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Assessment of Functional Independence and Community Participation in Children with Cerebral Palsy: The Caregiver Disability Burden

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Science in Pediatric Physical Therapy

By

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In the Name of Allah, the Most Gracious, the Most Merciful

بِسْمِ اللَّهِ الرَّحْمَٰنِ الرَّحِيمِ

Dedications

This thesis is wholeheartedly dedicated to my parents, family, and friends who encouraged and supported me through my educational journey.

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List of Abbreviations

CP	**Cerebral Palsy**
PVL	**Leukomalacia**
PVHI	**Periventricular hemorrhagic infarction**
WHO	**World Health Organization**
ICF	**International Classification of Functioning, Disability and Health**
GMFCS	**Gross Motor Function Classification System**
WeeFIM	**Pediatric Functional Independence Measure**
MBCBS	**Modified Montgomery Borgatta Caregiver Burden Scale**
BMI	**Body Mass Index**
ADL	**Activity of Daily Living**
PAC	**Preferences for Activities**
CAPE	**Children’s Assessment of Participation and Enjoyment**

1.INTRODUCTION

Cerebral Palsy (CP) is a disorder that affects one’s posture and movement, and it can be related to sensory, cognitive, perceptual, and psychological disturbances (Sankar and Mundkur, 2005; Bax, Flodmark and Tydeman, 2007). This disorder's etiology is multifactorial in nature, and it is possible during the prenatal, perinatal, or post-natal periods (Sankar and Mundkur, 2005).

Children suffering from CP have many neurological deficits, which interfere with their motor functions and, in turn, their ability to engage in daily activities (Gormley, 2001). Hence these activities are affected. Performing a functional assessment has become a necessary part of a rehabilitation program to measure the program's effectiveness and the patient's clinical progress (Hall *et al.*, 1993). Therapeutic intervention with CP children should primarily strive toward equipping such children with the relevant skills to help them execute essential tasks and engage in day-to-day activities. These activities of daily living are associated with life, such as self-care, transfers, mobility, communication and social cognition (Tur *et al.*, 2009). However, few studies have addressed the performance of daily activities in children with CP (Ostensjø, Carlberg and Vøllestad, 2003)

Beyond the consideration of functional activities, physiotherapists must also keep participation in mind while assessing cases of patients suffering from CP. Participation is becoming increasingly significant in childhood, particularly in the realm of childhood disability, since children with disabilities are typically more constrained when participating in recreational activities, daily activities, social events and sports than their peers. This leads to low life satisfaction as children turn into adults, and this gap widens as they grow up. Importantly, it is not merely a child's physical or mental ability that is associated with participation. In contrast, participation engages with multiple other factors within the child and the environment wherein a child's growth occurs. For example, family perceptions, gender, age and family income are linked to participation in many previous studies (Anastasiadi and Tzetzis, 2013).

Another aspect often undermined and frequently overlooked is the caregiver's quality of life. This factor plays a vital role in the life of children suffering from CP. Over the past two decades, healthcare strategies and technological advances in medicine have radically increased the life span of many children suffering from CP. Simultaneously, many parents have started seeking innovative ways to raise their children with CP at home and include them in a productive and meaningful manner in their communities. In addition, a home environment can maximize the child's capabilities, minimize the adverse effects of the impairments and reduce or completely prevent the hospitalization stay period ('Guidelines for home care of infants, children, and adolescents with chronic disease. American Academy of Pediatrics Committee on Children with Disabilities,' 1995).

Despite such positive benefits and the consideration that caregiving is a natural component of parenting young children in general, the demands associated with facilitating high levels of care required by a child with functional limitations that persist in the long term can quickly become burdensome for the caregivers and, in turn, affect their physical and mental health and well-being (Raina *et al.*, 2004). Moreover, the families of children with disabilities have to handle more significant financial stress, struggle with frequent disruptions of family routines, and reduced social activities (Thyen, Kuhlthau and Perrin, 1999). Only a few studies have directly addressed how the mothers' quality of life is affected due to their engagement in caregiving activities for children with a disability (Eker and Tüzün, 2004).

Hence Saudi Arabia has a different culture than the western world, and CP is a common disorder here; we are interested in finding the children's functional capacities, participation levels, along with their caregiver’s burden and various factors affecting these parameters along with the relationship between these variables.

2.REVIEW OF LITRATURE

2.1. CP Definition and Its Prevalence:

The definition of cerebral palsy has changed many times over the years. According to the definition currently developed by an international team of experts, cerebral palsy is a group of disorders of movement and/or posture and motor skills, caused by non-progressive disorders, lesions, or abnormal development/immaturity of the brain (Sadowska, Sarecka-Hujar and Kopyta, 2020)

Globally, CP affects around 17 million people the prevalence of CP in high-income countries is reported to be 2.11 per 1000 live births (Oskoui *et al.*, 2013), while it is estimated to be 2.0 to 2.8 per 1000 children in low and mid-income countries (Gladstone, 2010).

According to a study conducted in 1984 – 2003 in Saudi Arabia, 99,788 live births were recorded at Riyadh Military Hospital. The incidence of 412 positive cases of cerebral palsied children between 1 and 10 years old was investigated. The incidence of CP was 0.41%, which is relatively high.(Al-Asmari *et al.*, 2006).

2.2. Etiology and Risk Factors:

Multiple etiologies of cerebral palsy can impact various brain regions, which contributes to the wide spectrum of clinical symptoms. Cerebral palsy cases can be linked to the prenatal stage in about 92% of cases. Preterm delivery, perinatal infection (especially chorioamnionitis), intrauterine growth restriction, use of preterm antibiotics prior to membrane rupture, acidosis or asphyxia, and multiple gestations are risk factors that can all result in brain damage. The cause of less than 10% of cases is intrapartum hypoxia. About 8% of patients develop cerebral palsy later in life, frequently as a result of a brain injury or infection. Despite the presence of risk factors, 80% of cases are thought to be idiopathic because there is no known cause (Vitrikas, Dalton and Breish, 2020).

2.3. Types of CP:

There are three CP syndromes that predominate (spastic, dyskinetic and ataxic). The modern classifications do not include hypotonic CP. Most kids who were diagnosed with "hypotonic CP" in their early childhood go on to develop spastic, dyskinetic, or ataxic CP *(Gulati and Sondhi, 2018).*

2.3.1. Spastic CP: Spastic syndrome patients display upper motor neuron symptoms. Additionally, these kids move in mass (as opposed to small, individual movements), and their voluntary movements are slow and difficult *(Gulati and Sondhi, 2018).*

Most common types of spastic syndromes are:

- Spastic diplegia: Children have gross motor difficulties, especially in the lower limbs, but typically still have fine motor control in the upper limbs. It's possible that some of these kids struggle visually *(Gulati and Sondhi, 2018).*
- Spastic quadriplegia: Children who have spastic quadriplegia suffer from severe motor deficits. The majority have very minimal language and speech development, vision impairment, seizures, and feeding difficulties, and both the upper and lower limbs are afflicted almost equally *(Gulati and Sondhi, 2018).*
- Spastic hemiplegia: This condition often affects the arm more frequently than the leg. Children may also suffer from hemianopia, an intellectual disability, and other visual issues. Additionally, behavioral issues like phobias, oppositional defiance, and anxiety are quite typical *(Gulati and Sondhi, 2018).*

2.3.2 Dyskinetic CP: People with dyskinetic CP frequently experience many involuntary movement patterns. When trying to move or when feeling emotion, the limbs frequently become rigid. Purely dyskinetic disorders do not result in contractures. The dyskinetic CP can also be divided into:

- Choreo-athetoid CP: This condition is marked by sudden, chaotic muscle spasms that affect the face, bulbar muscles, proximal extremities, and fingers *(Gulati and Sondhi, 2018)***.** Additionally, they writhe slowly while using their distal muscles. Facial grimacing may lead to oropharyngeal problems. Many times, primitive responses continue into infancy *(Gulati and Sondhi, 2018).*
- Dystonic CP: It is defined by the co-contraction of the muscles of the agonist and antagonist. They frequently have both dysarthria and pyramidal symptoms *(Gulati and Sondhi, 2018).*

2.3.3 Ataxic CP: Although uncommon, ataxic CP should be separated from conditions of progressive neurodegeneration. Language and motor milestones lag. Usually, ataxia gets better over time *(Gulati and Sondhi, 2018).*

2.4 The International Classification of Function, Disability and Health (ICF):

As a framework, the International Classification of Functioning, Disability and Health (ICF) provides a standard and unified language that can help people elucidate their health and health-related conditions.

The World Health Assembly agreed upon it in 2001. The classification comprises three components: The Body component includes classifications concerning body structures, functions, activities, and participation. This covers all facets of functioning from societal and individual perspectives, contextual factors, and environmental/personal factors. Using shared knowledge, the ICF can potentially connect information across various stages wherein physical therapy is offered: community services, hospitals, mental disability services, and health services regardless of the method of provider and service provision. It presents a comprehensive and consistent evaluation of the health of people. It also helps planners obtain an exact scenario about the health of populations. Through a systematic collection of information on functional status across the health system, we can compare treatments, estimate and examine outcomes, manage costs linked to healthcare delivery and determine the eligibility for government programs. Awareness about the populations’ functional status could also help guide social policies like pensions, social security, long-term care of older people, retirement, employment, education, transport and housing policies for younger individuals (Sykes, 2006).

2.5 Functional Independence in Cerebral Palsy:

Children with CP might suffer from several neurological impairments obstructing their daily activities and motor functions. These include musculoskeletal ailments like contractures of muscles, spasticity, weakness, loss of selective motor control, and dyscoordination. Spasticity is the velocity-dependent increase in muscle tone due to the exaggeration of the stretch reflex. Spasticity has been seen as a critical impairment of bodily functionality CP. Another deficit that could impact functional mobility is contractures. Spasticity may result in contractures caused by a distinct loss of muscle-based sarcomeres, enhanced stiffness around the spastic muscle, and alterations in connective tissues. Increasing or maintaining connective/contractile tissue length forms a key component in managing CP. Typically, range of motion measurements is used for examining joint contractures and muscle shortening and assessing interventions' overall impact (Ostensjø, Carlberg and Vøllestad, 2004). Recently, it has been observed that the deficits in central neural systems controlling movements aggravate inhibited motor behaviours. Significantly, these deficits are manifested as inadequate coordination, muscle activity, the timing of forces, deficiencies in anticipatory adjustments and sensory processing (Ostensjø, Carlberg and Vøllestad, 2004).

A multidisciplinary team typically performs the functional evaluation of each child suffering from CP. Such evaluations gather complete information on the child's functional activity to determine the best treatment possible (de Mello Sposito and Riberto, 2010). Notably, a review identifies the instruments to examine functional capacity in children with CP. The instruments listed below examine various areas for illustrating functional independence in CPs (dos Santos *et al.*):

- *Gross Motor Function Classification System (GMFCS):*

This system uses functionality-assessing instruments to classify children with CP based on their gross motor abilities. It is one of the most commonly used scales to evaluate children's locomotive abilities and categorize them into five stages (de Mello Sposito and Riberto, 2010).

- *Pediatric Evaluation of Disability Inventory (PEDI):*

It involves structured interviews of the patient's parents or guardians (ages 6 months to 7.5 years) to gather information. The set of predefined questions is divided into three domains: social function, social care, and mobility, and three distinct scores are calculated for all domains: 1) level of functional ability, 2) caregiver assistance, and 3) modifications (Camargos *et al.*, 2012).

- *Pediatric Functional Independence Measure (WeeFIM):*

WeeFIM refers to an 18-item, seven-level instrument of an ordinal scale measuring how a child consistently performs his/her daily functional skills. (Wong *et al.*, 2002).

- *Activities Scale for Kids:*

It examines and tracks functional changes among child patients aged 5-15 years experiencing musculoskeletal disorder-induced disabilities. With a self-explanatory questionnaire, parents or caregivers can address the changes. The instrument includes 30 items categorized into nine areas: dressing up, self-care, eating and drinking, locomotion, standing skills, playtime, stair use, transfers, and other skills (Plint *et al.*, 2003).

- *Pediatric Outcomes Data Collection Instrument:*

It examines pain, general well-being, and daily routines and activities of children aged 2-18 years with common ailments. It comprises ten items categorized into five areas: happiness, pain and comfort, mobility/transfers, upper extremity and physical function, sports and physical activity, symptom satisfaction, and treatment expectations (Plint *et al.*, 2003).

2.6. Community Participation in Cerebral Palsy:

The ICF defines participation as ‘involvement in a life situation’ participation restriction is defined as ‘problems an individual may experience in involvement in life situations’ (Imms *et al.*, 2016).

Participation as a concept with face validity is becoming increasingly significant in childhood disability. It captures what is most important for children and their families (Forsyth and Jarvis, 2002). It occupies a key spot in the World Health Organization's (WHO) (2001) International Classification of Functioning, Disability and Health. Participation is becoming increasingly a vital result of rehabilitation services and programs that aims to help families and children gear up for new challenges (King *et al.*, 2002).

In terms of service delivery, the concept elicits attention to person-environment fit (Christiansen and Baum, 1997) and ecological/experimental interventions, which help them address real-world situations and address challenges in their immediate environment (King *et al.*, 2005). However, not much is known about disabled children's participation. Compared to those without disabilities, children with disabilities do not engage in varied leisure activities and prefer quieter recreation activities with lesser social activities, particularly those whose nature is spontaneous (Brown and Gordon, 1987). As children transition into adolescence and adulthood, their participation's diversity diminishes (Stevenson, Pharoah and Stevenson, 1997). Not much is known about the details of the recreational participation activities that they engage with, with the company they prefer, the extent to which they relish their participation and whether or not their participation is community-based or occurs at home.

Furthermore, little is known about the comparative significance of all the factors that could impact such children's participation, including family factors like preferences for specific activities, environmental factors like supportive ambience, and child factors like physical functioning. This limited information is attributed to the fact that we need to know appropriate means of gauging significant elements of children's participation. Thus, developing an adequate participation measure is challenging but necessary (Forsyth and Jarvis, 2002).

Differences concerning participation have been seen in children without and with physical disabilities. Notably, children with physical disabilities invariably demonstrate more passive activity patterns and are more likely to experience loneliness and social isolation. As mentioned above, these children with disabilities do not engage in varied leisure activities and prefer quieter recreational activities with lesser social activities, in comparison to children without disabilities (Brown and Gordon, 1987; Imms, 2008) undertook a comparison of children in the 10-12 age group with and without CP. According to the findings, those with CP were known to have a higher participation rate in electronic games and arts and crafts. Such adolescents also prefer less intense and less structured physical activities than peers without disabilities (Maher *et al.*, 2007).

Age and gross motor function affect the type and intensity of participation of children and young individuals with physical disabilities. Out of 427 physically disabled children and adolescents in the age range of 6 to 15 years, the number and frequency of leisure activities were fewer among adolescents aged at least 12 years, differing based on activity type (King *et al.*, 2007; Law *et al.*, 2006). In comparison to children, young people did not participate in recreational activities but were more involved in social pursuits (King *et al.*, 2007). There is a positive relationship between participation and gross motor function in everyday activities (Forsyth *et al.*, 2007; Morris *et al.*, 2006; Kerr, McDowell and McDonough, 2007). Among such children, functional ability was a forecaster of participation intensity when it came to formal and informal leisure activities. Regarding adolescents with CP, higher gross motor function and younger age are linked to heightened physical activity (Maher *et al.*, 2007).

Measures of children's participation are relatively few; their involvement in mobility, personal maintenance, education, home life, and social relationships assumes significance in the participation measurement (World Health Organization 2001). Some existing measures focus on children's physical activities (Hay, 1992), while the emphasis of others is on play (Henry, 2000) and activities based on school (Diller *et al.*, 1981; Hay, 1992; Posner and Vandell, 1999). In terms of how the evaluations are administered, some outcomes were self-administered measures (Garton and Pratt, 1991; Hay, 1992) and some are completed by parents (Diller *et al.*, 1981), while still others are premised on the utilization of children's accounts when it comes to their everyday activities (Posner and Vandell, 1999). Kid Play Profile and Preteen Play Profile, which encapsulates people with whom activities occur, instruments generally do not document whether or not children perform activities in isolation or company. Whether this participation is done with others or undertaken solitary assumes as much significance as the types of activities children participate in (Edwards and Whiting, 1988). Capturing the extent to which activities are performed alone, with family members, or with others in the community can provide critical assessment and outcome information for designing and implementing interventions to increase children's social participation. Furthermore, existing measures need to document 'where' participation takes place; the degree to which participation is home vs community-based provides essential information about an aspect of participation that might be the target of change through intervention (King *et al.*, 2007). The Children’s Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities in Children (PAC) is one of such ideal participation assessment tools among children with CP.

2.6.1. CAPE and PAC:

Children’s assessment of participation and enjoyment (CAPE) estimates the participation level of children, with or without disabilities, in out-school activities. In this context, the preferences for activities of children (PAC) scale identifies children’s priorities in terms of activity selection. CAPE and PAC are used together to investigate the participation level of a child in terms of the six dimensions of activity. CAPE is used to analyze how diverse and intense a child’s participation is, with whom and where the activities are executed, and whether the child enjoys participating in these activities. On the other hand, PAC analyzes how a child prioritizes one activity over another during activity selection. Although PAC acts as an extension of CAPE, it can be used independently of the latter. Notably, when both CAPE and PAC are used together, CAPE is performed first so that the child’s actual Esperance can be identified before their activity preferences (Imms, 2008).

Both CAPE and PAC are administered to children aged 6–21 years in the form of a record form that must be filled out by the child. If required, the child can be assisted by their parent or caregiver (self-administered). Alternatively, the child can be assisted with activity cards and visual response pages (interviewer-administrated) (Imms, 2008).

2.7. Caregiver Disability Burden:

Caregiver Burden is a “strain or load borne by a person who cares for a disabled family member” (Oh and Lee, 2009). Over the past two decades, there have been significant shifts in the treatments for patients with CP, from being hospitalized to being a part of the outpatient community or home-based settings which resulted in increased responsibilities of the caregivers (Dumas, Peron and Peron, 1992).

Parents generally invest large amounts of energy in child-rearing while simultaneously enjoying their parenting role. When they are required to care for a child with a developmental disability, the family often faces additional long-term physical, financial, and emotional problems (J. DeMarle, 2001; Lin, 2000).

The impact of CP on the family's internal dynamics cannot be ignored because its members are confronted with a different reality that demands new functions. These sudden changes generate conflicts and sudden changes in routines, generally putting the greatest overload on the mother. How parents adjust is crucial for the child's future well-being and the entire family. This unique experience is processed in diverse ways by every family. The disabled child plays the role of a unifier for many families, thereby strengthening the family dynamics. However, in other families, it can lead to the disintegration of the family (Prudente, Barbosa and Porto, 2010). The effort required to deliver care to a family member suffering from a chronic disease can develop feelings of tension or overload and result in the deterioration of the caregiver's quality of life (Sales, 2003). It is also normal for parents to experience psychological stress when they cannot have perfect or healthy offspring (Barnett *et al.*, 2003). Therefore, the stress entailed in bringing up a child with a developmental disability involves a stronger need to take care of the child with atypical development and the accompanying emotional responses to the presence of disability in the family (McCubbin and Patterson, 1983). As per many studies, stress among parents is caused by the unique physical and emotional demands of child-rearing, especially when the offspring has a developmental disability or any health ailment (Florian and Findler, 2001; Hauser-Cram *et al.*, 2001). Increased demands of care for a child suffering from CP could have long-term repercussions on parents' physical and psychological well-being (Brehaut *et al.*, 2004).

Besides being unsure about the outcome of their child's condition and prognosis, they are also required to undertake medical procedures and fulfil particular demands associated with the condition. In case the stressors induced by heightened childcare demands become increasingly comprehensive, it is not unusual for parents to feel stressed, helpless, and depressed (Crnic, Friedrich and Greenberg, 1983). This is because they are not only required to confront their child's diagnosis with courage but also expected to offer the offspring sufficient care and adjust to their lifestyle (Ketelaar *et al.*, 2008; Sen and Yurtsever, 2007).

Children with physical disabilities need extra care, attention, and personal supervision compared to children without such problems. Unfortunately, such high needs for care in children are often assumed to be linked with the immediate family members and relatives inferior physical and psychological health statuses (Ryan *et al.*, 2006).

Parents also react with disbelief, loss of normality, fear, despair, hopelessness, and misery and operate with the feeling of being unable to cope with the situation when their children are diagnosed with a long-term, chronic illness/disability (Sanders, 1979; Young *et al.*, 2002). To that end, it is vital to routinely analyze caregivers' health statuses/outcomes since their care is priceless in the rehabilitation of such children (Dambi, Makotore and Kaseke, 2015; Dambi and Jelsma, 2014). For example, an assigned caregiver may act as a provider, decision-taker, custodian, companion, and advocate of the child they care for (Dambi, Makotore and Kaseke, 2015). Hence, a periodic assessment of the caregiver's mental health and the burden is essential for the optimal functioning of disabled children (Dambi *et al.*, 2016). Furthermore, suppose health professionals can acquire comprehensive and holistic knowledge about all factors affecting caregivers' lives. In that case, they can aid in the improvement of the physical commitment of the child but also the family's routine, thereby improving the mothers' quality of life, who is primarily involved in the care process (Prudente, Barbosa and Porto, 2010).

The caregiver burden is higher with older children, as the mothers do all basic, yet crucial tasks, such as lifting and assisting their children in any activity that involves movement. In addition, caregivers will be aiding them during bathroom usage, giving them baths, putting them to sleep, dressing and grooming them, and generally doing even the bare minimum that a person should do by himself for them. All these tasks put a massive amount of physical strain on the mothers (Al-Gamal, 2013).

Additionally, parents face a negative impact on the quality of their parental life when living with a child disabled with CP (Terra *et al.*, 2011). When we speak of Quality Of Life (QOL), it is a multi-dimensional concept which is mindful of a person’s physical and mental state, level of independence, degree of social relationships, and the quality of personal beliefs ('The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization,' 1995)

Eker and Tuzun conducted a comparative study between 40 mothers of CP patients and 44 mothers of children with minor health issues. This study aimed to evaluate the burden of care for these children and the mothers' QOL, divided into the said two groups. In the end, the results showed that the QOL of children with CP was significantly lower than mothers of children with minor health issues (Eker and Tüzün, 2004).

Another study conducted by (Romeo *et al.*, 2010) aimed at interpreting the QOL around 100 subjects who have been parenting children with CP, aged from 4-10 years. The subjects were compared to 60 parents of healthy children. The study results showed that the former parents of such children experience less healthy physical and psychological health than any other group in question. Besides, the results also displayed that the mother subjects had poorer scores than the father subjects in the physical statuses, with children suffering from quadriplegia and Diplegia. Supporting these parents, especially mothers, was therefore considered crucial.

(Mugno *et al.*, 2007) also conducted a study on the levels of impairment of the QOL in Italian parents of children suffering from CP under the questions of physical and psychological domains. Subjects parenting children with a pervasive developmental disorder and CP reported worse QOL than the parents of healthy children. The affected mothers in question are also said to have a poorer quality of life than the fathers.

Another Brazilian study compared the caregivers' QOL, including the caregivers of children affected by CP and non-disabled children. Results showed that the former caregivers have an unspeakably impaired QOL compared to the latter, who treat children with no physical, emotional, or mental disabilities and a better general health condition (Rodrigues dos Santos *et al.*, 2009).

