High**
		Sometime	55	36.7		
		Never	14	9.3		
18	I feel that my child depends on me only	Always	83	55.3	1.52±0.631	**High**
		Sometime	56	37.3		
		Never	11	7.3		
19	I feel about to collapse	Always	96	64.0	1.5±0.730	**High**
		Sometime	33	22.0		
		Never	21	14.0		
20	I feel guilty about my affections on my child	Always	119	79.3	1.26±0.563	**High**
		Sometime	22	14.7		
		Never	9	6.0		
21	I find it difficult to deal with my child	Always	76	50.7	1.82±0.902	**Moderate**
		Sometime	24	16.0		
		Never	50	33.3		
22	I feel desperate to go ahead and take care of my child	Always	87	58.0	1.50±0.652	**High**
		Sometime	50	33.3		
		Never	13	8.7		
23	I feel that my health has been affected because of my preoccupation with my child	Always	102	68.0	1.38±0.610	**High**
		Sometime	38	25.3		
		Never	10	6.7		
24	I feel less competent to care for my child	Always	83	55.3	1.51±0.621	**High**
		Sometime	57	38.0		
		Never	10	6.7		
25	I feel sad and gloom	Always	111	74.0	1.38±0.691	**High**
		Sometime	21	14.0		
		Never	18	12.0		

26	I hope to leave care of my child to someone better than me	Always	95	63.3	1.56±0.806	**High**
		Sometime	25	16.7		
		Never	30	20.0		
27	I feel a loss of desire to go to work	Always	80	53.3	1.66±0.784	**High**
		Sometime	41	27.3		
		Never	29	19.3		
28	I feel lost interest in anything	Always	103	68.7	1.37±0.596	**High**
		Sometime	38	25.3		
		Never	9	6.0		
29	I feel a loss of possession of anything good	Always	85	56.7	1.48±0.599	**High**
		Sometime	57	38.0		
		Never	8	5.3		
30	I feel that everything I do make me fatigue	Always	87	58.0	1.5±0.642	**High**
		Sometime	51	34.0		
		Never	12	8.0		
31	I feel that everything I do to my child is useless or meaningless	Always	82	54.7	1.50±0.599	**High**
		Sometime	60	40.0		
		Never	**8**	**5.3**		

"(M.s.) Mean of score, (S.D) Standard deviation, Level of Assessment (High [M.s.= 1-1.66], Moderate [M.s.=1.67-2.33], Low [M.s. ≥2.34])"

Take into account statistical analysis of mean, the **Table (4.4.1)** demonstrated that the psychological burden among mothers were high level at all items of the scale (M.s=1-1.66) except, the items number (1, 9, 10, 11, 12, 13, 14, and 21) the responses were moderate burden (M.s.=1.67-2.33).

Table 4.4. 2 Overall Psychological Burden for Mothers of Cerebral Palsy Children

Weighted	Freq.	%	*M ± SD*
High	74	49.3	***50.06 ± 10.830***
Moderate	70	46.7	
Low	6	4.0	
Total	**150**	**100.0**	

M: Mean of total Scores, SD: Standard Deviation for total scores (High=31-51; Moderate 52-72, Low=73-93)

Table (4.4.2) showed that the (49.3%) of mothers who have cerebral palsy children expressed a high level of psychological burden (*M ± SD=50.06±10.830*).

Table 4.4. 3Social Burden of Mothers

List	Social Burden Items	Weighted	Freq.	%	M.s. ± SD	Ass.
1	You don't have enough time for yourself	Always	92	61.3	1.593±0.811	**High**
		Sometime	27	18.0		
		Never	31	20.7		
2	Child care has affected your relationships with family members or friends in a negative way	Always	101	67.3	1.45±0.710	**High**
		Sometime	30	20.0		
		Never	19	12.7		
3	I don't have a lot of privacy, because of my child	Always	83	55.3	1.62±0.773	**High**
		Sometime	40	26.7		
		Never	27	18.0		
4	You feel that your social life has suffered because of your care for your child	Always	95	63.3	1.62±0.864	**High**
		Sometime	17	11.3		
		Never	38	25.3		
5	You feel uncomfortable about having friends over because of your child	Always	111	74.0	1.42±0.762	**High**
		Sometime	14	9.3		
		Never	25	16.		

				7		
6	Your child is completely dependent on you	Always	96	64.0	1.57±0.822	**High**
		Sometime	22	14.7		
		Never	32	21.3		
7	You feel that you don't have enough money to take care of your child in addition to the rest of your expenses	Always	105	70.0	1.53±0.848	**High**
		Sometime	10	6.7		
		Never	35	23.3		
8	You feel you have lost control of your life since your child's illness	Always	102	68.0	1.57±0.869	**High**
		Sometime	10	6.7		
		Never	38	25.3		
9	The situation of my child led to the identification of my social relationship outside the family	Always	110	73.3	1.43±0.763	**High**
		Sometime	15	10.0		
		Never	25	16.7		
10	I feel uncomfortable with my friends because of my child	Always	97	64.7	1.62±0.879	**High**
		Sometime	13	8.7		
		Never	40	26.7		
11	I have to stay home for the main public holidays	Always	108	72.0	1.42±0.726	**High**
		Sometime	21	14.0		
		Never	21	14.0		
12	Child's situation reduced my time with my friends	Always	83	55.3	1.78±0.918	**Moderate**
		Sometime	17	11.3		
		Never	50	33.3		
13	I find that my child's unexpected behavior prevents me from going out of the house	Always	81	54.0	1.67±0.806	**Moderate**
		Sometime	37	24.7		
		Never	32	21.3		
14	There are interruptions I do not want for my family routine	Always	88	58.7	1.64±0.829	**High**
		Sometime	28	18.7		
		Never	34	22.		

				7		
15	I feel that my child is affecting my responsibilities towards my family and my work	Always	88	58.7	1.76±0.944	**Moderate**
		Sometime	9	6.0		
		Never	53	35.3		
16	I feel the isolation of other children in the family because of the behavior of the child	Always	92	61.3	1.71±0.929	**Moderate**
		Sometime	9	6.0		
		Never	49	32.7		
17	My relationship with my partner became tense	Always	79	52.7	1.89±0.970	**Moderate**
		Sometime	8	5.3		
		Never	63	42.0		
18	I feel ashamed and embarrassed when	Always	94	62.7	1.74±0.965	**Moderate**
		Sometime	1	.7		
		Never	**55**	**36.7**		

"(M.s.) Mean of score, (SD) Standard deviation, Level of Assessment (High [M.s.= 1-1.66], Moderate [M.s.=1.67-2.33], Low [M.s. ≥2.34])"

In the light of statistically cut off point, the **Table (4.4.3)** demonstrated that the social burden among mothers were high level at all items of the scale (M.s=1-1.66) except, the items number (12, 13, 15, 16, 17, and 18) the responses were moderate burden (M.s.=1.67-2.33).

Weighted	**Freq.**	**%**	***M ± SD***

Table 4.4. 4Overall Social Burden for Mothers of Cerebral Palsy Children

High	103	68.7	***29.08 ± 6.803***
Moderate	37	24.7	
Low	10	6.7	
Total	**150**	**100.0**	

"M: Mean of total Scores, SD: Standard Deviation for total scores(High=18-30; Moderate 31-42, Low=43-54"

Table (4.4.4) demonstrated that the (68.7%) of mothers who have cerebral palsy children expressed a high level of social burden (*M ± SD=29.08±6.803*)

Table 4.4. 5 Overall Assessment of Psychosocial Burden among Cerebral Palsy Children Mothers

Weighted	**Freq.**	**%**	***M ± SD***
High	76	50.7	***78.14 ± 12.026***
Moderate	72	48.0	
Low	2	1.3	
Total	**150**	**100.0**	

"M: Mean of total Scores, SD: Standard Deviation for total scores (High=49-81; Moderate 82-114, Low=115-147)"

Table (4.4.5) demonstrated that the (50.7%) of mothers who have cerebral palsy children expressed a high level of psychosocial burden (*M ± SD=78.14±12.026*).

Table 4. 5 Quality of Life for Children with Cerebral Palsy

Table 4.5. 1 Quality of Life related to Physical Functioning

List	Physical Function items	Weighted	Freq.	%	M ± SD	Ass.
1	Walking more than one block	Never	15	10.0	4.31±1.275	**Almost always**
		Almost never	0	0.0		
		Sometime	15	10.0		
		Often	13	8.7		
		Almost always	107	71.3		
2	Running	Never	103	68.7	1.76±1.323	**Never**
		Almost never	13	8.7		
		Sometime	15	10.0		
		Often	4	2.7		
		Almost always	15	10.0		
3	Participating in sports activity or exercise	Never	116	77.3	1.57±1.160	**Never**
		Almost never	6	4.0		
		Sometime	10	6.7		
		Often	12	8.0		
		Almost always	6	4.0		
4	Lifting something heavy	Never	117	78.0	1.5±1.041	**Never**
		Almost never	6	4.0		
		Sometime	17	11.3		
		Often	5	3.3		
		Almost always	5	3.3		
5	Taking a bath or shower by him or herself	Never	33	22.0	2.11±0.886	**Almost never**
		Almost never	81	54.0		
		Sometime	26	17.3		
		Often	6	4.0		
		Almost always	4	2.7		
6	Doing chores around the house	Never	119	79.3	1.48±1.014	**Never**
		Almost never	1	.7		
		Sometime	22	14.7		
		Often	4	2.7		
		Almost always	4	2.7		
7	Having hurts or aches	Never	77	51.3	1.88±1.108	**Almost never**
		Almost never	31	20.7		
		Sometime	30	20.0		
		Often	6	4.0		

		Almost always	6	4.0		
8	Low energy level	Never	88	58.7	1.84±1.127	**Almost never**
		Almost never	15	10.0		
		Sometime	31	20.7		
		Often	14	9.3		
		Almost always	**2**	**1.3**		

"(M) Mean, (SD) Standard deviation, Level of Assessment (Never [M=1-1.79], Almost Never [M=1.80-2.59], Sometime [M= 2.60-3.39], often [M=3.40-4.19], Almost Always [M=4.20-5])"

In the light of statistical analysis of mean, the **Table (4.5.1)** illustrated that the mothers expressed the quality of life related to physical function of their children were never at all items of the scale except, items number (5, 7, and 8) the responses were almost never, also, the items number (1) the responses were almost always.

Table 4.5. 2 Overall Assessment of Quality of Life related to Physical Function

Weighted	Freq.	%	M ± SD
Poor	122	**81.3**	**16.48±5.005**
Moderate	21	14.0	
Good	7	4.7	
Total	**150**	**100.0**	

M: Mean for total score, SD: Standard Deviation for total score (Poor= 8-18, Moderate= 19-29, Good= 30-40)

In **Table (4.5.2)**, the findings of quality of life related physical function was demonstrating that mothers are express at *M± SD= 16.48±5.005*; the mothers expressed poor quality of life of physical function of their children (*n=122*; %=81.3).

Table 4.5. 3 Quality of Life related to Emotional Functioning

List	Emotional Function items	Weighted	Freq.	%	M ± SD	Ass.
1	Feeling afraid or scared	Almost always	66	44.0	1.78±0.961	**Almost always**
		Often	67	44.7		

		Sometime	8	5.3		
		Almost never	2	1.3		
		Never	7	4.7		
2	Feeling sad or blue	Almost always	75	50.0	1.70±0.916	**Almost always**
		Often	56	37.3		
		Sometime	11	7.3		
		Almost never	4	2.7		
		Never	4	2.7		
3	Feeling angry	Almost always	48	32.0	2.11±1.013	**Often**
		Often	52	34.7		
		Sometime	41	27.3		
		Almost never	3	2.0		
		Never	6	4.0		
4	Trouble sleeping	Almost always	41	27.3	2.2±0.919	**Often**
		Often	46	30.7		
		Sometime	57	38.0		
		Almost never	4	2.7		
		Never	2	1.3		
5	Worrying about what will happen to him or her	Almost always	48	32.0	2.04±0.903	**Often**
		Often	55	36.7		
		Sometime	43	28.7		
		Almost never	1	.7		
		Never	**3**	**2.0**		

"(M) Mean, (SD) Standard deviation, Level of Assessment (Almost Always [M=1-1.79], Often[M=1.80-2.59], Sometime [M= 2.60-3.39], Almost Never [M=3.40-4.19], Never [M=4.20-5])"

In the light of statistical analysis of mean, the **Table (4.5.3)** demonstrated that the mothers expressed the quality of life related to emotional function of their children were often suffers of emotional problems at all items of the scale except, items number (1) the responses were almost always suffering of emotional problems.

Table 4.5. 4 Overall Assessment of Quality of Life related to Emotional Function

Weighted	Freq.	%	M ± SD
Poor	118	78.7	**9.84±3.299**
Moderate	24	16.0	
Good	8	5.3	
Total	**150**	**100.0**	

M: Mean for total score, S.d: Standard Deviation for total score (Poor= 5-11, Moderate= 12-18, Good= 19-25)

In **Table (4.5.4)**, the quality of life related emotional function was demonstrating that mothers are express at *M ± SD= 9.84±3.299*; the mothers expressed poor quality of life of emotional function of their children (*n=118*; %=78.7).

Table 4.5. 5 Quality of Life related to Social Functioning

List	Social Function items	Weighted	Freq.	%	M ± SD	Ass.
1	Getting along with other children	Almost always	94	62.7	1.42±0.616	**Almost always**
		Often	50	33.3		
		Sometime	4	2.7		
		Almost never	2	1.3		
		Never	0	0.0		
2	Other kids not wanting to be his or her friend	Almost always	94	62.7	1.44±0.660	**Almost always**
		Often	48	32.0		
		Sometime	5	3.3		
		Almost never	3	2.0		
		Never	0	0.0		
3	Getting teased by other children	Almost always	87	58.0	1.56±0.772	**Almost always**
		Often	44	29.3		
		Sometime	17	11.3		
		Almost never	1	0.7		
		Never	1	0.7		
4	Not able to do things that other children his or her age can do	Almost always	73	48.7	2.32±1.373	**Often**
		Often	6	4.0		
		Sometime	20	13.3		
		Almost never	51	34.0		
		Never	0	0.0		
5	Keeping up when playing with other children	Almost always	83	55.3	2.12±1.340	**Often**
		Often	9	6.0		
		Sometime	15	10.0		
		Almost never	43	28.7		

		Never	**0**	**0.0**		

"(M) Mean, (SD) Standard deviation, Level of Assessment (Almost Always [M=1-1.79], Often[M=1.80-2.59], Sometime [M= 2.60-3.39], Almost Never [M=3.40-4.19], Never [M=4.20-5])"

In the light of statistical analysis of mean, the **Table (4.5.5)** demonstrated that the mothers expressed the quality of life related to social function of their children were almost always too often suffers of social problems at all items of the scale.

Table 4.5. 6 Overall Assessment of Quality of Life related to Social Function

Weighted	Freq.	%	M ± SD
Poor	120	**80.0**	**8.88±4.763**
Moderate	28	18.7	
Good	2	1.3	
Total	**150**	**100.0**	

M: Mean for total score, SD: Standard Deviation for total score (Poor= 5-11, Moderate= 12-18, Good= 19-25)

Table (4.5.6) demonstrated that the quality of life related social function was demonstrating that mothers are express at *M ± SD = 8.88±4.763*; the mothers expressed poor quality of life of social function of their children (*n=120*; %=80.0).

Table 4.5. 7 Quality of Life related to School Functioning

List	School Function items	Weighted	Freq.	%	M ± SD	Ass.
1	Keeping up with schoolwork	Almost always	110	73.3	1.34±0.632	**Almost always**
		Often	31	20.7		
		Sometime	7	4.7		
		Almost never	2	1.3		
		Never	0	0.0		
2	Missing school because of not feeling well	Almost always	121	80.7	1.24±0.554	**Almost always**
		Often	22	14.7		

		Sometime	6	4.0		
		Almost never	1	0.7		
		Never	0	0.0		
3	Missing school to go to the doctor or hospital	Almost always	98	65.3	1.52±0.783	**Almost always**
		Often	27	18.0		
		Sometime	24	16.0		
		Almost never	1	.7		
		Never	0	0.0		
4	Paying attention in class	Almost always	89	59.3	1.97±1.252	**Often**
		Often	6	4.0		
		Sometime	25	16.7		
		Almost never	30	20.0		
		Never	0	0.0		
5	Forgetting things	Almost always	98	65.3	1.84±1.241	**Often**
		Often	7	4.7		
		Sometime	15	10.0		
		Almost never	30	20.0		
		Never	**0**	**0.0**		

"(M) Mean, (SD) Standard deviation, Level of Assessment (Almost Always [M=1-1.79], Often[M=1.80-2.59], Sometime [M= 2.60-3.39], Almost Never [M=3.40-4.19], Never [M=4.20-5])"

In the light of statistical analysis of mean, as listed in **Table (4.5.7)** demonstrated that the mothers expressed the quality of life related to school function of their children were almost always too often suffers of school problems at all items of the scale.

Table 4.5. 8 Overall Assessment of Quality of Life related to School Function

Weighted	Freq.	%	M ± SD
Poor	134	**89.3**	**7.92±4.464**
Moderate	15	10.0	
Good	1	0.7	
Total	**150**	**100.0**	

M: Mean for total score, S.d: Standard Deviation for total score (Poor= 5-11, Moderate= 12-18, Good= 19-25)

Table (4.5.8) demonstrated the quality of life related school function was demonstrating that mothers are express at *M* ± *SD* = *7.92±4.464*; the mothers expressed poor quality of life of school function of their children (*n=134*; %=89.3).

Table 4.5. 9 Overall Assessment of Quality of Life for Children with Cerebral Palsy

Weighted	Freq.	%	M ± SD
Poor	138	**92.0**	**43.14±7.275**
Moderate	12	8.0	
Total	**150**	**100.0**	

M: Mean for total score, SD: Standard Deviation for total score (Poor= 23-53, Moderate= 54-84, Good= 85-115)

Table (4.5.9) listed the quality of life for children with cerebral palsy was demonstrate mothers at *M* ± *SD* = *43.14±7.275*; the mothers expressed poor quality of life for those who are suffers of cerebral palsy (*n=138*; %=92.0).

Table 4. 6 Significant Association between Psychosocial Burden for Mothers of Cerebral Palsy Children and their Socio-demographic Characteristics

	Rating	Psychological burden			Total	d.f	*Sig.*	
		High	Moderate	Low				
Age	<20 years old	8	0	3	11	10	χ^2 =119.099 P-value=0.000	S
	20-24 years old	38	5	0	43			
	25-29years old	2	28	0	30			
	30-34years old	1	29	0	30			
	35-39 years old	12	8	1	21			
	≥40 years old	13	0	2	15			
	Total	74	70	6	150			
Education level	Do not read or write	25	0	3	28	6	χ^2 =67.096 P-value=0.000	S
	Read and write	24	58	0	82			
	Secondary	9	12	0	21			
	Institutes and	16	0	3	19			

	more							
	Total	74	70	6	150			
Occupation	Employ	31	0	3	34	2	χ^2 =38.678 P-value=0.002	S
	Unemployed	43	70	3	116			
	Total	74	70	6	150			
Monthly income	Enough	30	0	3	33	4	χ^2 =52.972 P-value=0.000	S
	Certain limit enough	18	52	0	70			
	Is not enough	26	18	3	47			
	Total	74	70	6	150			
Residents	Countryside	48	17	3	68	3	χ^2 =54.810 P-value=0.000	S
	Outskirts	0	35	0	35			
	City	26	18	3	47			
	Total	74	70	6	150			
Family size	<4	25	0	3	28	4	χ^2 =36.548 P-value=0.000	S
	4-5	23	44	0	67			
	>5	26	26	3	55			
	Total	74	70	6	150			
Family type	Nuclear	48	7	3	58	2	χ^2 =45.799 P-value=0.000	S
	Extended	26	63	3	92			
	Total	74	70	6	150			

"χ^2 = Chi-square, Df= Degree of freedom, P-value= Probability value, S= significant, NS= non significant"

(Table 4.6) This table indicate that there were Association between psychosocial burden of cerebral children’s mothers and their socio-demographic characteristics at *p-value <0.05*.

Table 4. 7 Association between QoL of cerebral palsy children and their Characteristics

	Rating	QoL		Total	d.f	*Sig.*	
		Poor	Moderate				
Age	<5 years	85	10	95	2	χ^2=8.190 P-value=0.017	S
	5-10 years	40	6	46			
	>10 years	5	4	9			
	Total	130	20	150			
Gender	Male	73	8	81	1	χ^2=1.182 P-value=0.177	NS
	Female	57	12	69			
	Total	130	20	150			
No. children	<3	97	12	109	2	χ^2=15.389 P-value=0.000	S
	3-5	31	4	35			
	>5	2	4	6			
	Total	130	20	150			

Child order	First	27	4	31	3	χ^2=3.045 P-value=0.385	NS
	Second	35	3	38			
	Third	38	5	43			
	Beyond that	30	8	38			
	Total	130	20	150			
age at diagnosis	Before birth	5	0	5	2	χ^2=1.818 P-value=0.403	NS
	Newborn	65	8	73			
	Infant	60	12	72			
	Total	130	20	150			

"χ^2 = Chi-square, Df= Degree of freedom, P-value= Probability value, S= significant, NS= non significant"

(**Table 4.7**) This table indicate that there were Association between quality of life among cerebral palsy children and their age, number of sibling at *p-value <0.05*.

Table 4. 8 Significant Association between Psychosocial Burden for Mothers of Cerebral Palsy Children and their Clinical Characteristics

History of CP	**Rating**	**QoL**		**Total**	**d.f**	***Sig.***	
		Poor	Moderate				
	Yes	10	2	12	2	χ^2=0.125 P-value=0.723	NS
	No	120	18	138			
	Total	130	20	150			
Type of birth	Normal delivery	89	13	102	1	χ^2=.095 P-value=0.757	NS
	Caesarean Section	41	7	48			
	Total	130	20	150			
Feeding type	Breast feeding	36	7	43	2	χ^2=0.125 P-value=0.723	NS
	Artificial feeding	62	5	67			
	Mixed feeding	32	8	40			
	Total	130	20	150			
Risk of CP	Suffocation	25	4	29	4	χ^2=0.277 P-value=0.964	NS
	Meningitis	53	7	60			
	Jaundice	47	8	55			

	Twins pregnancy	5	1	6			
	Total	130	20	150			
CP Classification	Hemiplegia	21	4	25	3	χ^2=3.188 P-value=0.364	NS
	Monoplegia	59	5	64			
	Triplegia	3	1	4			
	Tetraplegia	47	10	57			
	Total	130	20	150			

"χ^2 = Chi-square, Df= Degree of freedom, P-value= Probability value, S= significant, NS= non significant"

Table(4.8) This table indicate that there were no association between quality of life among cerebral palsy children and their clinical characteristics at *p-value* >0.05.

Table 4. 9 Correlation between Mothers Psychosocial Burden and their Children Quality of Life

Mothers Burdens	**Children QOL**				
	Physical	Emotional	Social	School	Total score
	*r= -0.149**	*r= -0.187**	*r= -0.298***	*r= -0.186**	*r=-0.142**
	p= 0.058	*p= 0.022*	*p= 0.000*	*p= 0.023*	*p=0.012*

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

r: Spearman's rho, p= Probability value

Table (4.9) There were significant correlations between the mother's burden and their child's quality of life profiles, including: Physical functions very low correlation (reverse) with mothers burdens ($r=-0.149$; $p=0.058$). Emotional functioning have been correlated (reverse) with mothers burdens ($r = -0.187$; $p=0.022$). Social functioning have been correlated (reverse) with mothers burdens ($r = -0.298$; $p < 0.000$). School functioning have been correlated (reverse) with mothers burdens ($r = -0.186, p < 0.023$). The quality of life for cerebral palsy children had been significantly correlated (reverse) to their mother’s psychosocial burden ($r=-0.142; p=0.012$) as shown in **Table (4.8)**.