Several outcomes are employed to quantify and qualify the quality of life and the burden of care. These outcomes are as follows:

- Zarit Burden Interview: Many ageing agencies utilize this popular self-report measure for caregivers that had its inception as a 29-item questionnaire. This interview helps evaluate the perceptions of the burden held by the caregiver, which might affect their personal, financial or social well-being as well as their health. Furthermore, the assessment areas include mental health, depression, negative affect, stress and coping modes, and social support (Lu *et al.*, 2009).

- Medical Outcomes 36-Item Short Form Health Survey (SF-36): This measure is employed to evaluate any individual's general quality of life. SF-36 comprises eight multi-item scales, each of which includes between 2 and 10 items in addition to a single item that helps in comparing the health of a person currently with the health of a person one year ago (concerning health transition). The dimensions covered by these scales include mental health (MH), physical functioning (PF), bodily pain (P), physical role (RP), general health (GH), social functioning (SF), vitality (V), and role emotional (RE). All the items associated with each item are transformed and summed to form a scale that ranges from 0 to 100. In this instance, if a person has a higher score on the scale, then it signifies a better state of well-being or health (Ware and Gandek, 1998)

- The World Health Organization Quality of Life assessment (WHOQOL-BREF):
This is another outcome that includes the following four QOL domains:
Domain I – Physical domain.
Domain II – Psychological domain.
Domain III – Social relationships
Domain IV – Opportunities for acquiring new information and skills
In addition to these domains, the first two questions in WHOQOL-BREF help assess the general health perception and global QOL ('The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization,' 1995).

- Modified Montgomery Borgatta Caregiver Burden Scale (MBCBS):
The MBCBS's modified version was generated to measure caregiver burden. Also, it was translated into Arabic, and the Arabic version is available. So, this study used the Arabic version. The overall reliability score of the translated scale (with all translated items) was 0.88. MBCBS’s modified version undertakes the measurement of three burden scores: objective burden, which disrupts the life of a caregiver because of the tasks involved (six items); stress burden, which measures caregiving's emotional impact (five items); and relationship burden, which ascertains the bond between the receiver and the caregiver (five items) (Hamad *et al.*, 2018).

2.8. Purpose of the Study:

1. To examine the functional status and the community participation level in children with CP.
2. To examine the possible disability burden among the caregivers of children with CP.

3. To determine any possible association between the clinical characteristics of CP, functional impairments, community participation level, and the caregiver disability burden.

2.9. Study Hypotheses: Alternate Hypothesis (Directional):

1. We hypothesize that CP children have impaired functional abilities and community participation.
2. We hypothesize that children with CP caregivers have a high disability burden.
3. We hypothesize that the functional abilities of children with CP have a positive relationship with their community participation and a negative relationship with the caregiver's disability burden.

2.10. Study Rationales:

Although CP frequently and seriously affects the functional status and the quality of life of many children with CP and their caregivers, little research has been conducted, and limited knowledge is available on this aspect. For example, which functional domain(s) is more impaired, and which is less? To what extent are they handicapped and lost their community roles? Furthermore, the quality of life and the successful community integration of caregivers for children with CP are not investigated. In addition, researchers that investigate the relationship between functional impairment, community integration level, and caregiver disability burden are scarce.

***2.11.* Significance of the Study:** This study will:

1. Provide physiotherapists and other clinicians with valuable data regarding the functional impairments and the community integration level in children with CP.
2. Identify which functional domain(s) is more impaired in children with CP. Moreover, it suggests effective interventions to prevent /treat these impairments.
3. Raise awareness and educate the community about the load on caregivers for children with CP.
4. This study will announce the importance of directing research in rehabilitation to improve the quality of life and the community integration of CP caregivers.

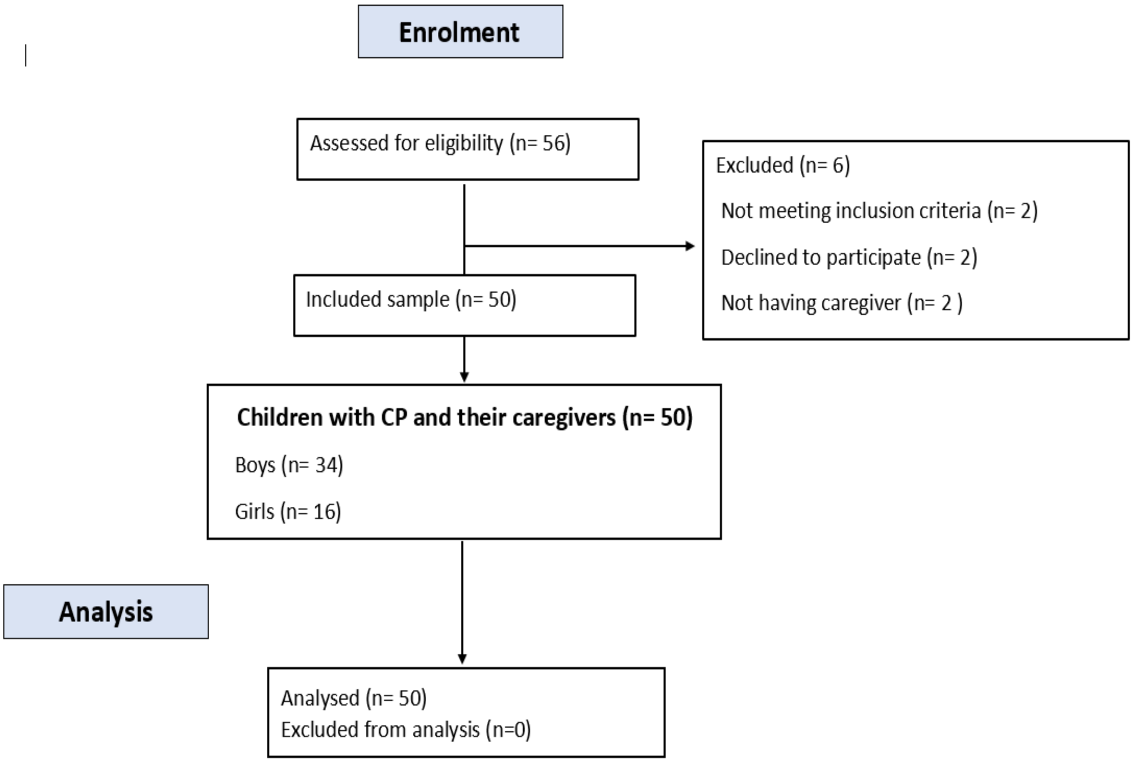
3. METHODS AND PROCEDURE

3.1. Study design

This was a cross-sectional study with analytic descriptive structure. This study is ethically approved by the institutional review board (IRB) committee at Sultan Bin Abdulaziz Humanitarian City (SBAHC), with IRB number: 59-2021-IRB (Appendix A).

3.2. Participants

A convenience sampling of children with CP and their caregivers were screened for the eligibility to participate in the current study. Children with CP were selected from one center that is Sultan Bin Abdulaziz Humanitarian City (SBAHC) in Riyadh, Saudi Arabia. Fifty-six children were included in the current study. Six children were excluded (two children did not meet the inclusion criteria, and two were refused to continue participation, whereas the last two they do not have caregivers). Finally, 50 children aged from 6 to 12 years old were participated and completed all study procedure.



Flowchart 1: The flow diagram of participants demonstrating, enrolment process and number of subjects participated in each level.

3.2.1. Sample Size Calculation:

The sample size was calculated by the sample size calculator for cross sectional studies by Wang and Ji(2020) presented at: https://riskcalc.org/samplesize/. The study of Erkin et al., (2005) was used to calculate the sample size utilizing the values of: Type I error rate, $\alpha = 0.05$; Standard deviation of outcome, SD = 24.2; Absolute error or precision, d = 8. The calculated sample size = 45. Including a 10 percent dropout rate, we got a sample size of 50.

3.2.2. Inclusion criteria: children with following characteristics were included in the study

- Children with CP aged ranged from 6 to 12 years.
- Children with CP regardless the type of tonal abnormality (i.e., spasticity, dyskinesia, ataxia, hypotonia and mixed.)
- Children with a normal tone or with spasticity (mild to severe levels) with the following grades: 0, 1, +1, 2, 3, and 4 on the Modified Ashworth Scale (MAS) (Appendix B).

- The Gross Motor Function Classification system (GMFCS) severity levels range from I to V with a view to obtain various children in each pre-defined stratum (Appendix C).
- CP children who did not have a concomitant illness or health condition that might affect participation.

3.2.3. Exclusion criteria:

- Children with deformity of upper and lower limbs or fracture over the past 12 months.
- Children undergoing orthopedic or neurological surgical procedures over the past 12 months.
- Children receiving medications (Antiepileptic/Antispastic) which impact muscles or balance.
- Botulinum toxin injection for at a minimum of six months prior to the study.

3.3 Study procedures

The researcher decided who was eligible for participating in this study based on exclusion and inclusion criteria. Then, they were asked to take part in this study after explaining the details to children ‘s caregivers or parents. After parental agreement concerning the study participation, they signed the consent form which included the study goals, its duration, possible risks, if any, and solutions (Appendix D and E).

3.3.1 Demographic and Anthropometric Characteristics of Children with CP:

All demographic and anthropometric characteristics of children with CP were recorded, including gender, age, weight, and height. BMI was calculated using this formula: BMI = Weight in Kilogram / [Height in Meter] ^{2}. The children with CP who can stand and walk their height and weight are calculated by standard measure that is stadiometer and weighing machine. Some children cannot stand hence, their weight was obtained by a hoist machine and height was measured by tape.

Figure (1): A hoist weighing scale for measuring children who cannot stand

3.3.2 Clinical Characteristics of Children with CP:

The following characteristics of each child with CP was entered into a data entry sheet for children with CP (Appendix F)**.**

3.3.2.1. Gross Motor Functional Classification System (GMFCS) (Appendix C)**:**

The GMFCS, whose reliability and validity are well-established. The GMFCS grouped the children 's ability of gross movement in a scale of five-level based on the discrepancies between levels of motor functioning of five stages beginning from level I, which include children with minimal disability pertaining to community mobility, while level V, encompassing children who completely depended upon external help to facilitate their mobility
(Vargus-Adams, 2020).

3.3.2.2. Type of Tonal Abnormality:

Based on the type of tonal abnormality, the CP was classified into spastic, ataxic, dyskinetic, hypotonic, or mixed varieties. This information was obtained from the patient's file.

3.3.2.3. Distribution of Paralysis:

The recognition of all children with CP was made based on the topographical distribution of paralysis, and the CP was classified into monoplegia, implying that one leg or arm is affected, whereas hemiplegia denoted involvement of one arm as well as one leg on one side of the body. Similarly, diplegia means involvement of all four limbs but lower limbs were more affected than upper limbs. Whereas quadriplegia means the involvement of both legs and arms.

3.3.2.4. Severity of Tonal Abnormality:

Modified Ashworth scale (MAS) (Appendix B), which is the most common scale to measure spasticity, was used to evaluate the muscle tone severity by manually manipulating the joint through its available ROM and assessing the resistance of passive movements. It consisted of the following rating scale (0, 1, +1, 2, 3, and 4), where zero signified no enhancement occurring in muscle tone through flexion and extension; one denoted a marginal increase in muscle tone when the ROM ends, while one plus meant a marginal enhancement in muscle manifested through a catch succeeded by minimal resistance. Two denoted a more marked increase in muscle tone, while three meant difficulties in passive movement for the whole range of motion. Four denoted rigidity in flexion or extension. The representation of these scores in SPSS was coded for analysis purpose. The MAS evaluated spasticity among children suffering from CP in a reliable manner (Mutlu, Livanelioglu and Gunel, 2008). Figure (2) will be showing the general assessment and evaluation of muscle tone.

Figure (2): General assessment of included children A. Demonstrating the assessment of muscle tone for ankle musculatures. B. Assessment of muscle tone for hip musculatures.

3.3.2.5. Ambulation Capacity:

All CP patients were classified as ambulant or ambulant with assistive devices or non-ambulant. If they were intermittently ambulant and not always, the majority of the time was considered. If they were ambulant most of the time, they were classified as ambulant, but if not, they were classified as non-ambulant.

***3.3.3.* Characteristics of the Caregivers (Appendix G):**

We obtained the demographic characteristics of caregivers (gender, age, level of education, marital status, and income) and the general characteristic of the provided care (living with the CP, type of CG, employment status, type of care provided, and hours of daily caregiving. Caregiverwas included only if he/she was providing care for at least past 6 months.

***3.3.4*. Study Outcome Measurements:**

3.3.4.1.* Functional Capacity (*Functional Independence Measure for Children (WeeFIM) (Appendix H)):

As an assessment of pediatric function, the WeeFIM is undertaken by health and rehabilitation professionals and is administered via interview, direct observation, or a combination of interview and observation. The WeeFIM instrument comprises of 18 measurement items divided into three major areas that is self-care, mobility, and cognition: self-care area includes eight items, and they are eating, grooming, bathing, upper body dressing, lower body dressing, toileting, bladder, and bowel care. The mobility section comprises of five items, and they are bed, chair and wheelchair mobility, toileting, tub and shower transfers, walk or wheelchair mobility and stair climbing. Cognition subsection consists of five items, and they are comprehension, expression, social interaction, problem solving and memory. The motor subscale is inclusive of transfer, sphincter control, self-care, and locomotion, consisting of 13 items. Meanwhile, social cognition and communication consist of the cognitive subscale which consist of five items. A seven-level ordinal rating system ranging from seven to one rates of performance. A one to four rating denotes that the child needs some assistance from another individual to complete the activity. Score one implies that the patient requires total assistance, score two requires maximum assistance, while scores three to four are categorized as moderate assistance and minimal assistance, respectively. A rating of five indicates that the child needs adult cues or supervision or with a setting up the task. Signifying modified independence, level six utilizes assistive device to complete a task safely and quickly. A level seven patient does not require any assistance and makes it possible for children to complete the task without any assistive device.

Concerns are not raised about safety or taking a longer span of time. Non-applicable ratings and zeros are not allowed. The maximum and minimum possible total rating demonstrating complete independence and total dependence in all skills is 126 and 18, respectively. The administration time is 20 minutes. A variety of professionals can use the WeeFIM instrument. Training is necessary to make sure appropriate rating and administration. Various studies have examined validity and interrater reliability, finding them to be excellent in terms of value (Ottenbacher *et al.*, 1996; Ottenbacher *et al.*, 2000). Figure three, four and five were demonstrating various activities of WeeFIM assessment.

Figure (3): Assessment of WeeFIM tasks. A. Upper body dressing. B. Grooming

Figure (4): Assessment of WeeFIM tasks. Descending the stairs

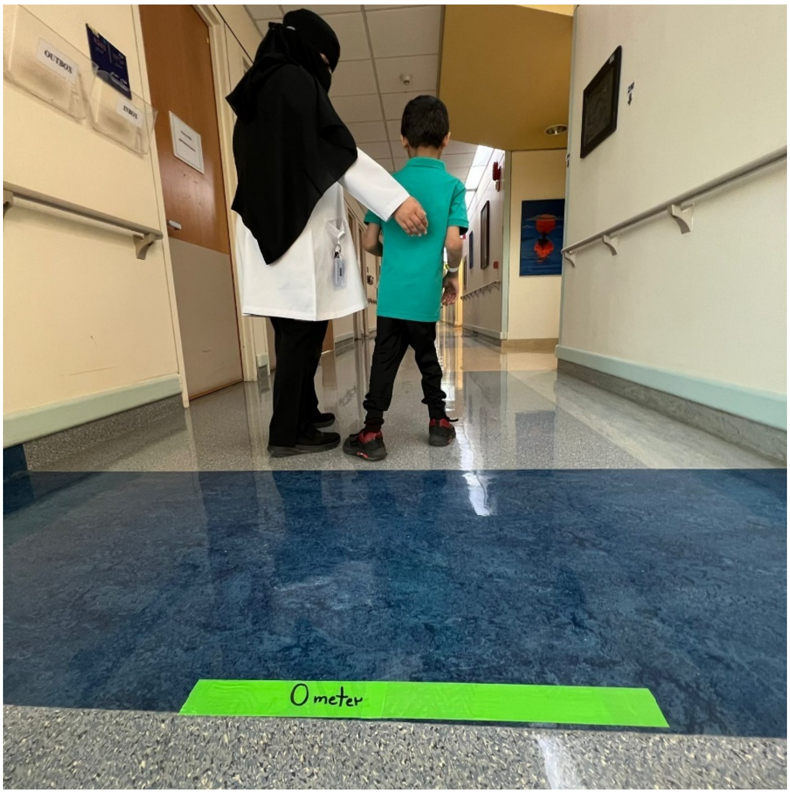


Figure (5): Assessment of WeeFIM tasks. Walking

3.3.4.2. Community Participation (Children’s Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC) (Appendix I and J):

The Children's Assessment of Participation and Enjoyment (CAPE) documents the manner in which children with or without disabilities participate in activities other than their assigned school activities. The Preferences for Activities of Children (PAC) evaluate the child’s preferences for these same activities. CAPE and PAC can be used independently or together. Both measures their reliability and validity are adequate (Imms, 2008). Both CAPE and PAC were translated into Arabic versions by (Almasri, Palisano and Kang, 2019). The Arabic CAPE and PAC are culturally valid measures for the participation of children with or without disabilities in Jordan. So, in this, we used the Arabic version.

The CAPE comprises 55 activities offering information concerning five participation dimensions that is diversity, intensity, social aspect, location, and enjoyment. The diversity means number of activities performed by the child and intensity means frequency of participation, which is gauged on one to seven scale, where one means participation in the chosen activity at least one time in the last four months and seven means everyday. The social aspect means with whom the chosen activity was participated, location is the area of participation, and the enjoyment is the extent to which the child enjoys participating in the activities. Each of these dimensions shows a column within the scoring sheet. Three levels of scoring for CAPE include: overall scores of their participation (Appendix I); formal and informal activities (scores for two domains) both are presented in (Appendix J); as well as scale scores for five kinds of activities (physical, recreational, skill-based, social, and self-improvement) (KERTOY *et al.*, 2008).

Depending on the number of activities the child does, the interview assisted CAPE takes around 30-45 minutes to complete. To conduct this assessment, you must be in possession of the following equipment: category cards (10), Activity cards (55), record forms booklet, summary score sheet, and assessment manual for scoring and administration.

With respect to the PAC, it is used for assessing preference. It comprises 55 activities organized by formal (organized) or informal (unorganized) and activity type: recreational, physical, social, skill-based, or self-improvement, also providing a three-point rating containing: 1= I would not like to do at all to 3= I would really like to do. The total time that might be needed for administration is 15-20 minutes (King *et al.*, 2007). For conducting this assessment, we need the equipment that has been mentioned previously in CAPE test with the difference that it is necessary to get rid of category cards from a pack of activity cards and then add PAC cue cards 3 in the test. Figure six demonstrating the CAPE and PAC interview.

Figure (6): Showing the CAPE and PAC interview

3.3.4.3. Caregiver Disability Burden (Modified Montgomery Borgatta Caregiver Burden Scale (MBCBS) (Appendix K):

The MBCBS's modified version generated to measure caregiver burden, also it was translated to Arabic language and the Arabic version is available. So, in this study we used the Arabic version. The overall reliability score of the translated scale (with all translated items) was 0.88 (Hamad *et al.*, 2018).

MBCBS's modified version undertakes the measurement of three burden scores: objective burden, which disrupts the life of a caregiver because of the tasks involved (six items), stress burden, which measures caregiving's emotional impact (five items), and relationship burden, which ascertains the bond between the receiver and the caregiver (five items). This means the total items for these burdens is 16. Framing of items of scale is undertaken by asking this question to the caregivers: "Have these aspects of your life changed due to your caregiving experiences?" Items get responded to a five-point scale that ranges from one to five (not at all to a great deal). In each subscale, the burden scales are added, and higher scores denote a higher burden. Findings for each scale dimension (burden type) could denote various kinds of interventions (Hamad *et al.*, 2018).

Calculation of Burden Scores: It is noteworthy that the exact phrasing of words used to ask them the question mentioned in Appendix J. In addition to the response set the construction of summary scores for all three burden measures are developed by adding individual items considered for all dimensions (Montgomery, 2002).

3.4. Statistical Analysis:

SPSS software (version 20.00; SPSS Inc, Chicago) was used to carry out the assessment. Normality distribution was tested for the variables by using Shapiro Wilk and Histogram tests. Regarding each parameter, the researcher obtained elucidative statistics that were inclusive of mean, standard deviation and percentage. Frequency distribution was done also for all categorical variables. Spearman bivariate correlation co-efficient was used to assess the relationship between the clinical characteristics of the CP, functional impairments, community participation, and the caregiver disability burden. Weak correlation was indicated When (r) or correlation coefficient is equal to or less than 0.3. Similarly, moderate correlation was shown when its range was between 0.4 to 0.6, whereas a range between 0.7 and 1.0 denoted a strong correlation (Akoglu, 2018). A 5% level of probability was used to indicate statistical significance. The further evaluation of the correlations was conducted by regression analysis and standardized beta values with significance less than 0.05 were considered.

3.5. Risks and safety issues:

All physical examinations were performed in an empty room without any furniture. It was essential to make the floor dry to prevent the child participants from falling in the presence of their guardians. The researcher had to stand behind the participants at the time of assessing the functional mobility and disability. This protected them from falling due to the loss of balance. Moreover, the researcher had first aid in case of any injury.

3.6. Protection of confidentiality:

An important objective of this study is to ensure the confidentiality of the information obtained. Only the researcher and the supervisor had access to the information of subjects.

4.RESULTS

4.1 Testing normal distribution:

Normally distribution was tested for the continuous variables by using Shapiro Wilk and Histogram tests. Findings revealed that our data approximately was not normally distributed.

4.2. Demographic and clinical characteristics of children with cerebral palsy:

Table (1) represents demographic and clinical characteristics of the study children. Our participant sample consisted of 50 children with CP, with a mean age of 8.5 (SD = 2.1) years. There were 34 males (68%), 16 females (32%), all from the spastic type of CP (100%). In regarding of distribution of paralysis the hemiplegic children were 6 (12%), diplegia 32 (64%), quadriplegia 12 (24%). Participants were with different levels of gross motor function [level I: 7 (14%); level II: 16 (32%); level III: 15 (30%); level IV:12 (24%)]. The means and standard deviations for subset scores and total WeeFIM scores for children with CP are given in table (1).

Table (1): Demographic and clinical characteristics of the study children.

Characteristics		Scores
Number		50
Age (Years) (Mean/SD)		8.5/2.1
Gender (NO/%)	♂	34/68
	♀	16/32
Weight (kg) (Mean/SD)		26.0/13.9
Height (cm) (Mean/SD)		124.8/14.7
BMI (kg/m^2)		15.9/4.6
Severity of Spasticity (MAS) (Mean/SD)		1.2/0.5
Type of Tonal Abnormality (NO/%)	Spastic	50/100
	Others	0/0
Distribution of Paralysis (NO/%)	Hemiplegia	6/12

	Diplegia	32/64
	Quadriplegia	12/24
GMFCS (NO/%)	I	7/14
	II	16/32
	III	15/30
	IV	12/24
Ambulation Capacity Paralysis (NO/%)	Walks Independently	20/40
	Walks with Mobility Device	17/34
	No Walking	13/26
(WeeFIM) (Mean/SD)	Selfcare Score (56)	40.6/10.0
	Mobility Score (35)	23.5/7.7
	Cognition Score (35)	28.8/3.9
	Total Score (126)	92.9/18.4

BMI: Body Mass Index; **GMFCS:** Gross Motor Functional Classification System; **WeeFIM:** Pediatric Functional Independence Measure.

4.3. Children's Assessment of Participation and Enjoyment (CAPE) (Mean/SD) (Activity rank):

Table-2 and Figure-7 contains descriptions of overall domains and activity participation patterns under leisure activities. Overall scores showed that the participants were involved in 56.4% of the 55 possible activities (M = 31.0, SD = 5.2), with low frequency (rated 2.5, SD = 0.6) and high enjoyment scores (rated 4.3, SD = 0.4). Informal activities occupied 63.8% of the 40 of the informal activities (M = 25.5, SD = 4.1), with low frequency (M = 2.8, SD = 0.6). While formal activities consisted of 15 activities and the percent of activities performed by children was 37.3%, which was equivalent to 5.6 activities (M = 5.6, SD = 1.8) with low frequency (rated 1.7, SD = 0.8). Among various activity types (see Table 3), participants reported significant participation in Social Activities 77% (M = 7.7, SD = 1.2) with a moderate intensity (M = 3.2, SD = 0.9), and the second-most engagement was found in recreational Activities 75.8% (M = 9.1, SD = 1.6) with moderate intensity (M = 3.7, SD = 1.0). The least performed activities were; physical and skill-based activities. For Physical Activities, the participants involved in 43.1% of the 13 activities (M = 5.6, SD = 2.4) with very low frequency (rated 1.8, SD = 1.0). While for the Skill-Based Activities, children participated in 25% of the 10 activities (M = 2.5, SD = 1.4) with a similar low frequency (M = 0.9, SD = 0.8).

Table-3 and Figure-8 illustrates the activities that children most participated in from both informal and formal domains. In the informal domain, the most frequently reported activities were playing video/computer games and visiting (100%). These were followed by playing with toys, playing on the equipment, and Going on a full-day outing (96%), then followed by Talking on the phone, hanging out, and listening to music which represents 94% of our population. the least informal activities were doing a paid job (12%), then fishing (8%) followed by the least activity which was writing a story (6%). In the formal domain, the most frequent activities doing religious activity was the most reported activity (100%), followed by racing track or field (80%), then followed by getting extra help with schoolwork (76%). The least frequent activities were doing gymnastics and learning to sing (4%), taking music lessons (2%), and then community organization (0%).

Table (2): Children Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC) Scores (Mean/SD).

Sub-domines of CAPE and their range of possible scores	*Diversity	Percentage of Activities Performed	Intensity (0-7)	With Whom (0-5)	Where (0-6)	Enjoyment (0-5)	Preferences for Activities (PAC) (0-3)
Overall Activities (0-55)	31.0/5.2	56.4	2.5/0.6	2.2/0.2	2.5/0.5	4.3/0.4	2.4/0.2
Recreational Activities (0-12)	9.1/1.6	75.8	3.7/1.0	2.0/0.3	2.0/0.5	4.4/0.4	2.4/0.3
Physical Activities (0-13)	5.6/2.4	43.1	1.8/1.0	2.3/0.6	2.6/1.1	4.3/0.8	2.5/0.3
Social Activities (0-10)	7.7/1.2	77.0	3.2/0.9	2.4/0.3	3.0/0.5	4.6/0.3	2.7/0.2
Skill-Based Activities (0-10)	2.5/1.4	25.0	0.9/0.8	2.6/0.8	3.0/1.4	4.6/0.6	2.4/0.4
Self-Improvement Activities (0-10)	6.1/1.7	61.0	3.1/0.9	2.0/0.3	2.2/0.5	3.9/0.6	2.2/0.4
Informal Domain (0-40)	25.5/4.1	63.8	2.8/0.6	2.1/0.2	2.5/0.3	4.4/0.3	2.5/0.2
Formal Domain (0-15)	5.6/1.8	37.3	1.7/0.8	2.4/0.4	2.5/0.8	4.1/0.7	2.4/0.3

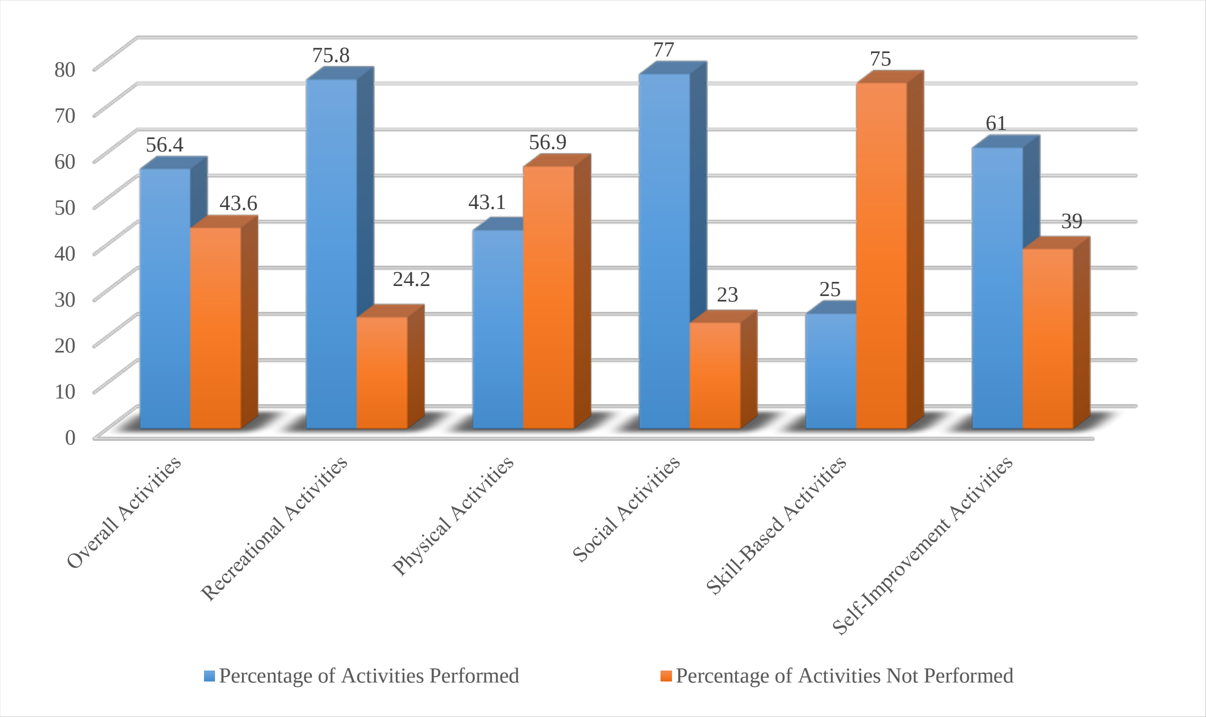


Figure (7): Representing the CAPE diversity overall and sub-components scores along with comparison of percentage of activities performed and not performed.

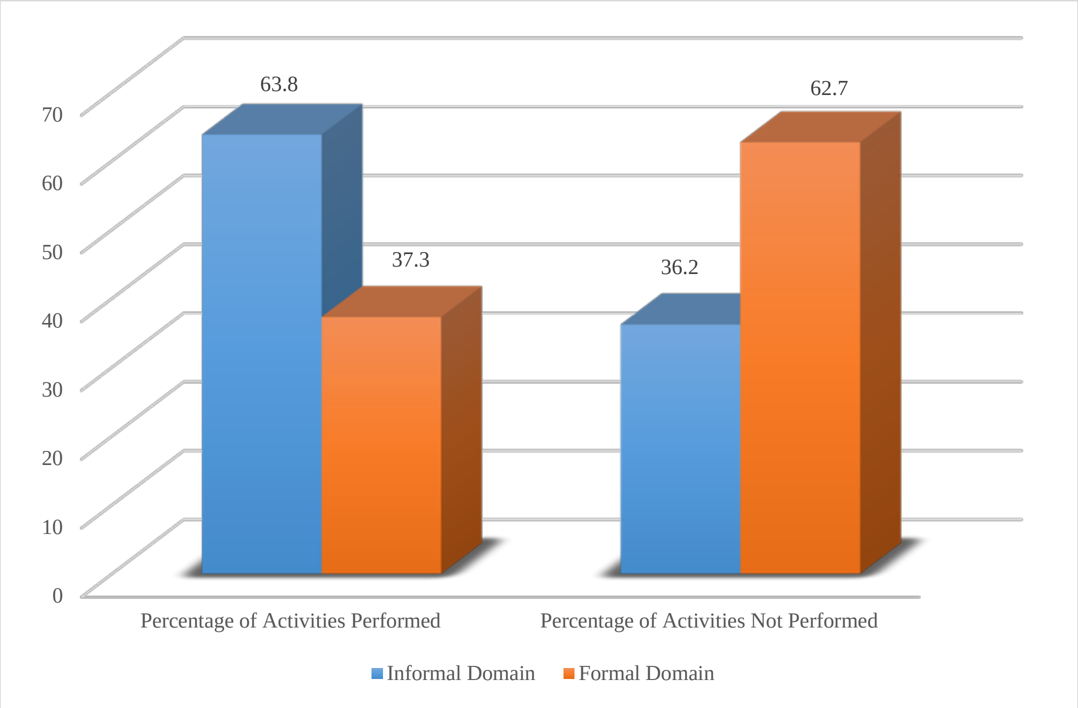


Figure (8): Representing the CAPE diversity overall scores in to formal and informal domains

Table (3): Activities' rank that children most participated in by domain.

Rank	Activity Number - Informal Domain	Percentage	Activity Number - Formal Domain	Percentage
1	5_Playing on computer	**100**	29_Doing religious activity	**100**
	9_Visiting			
2	15_Playing with toys	**96**	20_Racing track or field	**80**
	36_Playing on equipment			
	46_Going on a full-day outing			
3	6_Talking on the phone	**94**	25_Getting extra help with schoolwork	**76**
	8_Hanging out			
	48_Listening to music			
4	44_Watching TV/rented movie	**92**	21_Doing team sports	**64**
	54_Shopping			
5	3_Doing crafts	**88**	17_Swimming	**50**
6	4_Collecting things	**86**	19_Riding	**42**
	7_Going to party			
	11_Entertaining others			
7	53_Doing homework	**82**	16_Doing martial arts	**36**
			26_Playing an instrument	
8	2_Playing cards	**80**	24_Learning to dance	**28**
	10_Writing letters			
9	31_Dancing	**78**	30_School clubs	**16**
	50_Doing a chore			
10	14_Doing pretended play	**68**	23_Taking art lessons	**10**
11	32_Going for a walk	**64**	18_Doing gymnastics	**4**
	37_Playing games		22_Learning to sing	
12	33_Bicycling, skateboard, in-line skating	**58**	27_Taking music lessons	**2**

13	1_Puzzle	**56**	28_Community organizations	**0**
	34_Water sports			
	40_Doing individual physical activity			
	45_Going to live event			
14	52_Making food	**54**		
15	12_Playing with pets	**48**		
16	38_Gardening	**46**		
17	41_Playing non-team sports	**42**		
	49_Doing volunteer work			
	55_Taking care of a pet			
18	47_Reading	**30**		
19	43_Going to library	**28**		
20	35_Snow sports	**14**		
	42_Going to movie			
21	51_Doing a paid job	**12**		
22	39_Fishing	**8**		
23	13_Writing a story	**6**		

4.4. Demographic and characteristics of the caregivers:

The study included 50 caregivers responsible for young family members. Most of them (94%) were mothers, and 6% were fathers. The caregivers' mean age was 37.2 ± 7.2 years. More than half of them (52%) had received a university education, while 34% had completed secondary school, and only 12% had lower education. Most families belonged to the middle class (62%), while 11% belonged to the low-income group, and only, 8% belonged to the high-income group. Caregivers providing more than 8 hours of care comprised 44% of the participants, followed by 32% of caregivers providing less than 4 hours of care, and 18% providing 5 to 8 hours. The mean Modified-Montgomery test score was 39.0 with an SD of 12.3, as shown in Table 4.

Table (4): Characteristics of the caregivers.

Characteristics		**Scores**
Total Number of Subjects		50
Age (Years) (Mean/SD)		37.2/7.2
Gender (NO/%)	♂ Male	3/6
	♀ Female	47/94
Level of Education (NO/%)	Lower	6/12
	Secondary	17/34
	Bachelor	26/52
	Higher	1/2
Marital Status (NO/%)	Married	42/84
	Separated	4/8
	Widow	4/8
Income (NO/%)	Low Class	11/22
	Middle Class	31/62
	High Class	8/16
Caregiver Lives with the CP (NO/%)	Yes	50/100
	No	0/0
Caregiver Type (NO/%)	Father	3/6
	Mother	47/94
	*Others	0/0
Caregiver Type of Care (NO/%)	ADL	21/42
	Rehabilitation	0/0
	ADL & Rehabilitation	27/54
	Others	2/4
Daily Hours of Caregiving (NO/%)	< 4 hours	16/32
	5-8 hours	9/18

	> 8 hours	22/44
	Others	3/6
Modified Montgomery Overall Score (Mean/SD)	Objective Burden (30)	11.68 ± 3.52
	Stress Burden (25)	12.00 ± 3.55
	Relationship Burden (25)	10.58 ± 3.76
	Total score (80)	39.0/12.3

ADL: Activity of Daily Living; ***Others:** (Family/Housemaid/Employer).

4.5. Association between overall CAPE diversity and characteristics of the children with cerebral palsy and their caregivers:

Table-5 shows the only significant correlations between the overall CAPE diversity score and the clinical characteristic of CP children and their caregivers. GMFCS classifies children with a disability based on their functional capacity, it has five levels; where one indicates a high degree of independence, and five indicates a low degree of independence. Whereas the CAPE diversity score evaluates the child's capacity to carry out various activities and ranks from zero to fifty-five. Where zero means the child is not performing any activities and fifty-five indicates a high level of activity. The Spearman's Correlation between GMFCS and CAPE diversity scores was - 0.55 ($p < 0.001$) which indicated a moderate negative correlation. This demonstrated that, as the level of independence increased, the child's capacity to perform diversified activities also improved.

The distribution of paralysis for each child was as follows: 1-Monoplegia, 2-Paraplegia, 3-Hemiplegia, 4-Diplegia, 5-Quadriplegia, and 6-Double Hemiplegia. So, when he/she scored less it meant that he/she was more independent and the spearman correlation rho between the distribution of paralysis and overall diversity was - 0.47 ($p = 0.001$) which denoted moderate negative correlation.

The WeeFIM measures children with disability, based on their functional independence level and it has 7 values; where one indicates overall dependence and seven indicates that the child is independent. Three main areas were assessed: Self-care, mobility, and cognitive levels. Firstly, the WeeFIM self-care correlation coefficient with CAPE diversity was 0.79 ($p < 0.001$) which signified a strong positive correlation and for CAPE diversity it was moderately positive ($r = 0.61$, $p < 0.001$). Secondly, the WeeFIM mobility correlation with CAPE diversity was 0.73 ($p < 0.001$) which indicated a positive correlation, and for CAPE intensity, the correlation was 0.50 ($p < 0.001$) which signified a moderately positive correlation. Lastly, the total score of WeeFIM correlated with CAPE diversity ($r = 0.83$, $p < 0.001$) which showed a positive correlation. This revealed that as the total scores of WeeFIM increases, consequently, the level of CAPE diversity increased.

Ambulation capacity ranged from 1 to 3. Here, 1 indicates that the patient walks independently, 2 walks with a mobility assistive device, and 3) no walking. Its correlation is established with CAPE diversity by using spearman correlation rho was scores - 0.41 ($p = 0.003$) indicating moderate negative significant correlation. This means that the level of ambulation increased the child's capacity to perform the diversified activities was reduced.

The Spearman correlation rho between overall PAC and CAPE diversity score was 0.38 ($p = 0.006$). This indicated a weak positive significant correlation. This means when the overall PAC increased the overall CAPE diversity score increased. The Spearman correlation rho between income and CAPE diversity score was 0.38 ($p = 0.006$). This indicated a weak positive significant correlation.

Hours of caregiving scores range from 1 to 4. Notably, 1 means that the patient needs help only during weekends or every other day, and 4 means the patient need help for more than 8 hours. There is a moderate negative significant correlation between hours of caregiving and CAPE diversity that means when the hours of caregiving increased the level of CAPE diversity reduced and this is because the Spearman correlation rho between them was - 0.46 ($p = 0.001$).

There is a moderate negative significant correlation between the Modified Montgomery and CAPE diversity, and this can be recognized from the spearman correlation rho scores which was - 0.69 ($p < 0.001$). This relationship means when the score of Modified Montgomery increased the overall CAPE diversity score was reduced.

Table (5): Significant correlations between the overall CAPE diversity score (Dependent variable) and characteristics of the children with cerebral palsy and their caregivers (Independent variables).

Characteristics of the Children with Cerebral Palsy (Independent Variables)	**Spearman Correlation**	
	Overall CAPE Diversity Score (Dependent Variables)	
	r	**P**
GMFCS	-0.55	<0.001**
Distribution of Paralysis	-0.47	0.001**
Ambulation Capacity	-0.41	0.003**
WeeFIM Self Care Score	0.79	<0.001**
WeeFIM Mobility Score	0.73	<0.001**
WeeFIM Total Score	0.83	<0.001**
PAC Overall Score	0.38	0.006**
Characteristics of the Caregivers (Independent Variables)		
Income	0.38	0.006**
Hours of Caregiving	-0.46	0.001**
Modified Montgomery Overall Score (MBCBS)	-0.69	<0.001**

GMFCS: Gross Motor Functional Classification System**;** **CAPE:** Children’s Assessment of Participation and Enjoyment; **WeeFIM:** Functional Independence Measure; **r:** Correlation coefficient; **PAC:** Preferences for Activities; **MBCBS:** Modified Montgomery Borgatta Caregiver Burden Scale; **P:** Significant correlation.

* Significance difference (P≤ 0.05).

** Significance difference (P≤ 0.01)

4.6. Prediction of CAPE diversity:

The regression analysis carried out in the aftermath of the correlation analysis showed that significant predictors of CAPE diversity scores include the Ambulation Capacity, GMFCS, WeeFIM Self Care Score as well as Modified Montgomery Overall Score (MBCBS) as shown in table - 6 and Figure-9. The regression analysis involving GMFCS levels and CAPE diversity score showed a strong negative association with a standardized coefficient (β) value of - 0.72 ($p = 0.005$) revealing an inverse correlation between GMFCS levels and CAPE diversity scores. our regression analysis confirmed that when a child is observed to suffer from greater degrees of disability, the diversity of participants was curtailed.

The regression analysis involving Ambulation Capacity as well as CAPE diversity scores showed a strong and positive correlation with a standardized coefficient (β) value of 0.55 at the ($p = 0.01$). This positive association was also seen in the regression analysis involving WeeFIM Self Care Score and CAPE diversity scores with a standardized coefficient (β) value of 0.70 ($p = 0.04$) implying that the patient is involved in activities when there is a rise in WeeFIM Self Care.

As per the regression analysis, the MBCBS should forecast the CAPE diversity scores as a standardized coefficient (β) value of - 0.22 ($p = 0.04$) which reveals a vice versa association between the CAPE diversity scores and MBCBS scores. However, this regression analysis did not identify any important predictor of WeeFIM Mobility Score, Distribution of Paralysis, PAC Overall Score, WeeFIM Total Score, Hours of Caregiving, and Income. The regression equation for diversity was:

Y_{Div} = 20.00 – (3.70 x GMFCS) – (0.21 x Distribution of Paralysis) + (3.54 x Ambulation Capacity) + (0.36 x WeeFIM Self Care Score) + (0.17 x WeeFIM Mobility Score) – (0.11 x WeeFIM Total Score) + (2.97 x PAC Overall Score) + (0.86 x Income) + (0.35 x Hours of Caregiving) – (0.09 x MBCBS).

Table (6): Predicting CAPE diversity overall score.

Independent Variables	B	SEB	β	t	Sig	R	R^2	Adjusted R^2	Durbin Watson
Model Summary	20.00	6.62		3.03	0.004**	0.89	0.78	0.73	1.92
GMFCS	-3.70	1.26	-0.72	-2.95	0.005**				
Distribution of Paralysis	-0.21	0.86	-0.02	-0.24	0.81				
Ambulation Capacity	3.54	1.35	0.55	2.62	0.01**				
WeeFIM Self Care Score	0.36	0.17	0.70	2.10	0.04*				
WeeFIM Mobility Score	0.17	0.18	0.26	0.93	0.36				
WeeFIM Total Score	-0.11	0.14	-0.39	-0.79	0.44				
PAC Overall Score	2.97	1.87	0.13	1.59	0.12				
Income	0.86	0.67	0.10	1.28	0.21				
Hours of Caregiving	0.35	0.68	0.07	0.51	0.62				
Modified Montgomery Overall Score (MBCBS)	-0.09	0.05	-0.22	-2.09	0.04*				

CAPE: Children’s Assessment of Participation and Enjoyment; **GMFCS:** Gross Motor Functional Classification System; **WeeFIM:** Functional Independence Measure; **PAC:** Preferences for Activities; **MBCBS:** Modified Montgomery Borgatta Caregiver Burden Scale; **B:** Unstandardized Coefficients; **SEB:** Std. Error of B; **β:** **S**tandardized Coefficients; **R:** Multiple Correlation Coefficient.

* Significance difference ($P \leq 0.05$).