Chapter Five

Discussion of the Study Results

Chapter Five

Discussion of the Study Results

5.1. Socio-Demographic Characteristics of Mothers

The distribution of mothers age at mean 28.79+7.661, the age 20-24 years old, followed by those who are age 25-34 years old, followed by those who are age 35-39 years and old, followed by those who are age ≥ 40 years old and those who are age <20 years old. Findings come in agreement with Sternal et al., (2021), who stated that most of mothers who had cerebral palsy children were aged less than 25 years. This results due to maternal age is a factor that influences the risk of birth defects in babies, mothers aged 25 years and below, the risk of developing congenital anomalies.

The distribution of mother's education as follow, the read and write was the highest percentage, followed by those who are do not read and write mothers, followed by those who are secondary school mothers, and those who are graduated of institute and above. Although all the mothers interviewed expressed a high level of motivation and awareness about providing care for a child with a disability, the lack of knowledge due to the low level of education.

In regards with occupation, the distribution of mothers were unemployed mothers records the highest percentage, as compared with those who are employed mothers. In terms of monthly income, the mothers express is not enough income, followed by those who are enough income, and those who are sufficient to certain limit income. This finding come in line with Khayatzadeh et al., 2013 who assessed the economic status among mothers of cerebral palsy child's. Their findings reveal the most of mothers with poor economic due to there are no institutions or associations that donate to these disabled people.

Housing area related findings, most of mother's countryside residents, followed by those who are city residents, and those who are outskirts. A number of family member, most of families constituted from 4 to 5 member, followed by those who are >5 member, and those who are <4 member. Type of family, the extended families were records the highest percentage, as compared with those who are nuclear families.

This results parallel with a study conducted by Shaker (2015), under the title impact of spastic cerebral palsy upon the quality of life of children under the age of 12 years in Erbil City: parents’ reports, found that most of the mothers were living in urban areas and level of education was illiterate.

Another by Issa and Mohammed (2016), in Baghdad city investigated the psychological burdens on parents of children with cerebral palsy. He found that most of the participants (67%) were a housewife, which was the same result of the study underhand.

Also, the above findings are supported by study of Baiee et al., 2019, shows that the majority of the study sample 71 (48.0%) aged (18-27) years old; that their level of education was read and write estimating as 67 (45.3%); while their occupational status was not work approximating in 122 (82.4%), and 78 (52.7%) live in rural areas.

5.2. Cerebral Palsy Children Characteristics

Findings show the age of cerebral palsy children, most of children aged less than 5 years, followed by those who are age 5-10 years old, and followed by those who are aged more than 10 years and old, due to cerebral palsy is typically diagnosed in babies and toddlers as a mostly in under five years (Sewell et al., 2014).

In terms of child gender, most of cerebral palsy from male gender, as compared to those who are female. Cerebral palsy and related developmental disorders are more common in males than in females, but the reasons for this disparity are uncertain. Males born very preterm also appear to be more vulnerable to white matter injury and intraventricular hemorrhage than females (Johnston & Hagberg, 2007).

A study performed by Al-Azzawi (2012), at Iraq in Diyala province, who had a sample compatible in their ages but not with their sexes, found that the children ranged between the age of (7-12) months (48.8%), while male gender (58.5%) more than female.

Number of siblings related findings, most of them had a less than 3 siblings, followed by those who had 3-5 siblings, and those who had more than 5 siblings. Badran (2013), found that most of the parent’s had no other siblings affected by Cerebral Palsy.

Child order in the family, most of cerebral palsy its sequence third, followed by those who its sequence second and beyond it, and those who sequence the first older. While in a study carried out by Garb et al., 2016, in Iran, which resulted in 135 (67.5) out from 200 children the first baby in his family with cerebral palsy.

In regards with age at diagnosis of cerebral palsy, most of children diagnosed at new-born period, followed by those who are diagnosed at infancy period, and followed by those who are diagnosed before birth. This finding is supported by study carried out in Denmark by Granild-Jensen et al., 2015 their sample consists from 1222 of a child with cerebral palsy, out of them 628 (51%) diagnostic with this disease before 12 months of age.

There is limitation of previous investigation related to variables, but the findings of Parkes et al., 2008, indicated that most of participants with less than 5 siblings for disabled child's, and most of children at newborn diagnosed.

The above findings come in the same line with study of Baiee et al., 2019, in Babylon governorate. Their findings indicate that the highest per cent of sample 75 (50.7%) who considered as a toddler; 83 (56.1%) were male; 105 (70.9%) while 112 (75.7%) of the child order in the family between 1-3 and 72 (48.6%) of the population diagnosed at the newborn stage.

5.3. Clinical Information of Cerebral Palsy Children

The management of cerebral palsy is based on a multidisciplinary team approach and clinical information. The members of this team may vary depending on the age of the child, the level of development, the severity of the condition, and the availability of the services (Fairhurst, 2012).

Most mothers mention that they have no history in the family for this disease while other mothers mention that there is a history of disease in their family. Most of children normally delivered, compared with those who were Caesarean section delivered. Artificial feedings were the most common among cerebral palsy children, followed by those who were breast feeding, and followed by those who were mixed feeding. Mazumder et al., 2015, showed that most of the children with cerebral palsy are birth by vaginal delivery (61%) and were with artificial feeding (75%), these studies results support the results of the current study.

Mothers express that the meningitis was considered the most common risk factors for their cerebral palsy children due to viral encephalitis causes inflammation of the brain. CP can also be caused by brain injuries during the first few months or years of life, followed by those who are jaundice, followed by those who are suffocation, and those who have twine pregnancy. This finding come with MacLennan et al., 2015, who mentioned in their findings that families express were the genetic factors not interferes with their children cerebral palsy. Most of children normally delivered and feeding (Parkes et al., 2008; Dahlseng et al., 2012). The most of risk factors of cerebral palsy were antenatal care related to infection in study mentioned by McIntyre et al., 2013.

Baiee et al., 2019, showed that the 133 (89.9%) have no family history for the same condition; while 83 (56.1%) of the study sample their place of delivery where in non-governmental place and 105 (70.9%) with normal delivery; whereas 61 (41.2%) of the respondents follow artificial feeding; 75 (50.7%) of the children being low weight at birth and 72 (48.6%) of their children were Monoplegia.

Another study applied by Gabr et al., 2016, it was done in Saudi Arabia, investigated the foetal risk factors of cerebral palsy found that the majority of the study sample with low birth weight (86.4%), these results sustenance the existing results, another side from the same study found that most children suffering from Quadriplegic 53 (25.3%) these results do not support.

Monoplegia were the most common class among cerebral palsy children, followed by those who are Tetraplegia, followed by those who are hemiplegia, and followed by those who are Triplegia. This findings consisting with previous studies one that deals with the prevalence of different types of cerebral palsy among children was as Monoplegia (Türkoğluet al., 2016); also, findings in agreement with a previous Turkish study which showed that the most prevalent type of cerebral palsy among their study group was Monoplegia, with a prevalence of (43.3%) (Soliman et al., 2019).

Furthermore, the findings of Baiee et al., 2019, showed the majority of the study sample is 133 (89.9%) who have no family history for the same condition; 83 (56.1%) of the study sample their place of delivery wherein, not governmental place and 105 (70.9%) with normal delivery; while 61 (41.2%)

of the respondents follow artificial feeding; 75 (50.7%) of the children being low weight at birth and 72 (48.6%) of their children were Monoplegia.

5.4. Psychosocial Burden of Mothers

Parents (mothers) are, always at the core of management, with an active participation in every phase of treatment and management of cerebral palsy children. Evidence reported that in children with physical disabilities, participation of mothers in the physical therapy process significantly shortens the time needed to reach the targets of therapy. The family has a primarily important role in management of cerebral palsy in children this creates psychological and social burdens (Andrew et al., 2012).

Caregivers especially mothers of children with cerebral palsy suffer from a substantial psychosocial burden. However, there is a scarcity of documentation of the various sources of burden in low- and middle-income settings.

5.4.1. Psychological Burden among Mothers of Cerebral Palsy Children

The studies on children with cerebral palsy usually focused on the disease itself, and the family side was relatively neglected. In our literature search, limited studies examining the psychological burden. The mothers were tested on 31 items related to psychological burdens. Current study findings indicate that the mothers who had children with cerebral palsy were expressed a high level of psychological burden ($M \pm SD=50.06\pm10.830$) **Table (4.4.2)**

Through the results obtained after the statistical treatment of the data, it was found that the percentages of the distribution of degrees. The psychological burden of the study sample was as follows:

The proportion of mothers with high psychological burden was 49.3%.

The proportion of mothers with moderate psychological burden was 46.7%.

The proportion of mothers with low psychological burden was 0.4%.

From our point of view, this result clarifies the societal view of the families of the cerebral palsy children by members of the community, which causes increased pressure on them, especially the mother, who bears the responsibility of caring for this child.

In addition to that, mothers preoccupied with the requirements of the rest of the family and doing household chores, this may deprive her of performing her societal duties, and thus tend to isolate, thus neglect herself, ignore her rights, and her psychological condition deteriorates, and she becomes vulnerable to many diseases.

Similarly, the stress level in mothers of children with Konya cerebral palsy children was higher compared to control mothers with healthy children in a study by Yilmaz et al., 2013, due to psychological burden mostly arise during acute events and chronicity of the condition predisposes these mothers to psychological depressed.

Although cerebral palsy is considered an additional stress factor for the family, studies particularly examining this issue are scarce. In a study from Bangladesh, Mobarak et al., 2000, found that of the 91 mothers of children with cerebral palsy, 41.8% had a risk for psychiatric morbidity due to severe psychological burdens.

Yet another study, conducted by Brehaut et al., 2004, showed that the primary caregivers of children with cerebral palsy displayed a higher level of psychological and physical symptoms than the control group because the mothers feeling embarrassed and low self-esteem.

In a study investigating the relationship between the psychological well-being of mothers with cerebral palsy child children, it was observed that mothers mostly experienced depressive symptoms (Lee, 2013).

The most important predictors of caregiver burden were degree of disability, depression and self-efficacy. For this reason, studies believe that it is necessary to develop interventions to reduce depression and enhance self-efficacy in parents of children with CP as one of the primary objectives to minimizing the burden on caregivers of disabled children (Marrón et al., 2013).

During acute events and that chronicity of the condition predisposes these mothers to psychological burden mostly arise. It is possible that mothers may have experienced anxiety symptoms at the time of diagnosis; however, these symptoms have been turned into or have been replaced with depressive symptoms and this resulted in psychological burdens. Further studies will be required to determine the needs and problems of mothers with cerebral palsy children (Brown & Harris, 2012).

The mother caring for the child with cerebral palsy may impair her own quality of life while attempting to improve that of her child. It shouldn’t be forgotten that mothers, who are mostly the primary caregivers of children with cerebral palsy, play an integral part throughout the course of the treatment, and without their support, it is not possible to benefit optimally from treatment (Davis et al., 2010).

Therefore, health professionals working in the area of cerebral palsy and especial needs should also consider the psychological status and the quality of life of the mothers when making treatment decisions.

5.4.2. Social Burden among Mothers of Cerebral Palsy Children

The mothers were tested on 18 items related to social burdens. Current study findings showed that the mothers expressed high level of social burden (*M* ± *SD=29.08±6.803*) **(Table 4.4.4).** Through the results obtained after the statistical treatment of the data, it was found that the percentages of the distribution of degrees. The social burden of the study sample was as follows:

The proportion of mothers with high social burden was 68.7%.