** Significance difference ($P \leq 0.01$).

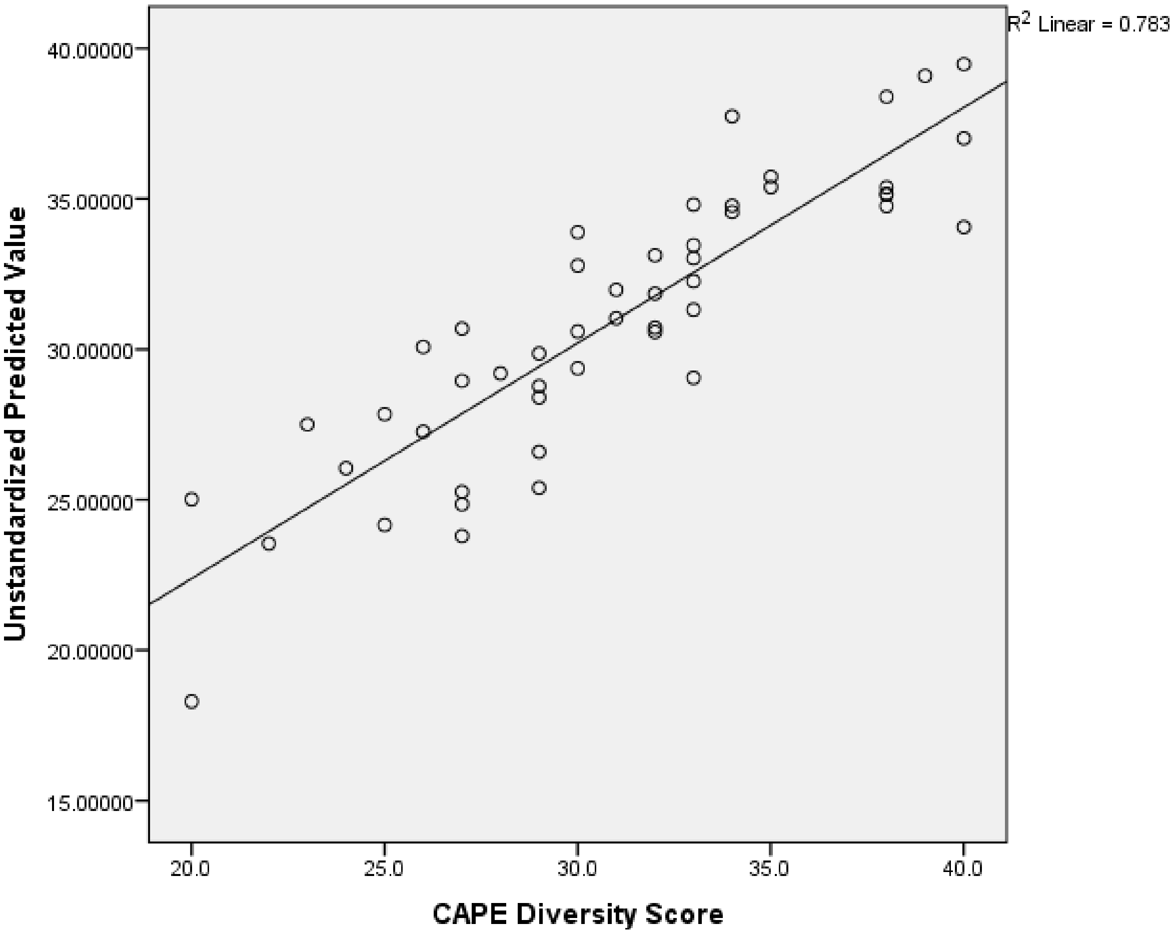


Figure (9): Regression analysis model summery for CAPE diversity scores

4.7. Association between overall CAPE intensity and characteristics of the children with cerebral palsy and their caregivers:

Table - 7 shows the only significant correlations between the overall CAPE intensity score and the clinical characteristic of CP children and their caregivers. The spearman correlation rho between the distribution of paralysis and intensity was - 0.34 (p = 0.02) which connoted a weak correlation.

Firstly, the WeeFIM self-care correlation coefficient with CAPE diversity was moderately positive (r = 0.61, p < 0.001). Secondly, the WeeFIM mobility correlation with CAPE intensity was 0.50 (p < 0.001) which signified a moderately positive correlation. Lastly, the total score of WeeFIM correlated with CAPE intensity (r = 0.58, p < 0.001) which indicated a moderately positive correlation. This revealed that as the total scores of WeeFIM increases, consequently, the level of CAPE intensity increased.

The Spearman correlation rho between overall PAC and CAPE intensity score was 0.34 (p = 0.02). This indicated a weak positive significant correlation. This means when the overall PAC increased the overall CAPE intensity score increased.

The Spearman correlation rho between income and CAPE intensity score was 0.28 (p = 0.05). This indicated a weak positive significant correlation.

There is a moderate negative significant correlation between the Modified Montgomery and CAPE intensity, and this can be recognized from the spearman correlation rho scores which were - 0.40 (p = 0.004). This relationship means when the score of Modified Montgomery increased the overall CAPE intensity score was reduced.

Table (7): Significant correlations between the overall CAPE intensity score (Dependent variable) and characteristics of the children with cerebral palsy and their caregivers (Independent variables).

Characteristics of the Children with Cerebral Palsy (Independent Variables)	**Spearman Correlation**	
	Overall CAPE Intensity Score (Dependent Variables)	
	r	**P**
Distribution of Paralysis	-0.34	0.02*
WeeFIM Self Care Score	0.61	<0.001**
WeeFIM Mobility Score	0.50	<0.001**
WeeFIM Total Score	0.58	<0.001**
PAC Overall Score	0.34	0.02*
Characteristics of the Caregivers (Independent Variables)		
Income	0.28	0.05*
Modified Montgomery Overall Score (MBCBS)	-0.40	0.004**

CAPE: Children's Assessment of Participation and Enjoyment; **WeeFIM:** Functional Independence Measure; **r:** Correlation coefficient; **PAC:** Preferences for Activities; **MBCBS:** Modified Montgomery Borgatta Caregiver Burden Scale; **P:** Significant correlation.

* Significance difference (P≤ 0.05).

** Significance difference (P≤ 0.01)

4.8. Prediction of CAPE intensity:

The correlation analysis and the regression analysis showed that significant predictors of CAPE intensity scores include the WeeFIM Self Care Score and PAC Overall Score as illustrated with table - 8 and Figure-10.

The WeeFIM Self Care Score found a strong positive association with a standardized coefficient (β) value of 1.15 (p = 0.02). Further, clinically, we observed that when a child has a more independent score with WeeFIM Self Care, the intensity of participation increases, as confirmed by our regression analysis. As per the regression analysis, the PAC Overall Score should forecast the CAPE diversity scores as a standardized coefficient (β) value of 0.32 (p = 0.009) which reveals an inverse relationship between the CAPE intensity scores and PAC Overall Score. The regression equation for intensity was:

Y_{Int} = 0.75 – (0.17 x Distribution of Paralysis) + (0.07 x WeeFIM Self Care Score) + (0.02 x WeeFIM Mobility Score) – (0.03 x WeeFIM Total Score) + (0.81 x PAC Overall Score) + (0.03 x Income) – (0.001 x MBCBS).

Table (8): Predicting CAPE intensity overall score.

Independent Variables	B	SEB	β	t	Sig	R	R^2	Adjusted R^2	Durbin Watson
Model Summary	0.75	1.05		0.71	0.48	0.69	0.47	0.39	1.76
Distribution of Paralysis	-0.17	0.13	-0.18	-1.27	0.21				
WeeFIM Self Care Score	0.07	0.03	1.15	2.51	0.02*				
WeeFIM Mobility Score	0.02	0.02	0.30	1.05	0.30				
WeeFIM Total Score	-0.03	0.02	-0.95	-1.48	0.15				
PAC Overall Score	0.81	0.29	0.32	2.75	0.009**				
Income	0.03	0.11	0.03	0.25	0.81				
Modified Montgomery Overall Score (MBCBS)	-0.001	0.01	-0.02	-0.11	0.92				

CAPE: Children's Assessment of Participation and Enjoyment; **WeeFIM:** Functional Independence Measure; **PAC:** Preferences for Activities; **MBCBS:** Modified Montgomery Borgatta Caregiver Burden Scale; **B:** Unstandardized Coefficients; **SEB:** Std. Error of B; **β: S**tandardized Coefficients; **R:** Multiple Correlation Coefficient.

* Significance difference (P≤ 0.05).

** Significance difference (P≤ 0.01).

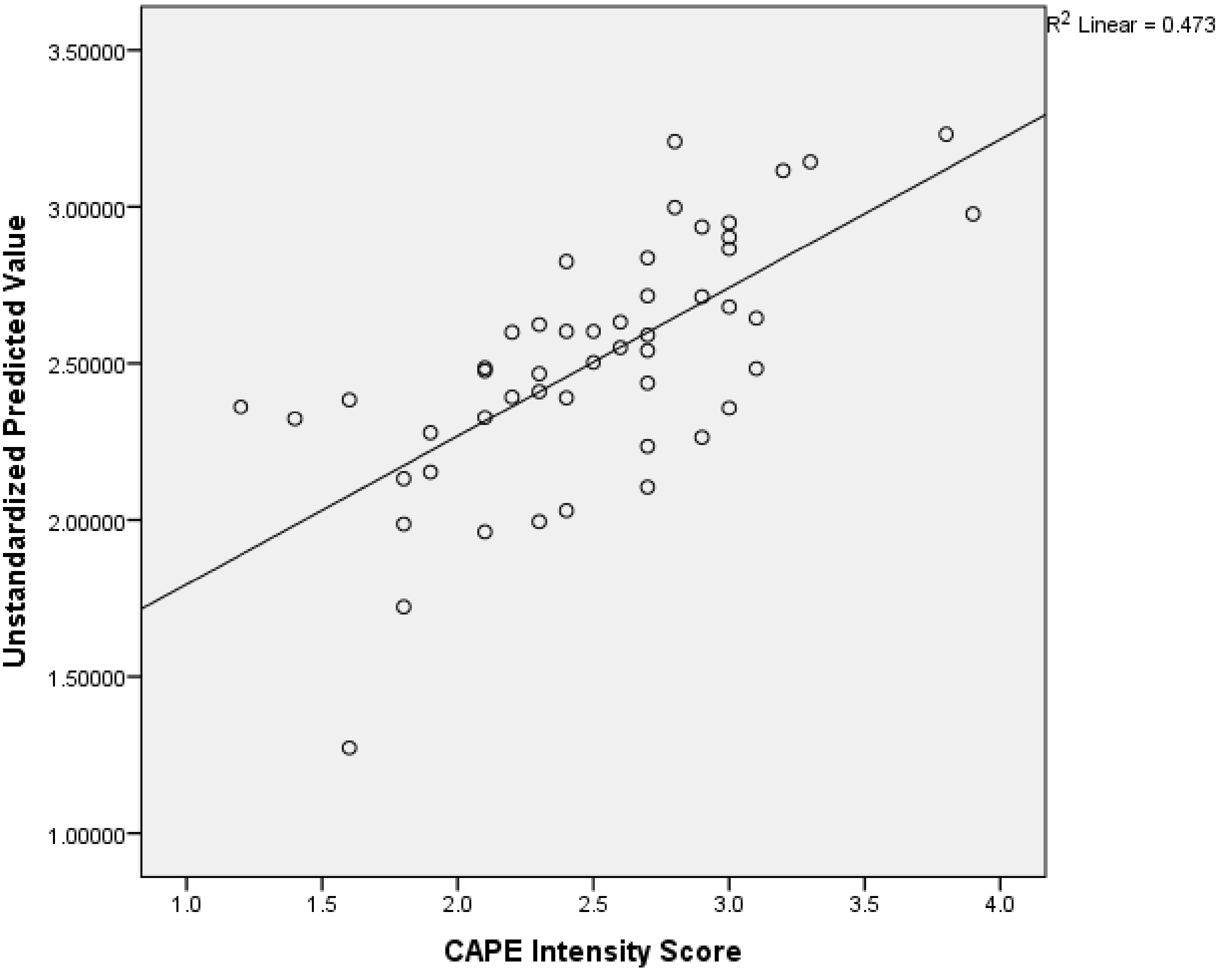


Figure (10): Regression analysis model summery for CAPE intensity scores

4.9. Association between caregiver disability burden (MBCBS) and the characteristics of the caregivers and their children with cerebral palsy:

Table - 9 shows the only significant correlations between the caregiver disability burden (MBCBS) (Dependent variable) and the characteristics of the caregivers and their children with CP (Independent variables). The Spearman correlation rho between the hours of caregiving and caregiver disability burden (MBCBS) was 0.49 ($p < 0.001$) which connoted a moderate correlation. This demonstrated that as the hours of caregiving increased, the Caregiver Disability Burden (MBCBS) also increased.

As per the statistical analysis, there was a moderate negative correlation between BMI scores and MBCBS scores with values of - 0.41 ($p = 0.003$). However, in our sample, most children were having BMI scores less than normal thus as the children were having BMI within normal limits their caregivers' burden was becoming less.

The Spearman’s Correlation between GMFCS and Distribution of Paralysis with Caregiver Disability Burden (MBCBS) were 0.44 ($p = 0.002$) and 0.50 ($p < 0.001$) respectively. which indicated a moderate positive correlation.

The correlation established between the ambulation capacity and the Caregiver Disability Burden (MBCBS) was scored 0.38 ($p = 0.007$) indicating a weak positive significant correlation. This means that as the level of ambulation increased, the Caregiver Disability Burden (MBCBS) was increased.

Firstly, the WeeFIM self-care correlation coefficient with Caregiver Disability Burden (MBCBS) was - 0.60 ($p < 0.001$) which signified a moderate negative correlation. Secondly, the WeeFIM mobility correlation with Caregiver Disability Burden (MBCBS) was - 0.50 ($p <0.001$) which indicated a moderate negative correlation. Lastly, the total score of WeeFIM correlated with MBCBS was - 0.62 ($p < 0.001$) which showed a moderate negative correlation. This revealed that as the total score of WeeFIM increased, the Caregiver Disability Burden (MBCBS) intensity decreased.

The Spearman correlation rho between the Caregiver Disability Burden (MBCBS) and overall diversity was - 0.69 ($p < 0.001$) which denoted a moderately negative correlation. In addition, the Spearman correlation rho between the Caregiver Disability Burden (MBCBS) and intensity was - 0.40 ($p = 0.004$) which connoted a moderate negative correlation.

Table (9): Significant correlations between the caregiver disability burden (MBCBS) (Dependent variable) and the characteristics of the caregivers and their children with cerebral palsy (Independent variables).

Characteristics of the Caregivers (Independent Variables)	**Spearman Correlation**	
	Caregiver Disability Burden (MBCBS) (Dependent Variables)	
	r	**P**
Hours of Caregiving	0.49	<0.001**
Characteristics of the Children with Cerebral Palsy (Independent Variables)		
BMI	-0.41	0.003**
GMFCS	0.44	0.002**
Distribution of Paralysis	0.50	<0.001**
Ambulation Capacity	0.38	0.007**
WeeFIM Self Care Score	-0.60	<0.001**
WeeFIM Mobility Score	-0.50	<0.001**
WeeFIM Cognition Score	-0.43	0.002**
WeeFIM Total Score	-0.62	<0.001**
CAPE Diversity Score	-0.69	<0.001**
CAPE Intensity Score	-0.40	0.004**

MBCBS: Modified Montgomery Borgatta Caregiver Burden Scale; **BMI:** Body Mass Index; **GMFCS:** Gross Motor Functional Classification System; **WeeFIM:** Functional Independence Measure; **CAPE:** Children's Assessment of Participation and Enjoyment.

* Significance difference ($P \leq 0.05$).

** Significance difference ($P \leq 0.01$).

4.10. Prediction of caregiver disability burden (MBCBS):

As illustrated in Table-10 and Figure-11, the caregiver disability burden score (MBCBS) can be predicted by BMI and CAPE Diversity Scores. The regression analysis involving BMI, as well as caregiver disability burden score (MBCBS), showed a negative correlation with a standardized coefficient (β) value of - 0.30 (p = 0.02). This negative association was also seen in the regression analysis involving CAPE Diversity Score and caregiver disability burden score (MBCBS) with a standardized coefficient (β) value of - 0.53 (p = 0.03) which means or predicted that, when the BMI and the diversity scores reduced, the caregiver disability burden score (MBCBS) increased. The regression equation for MBCBS was:

Y_{MBCBS} = 79.48 + (0.54 x Hours of Caregiving) – (0.82 x BMI) – (4.00 x GMFCS) + (3.75 x Distribution of Paralysis) + (4.80 x Ambulation Capacity) – (0.19 x WeeFIM Self Care Score) – (0.20 x WeeFIM Mobility Score) – (0.34 x WeeFIM Cognition Score) + (0.07 x WeeFIM Total Score) – (1.26 x CAPE Diversity Score) + (4.66 x CAPE Intensity Score).

Table (10): Predicting the caregiver disability burden (MBCBS).

Independent Variables	B	SEB	β	t	Sig	R	R^2	Adjusted R^2	Durbin Watson
Model Summary	79.48	21.75		3.65	0.001**	0.79	0.62	0.51	2.03
Hours of Caregiving	0.54	2.33	0.04	0.23	0.82				
BMI	-0.82	0.33	-0.30	-2.47	0.02*				
GMFCS	-4.00	4.39	-0.33	-0.91	0.37				
Distribution of Paralysis	3.75	2.76	0.18	1.36	0.18				
Ambulation Capacity	4.80	4.93	0.32	0.98	0.34				
WeeFIM Self Care Score	-0.19	1.85	-0.15	-0.10	0.92				
WeeFIM Mobility Score	-0.20	2.12	-0.13	-0.09	0.93				
WeeFIM Cognition Score	-0.34	1.97	-0.11	-0.17	0.86				
WeeFIM Total Score	0.07	1.94	0.11	0.04	0.97				
CAPE Diversity Score	-1.26	0.56	-0.53	-2.26	0.03*				
CAPE Intensity Score	4.66	3.70	0.21	1.26	0.22				

MBCBS: Modified Montgomery Borgatta Caregiver Burden Scale; **BMI:** Body Mass Index; **GMFCS:** Gross Motor Functional Classification System; **WeeFIM:** Functional Independence Measure; **CAPE:** Children's Assessment of Participation and Enjoyment; **B:** Unstandardized Coefficients; **SEB:** Std. Error of B; **β: S**tandardized Coefficients; **R:** Multiple Correlation Coefficient.

* Significance difference ($P \leq 0.05$).

** Significance difference ($P \leq 0.01$).

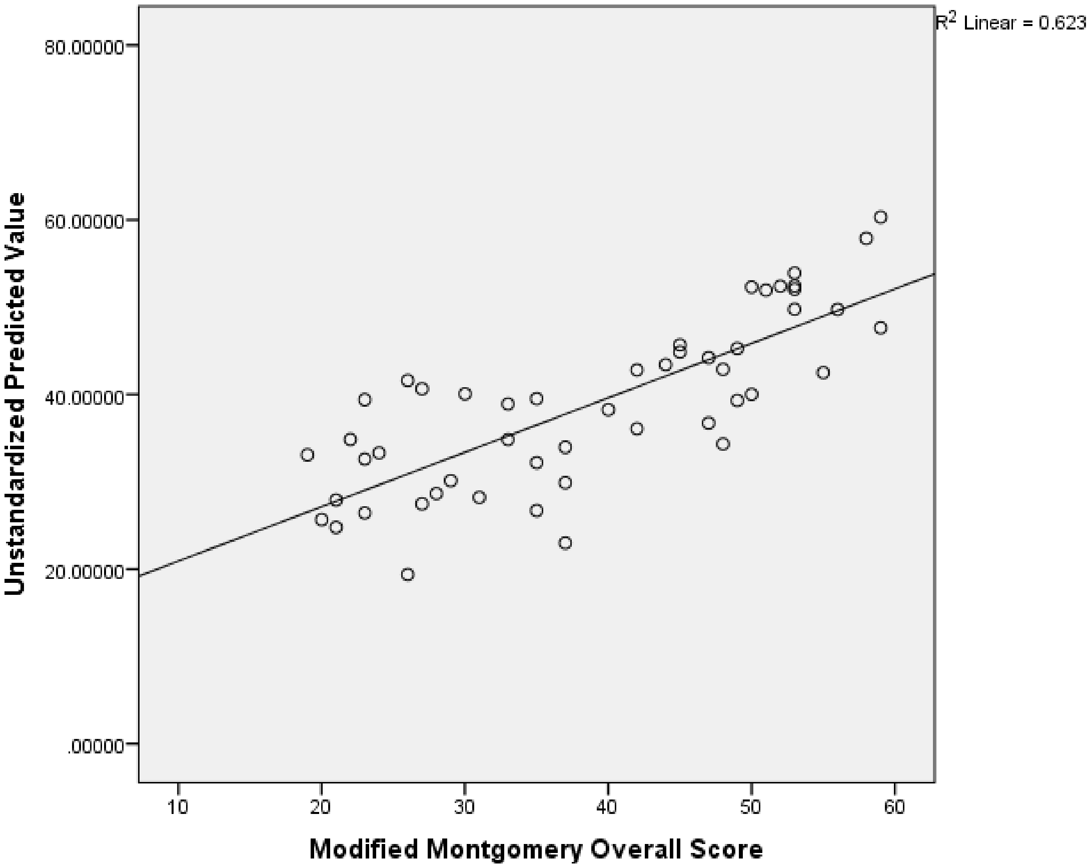


Figure (11): Regression analysis model summery for MBCBS overall scores

5. DISCUSSION

The study undertaken through this research aims at measuring the functional status and level of community participation in the Kingdom of Saudi Arabia among children with CP. The study is a one-of-its-kind endeavour, as it also sets out to recognize the burden of disability among the caregivers of these children. Moreover, this study looks into the associative relationship between the clinical characteristics of CP, functional impairments, community participation level, as well as, as mentioned before, the caregiver disability burden. Going further, the procedure discovers the close connection between the GMFCS level, ambulation, and the functional capacity in relation to the community participation measured by CAPE scores. Sifting through the several factors that have been affecting the burden on the shoulders of the caregivers, the CAPE diversity scores and the BMI of the affected children were found to have a strong correlation with the MBCBS scores.

5.1. Functional Capacity

The functional capacity of children is generally measured all by using the WeeFIM. The total maximum score that can be possibly achieved is 126, however, the functional scores were found to be dependent on the age of the individual. In a study conducted by (Karatekin *et al.*, 2021)assessed the effects of lockdown on the functional capacity of a total of 110 children affected with CP. The average values of WeeFIM were a mean of 60.45 and SD of 33.43 among children ranging from 1 to 18 years (Karatekin *et al.*, 2021). In the current study, 50 children ranging from the ages of 6 to 12 years were measured using the WeeFIM, and their mean value were of 92.9 and SD of 18.4.

(Özen *et al.*, 2021) conducted a study on electrical stimulation and cycling treatment effect on children with cerebral palsy and revealed the average WeeFIM post-treatment mean ± SD scores of 74.50 ± 17.65. Another study executed by (Duymaz, 2020) on the effect of Music therapy on children with cerebral palsy also measured functional capacity using

WeeFIM and obtained a maximum mean ± SD scores of 59.25±28.13 after follow-up sessions.

In contrast to the studies conducted by other authors like above mentioned the mean functional independence is believed to be better in this study. This may be due to the variability in the age and functional capacity of children participated in the current study, there were more than 75% of the children who have GMFCS levels of I, II, and III were included in our study and their age was more focused that is 6 – 12 years.

5.2. Community Participation

When it comes to children with certain disabilities, CAPE and PAC are applied together to get an estimate of the community participation and the intensity of the same. This study that was conducted on children from Saudi Arabia revealed the overall CAPE score to be 31 out of 55 with standard deviation of 5.2. The study conducted for validation of CAPE on Children with CP in Spain by (Longo *et al.*, 2014) showed overall CAPE mean ± SD scores of 20.4 ± 8.6, and another study conducted by (Vila-Nova, Oliveira and Cordovil, 2020) on participation levels of children with CP in Portuguese also revealed an overall CAPE mean ± SD scores of 20.8 ± 5.7.

The PAC scores conducted in Victoria, Australia, on children with CP had revealed mean ± SD scores of 2.3±0.4, 2.2±0.4, 2.6±0.4, 2.1±0.5, and 1.9±0.5 for recreational, physical, social, skill-based, and self-improvement activities respectively. Whereas, in the same study, PAC scores conducted in Ontario, Canada, on children with CP had revealed mean ± SD scores of 2.4±0.3, 2.4±0.4, 2.7±0.3, 2.1±0.5, and 2.1±0.5 for recreational, physical, social, skill-based, and self-improvement activities respectively (Imms *et al.*, 2017). When we compared the PAC scores obtained in our study with them, we got a better score than them in all the sub-components. The scores in the current study were observed as follows with mean ± SD scores of 2.45±0.29, 2.53±0.28, 2.69±0.24, 2.35±0.37, and 2.23±0.39 for recreational, physical, social, skill-based, and self-improvement activities respectively.