The proportion of mothers with moderate social burden was 24.7%.

The proportion of mothers with low social burden was 6.7%.

From our point of view, this result clarifies the lack of social support and the support that the mother desperately needs, may contribute to the high perceived social burden among mothers, with the lack of sufficient information on the issue of cerebral palsy, causing the mother to confuse how to deal with this disabled son.

These findings come with Michael et al. (2019), find that the mothers of children with cerebral palsy suffer from significant social problems that are often overlooked by the general public due to the following (1) the stress of caring for an overly dependent child; (2) restricting the participation of mothers in society; (3) the financial constraints of mothers of children with cerebral palsy; (4) health problems experienced by mothers of children with cerebral palsy; (5) Feeling uncertain about the future of the child; (6) The society's negative perception of the child's problems.

In the same regards, a qualitative exploration of psychosocial stress among mothers of children with cerebral palsy done in India revealed that the main issues were disturbed social relationships of the mothers, health problems, financial problems, worry about the future of the child and a need for more supportive services (Nimbalkar et al., 2014).

A similar, Iranian study showed very similar stressors and also, rude and unsupportive interactions with the society, due to lacked support from their husband and family in the process of care-giving, and had no support from the community members, and all that lead to felt isolated from others (Alaee et al., 2015).

This may be due to, at the individual level the mothers perceive aches and pains due to the heavy physical activity of care-giving. They also suffer from a feeling of guilt about the child's condition. Due to the difficulty in balancing family and work, they had significant social burdens. They also a lack of knowledge and awareness about possible options for the treatment of their child (Aisen et al., 2011).

At the interpersonal level, the mothers lacked support from their husband and family. They also had to suffer the ill effects of alcoholism and domestic violence from their husbands. They had to compromise on the care they provided to the family members and their children cerebral palsy (Marrón et al., 2013).

At the community level, the mothers had no support from the community members and felt isolated from others. The mothers also reported discrimination and lack of participation in social events. Environmental stressors like lack of inclusive public spaces, lack of options for public transport and unfriendly work timings and environment were major sources of burden. The mothers felt that the disability welfare support offered by the government was grossly insufficient and there was no platform for interactions with other peers and mothers suffering from a similar burden (Pousada et al., 2013).

5.5. Quality of Life for Children with Cerebral Palsy

Quality of life (QoL) has been described as an individual's perception of own his/her status in life as to cultural features and value system. Health-related quality of life, however, is a subcomponent of QoL including physical, social, and emotional status, is the happiness and satisfaction of individuals in different parts of life influencing or influenced by individuals' health.

Children with cerebral palsy are highly dependent on caregivers. Mothers are the most common caregivers of children with cerebral palsy. In low- and middle- income settings these mothers are often burdened with the care of the family, earning a livelihood as well as caring for the child with CP.

This puts substantial burden and stress on the parents due to the intersection between gender norms, poverty, social stigma and care-giving for a child with a disability. Which leads to disruption of their children quality of life (Thrush, 2014).

5.5.1. Quality of Life related to Physical Functioning

Findings demonstrate that mothers are expressed that the cerebral palsy children with poor quality of life related to physical function ($M \pm SD = 16.48 \pm 5.005$) **(Table 4.5.2).**

This finding come along with study confirmed that poor quality of life related to physical functions among cerebral palsy children due to that the physical function depends on severe disability, and poor quality of life positive associated with severity of disability (Tucker et al., 2008).

Approximately 1 in 8 subjects with severe CP suffers of poor quality of life. This depends on the care provided by the mother (Vargus-Adams, 2008). Parents reported reduced physical related quality of life for their children with cerebral palsy. In the physical function domain, most children scored over 3 SDs below a normative sample, and scores in parental impact domains were at least 1 SD below the normative sample (Vargus-Adams, 2005).

This may be because children with cerebral palsy have a poorer quality of life related to physical function and the degree of this decline is related to the severity of their cerebral palsy. The severity of the injury must be taken into account in providing care

5.5.2. Quality of Life related to Emotional Functioning

Findings demonstrate that the mothers expressed poor quality of life related to emotional function of their children ($M \pm SD = 9.84 \pm 3.299$) **(Table 4.5.4).** Children with CP, usually rate their quality of life in the emotional and social domains, equal to their typically developed peers. The findings listed above, suggest that children with cerebral palsy can adapt negative emotional function to their activity limitations and may have unsatisfactory quality of life and significant deficits (Parisi et al., 2016).

Erdoganoglu & Gunel (2007), reported that, quality of life children with cerebral palsy children is affected at a higher rate, related to mother's disturbance, and emotional life is influenced due to motor and functional levels of cerebral palsy children.

In a similar study, Oneş et al., 2005, suggested that, psychosocial burdens of mothers are affected negatively their emotional functions of cerebral palsy children, and poor quality of life related to emotional function expressed by the mother's feedback.

Children with cerebral palsy reported a significantly lower emotional quality of life (mean 65.9) than healthy children (mean 83.8). Children with cerebral palsy reported a similar quality of life to paediatric cancer patients receiving treatment (mean 68.9). Children diagnosed with quadriplegia (mean 49.4) reported more impaired quality of life than children with diplegia (mean 69.1) and hemiplegia (mean 72.4) (Varni et al., 2005).

Parent–child concordance was lowest for emotional functioning. Providers and parents should obtain the children's quality of life perceptions whenever possible.

5.5.3. Quality of Life related to Social Functioning

Findings demonstrate that the mothers expressed a poor quality of life related to social function of their cerebral palsy children (*M ± SD= 8.88±4.763*) **(Table 4.5.6).** With the same regards, Kaya et al., 2010, reported that the deterioration of mental health in mothers with CP children gives rise to experiencing further deterioration of social functions, leading to more deterioration in children quality of life.

In a study by Keller and Honig (2012), disability in children was reported to decrease social activities of mothers and to have an influence on social aspects deterioration for both parents and their children.

The course of social functioning over a 3-year period showed an increase in restrictions in children with cerebral palsy ($p<0.001$). Restrictions in social aspect increased more in children with the most severe forms of cerebral palsy ($p<0.001$). In addition to disease characteristics (presence of epilepsy, and speech problems), personal factors (externalizing behaviour problems) and environmental factors (having no siblings, low parental level of education, and parental stress) were associated with greater restrictions in social functioning and communication (Voorman et al., 2010).

From another side, mothers of children with cerebral palsy had poorer quality of life than mothers of healthy children in all investigated domains. In relation to mobility of the child, the quality of life was worse in mothers whose children did not move in the area of social functioning in comparison to mothers whose children had the ability to move independently (Glinac et al., 2017).

The motor functioning and intellectual ability can be used to identify children at risk for progressive restrictions in social functioning and communication. For children with CP and social and communicative restrictions, multidisciplinary assessment and treatment may be indicated to counteract an unfavourable development (van Schie et al., 2013).

Socialization in children affected by cerebral palsy has been observed to have life-altering positive benefits. For example, children who develop social skills have the valuable opportunity to learn from one another and form interpersonal relationships that can last for years (Whitney et al., 2019).

It is important to focus not only on the medical treatment of children with cerebral palsy, but also on their behavioural problems and social circumstances, and to support the parents so that social functioning and communication in these children may be improved.

5.5.4. Quality of Life related to School Functioning

Findings demonstrate that mothers are expressed a poor quality of life related to school function of their cerebral palsy children (*M*± *SD*= 7.92±4.464) **(Table 4.5.8).** This finding come with Shikako-Thomas et al. 2012, confirmed that the quality of life is highly variable in children with cerebral palsy, with about half experiencing a life quality similar to typically developing children. Motor and other activity limitations are indicators for poor quality of life related to school functions.

Varni et al. 2005, stated that lower school functioning is associated with lower academic achievement and, to a lesser extent, intelligence testing scores. Unfortunately, children with cerebral palsy are at a significant academic disadvantage when compared with healthy controls.

Within the multidimensional quality of life construct, some dimensions may be more negatively affected depending on the particular health condition. School functioning is of particular concern, given the negative impact of academic failure on a child’s physical, emotional, and social (Haverman et al., 2017).

Family functioning, behavioural difficulties, and motivation are important predictors of social-emotional adaptation. Determinants of life quality may guide resource allocation and health promotion initiatives to optimize health of the child and family (Berrin et al., 2007).

Identifying quality of life related to school functioning in children with cerebral palsy may aid in developing intervention programs to improve academic performance.

5.6. Significant Association between Psychosocial Burden for Mothers of Cerebral Palsy Children and their Socio-demographic Characteristics

Findings demonstrated that there were indicate that there were association between psychosocial burden of cerebral children mothers and their socio-demographic characteristics at *p-value* <0.05.

Singh et al. (2014), stated that the burdens of mother's increase as their age decreases (under 30 years), and their ability to withstand burden decreases. If the burdens of a disabled child are added to this, it is expected that the feeling of psychosocial burden will increase. On the other hand, younger mothers face the disability of their child at the beginning of their lives with a lack of experience regarding raising this disabled child, which makes them more A feeling of shock and unhappiness, and therefore those reasons for the younger age groups may be the reasons that made them more burdensome.

The results show that there is an effect of educational levels in the levels of psychosocial burden among mothers of cerebral palsy children, as it appeared in general that the burden is not equal at all different educational levels. Whereas, the psychosocial burden is significantly increased with those who are don't read and write, due to they do not know how to properly seek treatment, they are different from the educated and the uneducated.

The existence of differences in the perceived pressure among mothers of mentally handicapped children indicates that the mother who can read and write (average educational level) may be subject to perceived pressure as a result of her child’s disability. Her personality pattern due to frustration and grumbling about her son's condition, and the way she interprets the stressful situation or event she was exposed to (Vadivelan et al., 2020).

This finding consisting with findings Issa and Mohammed (2016), stated that the mother's occupation is significantly associated with mother's burden

($p<0.05$), mothers who are employment expressed a high level of psychosocial burden that the mothers unemployed (Havaei et al., 2019).

From our findings, the psychosocial burden is significantly increased with those who are employment ($M \pm SD=1.67\pm0.214$) than those who are unemployment ($M \pm SD=1.41\pm0.276$). due a mothers who are working mother is looking for a cure for her child's untreated condition.

Whereas, the psychosocial burden is significantly increased with those who make enough monthly income**.** Because they have more therapeutic research behaviour for their child than those who do not have enough income.

Cheshire et al. (2010), find that the high and moderate level of monthly income had been associated with high level of psychosocial burden in deals with cerebral palsy children treatment. The significant differences can be attributed to the lack of similarity in the circumstances of these families in the health problems they are exposed to, specific to the disabled child, and other economic problems that make them different in the degree of perceived stress.

Whereas, the psychosocial burden is significantly increased with those who countryside residents because of the distance of health attachments from them. In this regard, findings of Sternal et al. (2021), who mentioned that mother's residents had been influenced their burden related to cerebral palsy children, due to the limitations of health facilities.

Whereas, the psychosocial burden is significantly increased with those who composed more than 5 family number. The more family members lead to more burdens the mother, because she is responsible for taking care of all family members. There is a significant difference between the number of family members and the responsibility to care for their children with cerebral palsy. The large number of family members leads to the deterioration of the psychological and social aspect of the mother (Draz & Elsayed, 2015).

Whereas, the psychosocial burden is significantly increased with those who are nuclear families (*M ± SD=1.48±0.25046*) than those who are extended families (*M ± SD=1.69±0.221*) (**Table 4.6.7**).

The association can also be attributed to the lack of sufficient awareness of disability and how to deal and coexist with these children in relation to extended families, as understanding and comprehending the reality of disability requires special knowledge and skills between families, and it can also be attributed to the lack of similarity in the circumstances of those families with regard to the special health problems they are exposed to. with a handicapped child.

5.7. Relationship between QoL of cerebral palsy children and their Characteristics

The findings demonstrated that there was association between quality of life among cerebral palsy children and their age, number of siblings at *p-value <0.05*. Due to most common major disabling motor disorder of childhood, is frequently thought of as a condition that affects only children (Haak et al., 2009). Anecdotal reports from children with CP often include symptoms perceived as premature aging that had been significant associated with quality of life in physical function (Tosi et al., 2009). The scores of the externalizing and competence domains for Chinese toddlers with cerebral palsy at different ages were lower quality of life and associated with their social function (p< 0.05) (Wu et al., 2021).

Cerebral palsy is more common in males than in females, but the reasons for this disparity are uncertain. Males born very preterm also appear to be more vulnerable to white matter injury and Intraventricular haemorrhage than females. Also, there were differences in physical abilities and emotional function (Johnston & Hagberg, 2007). There was statistically significant difference between males and females regarding gross motor function or manual ability (Chounti et al., 2013).

The parent-reported quality of life for children physical and emotional function and various daily living profile with cerebral palsy is associated strongly with number of siblings ($P<0.05$). However, depending on the areas of life, the most severely impaired children (in terms of motor functioning or intellectual ability) do not always have the poorest quality of life (Arnaud et al., 2008).

These association are due to the awareness of mothers towards their children (Allik et al., 2006). There are significant differences in quality of life in emotional and social functions with regard to children age at diagnosis at $p\text{-value} <0.05$. The low level of mean age at being of cerebral palsy has been significant impact on physical health, social and feeling of disability among cerebral palsy children from parent's reports (Shelly et al., 2008).

Birth asphyxia have been influenced the children type of cerebral palsy and disturbances physical and motor function (Phelan et al., 2005).

Cerebral palsy happens because something goes wrong during a child's birth. Premature babies (babies born early) have a higher chance of having CP than full-term babies. So do other low-birth-weight babies and multiple births, such as twins and triplets. Type of delivery also can lead to CP and interruption with quality-of-life profile (Jones et al., 2007).

Due to cerebral palsy children commonly have feeding disorders and swallowing problems (dysphagia) that in many instances place them at risk for aspiration with oral feeding, with potential pulmonary consequences. They also commonly have reduced nutrition/hydration status and prolonged stressful health (Arvedson et al., 2013).

The quality of life among cerebral palsy have been associated with severity of cerebral palsy. Where children with CP have the potential to report a high psychosocial QOL score even if they have poor functioning (Shelly et al., 2008).

From point of view, children with cerebral palsy are no different than any other child. They want to living activities, make friends, and be accepted by peers. Yet, due to their disorder, some children with cerebral palsy may develop physical, emotional, social and also school functions issues when daily challenges arise.

5.8. Correlation between Mothers Psychosocial Burden and their Cerebral Palsy Children Quality of Life

Mothers of cerebral palsy children express by the overall a poor quality of life for their cerebral palsy children related to physical, emotional, social, and school functions due to a high level of psychosocial burdens.

Mothers of children with cerebral palsy have unique burdens in Babylon Province including an intersection of gender norms, poverty, stigmatization, lack of support and non-inclusive public policy, which need to be addressed to improve the quality of life for both children and their caregivers.

Care-giving (mothers) has been shown impair the quality of life of the caregiver. Caregivers often suffer from stress and depression (Albayrak et al., 2019). The level of stress and depression suffered by the mothers is inversely proportional to their self-efficacy and level of social support (Zhang et al., 2020).

Seeking social support reduced the increased burden associated with greater functional impairments. Psychosocial interventions focused on evaluating and improving social support for care may help families at high risk for care distress, to minimize negative outcomes and improve quality of life for both (mothers-children) (Wijesinghe et al., 2015).

The burden of mothers for children with cerebral palsy is a neglected phenomenon. In addition to the psychological problems described above, the parents also feel socially isolated, unable to participate in social life, stigmatized and develop conflicts in their family and society. Besides, they also undergo physical stress including lack of sleep, musculoskeletal aches and pains, and hypertension. Therefore, this neglected phenomenon of caregiver burden must be understood clearly and addressed.

Current study findings depict there were significant correlations between the mother's burden and their child's quality of life profiles as follow:

Physical functions very low correlation (reverse) with mother's burdens ($r=-0.149; p=0.058$). Emotional functioning has been correlated (reverse) with mother's burdens ($r = -0.187; p=0.022$). Social functioning has been correlated (reverse) with mother's burdens ($r = -0.298; p < 0.000$). School functioning have been correlated (reverse) with mother's burdens ($r = -0.186, p < 0.023$).

The quality of life for cerebral palsy children had been significantly correlated (reverse) to their mother's psychosocial burden ($r=-0.142; p=0.012$) **(Table 4.8).**

Previous studies that used the same variables showed significant correlation between the psychosocial burdens level and the child's quality of life related to emotional, social and school function (Lai et al., 2017; Ozkan, 2018). This latter finding is consistent with the current study results based on quality of life and burden. This suggests that children quality of life from mother's responses, which is a simple evaluation method, may be a good indicator for the child’s QoL in cerebral palsy cases.

Additionally, previous studies used the Gross Motor Function Classification System (GMFCS) and reported inconsistent findings (negative significant association between mother's burden and their quality of life related physical function of children with cerebral palsy (Basaran et al., 2013).

Parents, especially mothers, who have children with CP can be negatively affected and may have high levels of burden (Parisi et al., 2016). Previous studies have shown high levels of stress and depression, and low QoL among children with cerebral palsy (Pousada et al., 2013).

Nonetheless, a positive effect of caring for a child with cerebral palsy on a parent’s life has also been reported, suggesting the families’ potential for adaptation (Carona et al., 2013). However, why some parents cope well with the difficulty of caring for their child and others do not is not fully understood (Raina et al., 2005).

This may be related to the common medical comorbidities associated with cerebral palsy, leading to a relative reduction or induction of parents’ demands. Parkes et al. (2008), reported that among parents who have children with CP who suffer from psychological problems, 42% said they burdened the family at least “quite a lot”.

Other factors that are consistently related to an increased the burden of caregiver have been identified as child behaviour and cognitive problems, low caregiver self-efficacy, and low social support (Pousada et al., 2013).

Besides these factors, severity of the condition has been investigated, and milder conditions have been found to be associated with better outcomes for parents of children with cerebral palsy (Bemister et al., 2014).

Taken together, previous research and the present study indicate that severe disability in children with cerebral palsy is associated with a lower quality of life and higher burden in mothers. These findings support the notion that family-focussed intervention strategies tend to replace child-focussed methods (Aydin & Nur, 2012).

Rearing a child with cerebral palsy is associated with the psychosocial of the caregiver, and mothers wellbeing is positively influenced by the health and functioning of children with paediatric disabilities (Basaran et al., 2013; Bemister et al., 2014). Which are in accordance with the current results. Therefore, therapy planning should encompass not only children who are affected, but also caregiver mothers.

Limitation, in children with cerebral palsy, parents' ratings of their children's quality of life are generally comparable as a group to their child's self-report. Disparities do exist, particularly in psychosocial domains, and, therefore, the child's own perspective should be considered whenever feasible.

Chapter Six

Conclusions & Recommendations

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6.1. Conclusion:

1) Burden in terms of psychological, mothers expressed a high level, as being a risk for psychiatric morbidity because cerebral palsy is considered an additional stress factor for the family, and psychological burden mostly arise during acute events and chronicity of the condition predisposes these mothers to psychological depressed.

2) Burden in terms of social, mothers expressed a high level, due to the mother's difficulty in balancing family and work, lacked support from their husband and family in the process of care-giving, and had no support from the community members, and all that lead to felt isolated from others.

3) Overall Burden, mothers of children with cerebral palsy have high level of psychosocial burdens that may be due to gender norms, poverty, stigmatization, non-inclusive public policy, lack of support and there are no institutions to adopt these children

4) Quality of life in terms of physical, emotional, social, and school functions, mothers of children expressed a poor quality of life due to unhappiness and dissatisfaction of mothers in different parts of life influence health of their children.

5) Psychosocial burdens of mothers had been significantly correlated with their children quality of life, due to burden of care leading to a relative reduction or induction of parents’ demands

6.2. Recommendations:

1) It is necessary to develop interventions program to reduce psychosocial burden in parents of children with cerebral palsy as one of the primary objectives for minimizing the burden on mothers of disabled children.

2) It is desirable to have qualified health professionals present in rehabilitation centres to relieve the psychological burden of mothers during their review and to explain the disease and its nature for the mother to reduce the social burden and make them accept the child without feeling embarrassed about his presence in the family.

3) A manual booklet of how to deal with cerebral palsy children, it should be write in simple words and use attractive pictures given to the parents.

4) Further studies will be required to determine the needs and problems of families with cerebral palsy children.

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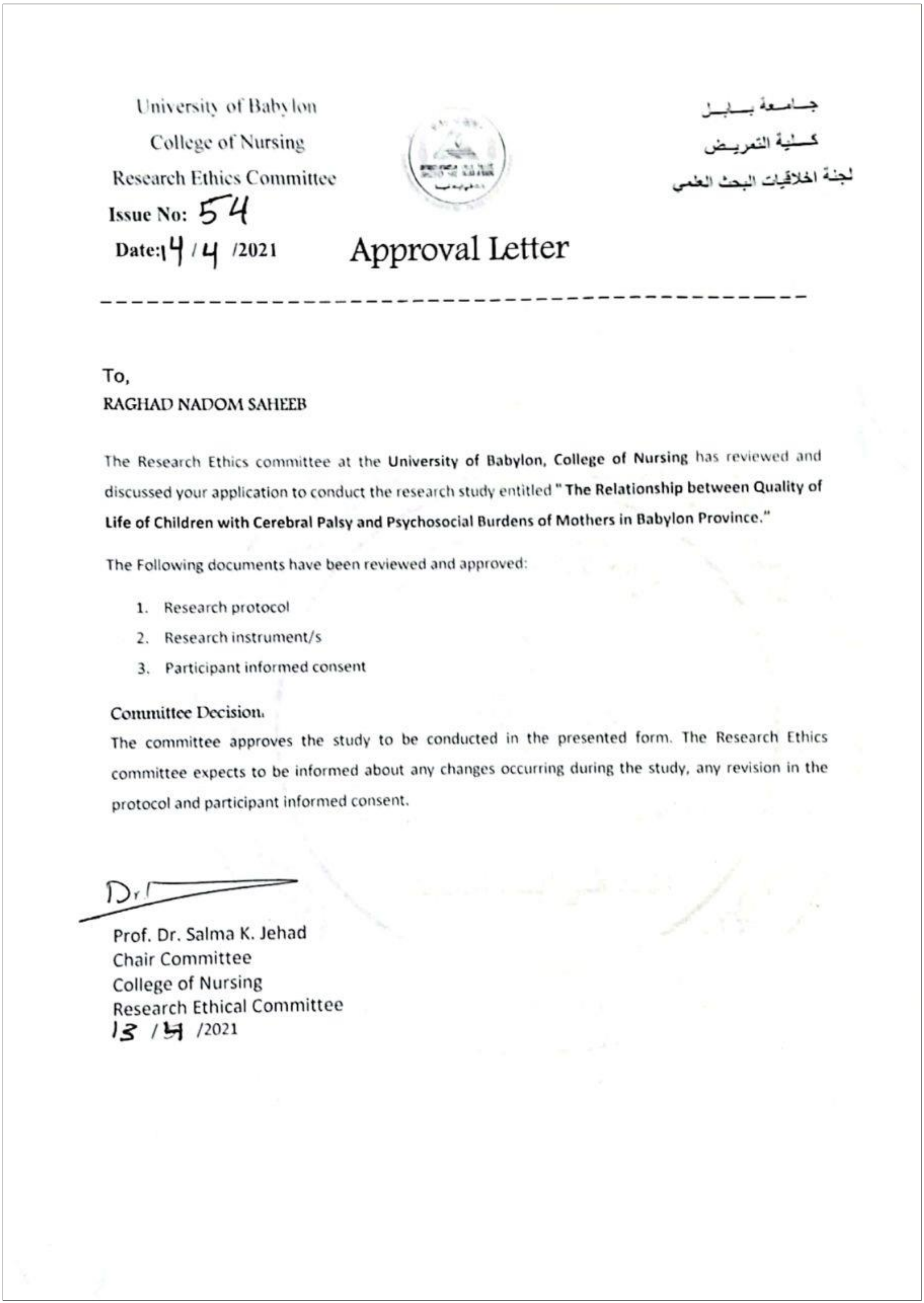

University of Babylon
College of Nursing
Research Ethics Committee

جامعة بابل
كلية التمريض
لجنة اخلاقيات البحث العلمي

Issue No: 54
Date: 14 / 4 /2021

Approval Letter

To,
RAGHAD NADOM SAHEEB

The Research Ethics committee at the **University of Babylon, College of Nursing** has reviewed and discussed your application to conduct the research study entitled **" The Relationship between Quality of Life of Children with Cerebral Palsy and Psychosocial Burdens of Mothers in Babylon Province."**

The Following documents have been reviewed and approved:

1. Research protocol
2. Research instrument/s
3. Participant informed consent

Committee Decision.