Although most of the scores were better in CAPE scores and identical in PAC indicates that diversity of choosing activities is better in the current study but the preference is similar to the other authors. It is assumed that these differences in CAPE are due to the differences in characteristics, such as, age, BMI, level of GMFCS, and type of care the children are receiving.

Vila-Nova (2020), conducted a study on Portugal children with CP and measured their participation in leisure activity. Similar to our study finding the informal activities which were most commonly preferred by the children were watching TV/rented movie (98.6), Listening to music (94.2) and playing computer or video games (92.8), whereas in our study it was playing computer and visiting were most common (100) listening to the music was next (94) and watching TV / rented movie was 92 percent. When compared the formal activities the most preferred formal activity here was doing a religious activity (100) and racing track (80) whereas in their study it was the Swimming (42.0) and doing a religious activity (36.2). The differences in the informal activities may be due to the cultural practices in their region.

5.3. Caregiver Disability Burden

The questionnaire used for getting an estimate of the caregiver burden was the modified Montgomery questionnaire. Since the MBCBS questionnaire was not used commonly in the caregivers of the CP children the results were formulated in comparison to the results noted on other disabled subjects like stroke. The author of the scale (Montgomery *et al.*, 2011) conducted a study on Caregiver Burden among Alzheimer's Disease and Related Dementia subjects by using MBCBS, and the mean ± SD values of objective, stress, and relative burden obtained in their study were 21.52 ± 6.35, 10.59 ± 4.82, and 13.99 ± 5.27. Whereas another study also conducted by (Bailes, Kelley and Parker, 2016) on Caregiver

Burden among subjects with Alzheimer’s Disease and Dementia by using MBCBS, and the mean ± SD values of objective, stress, and relative burden obtained in their study were 20.72 ± 6.84, 12.06 ± 6.06, and 15.02 ± 5.46. Whereas in the current study, mean ± SD values of MBCBS objective, stress, and relative burden obtained were 11.68 ± 3.52, 10.58 ± 3.76, and 12.00 ± 3.55.

The caregiver burden compared to the other studies was less in our study. These variations in the mean scores can be attributed to differences in patient population and the level of GMFCS the children displayed in our study. Many children were found to be able to ambulate and take care of themselves, thus reducing the burden on the caregivers.

5.4. The parameters associated with CAPE diversity and intensity

A positive correlation was recorded in this study between the GMFCS and WeeFIM total scores with the CAPE total scores, denoting a r value of – 0.55 ($p<0.001$) and 0.83 (<0.001) respectively. The (Lee, 2017) study also found similar correlations where the levels of GMFCS and WeeFIM total scores were compared by the researcher with International Classification of Functioning, Disability, and Health Child and Youth Checklist for activities and participation. The r value obtained was of – 0.711 ($p<0.01$), 0.838 ($p<0.01$) respectively. Although the assessments used for examining the participation were different, the important finding was that there was a correlation between the functional capacity and community participation. The children participated in the study of (Lee, 2017) were mainly of the spastic type, leading to a different outcome measure. As a result, the values were not similar, but the relation was common.

Another noteworthy study was one conducted by (Longo, Badia and Orgaz, 2013) where they analyzed the GMFCS levels of adults and children with CP with respect to their total scores of CAPE. The beta value obtained through this analysis was -0.39 ($p < 0.001$) in their regression analysis. In this current study, the beta value obtained was -0.72 ($p = 0.005$)

in the regression analysis. This difference in the results, and a better regression values in the current study may be attributed to the focused population chosen to participate in the present study. The children recruited were of a specific age group with an apparent good functional mobility hence they had better association between these two variables.

The ambulation capacity also had significant regression on the CAPE score. This is sensible to understand that as the ambulation capacity of the child increases the capacity to participate in the community will be increased automatically because they are more mobile, and this is what we have observed in our study also (Shikako-Thomas *et al.*, 2008).

The other factors like distribution of paralysis, PAC overall score, income of the parents, hours of caregiving did not have significant regression with the CAPE score. The distribution of paralysis was done based on the sub type of the CP and they are mentioned in numbers for coding and analysis purpose in the SPSS. The monoplegia is coded as one, paraplegia as two, hemiplegia is three, diplegia is four and quadriplegia is five. However, in the current study after collection of the data we did not have any monoplegia or paraplegia, hence we had left out with only three numbers that is three, four and five. Moreover, the PAC is also graded on three points and the total score is also ranging from 1 to 3. Hence, statistically getting correlation between three numbers versus zero to 55 (CAPE score) numbers will be not suitable and we believe that this is the reason for not getting any significant regression for distribution of paralysis, PAC overall score with CAPE scores.

(Shikako-Thomas *et al.*, 2013) measured income of the parents in Canadian dollars under five categories whereas (Longo *et al.*, 2014) measured income of the parents in Euros under three categories and the current study had taken income of parents (mostly the caregivers) in Saudi Riyals under three categories. In all the three studies they compared income of the parents with CAPE diversity scores and they found no correlation between these two variables. We also believe that the participation is not purely dependent on income rather it is dependent on the interest of the parents and child to involve in the community activities hence we did not find a significant correlation.

Unfortunately, we did not find any literature on correlating the duration of caregiving with CAPE diversity score. Consequently, in the current study we correlated these two parameters and we found there is no significant correlation between these two parameters. It is logical that if the child is receiving more hours of care that means the child require help in many aspects of daily living and they are totally dependent on the caregivers (Fuhrmann *et al.*, 2015) and this may be the reason that the child could not participate in the activities. Therefore, these two parameters did not correlate significantly in the current study.

5.5. Association between levels of GMFCS, Functionality, and Caregiver Burden

An analysis of the relationship between functional capacity of children with CP and the burden faced by their caregivers was presented by (Schneider *et al.*, 2001) The process enabled records of a moderate positive correlation between the WeeFIM score and caregiver questionnaire with a r value of 0.460 ($p<0.05$). In the current study the correlation value obtained was a r value with -0.62 ($p<0.001$). It was noticed that there was disparity in the outcome measures used between studies, the association between the caregiver burden and the functional capacity of the children showed opposite results. In the (Schneider *et al.*, 2001) study the author mentioned that the outcome measure they used to assess caregiver burden was designed for children after Dorsal Rhizotomy and in the current study there were no children with Dorsal Rhizotomy and hence there was some disparities in their study results. However, in our study the relationship was clear that as the children were becoming more independent the caregiver burden was becoming less and this relation is more realistic.

(Gokcin Eminel, Kahraman and Genc, 2021) put forth a comparison done between the physical workload of the caregivers in accordance with a number of factors among children with CP. A moderate level of correlation was observed between the level of GMFCS and

Physical Workload Questionnaire for caregivers with r value 0.50 ($p<0.001$). This value is identical to the one received through this study, where the exact r value is 0.44 ($p=0.002$). The common observation made by the study referenced and this research is that with increasing level of GMFCS, the activeness in a child starts decreasing. This causes an increase in the burden on the caregivers (Gokcin Eminel, Kahraman and Genc, 2021)

Next, the analysis put forth by (de Zabarte Fernández *et al.*, 2021) shall be considered. They analyzed the variety of the factors that can exert an influence on the burden on the shoulders of the caregivers of the children with CP. A similar association between the BMI of the child and caregiver burden was found, identical to the one found through this study. To give an exact number, the correlation r values were -0.41($p=0.003$) in the current study and -0.361 ($p=0.003$) in the Fernandez study. Thus, it can be inferred that both the studies direct towards the fact that as BMI increases up to the normal levels then it decreases the burden on caregivers. As explained in the previous study by (de Zabarte Fernández *et al.*, 2021) as the children were having ideal BMI values means they have good health and thus their caregivers burden was less and if the children were more underweight they have more health issues and thus requires more care giving. This can be observed by seeing the BMI range in the current study, that all the subjects included in the current study were ranging between under nourished with sub normal BMI values to normal BMI values (de Zabarte Fernández *et al.*, 2021).

The CAPE overall score increasing that means the child is more actively participating in the activities of life and when the MMBCB scores are increasing then the caregiver's burden is increasing. However, in our study we got a significant negative correlation between these two parameters with -0.69 showing that one value is increasing, and other value is decreasing. It is rational to think that when child is actively participating in the community that means they don't require much care-by-caregiver and hence their burden will be less. This the same relation we also observed in the current study.

5.6. Study limitations

Despite out best efforts to reduce our study’s limitations, some of them did seem to persist that must be clarified in the future.

- The sample size was done via convenience sampling and was confined to very few children with CP (50). Bias may be encouraged by convenience sampling, whereas the small sample size means the results cannot be generalized.
- Each participant was chosen from just one hospital located in Riyadh, thus falling short of representing children with CP across Saudi Arabia.
- Most of the children who took part in this study belong to the category of spastic CP; and due to the sample’s small size, it was not possible to perform subgroup analysis on the basis of type of CP, gender or GMFCS level.
- Children who participated in this study were 6-12 years in age, which means limitations in ensuring the results’ applicability.
- The investigator is a graduate student of Physical Therapy, and this study was done as part of the master’s thesis, hence she has done all the important components of research by herself like patient selection, their assessment, data entry and analysis, data interpretation, and writing process. This bias was not avoidable, and was one of our study limitations.

6. CONCLUSION AND RECOMMENDATION

6.1. Conclusions

The findings of our study include:

1. The functional capacity among children with CP measured by WeeFIM in our study was higher in comparison to the population of other studies.
2. The CAPE diveristy score of 31 out of 55 with PAC score of 2.4 out of 3 showed better community participation where the intensity was good.
3. The caregiver burden was assessed by MBCBS in the current study, where the total score obtained was 39 for 80 with 12.3 standard deviation. The caregivers' burden was not too intense when compared to the data used by other researchers.
4. Ambulation capacity, GMFCS levels, self-care WeeFIM, and caregiver burden scores are significant predictors of community participation.
5. BMI and community participation were significant predictors of caregiver burden scores among children with CP.

6.2. Recommendations

1. Studies in the future must increase the sample size via random sampling from various parts of the nation, which includes many age groups.
2. In case the sample size is increased, it will be possible to undertake subgroup based on type of CP, gender, or level of GMFCS, which will help in better understanding the needs of the children and families in Saudi Arabia.
3. Making an increase in the number of researchers may reduce assessment bias in the study

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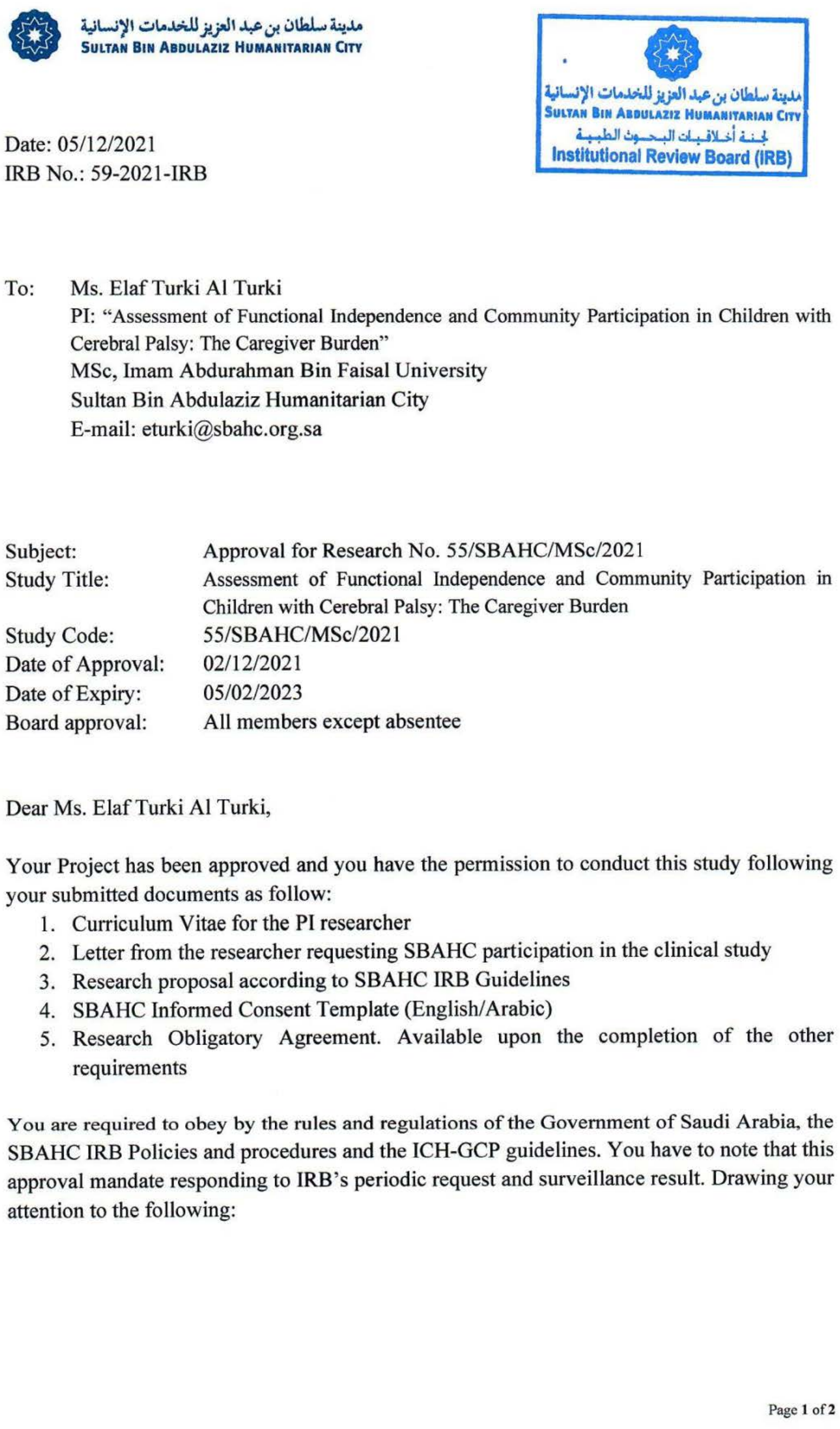
APPENDICES

Appendix A: Ethical Approval



مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY
لجنة أخلاقيات البحوث الطبية
Institutional Review Board (IRB)

Date: 05/12/2021
IRB No.: 59-2021-IRB

To: Ms. Elaf Turki Al Turki
PI: "Assessment of Functional Independence and Community Participation in Children with Cerebral Palsy: The Caregiver Burden"
MSc, Imam Abdurahman Bin Faisal University
Sultan Bin Abdulaziz Humanitarian City
E-mail: eturki@sbahc.org.sa

Subject:	Approval for Research No. 55/SBAHC/MSc/2021
Study Title:	Assessment of Functional Independence and Community Participation in Children with Cerebral Palsy: The Caregiver Burden
Study Code:	55/SBAHC/MSc/2021
Date of Approval:	02/12/2021
Date of Expiry:	05/02/2023
Board approval:	All members except absentee

Dear Ms. Elaf Turki Al Turki,

Your Project has been approved and you have the permission to conduct this study following your submitted documents as follow:

1. Curriculum Vitae for the PI researcher
2. Letter from the researcher requesting SBAHC participation in the clinical study
3. Research proposal according to SBAHC IRB Guidelines
4. SBAHC Informed Consent Template (English/Arabic)
5. Research Obligatory Agreement. Available upon the completion of the other requirements

You are required to obey by the rules and regulations of the Government of Saudi Arabia, the SBAHC IRB Policies and procedures and the ICH-GCP guidelines. You have to note that this approval mandate responding to IRB's periodic request and surveillance result. Drawing your attention to the following:

- Amendment of the project with the required modification to providing Periodical report for this project especially when study extension is required or expiry before study completion
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the IRB as soon as possible
- Personal identifying data should only be collected when necessary for research.
- Secondary disclosure of personal identifiable data is not allowed.
- Monitoring: projects may be subject to an audit by the IRB at any time.
- The PI is responsible for the storage and retention of original data pertaining to the project for a minimum period of five (5) years.
- Data should be stored securely so that a few authorized users are permitted access to the database.

The IRB registered with the IRB KACST Registration No. H-01-R-090. It is authorized to conduct the ethical review of clinic studies and operates in accordance with ICH-GCP Guidelines and all applicable national/local and institutional regulations and guidelines which govern Good Clinical Practices.

For Future Correspondence, please quote the project number and project title above and you are requested to keep IRB informed about your study progress and submit project progress report every six (6) months. A final report should be provided upon completion of the study.

Wish you a success in your research project.

Yours sincerely,

Prof. Khalid Al-Rubeaan
Chairman-IRB
Sultan Bin Abdulaziz Humanitarian City

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
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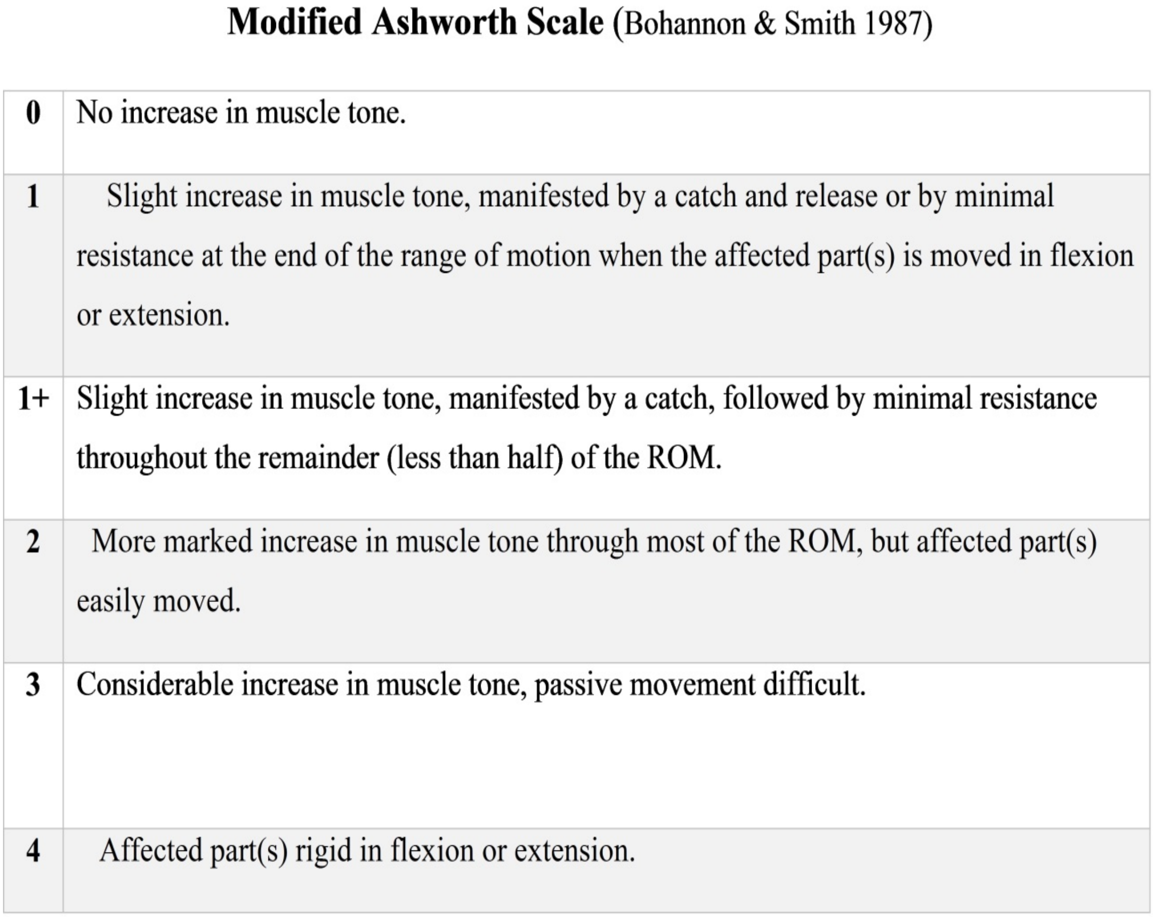
Institutional Review Board (IRB)

Appendix B:

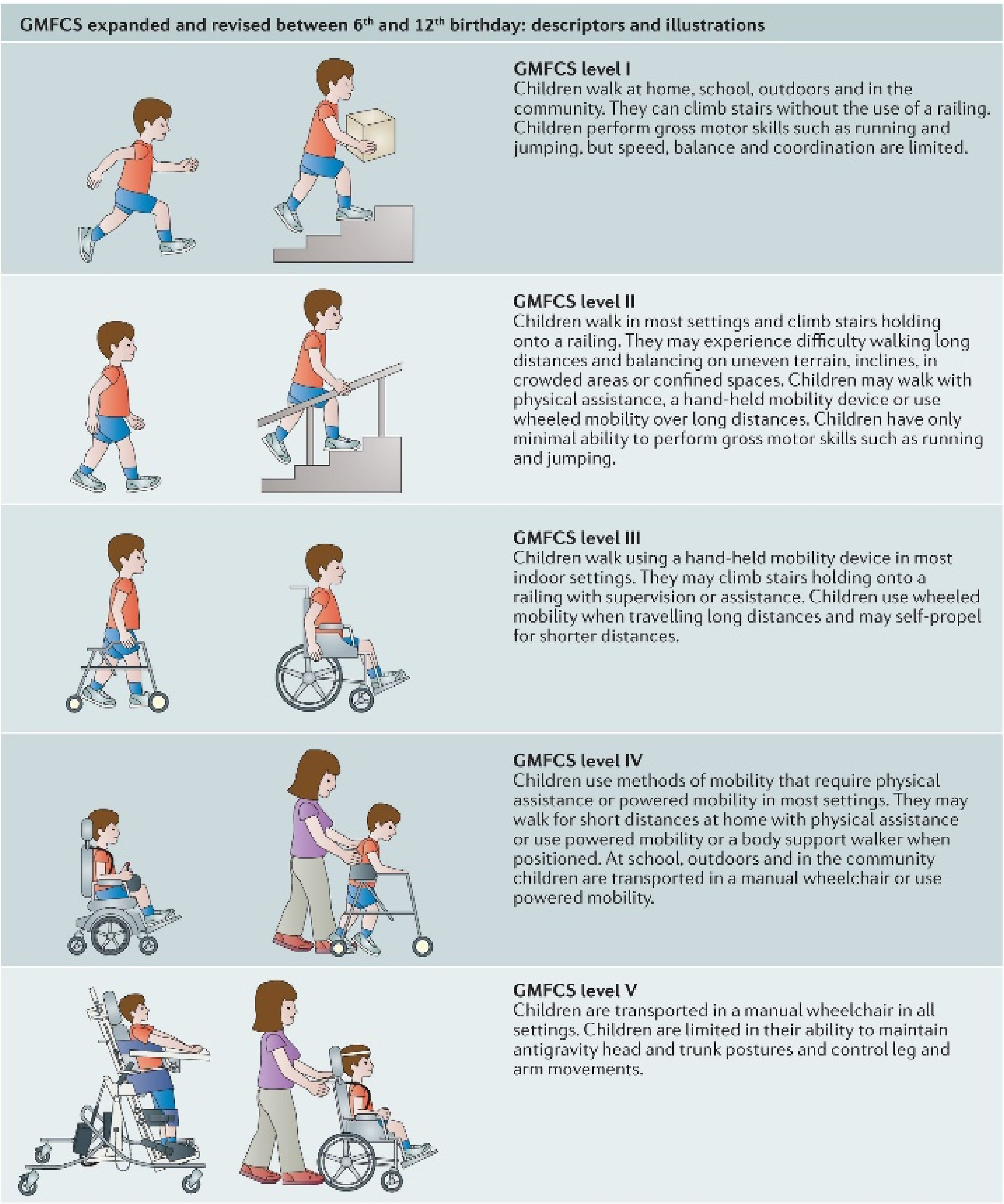


Modified Ashworth Scale (Bohannon & Smith 1987)

0	No increase in muscle tone.
1	Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension.
1+	Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM.
2	More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved.
3	Considerable increase in muscle tone, passive movement difficult.
4	Affected part(s) rigid in flexion or extension.

Appendix C:

Gross Motor Function Classification Scale (GMFCS)



GMFCS expanded and revised between 6th and 12th birthday: descriptors and illustrations

GMFCS level I
Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

GMFCS level II
Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS level III
Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when travelling long distances and may self-propel for shorter distances.

GMFCS level IV
Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

GMFCS level V
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

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Appendix D:

English and Arabic Consent Forum

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY

INFORMED CONSENT FOR MEDICAL & CLINICAL STUDIES
الموافقة المستنيرة للمعلومات الطبية والدراسات السريرية

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SECTION A:
STUDY INFORMATION

Study Title:	Assessment of Functional Independence and Community Participation in Children with Cerebral Palsy: The Caregiver Disability Burden	تقييم الاستقلال الوظيفي والمشاركة المجتمعية لدى الأطفال المصابين بالشلل الدماغي: عبء الإعاقة على مقدم الرعاية.	عنوان الدراسة:
Protocol Number/Study Code:			رقم البروتوكول/ رمز الدراسة:
Principal Investigator:	Elaf Truki AlTurki	ايلاف تركي التركي	الباحث المسؤول:
Principal Investigator Address:	Riyadh – AlNarjis Distric	الرياض – حي النرجس	عنوان الباحث المسؤول:
Telephone:	0551151595	0551151595	الهاتف:
Email:	etaltruki@yahoo.com	etalturki@yahoo.com	البريد الإلكتروني:
Sponsor	0	٠	الممول

القسم أ:
معلومات عن الدراسة

INTRODUCTION
Dear Participant,

You are invited to take part in a clinical research study. To help you decide, you should understand the study and what it will involve for you. To make an informed decision to take part you should know the purpose of the study, the procedures, the benefits and risks of the study, the discomforts and the precautions taken. This process is called 'informed consent'. Please take the time to read the following information carefully and discuss it with others. Please ask your study doctor if there is anything that is not clear or if you would like more information.

You can leave the study at any time without giving a reason if you do not wish to provide one. It will not affect your regular medical care. Before your participation in the study can be confirmed, you have to complete initial tests for the study doctor.

It cannot be promised that the study will help you but in the future the information we get from this study may help improve the future treatment of people with the same condition.

Once you have decided that you want to take part, you (or legally acceptable representative) will be asked to sign the informed consent form. You will be given a copy of the signed form to keep, and the original will stay at the study center.

مقدمه
عزيزي المشارك،

أنت مدعو للمشاركة في دراسة بحثية سريرية، ولكن ينبغي عليك فهم الدراسة وماستتضمنه لمساعدتك على اتخاذ القرار. يجب عليك معرفة الغرض من الدراسة والإجراءات والفوائد والمخاطر والعوامل المقلقة والإجراءات المتخذة وذلك لاتخاذ قرار مستنير للمشاركة، وتسمى هذه العملية "موافقة مستنيرة". يُرجى تخصيص وقت لقراءة المعلومات التالية بعناية ومناقشتها مع الآخرين، ويمكنك سؤال طبيب الدراسة في حالة عدم وضوح أي أمر أو رغبت بالحصول على معلومات إضافية.

يمكنك الانسحاب من الدراسة في أي وقت بدون إبداء سبب إن لم يكن لديك الرغبة في التبرير، فذلك لن يؤثر على الرعاية الطبية العادية التي تتلقاها، كما يجب عليك إكمال الاختبارات الأولية لطبيب الدراسة قبل التأكيد على مشاركتك.

لا نعدك بأن الدراسة ستساعدك ولكن قد تساعد المعلومات المستمدة من هذه الدراسة في تحسين العلاج في المستقبل للأشخاص المصابين بنفس الحالة.

بمجرد أن تقرر بأنك ترغب بالمشاركة، سيُطلب منك (أو من ممثلك المعترف به قانونيًا) التوقيع على نموذج الموافقة المستنيرة وسيتم تسليمك نسخة من النموذج الموقّع لتحتفظ به وستكون النسخة الأصلية محفوظة في مركز الدراسة.

SECTION B:

1. What is the purpose of the study?

To examine functional status, community participation, caregiver's disability burden in children with cerebral palsy. Also, to determine any possible association between the clinical characteristics of the cerebral palsy, functional impairments, community participation, and the caregiver disability burden.

2. How many people will take part in the study?

36

3. Study location?

Sultan Bin Abdulaziz Humanitarian City.

4. What will happen if I take part in this study?

All children with CP will be examined for functional status by using the Functional Independent Measure (WeeFIM), their community participation by using the Children Assessment of Participation and

القسم ب:

١. مالغرض من الدراسة؟

فحص الحالة الوظيفية ، ومشاركة المجتمع ، وعبء الإعاقة على مقدم الرعاية لدى الأطفال المصابين بالشلل الدماغي. أيضًا ، لتحديد أي ارتباط محتمل بين الخصائص السريرية للشلل الدماغي والضعف الوظيفي والمشاركة المجتمعية و العبء على مقدم الرعاية.

٢. كم عدد الأشخاص الذين سيشاركون في الدراسة؟

٣٦

٣. موقع الدراسة؟

مدينة سلطان بن عبدالعزيز للخدمات الإنسانية.

٤. ماذا سيحدث إذا شاركت في هذه الدراسة؟

سيتم تقييم جميع الأطفال المصابين بالشلل الدماغي لمعرفة الحالة الوظيفية باستخدام مقياس التدبير الوظيفي المستقل (WeeFIM) ، ومشاركتهم في المجتمع باستخدام تقييم الأطفال للمشاركة والاستمتاع (CAPE) وتفضيلات أنشطة الأطفال (PAC). بالإضافة إلى ذلك ،

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IRB Form 006 – E&A

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Enjoyment (CAPE) and Preferences for Activities of Children (PAC). In addition, their caregiver will be assessed for the disability burden by using the Modified Montgomery Borgatta Caregiver Burden Scale (MBCBS).	سيتم تقييم مقدم الرعاية الخاص بهم فيما يتعلق بعبء الإعاقة باستخدام مقياس مونتغمري بورجاتا المعدل (MBCBS).
5. What is expected of me during the study?	**٥. مالمتوقع مني خلال الدراسة؟**
Commitment, follow instructions and attend the study according to the schedule given.	الالتزام واتباع التعليمات و حضور موعد الدراسة حسب الجدول المعطى.
6. How long will I be in the study?	**٦. مالفترة التي سأقضيها في الدراسة؟**
2 hours.	ساعتين
7. What are my responsibilities?	**٧. ما هي مسؤولياتي؟**
Commitment, follow instructions and attend the study according to the schedule given.	الالتزام واتباع مدى التعليمات و حضور موعد الدراسة حسب الجدول المعطى
8. Can I stop being in the study?	**٨. هل يمكنني التوقف عن المشاركة في الدراسة؟**
Yes	نعم
9. Are there risks if I stop being in the study?	**٩. هل هناك مخاطر إذا توقفت عن المشاركة في الدراسة؟**
[Provide description of any risks which research subject can come through in case of withdrawal, study treatment discontinuation, or becoming ineligible or loss of any rights from getting treatment]	[تقديم وصف للمخاطر التي يمكن أن يتعرض لها المشارك في البحث في حالة الانسحاب أو إيقاف الدراسة أو عدم الأهلية أو فقدان الحقوق من الحصول على العلاج]
There are no risks.	لا يوجد أي مخاطر
10. What side effects or risks can I expect from being in the study?	**١٠. ماهي الآثار الجانبية أو المخاطر التي يمكن أن أتوقعها من المشاركة في الدراسة؟**
There are no risks.	لا يوجد أي مخاطر
11. Are there benefits to taking part in the study?	**١١. هل توجد فوائد للمشاركة في الدراسة؟**
Your participation in this study is entirely voluntary. No payment will be made if you involved in the study. The goals of this study is to To examine functional status, community participation, caregiver's disability burden in children with cerebral palsy. Also, to determine any possible association between the clinical characteristics of the cerebral palsy, functional impairments, community participation, and the caregiver disability burden.	مشاركتك في هذه الدراسة طوعية تماما. كما أنه لن يتم دفع أي مقابل في حال المشاركة في الدراسة. والهدف من هذه الدراسة فحص الحالة الوظيفية ومشاركة المجتمع، وعبء الإعاقة على مقدم الرعاية لدى الأطفال المصابين بالشلل الدماغي. أيضًا، تحديد أي ارتباط محتمل بين الخصائص السريرية للشلل الدماغي والضعف الوظيفي والمشاركة المجتمعية و العبء على مقدم الرعاية.
12. What if I will travel outside the kingdom or abroad while in the study?	**١٢. ماذا لو سافرت خارج المملكه اثناء المشاركه في الدراسه؟**
If you travel, remember to inform the researcher and make another appointment after your return.	في حالة سفرك تذكر ابلاغ الباحث الرئيسي بسفرك و تحديد موعد آخر بعد عودتك.
13. What happens if I am injured because I took part in this study?	**١٣. ماذا يحدث إذا أصبت بالضرر بسبب مشاركتي في هذه الدراسة؟**
There are no risks and if any damage occurs, the researcher will held the responsibility.	لا يوجد أي ضرر و وإذا حدث أي ضرر سيتحمل الباحث الرئيسي المسؤولية.
14. What are the costs of taking part in the study?	**١٤. ما هي تكاليف المشاركة في الدراسة؟**
You will not be required to pay to participate in the study or any study-related procedure.	لن يطلب منك الدفع للمشاركة في الدراسة او أي اجراء متعلق بالدراسة.
15. Will I be paid for my taking part in this study?	**١٥. هل سأتلقى مقابلاً بسبب مشاركتي في هذه الدراسة؟**
Your participation in this study is entirely voluntary. No payment will be made if you involved in the study.	مشاركتك في هذه الدراسة طوعية تماما. كما أنه لن يتم دفع أي مقابل في حال المشاركة في الدراسة.
16. Will my medical information be kept private?	**١٦. هل سيتم الحفاظ على خصوصية معلوماتي الطبية؟**
Yes	نعم

SECTION C:	**القسم ج:**
NOTE: Fill this section in case subject's bio-specimens are required as part of the study	**ملاحظة: أكمل هذا القسم في حالة كانت العينات الحيوية للمشارك مطلوبة كجزء من الدراسة**
17. I am being asked to give my bio-sample(s) as mentioned in the study procedure(s).	**١٧. يُطلب مني تقديم عينة (عينات) حيوية بحسب ماتم ذكره في إجراء (إجراءات) الدراسة.**
[Description of subject's bio-sample(s) required as part of research protocol. E.g. blood, urine, saliva, semen, ascites, stool, surgically resected/excised tissue, etc.]	[وصف العينات الحيوية المطلوبة كجزء من بروتوكول البحث، على سبيل المثال الدم، البول، اللعاب، السائل المنوي، الاستسقاء، البراز، الأنسجة المستئصلة جراحيًا، إلخ.]
Not applicable.	لا ينطبق
18. I am asked for the bio-sample(s) listed with the mentioned condition(s).	**١٨. طلبت مني العينات الحيوية المدرجة في الشرط (الشروط) المذكورة.**
[Please mention the subject's bio-sample(s) required with their quantity,	[يرجى ذكر العينات الحيوية المطلوبة بكميتها ووزنها / حجمها ووضعها]

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weight/volume and condition(s)]	
Not applicable.	لا ينطبق
19. Why I am asked to give my bio-sample(s)?	١٩. لماذا يطلب مني تقديم عينات حيوية؟
[Description mentioning the use and reasons of bio-sample(s) as part of study]	[وصف يذكر استخدام العينات الحيوية وأسبابها كجزء من الدراسة]
Not applicable.	لا ينطبق
20. My bio-sample(s) will be sent to Central Laboratory/Company (Local/ Abroad).	٢٠. سيتم إرسال عيناتي الحيوية إلى مختبر محلي/ شركة (محلية/في الخارج).
Your blood samples will be shipped to a local laboratory for analysis and will be destroyed after analysis. Your blood samples will not be kept for research purposes after the end of the study	سوف يتم إرسال عينات الدم الخاصة بك إلى مختبر محلي للتحليل وسيتم التخلص منها بعد ذلك، ولن يتم الاحتفاظ بعينات الدم لأغراض البحث بعد الانتهاء منها.
Not applicable.	لا ينطبق
21. I hereby consent to provide my clinical data required with the bio-sample(s).	٢١. أوافق بموجبه على تقديم بياناتي السريرية المطلوبة مع العينات الحيوية.
☐ Yes ☐ No	نعم ☐ لا ☐
[Please mention subjects clinical data required along with the bio-sample(s), justifying the use, ensuring the limitations and privacy of subjects' data, with coding the identifiers. No national or government identity/database information could be allowed with the subject's data]	[يرجى ذكر المعلومات السريرية المطلوبة للمشارك والعينات الحيوية التي تبرر الاستخدام وتضمن خصوصية معلوماته وترميز المعرّفات. لن يُسمح بظهور معلومات الهوية / قاعدة البيانات الوطنية أو الحكومية مع بيانات المشارك]
Not applicable.	لا ينطبق
22. My bio-sample(s) will not be used for genetic testing.	٢٢. لن يتم استخدام عيناتي الحيوية للاختبارات الوراثية.
☐ Yes ☐ No	نعم ☐ لا ☐
SECTION D:	القسم د:
23. What are my rights if I take part in this study?	٢٣. ماهي حقوقي إذا شاركت في هذه الدراسة؟
Your participation in this study is your choice. You can choose whether or not to participate in the study and you can drop out at any time. There will also be no penalty if you stop participating in the study.	مشاركتك في هذه الدراسة هو اختيارك. يمكنك اختيار إما المشاركة أو عدم المشاركة في الدراسة ويمكنك ترك الدراسة في أي وقت. كما لن تكون هناك أي عقوبة في حال توقفت عن المشاركة في الدراسة.
24. What are the possible disadvantages or risks of taking part?	٢٤. ماهي السلبيات أو المخاطر المحتملة للمشاركة؟
There are no risks.	لا يوجد مخاطر.
25. What happens when the research study stops?	٢٥. ماذا يحدث حين تتوقف هذه الدراسة البحثية؟
you can drop out at any time. There will also be no penalty if you stop participating in the study.	يمكنك ترك الدراسة في أي وقت. كما لن تكون هناك أي عقوبة في حال توقفت عن المشاركة في الدراسة.
26. What alternative treatments are available?	٢٦. ما العلاجات البديلة المتاحة؟
Not applicable.	لا ينطبق
27. Who do I call if I have questions or problems?	٢٧. بمن يجب علي الاتصال إذا كانت لدي أسئلة أو مشكلات؟
Principle investigator	الباحث الرئيسي
28. What if new information about the study drug becomes available?	٢٨. ماذا إذا توفرت معلومات جديدة حول عقار الدراسة؟
Not applicable.	لا ينطبق
29. What will happen if you don't want to carry on with the study?	٢٩. ماذا سيحدث إذا لم ترغب في الاستمرار في الدراسة؟
You will always have the right to withdraw at any time without giving reasons and without affecting your health care and your relationship with the researchers who conducted the study.	مشاركتك في هذه الدراسة طوعية تماما. وسيكون لك دائما الحق في الانسحاب في أي وقت دون إبداء الأسباب ودون التأثير على رعايتك الصحية على علاقتك بالباحثين الذين أجروا الدراسة.
30. Why are my data being collected and analyzed?	٣٠. لماذا يتم جمع بياناتي وتحليلها؟
To determine any possible association between the clinical characteristics of the cerebral palsy, functional impairments, community participation, and the caregiver disability burden.	لتحديد أي ارتباط محتمل بين الخصائص السريرية للشلل الدماغي والضعف الوظيفي والمشاركة المجتمعية والعبء على مقدم الرعاية.
SECTION E:	القسم هـ:
CONSENT	الموافقة
Subject:	المشارك:
The research and procedures have been explained to me. I have been allowed to ask any questions and all my questions have been answered. I have read the consent and have had time to think about participating. I can ask any additional questions I may think of later. I may refuse to participate in the study, and I may quit being in the study at any time without any penalty and without affecting my health care.	تم توضيح البحث والإجراءات لي وقد سُمح لي بطرح أي سؤال وتمت الإجابة على جميع أسئلتي. قرأت الموافقة وفكرت في المشاركة ويمكنني طرح أي أسئلة إضافية فيما بعد. قد أرفض المشاركة في الدراسة وقد أنسحب منها في أي وقت دون عقوبة ولن يؤثر ذلك على رعايتي الصحية.
I have been given permission for the study doctor and sponsor to use and disclose my personal health information.	أسمح لطبيب الدراسة والراعي باستخدام معلوماتي الصحية الشخصية والكشف عنها.
I will receive a signed copy of this consent form.	سأستلم نسخة موقعة من نموذج الموافقة.
	أوافق على المشاركة في هذه الدراسة وموافقتي هي تطوعًا مني وليس مطلوبًا مني التوقيع على هذا النموذج إذا لم أرغب بالمشاركة في هذه الدراسة البحثية.

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INFORMED CONSENT FOR MEDICAL & CLINICAL STUDIES

الموافقة المستنيرة للمعلومات الطبية والدراسات السريرية

I agree to participate in this study. My agreement is voluntary. I do not have to sign this form if I do not want to be part of this research study.

Subject Signature:
Date:
Time: ☐ AM ☐ PM

Person Obtaining Consent:

I have explained the nature and purpose of the study and the risks involved. I have answered and will answer questions to the best of my ability. I will give a signed copy of the consent form to the subject.

Signature of Person Obtaining Consent:
Date:
Time: ☐ AM ☐ PM

Principal Investigator:
Signature of Principal Investigator:
Date:
Time: ☐ AM ☐ PM

توقيع المشارك :
التاريخ:
الوقت : صباحًا ☐ مساءً ☐

الشخص الذي يحصل على الموافقة:

لقد وضحت طبيعة الدراسة والغرض منها والمخاطر المتعلقة بها، كما أجبت على الأسئلة وسوف أجيب عليها بأقصى استطاعتي. سأسلم نسخة موقعة من نموذج الموافقة للمشارك.

توقيع الشخص الذي يحصل على الموافقة:
التاريخ
الوقت : مساءً ☐

الباحث المسؤول :
توقيع الباحث المسؤول
التاريخ:
الوقت : صباحًا ☐ مساءً ☐

SECTION F:

STOP! Do not use the following signature lines unless third party consent is being requested.
(For subjects who are unable to give consent).

For subjects unable to consent:

Legally Authorized Representative:
Date:
Person Obtaining Consent:
Date:

For children who cannot give consent:

The person being considered for this study is unable to consent for himself/herself because he/she is a minor. By signing below, you are giving your permission for your child to be included in this study.

Parent or Legal Guardian:
Date:

القسم و:

توقف! لا تستخدم خطوط التوقيع التالية ما لم يتم طلب موافقة طرف ثالث.
(بالنسبة للمشاركين غير القادرين على منح الموافقة).

بالنسبة للمشاركين غير القادرين على منح الموافقة:

الممثل القانوني المعتمد :
التاريخ:
الشخص الذي يحصل على الموافقة:
التاريخ:

للأطفال الذين لا يستطيعون الموافقة:

الشخص المعني لهذه الدراسة غير قادر على الموافقة بنفسه/ نفسها كونه/ كونها قاصرًا. بالتوقيع أدناه، فإنك تسمح بضم طفلك إلى هذه الدراسة.

الوالد أو الوصي القانوني:
التاريخ:

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY

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الشاهد المحايد : في الحالات المذكورة أعلاه يلزم وجود شاهد في حال عدم قدرة الشخص على قراءة أو فهم نص نموذج الموافقة المستنيرة والدراسة وطبيعتهما..