The committee approves the study to be conducted in the presented form. The Research Ethics committee expects to be informed about any changes occurring during the study, any revision in the protocol and participant informed consent.

Prof. Dr. Salma K. Jehad
Chair Committee
College of Nursing
Research Ethical Committee
13 / 4 /2021

جمهورية العـــراق

Ministry Of Health
Babylon Health Directorate
Email:-
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Tel:282628 or 282621

وزارة الصحة والبيئة
دائرة صحة محافظة بابـــل
المديـــر العـــام
مركـــز التدريب والتنمية البشرية
لجنة البحوث

استمارة رقم :- ٢٢
رقم القرار :- ٢٢
تاريخ القرار :- ٢٧/ ٦/ ٢٠٢١

وزارة الصحة
دائرة صحة بابل
مركز التدريب والتنمية البشرية

قرار لجنة البحوث

تحية طيبة ...

درست لجنة البحوث في دائرة صحة بابل مشروع البحث المعنونة (العلاقة بين جودة الحياة للاطفال المصابين بشلل الدماغ والاعباء النفسية والاجتماعية للامهات في محافظة بابل) والمقدم من الباحث (رغد ناظم صاحب) إلى وحدة أدارة البحوث والمعرفي مركز التدريب والتنمية البشرية في دائرة صحة بابل بتاريخ ٢٠٢١/٦/٢٧ وقررت :

قبول مشروع البحث أعلاه كونه مستوفيا للمعايير المعتمدة في وزارة الصحة والخاصة بتنفيذ البحوث ولا مانع من تنفيذه في مؤسسات الدائرة .

مــــــع الاحتـــــرام

الدكتور / محمد عبد الله عجرش
رئيس لجنة البحوث

/ /٢٠٢١

نسخة منه إلى :
- مكتب المدير العام / مركز التدريب والتنمية البشرية / وحدة إدارة البحوث ... مع الأوليات.

دائرة صحة محافظة بابل / مركز التدريب والتنمية البشرية // ايميل المركز babiltrainning@gmail.com

Ministry of Higher Education
and Scientific Research
University of Babylon
College of Nursing

وزارة التعليم العالي والبحث العلمي
جمهورية العراق
جامعة بابل
كلية التمريض
لجنة الدراسات العليا

Ref. No. :
Date: /

العدد : ١٢٢١
التاريخ : ٢ / ٥ / ٢٠٢١

الى / دائرة صحة بابل- مركز التدريب والتنمية البشرية

م/ تسهيل مهمة

تحية طيبة :

يطيب لنا حسن التواصل معكم ويرجى تفضلكم بتسهيل مهمة طالبة الدكتوراه (رغد ناظم صاحب نصيف) لغرض جمع عينة دراسة الدكتوراه والخاصة بالبحث الموسوم :

العلاقة بين جودة الحياة للأطفال المصابين بالشلل الدماغي والأعباء النفسية والاجتماعية للأمهات في محافظة بابل

The Relationship between Quality of Life of Children with Cerebral Palsy and Psychosocial Burdens of Mothers in Babylon Province

مع الاحترام ...

المرافقات //
- بروتوكول .
- استبانة .

أ.م.د. حسام عباس داود
معاون العميد للشؤون العلمية والدراسات العليا
٣ /٥/ ٢٠٢١

صورة عنه الى //
- مكتب السيد العميد للتفضل بالاطلاع مع الاحترام .
- لجنة الدراسات العليا
- الصادرة .

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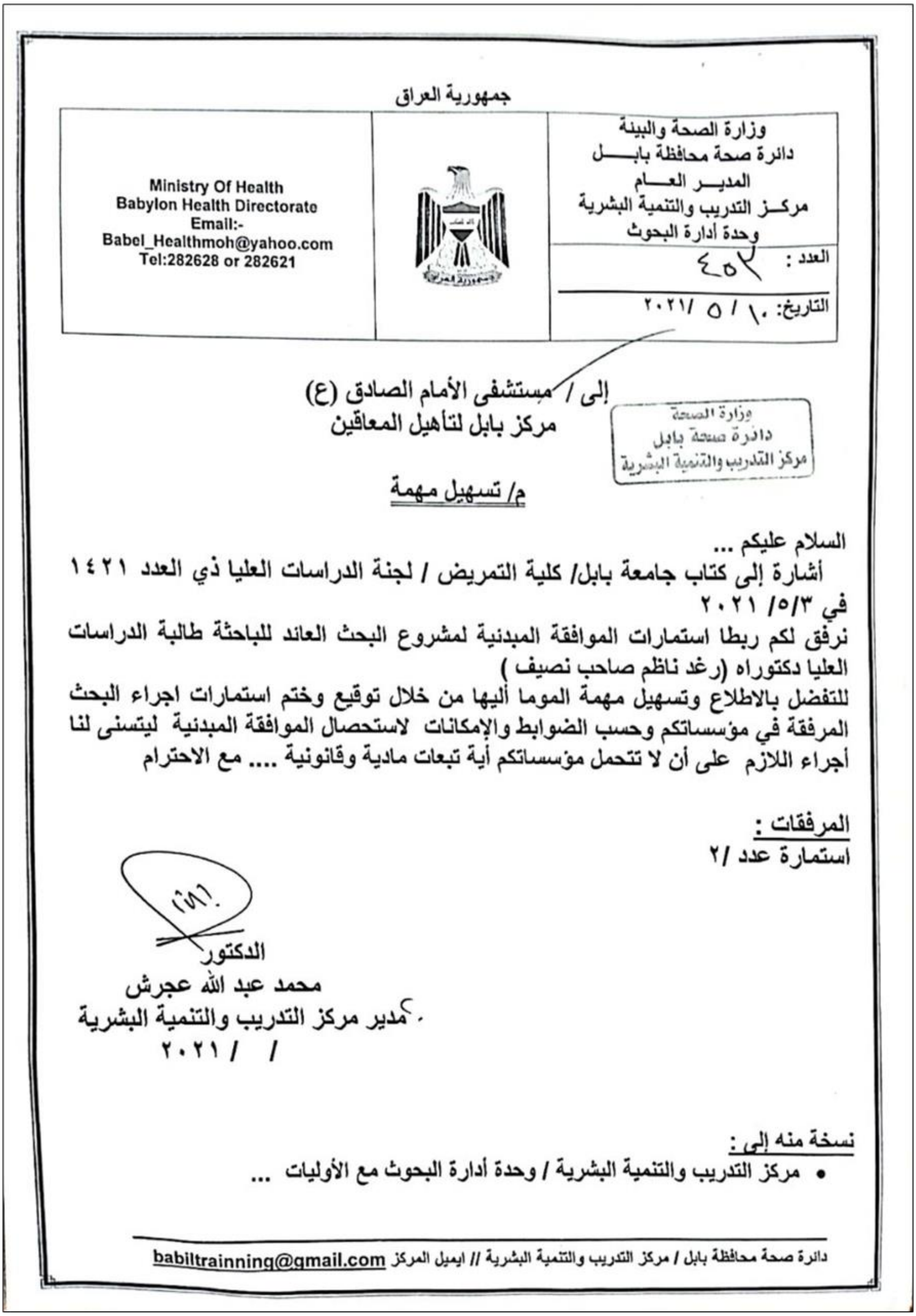

جمهورية العراق

وزارة الصحة والبيئة
دائرة صحة محافظة بابـــل
المديــر العـــام
مركــز التدريب والتنمية البشرية
وحدة أدارة البحوث

Ministry Of Health
Babylon Health Directorate
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العدد : ٤٥٧

التاريخ: ١٠ / ٥ /٢٠٢١

إلى / مستشفى الأمام الصادق (ع)
مركز بابل لتأهيل المعاقين

وزارة الصحة
دائرة صحة بابل
مركز التدريب والتنمية البشرية

م/ تسهيل مهمة

السلام عليكم ...

أشارة إلى كتاب جامعة بابل/ كلية التمريض / لجنة الدراسات العليا ذي العدد ١٤٢١ في ٣/٥/ ٢٠٢١

نرفق لكم ربطا استمارات الموافقة المبدنية لمشروع البحث العائد للباحثة طالبة الدراسات العليا دكتوراه (رغد ناظم صاحب نصيف)
للتفضل بالاطلاع وتسهيل مهمة الموما أليها من خلال توقيع وختم استمارات اجراء البحث المرفقة في مؤسساتكم وحسب الضوابط والإمكانات لاستحصال الموافقة المبدنية ليتسنى لنا أجراء اللازم على أن لا تتحمل مؤسساتكم أية تبعات مادية وقانونية .... مع الاحترام

المرفقات :
استمارة عدد /٢

الدكتور
محمد عبد الله عجرش
مدير مركز التدريب والتنمية البشرية
/ / ٢٠٢١

نسخة منه إلى :
- مركز التدريب والتنمية البشرية / وحدة أدارة البحوث مع الأوليات ...

دائرة صحة محافظة بابل / مركز التدريب والتنمية البشرية // ايميل المركز babiltrainning@gmail.com

جمهورية العراق

وزارة الصحة والبيئة
دائرة صحة محافظة بابـــــل
المديـــر العـــام
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Ministry Of Health
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العدد : ٤٥٢
التاريخ: ١٠/٥/٢٠٢١

إلى / مستشفى الأمام الصادق (ع)
مركز بابل لتأهيل المعاقين

وزارة الصحة
دائرة صحة بابل
مركز التدريب والتنمية البشرية

م/ تسهيل مهمة

السلام عليكم ...

أشارة إلى كتاب جامعة بابل/ كلية التمريض / لجنة الدراسات العليا ذي العدد ١٤٢١ في ٣/٥/ ٢٠٢١
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/ / ٢٠٢١

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Part 1: Demographic Data:

I: Demographic information for parents

1 .Age of the mother ☐

2 . The educational level of the mother:-

- Do not read or write ☐
- Read and write ☐
- Secondary ☐
- Institutes and more ☐

3 .Occupational Status:-

- Employ ☐
- Unemployed ☐

4. Family income:

- Sufficient enough ☐ - is not enough ☐ -enough ☐

5. Housing area:-

- Countryside ☐ -outskirts ☐ - city ☐

6. Number of family members:- ☐

7- type of family :- nuclear ☐ -extended ☐

II: Demographic information for children with CP.

1- Age of the child :- ☐

2 gender

- Male ☐ -Female ☐

3- Number of sblings (brothers and sisters):- ☐

5- Child older in the family :- ☐

6- Child's age at diagnosis:

-Before Birth ☐ - Newborn ☐ -Infant ☐

III: Clinical Information for child with cerebral palsy:-

1- Family history for same case: -

-Yes ☐ - No ☐

2- Type of birth: -

-Normal delivery ☐ - Caesarean section ☐ -Other ☐

3- Type of feeding: -

-Breast feeding ☐ - Artificial ☐ -Mixed ☐

5- Risk factors:-

-Suffocation ☐ - meningitis ☐

-Jaundice (blood change) ☐ -Twins pregnancy ☐

-Premature ☐ - others ☐

6- Classification of Cerebral Palsy by Region:- (from chart)

-Hemiplegia ☐ -Monoplegia ☐

-Trilegiant ☐ -Tetraplegia ☐

Part 2: Psychological burden

No.	Question	Always	Sometimes	Never
1.	You find it difficult to balance caring for your child with your family responsibilities.			
2.	You feel embarrassed by your child's behavior			
3.	You feel angry when you are around your child			
4.	You feel afraid for your child from the future			
5.	You feel nervous when you are close to your baby			
6.	You feel that your mental health has been affected because of your care (or care) for your child			
7.	You feel that you will be unable to take care of your child much longer			
8.	You wish to leave someone else's care for your baby			
9.	You feel you must do more for your baby			
10.	I feel fear and panic for no good reason			
11.	I worry that people close to me will leave me because of my child			
12.	I am afraid of what the future holds for my child			
13.	I feel very sensitive to the behavior of others			
14.	I find it difficult to concentrate in my work			
15.	I feel tired and overwork as a result of caring for my child			
16.	I have lost control of my life since my child's illness			
17.	I feel the loss of time to rest and take care of myself			
18.	I feel that my child depends on me only			
19.	I feel about to collapse			
20.	I feel guilty about my affections on my child			
21.	I find it difficult to deal with my child			

22.	I feel desperate to go ahead and take care of my child			
23.	I feel that my health has been affected because of my preoccupation with my child			
24.	I feel less competent to care for my child			
25.	I feel sad and gloom			
26.	I hope to leave care of my child to someone better than me			
27.	I feel a loss of desire to go to work			
28.	I feel lost interest in anything			
29.	I feel a loss of possession of anything good			
30.	I feel that everything I do make me fatigue			
31.	I feel that everything I do to my child is useless or meaningless			

Part3: Social Burden

No	Question	Always	Sometimes	Never
1.	You don't have enough time for yourself			
2.	Child care has affected your relationships with family members or friends in a negative way			
3.	I don't have a lot of privacy, because of my child			
4.	You feel that your social life has suffered because of your care for your child			
5.	You feel uncomfortable about having friends over because of your child			
6.	Your child is completely dependent on you			
7.	You feel that you don't have enough money to take care of your child in addition to the rest of your expenses			
8.	You feel you have lost control of your life since your child's illness			
9.	The situation of my child led to the identification of my social relationship outside the family			

10.	I feel uncomfortable with my friends because of my child			
11.	I have to stay home for the main public holidays			
12.	child's situation reduced my time with my friends			
13.	I find that my child's unexpected behavior prevents me from going out of the house			
14.	There are interruptions I do not want for my family routine			
15.	I feel that my child is affecting my responsibilities towards my family and my work			
16.	I feel the isolation of other children in the family because of the behavior of the child			
17.	My relationship with my partner became tense			
18.	I feel ashamed and embarrassed when			

Part4: quality of life child

No	Physical functioning (problems with)	Never	almost never	sometimes	often	almost always
1.	Walking more than one block					
2.	Running					
3.	Participating in sports activity or exercise					
4.	Lifting something heavy					
5.	Taking a bath or shower by him or herself					
6.	Doing chores around the house					
7.	Having hurts or aches					

8.	Low energy level					
No	**Emotional Functioning** **(problems with)**	**Never**	**almost never**	**sometimes**	**often**	**almost always**
1.	Feeling afraid or scared					
2.	Feeling sad or blue					
3.	Feeling angry					
4.	Trouble sleeping					
5.	Worrying about what will happen to him or her					
No	**Social Functioning** **(problems with)**	**Never**	**almost never**	**sometimes**	**often**	**almost always**
1.	Getting along with other children					
2.	Other kids not wanting to be his or her friend					
3.	Getting teased by other children					
4.	Not able to do things that other children his or her age can do					
5.	Keeping up when playing with other children					
No	**Social Functioning** **(problems with)**	**Never**	**almost never**	**sometimes**	**often**	**almost always**
1.	Getting along with other children					
2.	Other kids not wanting to be his or her friend					
3.	Getting teased by other children					

4.	Not able to do things that other children his or her age can do					
5.	Keeping up when playing with other children					
No	**School Functioning** **(problems with)**	**Never**	**almost never**	**sometimes**	**often**	**almost always**
1.	Keeping up with schoolwork					
2.	Missing school because of not feeling well					
3.	Missing school to go to the doctor or hospital					
4.	Paying attention in class					
5.	Forgetting things					

عزيزي إلام

إن المعلومات التي تصدر عنك ستكون في غاية السرية ولن تستخدم إلا لغرض البحث العلمي فقط.. لذا يمكنك الإدلاء برأيك بكل جدية ومصداقية

الجزء الأول: البيانات الديموغرافية:-

اولا: المعلومات الديموغرافية للأبوين:-

1. عمر الام ☐
2. المستوى التعليمي للام
   - -لا تقرأ ولا تكتب ☐
   - - تقرأ وتكتب ☐
   - - خريجة ثانوي ☐
   - - دبلوم فاكثر ☐
3. الحالة المهنية للام
   - تعمل ☐ -لا تعمل ☐

دخل الأسرة:-

يكفي ☐ يكفي الى حد ما ☐ لا يكفي ☐

4. منطقة السكن:-

ريف ☐ اطراف مدينة ☐ مدينة ☐

5. عدد افراد الاسرة:- ☐

ثانيا : المعلومات الديموغرافية للطفل المصاب بالشلل الدماغي

1-عمر الطفل :- ☐

2- الجنس

ذكر ☐ انثى ☐

3- عدد الاخوة و الأخوات:- ☐

4- ترتيب الطفل بين افراد الاسرة :- ☐

5- عمر الطفل عند التشخيص :-. قبل الولادة ☐ حديث الولادة ☐ رضيع ☐

ثالثا: المعلومات السريرية للطفل المصاب بالشلل الدماغي

1- التاريخ العائلي لنفس الحالة : نعم ☐ لا ☐

2- نوع الولادة : طبيعية ☐ قيصرية ☐ أخرى ☐

3-نوع الرضاعة : طبيعي ☐ صناعي ☐ مختلط ☐

4- -عوامل الخطورة :

الاختناق ☐ السحايا ☐

اليرقان: تبديل الدم ☐ حمل توئم ☐

طفل متعسر: خديج ☐ الصرع ☐

5- تصنيف الشلل الدماغي حسب المنطقة المصابة (من السجل المرضي للطفل-)

طرف واحد ☐ نصفي ☐

ثلاث أطراف ☐ رباعي ☐

الجزء الثاني :الاعباء النفسية

ت	الأسئلة	دائما	احيانا	ابدا
1.	تجدين صعوبة في الموازنة بين العناية بطفلك ومسؤولياتك الأسرية			
2.	تشعرين بالحرج من سلوك طفلك			
3.	تشعرين بالغضب عندما تكون قريباً من طفلك			
4.	تشعرين بالخوف على طفلك من المستقبل			
5.	تشعرين بأنك متوتر عندما تكون قريباً من طفلك			
6.	تشعرين ان صحتك النفسية تأثرت بسبب رعايتك او(عنايتك) بطفلك			
7.	تظنين أنك غير قادر على الاعتناء بطفلك لفترة طويلة			
8.	تتمنين أن تتركي رعاية طفلك لشخص آخر			
9.	تشعرين بأنك يجب أن تفعلين المزيد لطفلك			
10.	اشعر بالخوف والهلع بدون سبب وجيه			
11.	اشعر بالقلق من ان الناس المقربين لي سيتركونني بسب طفلي			
12.	اشعر بالانزعاج من اراء الناس السلبية عن طفلي			
13.	اشعر بفقدان المحيط الامن لطفلي			
14.	اشعر بالتحسس الشديد لسلوك الاخرين			
15.	تجدين صعوبة في التركيز في عملك			
16.	اشعر بالتعب والارهاق نتيجة العناية بطفل			

17.	اشعر بفقدان السيطرة على حياتي منذ مرض طفل			
18.	اشعر بفقدان الوقت الكافي للراحة والعناية بنفسي			
19.	اشعر انني على وشك الانهيار			
20.	اجد نفسي اضطرب وانزعج لأبسط الاشياء			
21.	اشعر بالذنب من انفعالي على طفل			
22.	اجد صعوبة في كيفية التعامل مع طفل			
23.	اشعر باليأس في امكانيات المضي قدما في العناية بطفلي			
24.	اشعر ان صحتي تأثرت بسبب انشغالي بطفلي			
25.	تشعرين بقلة كفاءتك للعناية بطفل			
26.	اشعر بالحزن والغم			
27.	اشعر بفقدان الرغبة للذهاب الى عملي			
28.	اشعر انني فقدت الاهتمام بأي شيء			
29.	اشعر بفقدان امتلاكي لأي شيء حسن			
30.	اشعر ان كل شيء اعمله يسبب لي التعب			
31.	اشعر ان كل شيء اعمله لطفلي بدون جدوى وفائدة			

الجزء الثالث: الأعباء الاجتماعية:-

ت	الاسئلة	دائما	أحيانا	ابدا
1.	ليس لديك ما يكفي من الوقت لنفسك			
2.	العناية بالطفل اثرت على علاقاتك مع افراد العائلة أو الأصدقاء بطريقة سلبية			
3.	لا أملك الكثيرٌ من الخصوصية، بسبب طفلي			
4.	تشعرين أن حياتك الاجتماعية عانت بسبب رعايتك طفلك			
5.	تشعرين بعدم الارتياح حول وجود أصدقاء كُثر بسبب طفلك			
6.	تشعرين طفلك يعتمد عليك بشكل كامل			
7.	تشعرين بأنك لا تملك المال الكافي للاِعتناء طفلك، بالإضافة إلى بقية النفقات الخاصة بك			
8.	تشعرين بأنك فقدت السيطرة على حياتك منذ اصابة طفلك			
9.	تشعر بالغموض(متردد) حول ما يجب القيام به حيال طفلك			
10.	اشعر بعدم الارتياح لارتباطي بأصدقائي بسبب طفلي			
11.	وجب على البقاء في البيت في العطل الرسمية الرئيسية			
12.	حاله طفلي تقلل الوقت الذي اقضيه مع اصدقائي			
13.	اجد أن سلوك طفلي غير المتوقع يمنعني من الخروج خارج المنزل			
14.	هنالك انقطاعات لا ارغب بها لروتين اسرتي الطبيعي			
15.	اشعر أن طفلي يؤثر على مسؤوليتي نحو اسرتي وعملي			
16.	اشعر بعزلة الاطفال الآخرين في الأسرة بسبب سلوك الطفل			
17.	اصبحت علاقتي بشريك حياتي متوترة			
18.	اشعر بالخجل والاحراج عند استقبال ضيوف في المنزل بسبب طفلي			