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الوقت :	صباحًا ☐	مساءً ☐

Appendix E:

Data Entry Sheet for Characteristics of Children with Cerebral Palsy

CP Number:					
Name:			**Weight:**		
Age:			**Height:**		
Sex:	**Male**	☐	**BMI:**		
	Female	☐	**GMFCS:**	**I**	☐
Type of Tonal Abnormality:	**Spasticity**	☐		**II**	☐
	Dyskinesia	☐		**III**	☐
	Ataxia	☐		**IV**	☐
	Hypotonia	☐		**V**	☐
	Mixed	☐	**Distribution of Paralysis:**	**Monoplegia**	☐
Severity of Spasticity:	**0**	☐		**Paraplegia**	☐
	1	☐		**Hemiplegia**	☐
	1+	☐		**Diplegia**	☐
	2	☐		**Quadriplegia**	☐
	3	☐		**Double Hemiplegia**	☐
	4	☐	**Ambulation Capacity:**	**Walks Independently**	☐
				Walks with Mobility Device	☐
				No Walking	☐

Appendix F:

Data Entry Sheet for Characteristics of the Caregiver

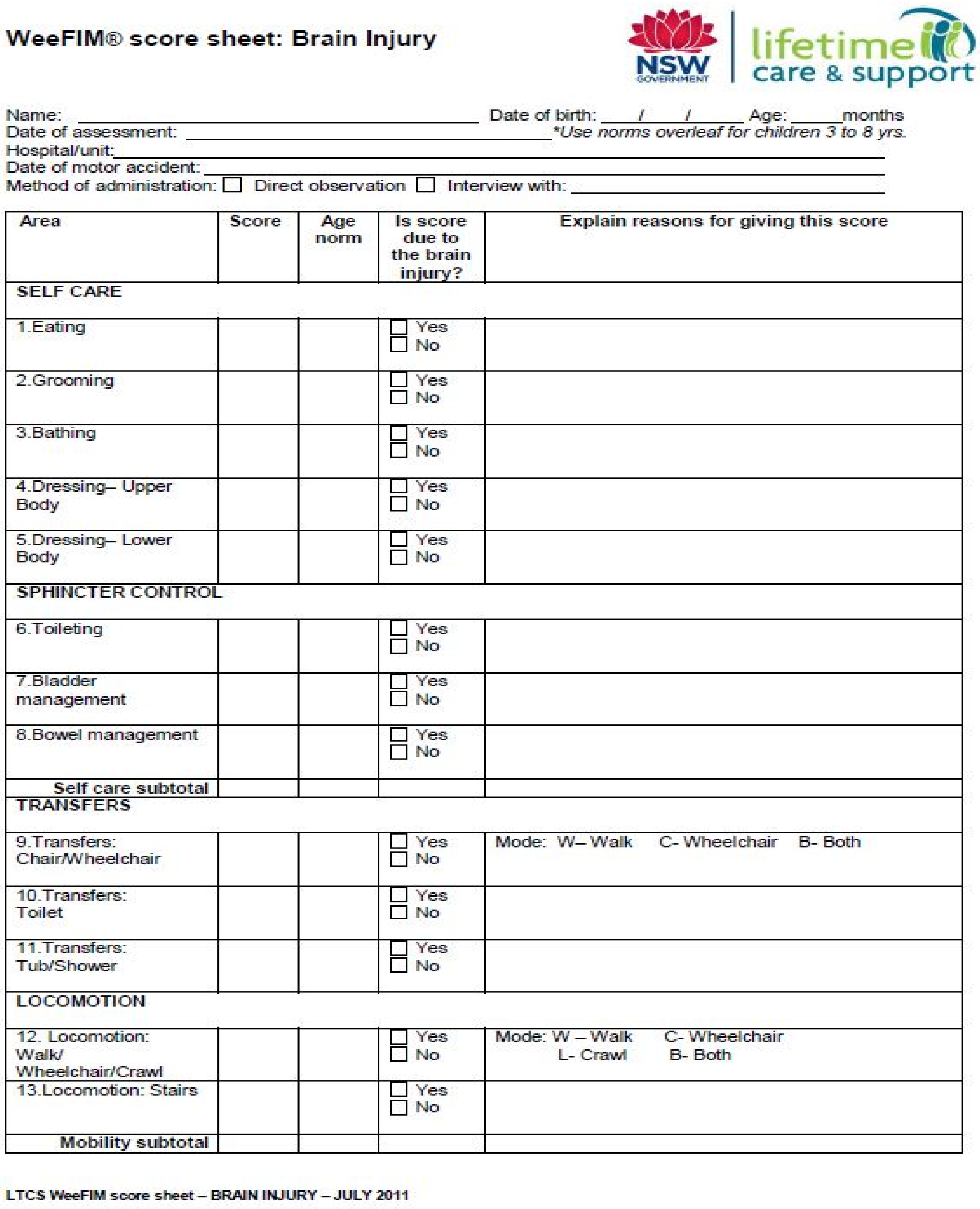
CG Number:					
Name:			**CG Lives with the CP:**	**Yes**	☐
Age:				**No**	☐
Sex:	**Male**	☐	**Type of CG:**	**Mother**	☐
	Female	☐		**Father**	☐
Level of Education:	**Nil**	☐		**Family**	☐
	Lower	☐		**Housemaid**	☐
	Secondary	☐		**Employer**	☐
	Bachelor	☐	**Employment status:**	**Full Time**	☐
	Higher	☐		**Part Time (# of Hours)**	☐
Marital Status:	**Married**	☐	**Type of Care Provided:**	**ADL**	☐
	Single	☐		**Rehabilitation**	☐
	Separated	☐		**ADL & Rehab**	☐
Income:	**Low Class**	☐		**Others***	☐
	Middle Class	☐	**Hours of Caregiving (Daily):**	**More than 8 hours**	☐
	High Class	☐		**5–8 hours**	☐
	No Answer	☐		**Less than 4 hours**	☐
				Other**	☐

* Other (e.g., daily supervision, weekend supervision, daily activities).

** Other (e.g., every other day, weekends, full-day backup care if needed).

Appendix G:

Functional Independence Measure WeeFim



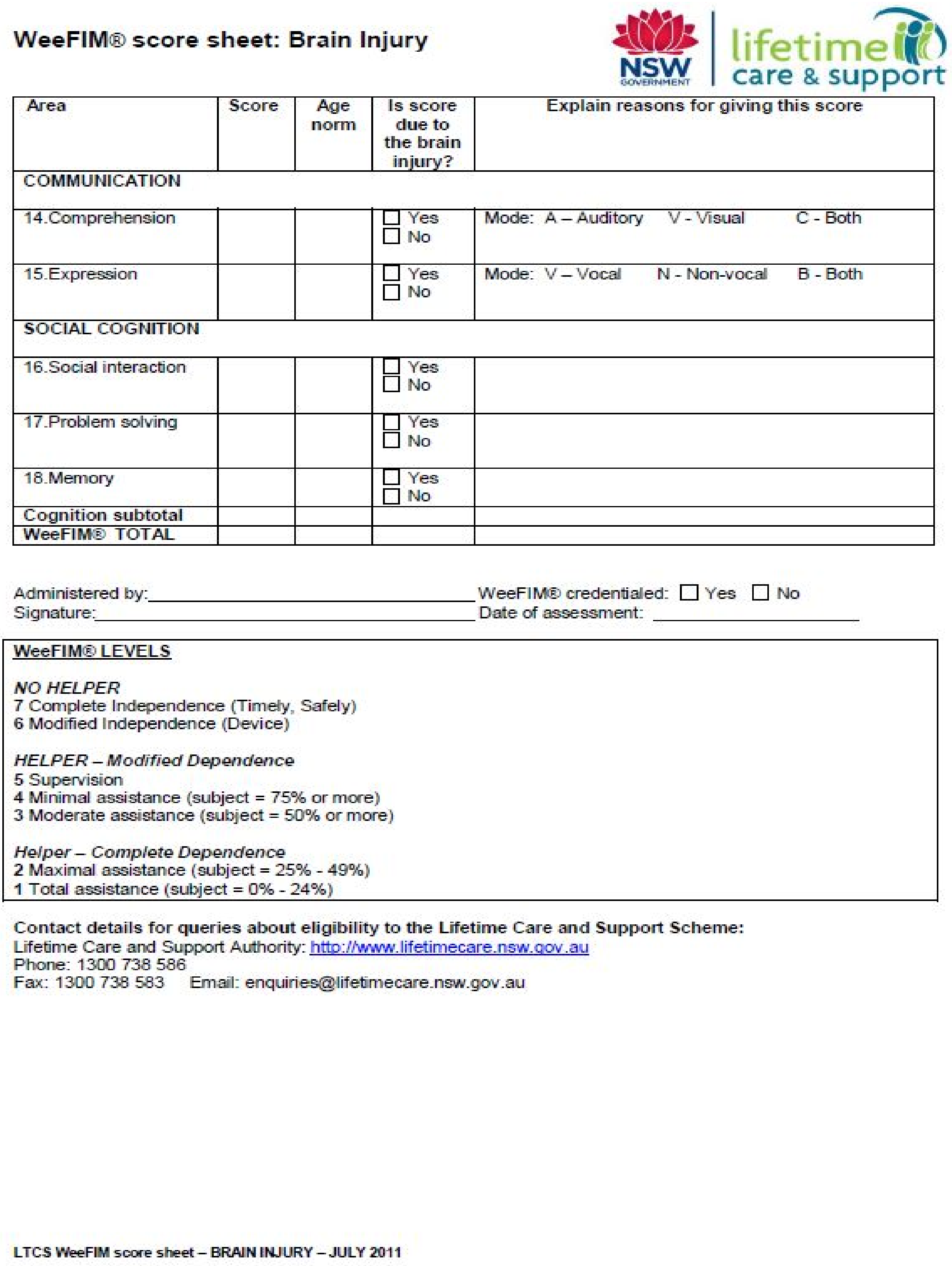
WeeFIM® score sheet: Brain Injury

NSW GOVERNMENT | lifetime care & support

Name: ____________________ Date of birth: ___/___/_____ Age: _____months
Date of assessment: ____________________ **Use norms overleaf for children 3 to 8 yrs.*
Hospital/unit: ____________________
Date of motor accident: ____________________
Method of administration: ☐ Direct observation ☐ Interview with: ____________________

Area	Score	Age norm	Is score due to the brain injury?	Explain reasons for giving this score
SELF CARE				
1.Eating			☐ Yes ☐ No	
2.Grooming			☐ Yes ☐ No	
3.Bathing			☐ Yes ☐ No	
4.Dressing– Upper Body			☐ Yes ☐ No	
5.Dressing– Lower Body			☐ Yes ☐ No	
SPHINCTER CONTROL				
6.Toileting			☐ Yes ☐ No	
7.Bladder management			☐ Yes ☐ No	
8.Bowel management			☐ Yes ☐ No	
Self care subtotal				
TRANSFERS				
9.Transfers: Chair/Wheelchair			☐ Yes ☐ No	Mode: W– Walk C- Wheelchair B- Both
10.Transfers: Toilet			☐ Yes ☐ No	
11.Transfers: Tub/Shower			☐ Yes ☐ No	
LOCOMOTION				
12. Locomotion: Walk/ Wheelchair/Crawl			☐ Yes ☐ No	Mode: W – Walk C- Wheelchair L- Crawl B- Both
13.Locomotion: Stairs			☐ Yes ☐ No	
Mobility subtotal				

LTCS WeeFIM score sheet – BRAIN INJURY – JULY 2011



WeeFIM® score sheet: Brain Injury

Area	Score	Age norm	Is score due to the brain injury?	Explain reasons for giving this score
COMMUNICATION				
14.Comprehension			☐ Yes ☐ No	Mode: A – Auditory V - Visual C - Both
15.Expression			☐ Yes ☐ No	Mode: V – Vocal N - Non-vocal B - Both
SOCIAL COGNITION				
16.Social interaction			☐ Yes ☐ No	
17.Problem solving			☐ Yes ☐ No	
18.Memory			☐ Yes ☐ No	
Cognition subtotal				
WeeFIM® TOTAL				

Administered by:________________________ WeeFIM® credentialed: ☐ Yes ☐ No
Signature:________________________ Date of assessment: ________________

WeeFIM® LEVELS

NO HELPER
7 Complete Independence (Timely, Safely)
6 Modified Independence (Device)

HELPER – Modified Dependence
5 Supervision
4 Minimal assistance (subject = 75% or more)
3 Moderate assistance (subject = 50% or more)

Helper – Complete Dependence
2 Maximal assistance (subject = 25% - 49%)
1 Total assistance (subject = 0% - 24%)

Contact details for queries about eligibility to the Lifetime Care and Support Scheme:
Lifetime Care and Support Authority: http://www.lifetimecare.nsw.gov.au
Phone: 1300 738 586
Fax: 1300 738 583 Email: enquiries@lifetimecare.nsw.gov.au

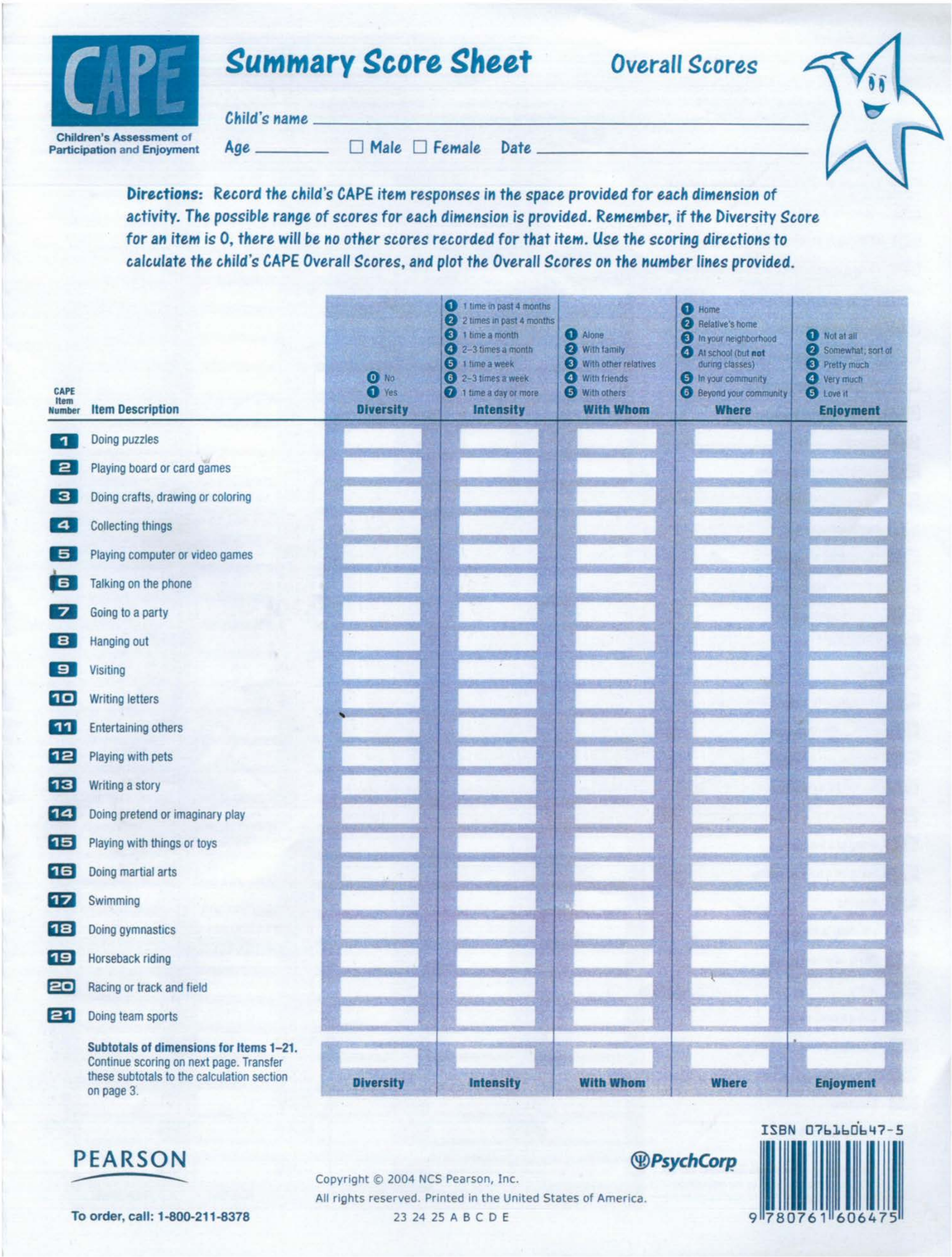
LTCS WeeFIM score sheet – BRAIN INJURY – JULY 2011

WeeFIM® norms for children 3 to 8 years

Apply to ages (months)	36>39	39>42	42>45	45>48	48>51	51>54	54>57	57>60	60>63	63>66	66>69	69>72	72>75	75>78	78>81	81>84	84>87	87>90	90>93	93>96
Norm for age (months)	36	39	42	45	48	51	54	57	60	63	66	69	72	75	78	81	84	87	90	93
1 Eating	5	5	6	6	6	6	6	6	6	6	6	7	7	7	7	7	7	7	7	7
2 Grooming	3	4	4	4	5	5	5	5	5	5	6	6	6	6	6	7	7	7	7	7
3 Bathing	3	3	4	4	4	4	5	5	5	5	6	6	6	6	6	6	7	7	7	7
4 Dressing Upper	4	4	4	5	5	5	5	5	6	6	6	6	6	6	7	7	7	7	7	7
5 Dressing Lower	4	4	4	4	5	5	5	5	5	6	6	6	6	6	7	7	7	7	7	7
6 Toileting	4	5	5	5	5	5	5	6	6	6	6	6	6	7	7	7	7	7	7	7
7 Bladder	5	5	5	5	5	6	6	6	6	6	6	6	7	7	7	7	7	7	7	7
8 Bowel	6	6	6	6	6	6	6	7	7	7	7	7	7	7	7	7	7	7	7	7
Self Care Total	**34**	**36**	**38**	**39**	**41**	**42**	**43**	**45**	**46**	**47**	**49**	**50**	**51**	**52**	**54**	**55**	**56**	**56**	**56**	**56**
9 Bed, Chair, Wheelchair	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7
10 Toilet	6	6	6	6	6	6	7	7	7	7	7	7	7	7	7	7	7	7	7	7
11 Tub, Shower	5	5	5	6	6	6	6	6	6	6	6	7	7	7	7	7	7	7	7	7
12 Walk/Wheelchair	6	6	6	6	6	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7
13 Stairs	5	6	6	6	6	6	6	6	7	7	7	7	7	7	7	7	7	7	7	7
Mobility Total	**29**	**30**	**30**	**31**	**31**	**32**	**33**	**33**	**34**	**34**	**34**	**35**	**35**	**35**	**35**	**35**	**35**	**35**	**35**	**35**
14 Comprehension	5	5	5	5	5	6	6	6	6	6	7	7	7	7	7	7	7	7	7	
15 Expression	6	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7
16 Social Interaction	3	3	4	4	4	4	4	5	5	5	5	5	5	5	6	6	7	7	7	7
17 Problem Solving	5	5	5	5	6	6	6	6	6	7	7	7	7	7	7	7	7	7	7	7
18 Memory	5	5	5	5	5	5	6	6	6	6	6	6	7	7	7	7	7	7	7	7
Cognition Total	**24**	**25**	**26**	**26**	**27**	**28**	**29**	**30**	**30**	**31**	**32**	**32**	**33**	**33**	**34**	**34**	**35**	**35**	**35**	**35**
Motor Total	**63**	**66**	**68**	**70**	**72**	**74**	**76**	**78**	**80**	**81**	**83**	**85**	**86**	**87**	**89**	**90**	**91**	**91**	**91**	**91**
Cognitive Total	**24**	**25**	**26**	**26**	**27**	**28**	**29**	**30**	**30**	**31**	**32**	**32**	**33**	**33**	**34**	**34**	**35**	**35**	**35**	**35**
Total	**87**	**91**	**94**	**96**	**99**	**102**	**105**	**108**	**110**	**112**	**115**	**117**	**119**	**120**	**123**	**124**	**126**	**126**	**126**	**126**

Source: Uniform Data System for Medical Rehabilitation. 1998, 2000. The WeeFIM Clinical System Guide, Version 5.01. Buffalo: UDSMR.

Appendix H: **Summery scoring sheet for total score of Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC).**



CAPE
Children's Assessment of Participation and Enjoyment

Summary Score Sheet

Overall Scores

Child's name ______________________________

Age __________ ☐ Male ☐ Female Date ______________________

Directions: Record the child's CAPE item responses in the space provided for each dimension of activity. The possible range of scores for each dimension is provided. Remember, if the Diversity Score for an item is 0, there will be no other scores recorded for that item. Use the scoring directions to calculate the child's CAPE Overall Scores, and plot the Overall Scores on the number lines provided.

CAPE Item Number	Item Description	⓪ No ① Yes **Diversity**	① 1 time in past 4 months ② 2 times in past 4 months ③ 1 time a month ④ 2–3 times a month ⑤ 1 time a week ⑥ 2–3 times a week ⑦ 1 time a day or more **Intensity**	① Alone ② With family ③ With other relatives ④ With friends ⑤ With others **With Whom**	① Home ② Relative's home ③ In your neighborhood ④ At school (but **not** during classes) ⑤ In your community ⑥ Beyond your community **Where**	① Not at all ② Somewhat; sort of ③ Pretty much ④ Very much ⑤ Love it **Enjoyment**
1	Doing puzzles					
2	Playing board or card games					
3	Doing crafts, drawing or coloring					
4	Collecting things					
5	Playing computer or video games					
6	Talking on the phone					
7	Going to a party					
8	Hanging out					
9	Visiting					
10	Writing letters					
11	Entertaining others					
12	Playing with pets					
13	Writing a story					
14	Doing pretend or imaginary play					
15	Playing with things or toys					
16	Doing martial arts					
17	Swimming					
18	Doing gymnastics					
19	Horseback riding					
20	Racing or track and field					
21	Doing team sports					
	Subtotals of dimensions for Items 1–21. Continue scoring on next page. Transfer these subtotals to the calculation section on page 3.	**Diversity**	**Intensity**	**With Whom**	**Where**	**Enjoyment**

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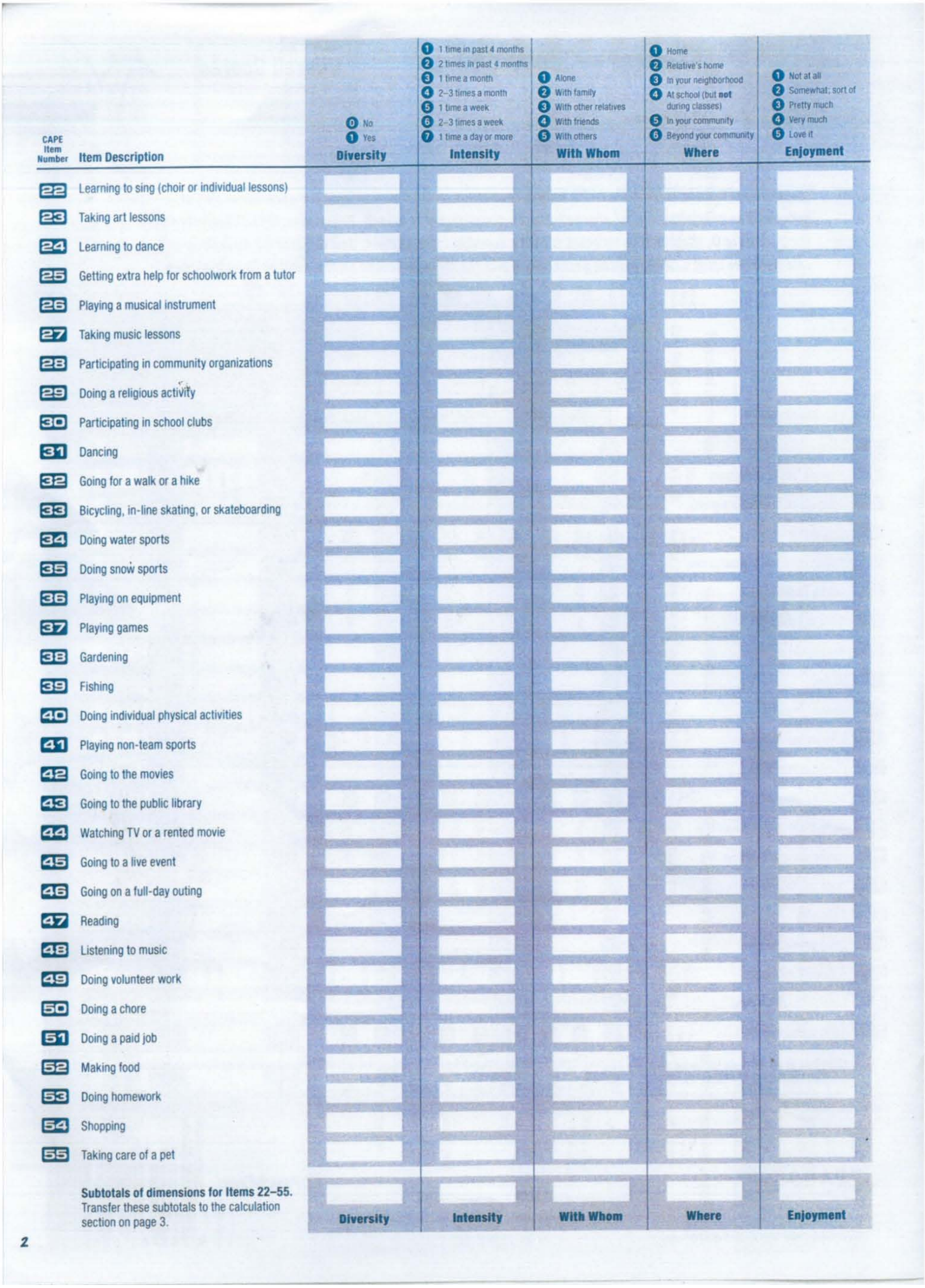


CAPE Item Number	Item Description	⓿ No ❶ Yes **Diversity**	❶ 1 time in past 4 months ❷ 2 times in past 4 months ❸ 1 time a month ❹ 2–3 times a month ❺ 1 time a week ❻ 2–3 times a week ❼ 1 time a day or more **Intensity**	❶ Alone ❷ With family ❸ With other relatives ❹ With friends ❺ With others **With Whom**	❶ Home ❷ Relative's home ❸ In your neighborhood ❹ At school (but **not** during classes) ❺ In your community ❻ Beyond your community **Where**	❶ Not at all ❷ Somewhat; sort of ❸ Pretty much ❹ Very much ❺ Love it **Enjoyment**
22	Learning to sing (choir or individual lessons)					
23	Taking art lessons					
24	Learning to dance					
25	Getting extra help for schoolwork from a tutor					
26	Playing a musical instrument					
27	Taking music lessons					
28	Participating in community organizations					
29	Doing a religious activity					
30	Participating in school clubs					
31	Dancing					
32	Going for a walk or a hike					
33	Bicycling, in-line skating, or skateboarding					
34	Doing water sports					
35	Doing snow sports					
36	Playing on equipment					
37	Playing games					
38	Gardening					
39	Fishing					
40	Doing individual physical activities					
41	Playing non-team sports					
42	Going to the movies					
43	Going to the public library					
44	Watching TV or a rented movie					
45	Going to a live event					
46	Going on a full-day outing					
47	Reading					
48	Listening to music					
49	Doing volunteer work					
50	Doing a chore					
51	Doing a paid job					
52	Making food					
53	Doing homework					
54	Shopping					
55	Taking care of a pet					
	Subtotals of dimensions for Items 22–55. Transfer these subtotals to the calculation section on page 3.	**Diversity**	**Intensity**	**With Whom**	**Where**	**Enjoyment**

Child's name ______________________________ **Date** ______________

Scoring Calculations

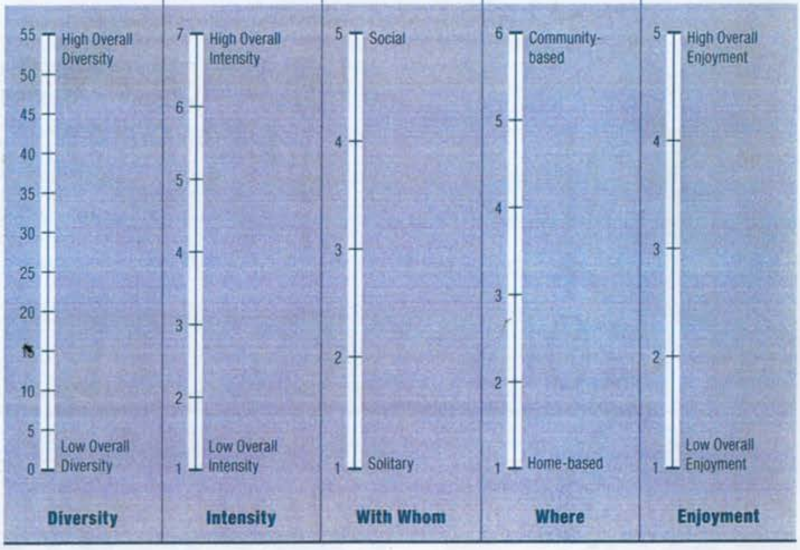
Follow the directions provided in each column to calculate the Overall Score for each dimension.