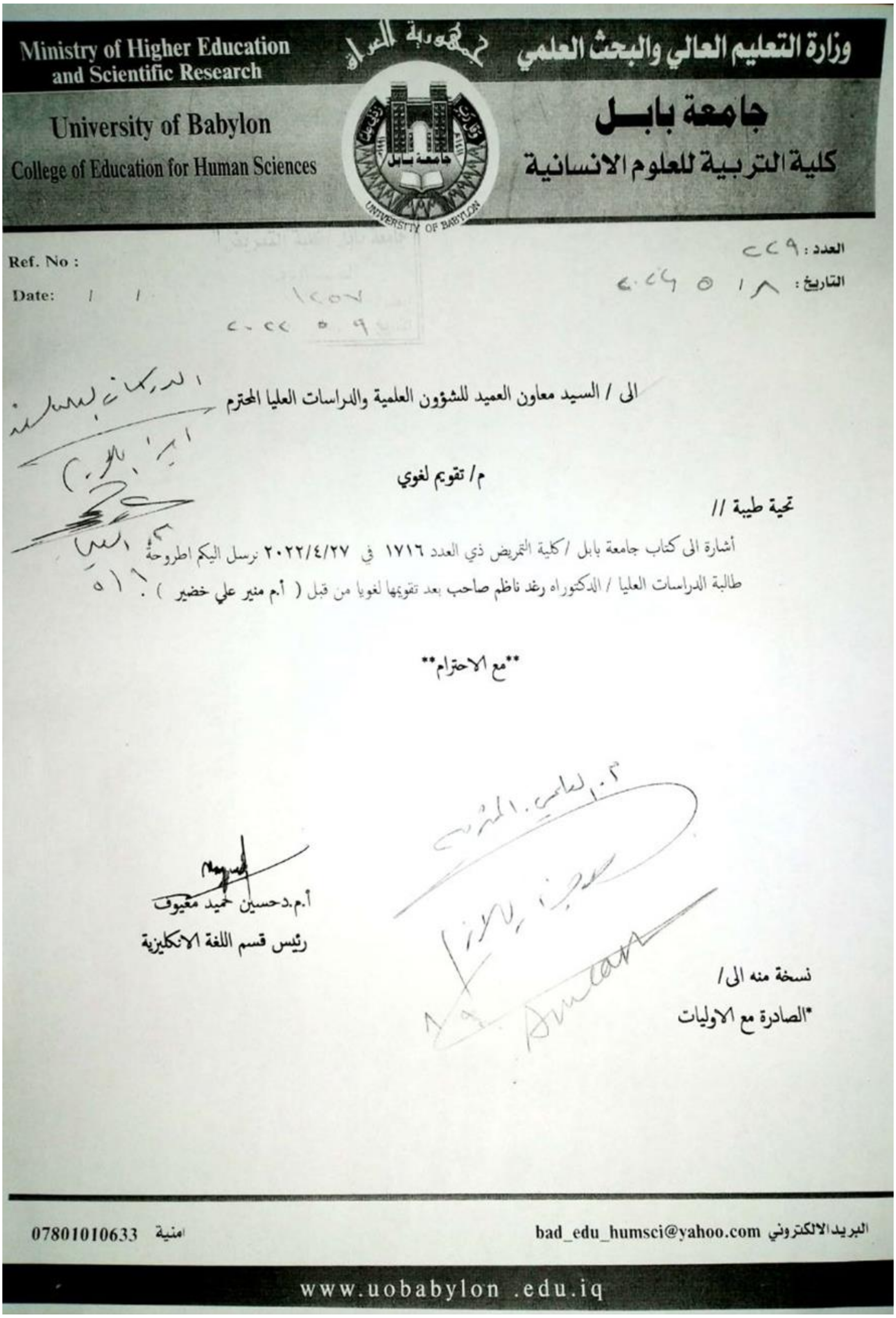
الجزء الرابع :جودة الحياة للطفل:-

ت	الاداء البدني (مشاكل مع)	أبدًا	نادرا	بعض الأحيانً	غالبًا	دائمًا
1.	مشاكل في المشي					
2.	الركض					
3.	المشاركة في النشاط الرياضي أو التمرين					
4.	رفع شيء ثقيل					
5.	الاستحمام بنفسه					
6.	القيام ببعض الأعمال المنزلية					
7.	شكو من الألم في الجسم					
8.	فقدان الطاقة للقيام بالأعمال اليومية					
ت	**الجانب النفسي والعاطفي**	**أبدًا**	**نادرا**	**بعض الأحيانً**	**غالبًا**	**دائمًا**
1.	الشعور بالخوف أو الرعب					
2.	الشعور بالحزن أو الكآبة					
3.	الشعور بالغضب					
4.	مشاكل في النوم					
5.	القلق بشأن ما سيحدث له أو لها في المستقبل					
ت	**الاداء الاجتماعي (مشاكل مع)**	**أبدًا**	**نادرا**	**بعض الأحيانً**	**غالبًا**	**دائمًا**
1.	يصعب التعامل مع الأطفال الآخرين					

2.	الأطفال الآخرون لا يرغبون أن يكونوا أصدقاء لطفلي					
3.	يتعرض للمضايقات من قبل الأطفال الآخرين					
4.	غير قادر على فعل الأشياء التي يمكن للأطفال الآخرين القيام بها في نفس عمرة					
5.	لا يمكنه الاستمرار باللعب مع الأطفال الآخرين					
ت	**الاداء المدرسي (مشاكل مع)**	**أبدًا**	**نادرا**	**بعض الأحيانً**	**غالبًا**	**دائمًا**
1.	يتابع الواجبات المدرسية					
2.	يتغيب عن المدرسة بسبب عدم الراحة					
3.	يتغيب عن المدرسة للذهاب إلى الطبيب أو المستشفى					
4.	الانتباه في الصف					
5.	نسيان الأشياء					

خبراء تحكيم استمارة الاستبانة

ت	اسم الخبير	اللقب العلمي	الاختصاص	مكان العمل	سنوات الخدمة
1.	د. عفيفة رضا عزيز	أستاذ	تمريض صحة الطفل والمراهق	جامعة بغداد /كلية التمريض	39
2.	د. سلمى كاظم جهاد	أستاذ	تمريض صحة المجتمع	جامعة بابل /كلية التمريض	36
3.	د. حسين جاسم محمد	أستاذ	تمريض صحة المجتمع	جامعة بابل /كلية التمريض	29
4.	د. علي كريم خضير	أستاذ	تمريض الصحة النفسية والعقلية	جامعة كربلاء/كلية التمريض	30
5.	د. عدنان حنظل طارش	استاذ	استشاري /اختصاص طب أطفال	جامعة بابل/كلية طب حمورابي	22
6.	د. عرفات حسين خضير الدجيلي	أستاذ	دكتوراة الطب النفسي	جامعة الكوفة /كلية الطب	17
7.	د. عبد المهدي عبد الرضا	أستاذ مساعد	تمريض صحة النفسية والعقلية	جامعة بابل /كلية التمريض	42
8.	د. معن حميد إبراهيم العامري	أستاذ مساعد	صحة نفسية وعقلية	جامعة ميسان /كلية المنارة للعلوم الطبية	40
9.	د. عبد القادر حسين حمد	أستاذ مساعد	تمريض الصحة النفسية والعقلية	جامعة هولير الطبية /كلية التمريض	39
10	د. نهاد محمد قاسم الدوري	أستاذ مساعد	تمريض صحة الطفل والمراهق	جامعة بابل /كلية التمريض	29
11.	د. ختام مطشر محمد	أستاذ مساعد	تمريض صحة الام والطفل	جامعة بغداد /كلية التمريض	24
12.	د. قحطان قاسم محمد	أستاذ مساعد	تمريض الصحة النفسية والعقلية	جامعة بغداد/ كلية التمريض	14
13.	د. حسن علي حسين	أستاذ مساعد	تمريض الصحة النفسية والعقلية	جامعة بغداد /كلية التمريض	13
14.	د. حيدر حمزة الحدراوي	أستاذ مساعد	تمريض الصحة النفسية والعقلية	جامعة بابل / كلية التمريض	12
15.	د. علي احمد الحطاب	مدرس	تمريض الصحة النفسية والعقلية	جامعة بابل/ كلية التمريض	10



Ministry of Higher Education
and Scientific Research
University of Babylon
College of Education for Human Sciences

وزارة التعليم العالي والبحث العلمي
جامعة بابـــل
كلية التربية للعلوم الانسانية

Ref. No :
Date: / /

العدد: ٢٢٩
التاريخ: ٢٠٢٢ /٥ /١٨

١٢٥٧
٢٠٢٢ /٥ /٩

الى / السيد معاون العميد للشؤون العلمية والدراسات العليا المحترم

م/ تقويم لغوي

تحية طيبة //

أشارة الى كتاب جامعة بابل /كلية التمريض ذي العدد ١٧١٦ في ٢٠٢٢/٤/٢٧ نرسل اليكم اطروحة طالبة الدراسات العليا / الدكتوراه رغد ناظم صاحب بعد تقويمها لغويا من قبل (أ.م منير علي خضير) .

مع الاحترام

أ.م.د.حسين حميد مغيوف
رئيس قسم اللغة الانكليزية

نسخة منه الى/
*الصادرة مع الاوليات

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المستخلص

الشلل الدماغي هو اضطراب عصبي مزمن يصاحبه تشوهات حركية تبدأ من الطفولة وتواجه المجتمع بشكل عام والأسرة بشكل خاص ولا تريد أي عائلة أن تصيب أحد أطفالها بمرض أو إعاقة بأي شكل من الأشكال. مقدمو الرعاية وخاصة أمهات الأطفال المصابين بالشلل الدماغي يعانون من عبء نفسي اجتماعي كبير.

هدفت الدراسة إلى تقييم العلاقة بين العبء النفسي الاجتماعي للأم ونوعية الحياة للأطفال المصابين بالشلل الدماغي.

تم تصميم الدراسة الوصفية المقطعية من نوفمبر / 2020/1 إلى 24 / أبريل / 2022. تم اختيار الدراسة التي شملت (150) أم باستخدام تقنية أخذ العينات الملائمة غير الاحتمالية. توزعت هذه العينة على مستشفيين بحسب مديرية صحة بابل هما (مستشفى الامام الصادق ومركز تأهيل بابل).

تم التأكد من مصداقية الاستبيان من خلال دراسة تجريبية ومن ثم عرضها على (15) خبيراً لإثبات صحتها بلغ إجمالي عدد العناصر التي شملها الاستبيان (49) فقرة للعبء النفسي و (23) فقرة لنوعية الحياة للأطفال المصابين بالشلل الدماغي.

أشارت نتائج الدراسة إلى أن (49.3٪) من الأمهات يعبرن عن مستوى عالٍ من العبء النفسي، و (68.7٪) عبّرن عن مستوى عالٍ من العبء الاجتماعي، و (92٪) من الأمهات أبدن تدني نوعية الحياة بالنسبة للأطفال المصابين بالشلل. توجد فروق ذات دلالة إحصائية بين العبء النفسي الاجتماعي والخصائص الاجتماعية الديموغرافية للأم مثل العمر والمستوى التعليمي والمهنة والدخل ومنطقة السكن والعدد ونوع الأسرة (p<0.05)؛ ونوعية الحياة للأطفال المصابين بالشلل الدماغي كانت مرتبطة بشكل كبير (عكسي) بالأمهات ذات العبء النفسي الاجتماعي (r=-0.142; p=0.012).

وخلصت الدراسة إلى أن رداءة نوعية الحياة للأطفال المصابين بالشلل الدماغي يعتمد على العبء النفسي والاجتماعي. كلما زاد العبء النفسي والاجتماعي انخفضت جودة حياة الأطفال المصابين بالشلل الدماغي. لقد تأثر العبء النفسي الاجتماعي بعوامل الأمهات مثل العمر ومستوى التعليم والمهنة والدخل ومنطقة السكن وعدد ونوع الأسرة.

أوصت الدراسة بضرورة أن يراعي العاملون الصحيون العاملون في مجال الشلل الدماغي الحالة النفسية ونوعية حياة الأم عند اتخاذ قرارات العلاج، وإعداد برامج رعاية نفسية بهدف مساعدتها على التعامل مع ظروف المرض. أطفالهم وتلبية احتياجاتهم.

جمهورية العراق
وزارة التعليم العالي والبحث العلمي
جامعة بابل
كلية التمريض

العلاقة بين جودة الحياة للأطفال المصابين بشلل الدماغ والأعباء النفسية والاجتماعية للأمهات في محافظة بابل

أطروحة مقدمة من قبل

رغد ناظم صاحب نصيف

الى مجلس كلية التمريض، جامعة بابل

كجزء من متطلبات نيل درجة الدكتوراه فلسفة في علوم التمريض

بإشراف
أ.د. سجاء هاشم محمد

2022ميلادي 1444هجري