Diversity	Intensity	With Whom	Where	Enjoyment
Subtotal for Items 1–21	Subtotal for Items 1–21	Subtotal for Items 1–21	Subtotal for Items 1–21	Subtotal for Items 1–21
+ Subtotal for Items 22–55	+ Subtotal for Items 22–55	+ Subtotal for Items 22–55	+ Subtotal for Items 22–55	+ Subtotal for Items 22–55
	÷ 55	÷ Overall Diversity Score	÷ Overall Diversity Score	÷ Overall Diversity Score
Write sum in box below	Write total in box below	Write total in box below	Write total in box below	Write total in box below

Record the calculated Overall Score for each dimension.

Overall Diversity Score	Overall Intensity Score	Overall With Whom Score	Overall Where Score	Overall Enjoyment Score

Plot values of Overall Scores for a graphic representation of the child's participation and enjoyment.



Use this space to record any additional activities and associated responses given by the child or to record any assessment notes or observations.

Comments

PAC
Preferences for Activities of Children

Summary Score Sheet

Activity Type and Overall Scores

Child's name ____________________ Age ________ ☐ Male ☐ Female Date ____________

Directions: The 55 PAC Items are categorized by the five Activity Types. Locate each PAC item number in one of the Activity Type categories and record the child's response. The possible PAC Preference Scores range from 1–3. Follow the scoring directions for each Activity Type to calculate the child's PAC Activity Type and Overall scores.

Preference Scores
① Would not like to do at all
② Would sort of like to do
③ Would really like to do

Recreational Activities

PAC Item Number	Item Description	Score ①②③
1	Doing puzzles	
2	Playing board or card games	
3	Doing crafts, drawing or coloring	
4	Collecting things	
5	Playing computer or video games	
12	Playing with pets	
14	Doing pretend or imaginary play	
15	Playing with things or toys	
32	Going for a walk or a hike	
36	Playing on equipment	
44	Watching TV or a rented movie	
55	Taking care of a pet	

Recreational Activities Sum ○
÷ 12
Preference Score Recreational Activities ☐

Physical Activities

PAC Item Number	Item Description	Score ①②③
16	Doing martial arts	
20	Racing or track and field	
21	Doing team sports	
30	Participating in school clubs	
33	Bicycling, in-line skating, or skateboarding	
34	Doing water sports	
35	Doing snow sports	
37	Playing games	
38	Gardening	
39	Fishing	
40	Doing individual physical activities	
41	Playing non-team sports	
51	Doing a paid job	

Physical Activities Sum ○
÷ 13
Preference Score Physical Activities ☐

Social Activities

PAC Item Number	Item Description	Score ①②③
6	Talking on the phone	
7	Going to a party	
8	Hanging out	
9	Visiting	
11	Entertaining others	
42	Going to the movies	
45	Going to a live event	
46	Going on a full-day outing	
48	Listening to music	
52	Making food	

Social Activities Sum ○
÷ 10
Preference Score Social Activities ☐

Skill-Based Activities

PAC Item Number	Item Description	Score ①②③
17	Swimming	
18	Doing gymnastics	
19	Horseback riding	
22	Learning to sing (choir or individual lessons)	
23	Taking art lessons	
24	Learning to dance	
26	Playing a musical instrument	
27	Taking music lessons	
28	Participating in community organizations	
31	Dancing	

Skill-Based Activities Sum ○
÷ 10
Preference Score Skill-Based Activities ☐

Self-Improvement Activities

PAC Item Number	Item Description	Score ①②③
10	Writing letters	
13	Writing a story	
25	Getting extra help for schoolwork from a tutor	
29	Doing a religious activity	
43	Going to the public library	
47	Reading	
49	Doing volunteer work	
50	Doing a chore	
53	Doing homework	
54	Shopping	

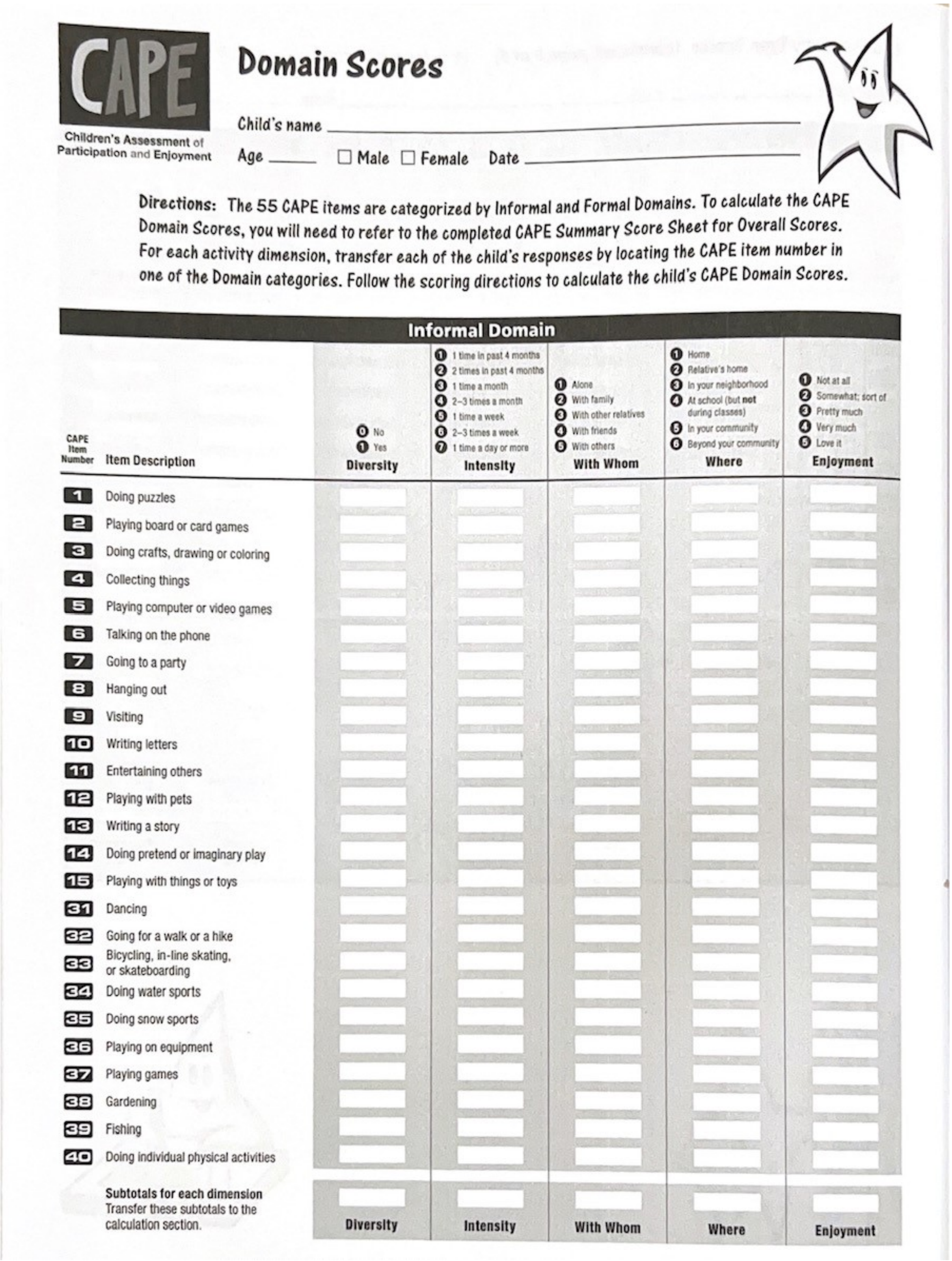
Self-Improvement Activities Sum ○
÷ 10
Preference Score Self-Improvement Activities ☐

Overall Score

Scoring Directions: Transfer each Activity Type Sum to the spaces provided. Add the Activity Type Sums together. Divide by 55. The value obtained is the PAC Overall Score.

Recreational Activities Sum ○ + **Physical Activities Sum** ○ + **Social Activities Sum** ○ + **Skill-Based Activities Sum** ○ + **Self-Improvement Activities Sum** ○ = **Total** ☐ ÷ 55 = **PAC Overall Score** ☐

Appendix I: Scoring Sheets for Informal and Formal domains of CAPE.



CAPE
Children's Assessment of Participation and Enjoyment

Domain Scores

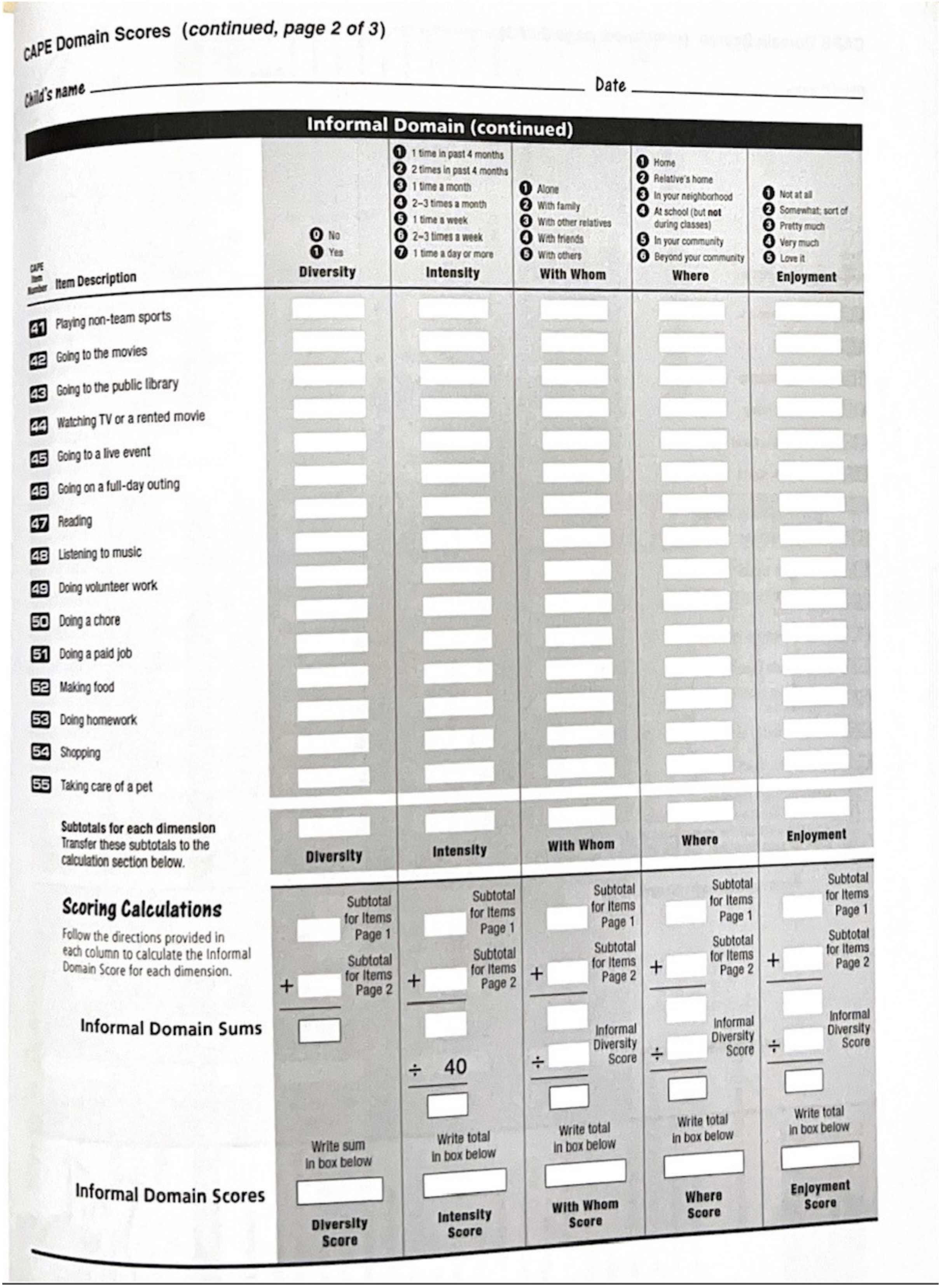
Child's name ________________

Age _____ ☐ Male ☐ Female Date ________________

Directions: The 55 CAPE items are categorized by Informal and Formal Domains. To calculate the CAPE Domain Scores, you will need to refer to the completed CAPE Summary Score Sheet for Overall Scores. For each activity dimension, transfer each of the child's responses by locating the CAPE item number in one of the Domain categories. Follow the scoring directions to calculate the child's CAPE Domain Scores.

Informal Domain

CAPE Item Number	Item Description	⓿ No ❶ Yes **Diversity**	❶ 1 time in past 4 months ❷ 2 times in past 4 months ❸ 1 time a month ❹ 2–3 times a month ❺ 1 time a week ❻ 2–3 times a week ❼ 1 time a day or more **Intensity**	❶ Alone ❷ With family ❸ With other relatives ❹ With friends ❺ With others **With Whom**	❶ Home ❷ Relative's home ❸ In your neighborhood ❹ At school (but **not** during classes) ❺ In your community ❻ Beyond your community **Where**	❶ Not at all ❷ Somewhat; sort of ❸ Pretty much ❹ Very much ❺ Love it **Enjoyment**
1	Doing puzzles					
2	Playing board or card games					
3	Doing crafts, drawing or coloring					
4	Collecting things					
5	Playing computer or video games					
6	Talking on the phone					
7	Going to a party					
8	Hanging out					
9	Visiting					
10	Writing letters					
11	Entertaining others					
12	Playing with pets					
13	Writing a story					
14	Doing pretend or imaginary play					
15	Playing with things or toys					
31	Dancing					
32	Going for a walk or a hike					
33	Bicycling, in-line skating, or skateboarding					
34	Doing water sports					
35	Doing snow sports					
36	Playing on equipment					
37	Playing games					
38	Gardening					
39	Fishing					
40	Doing individual physical activities					
	Subtotals for each dimension Transfer these subtotals to the calculation section.	**Diversity**	**Intensity**	**With Whom**	**Where**	**Enjoyment**



CAPE Domain Scores *(continued, page 2 of 3)*

Child's name ______________________________ Date ______________

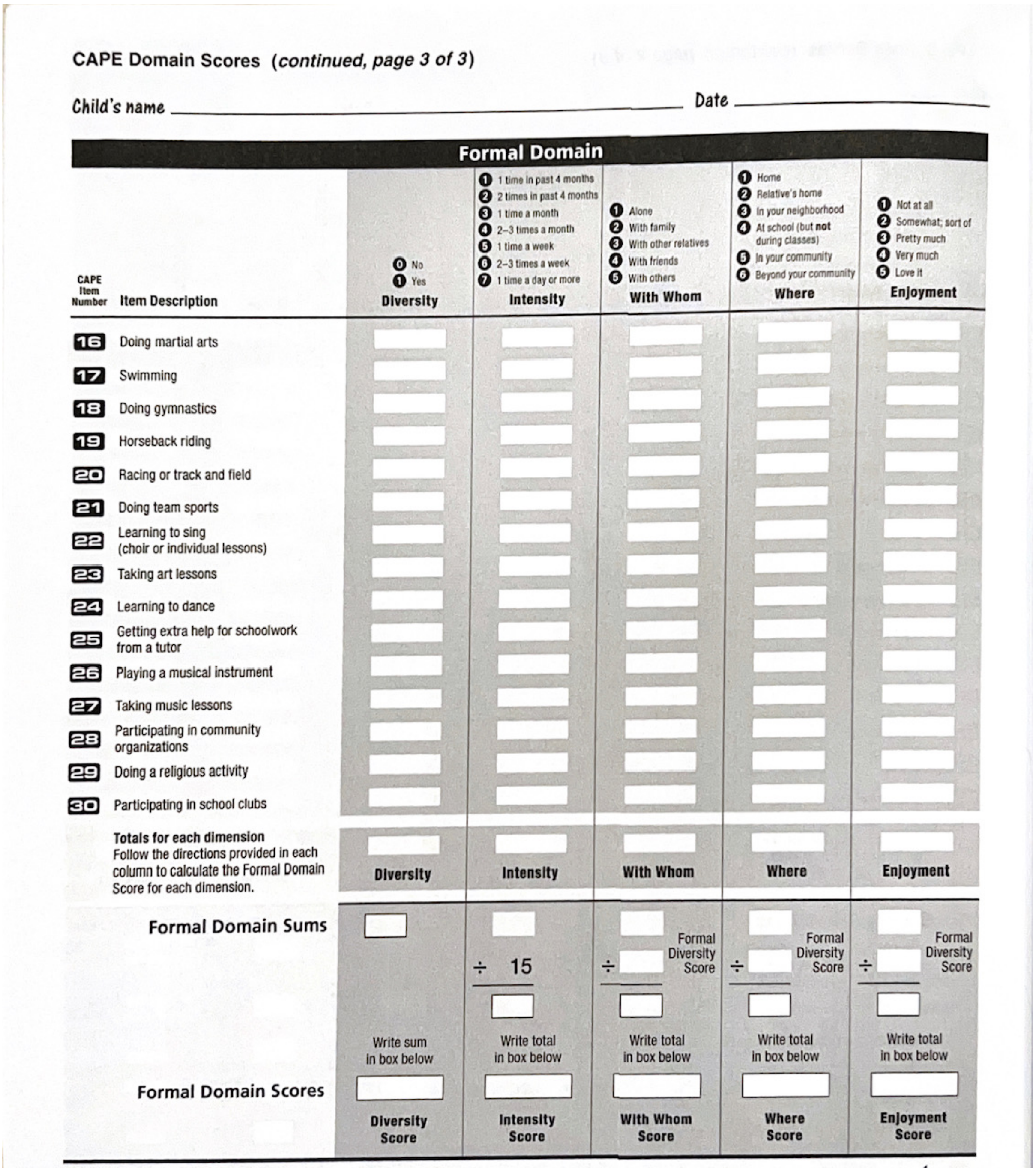
Informal Domain (continued)

CAPE Item Number	Item Description	⓿ No ❶ Yes **Diversity**	❶ 1 time in past 4 months ❷ 2 times in past 4 months ❸ 1 time a month ❹ 2–3 times a month ❺ 1 time a week ❻ 2–3 times a week ❼ 1 time a day or more **Intensity**	❶ Alone ❷ With family ❸ With other relatives ❹ With friends ❺ With others **With Whom**	❶ Home ❷ Relative's home ❸ In your neighborhood ❹ At school (but **not** during classes) ❺ In your community ❻ Beyond your community **Where**	❶ Not at all ❷ Somewhat; sort of ❸ Pretty much ❹ Very much ❺ Love it **Enjoyment**
41	Playing non-team sports					
42	Going to the movies					
43	Going to the public library					
44	Watching TV or a rented movie					
45	Going to a live event					
46	Going on a full-day outing					
47	Reading					
48	Listening to music					
49	Doing volunteer work					
50	Doing a chore					
51	Doing a paid job					
52	Making food					
53	Doing homework					
54	Shopping					
55	Taking care of a pet					
	Subtotals for each dimension Transfer these subtotals to the calculation section below.	**Diversity**	**Intensity**	**With Whom**	**Where**	**Enjoyment**

Scoring Calculations

Follow the directions provided in each column to calculate the Informal Domain Score for each dimension.

	Diversity	Intensity	With Whom	Where	Enjoyment
	Subtotal for Items Page 1	Subtotal for Items Page 1	Subtotal for Items Page 1	Subtotal for Items Page 1	Subtotal for Items Page 1
	+ Subtotal for Items Page 2	+ Subtotal for Items Page 2	+ Subtotal for Items Page 2	+ Subtotal for Items Page 2	+ Subtotal for Items Page 2
Informal Domain Sums					
		÷ 40	÷ Informal Diversity Score	÷ Informal Diversity Score	÷ Informal Diversity Score
	Write sum in box below	Write total in box below	Write total in box below	Write total in box below	Write total in box below
Informal Domain Scores	**Diversity Score**	**Intensity Score**	**With Whom Score**	**Where Score**	**Enjoyment Score**



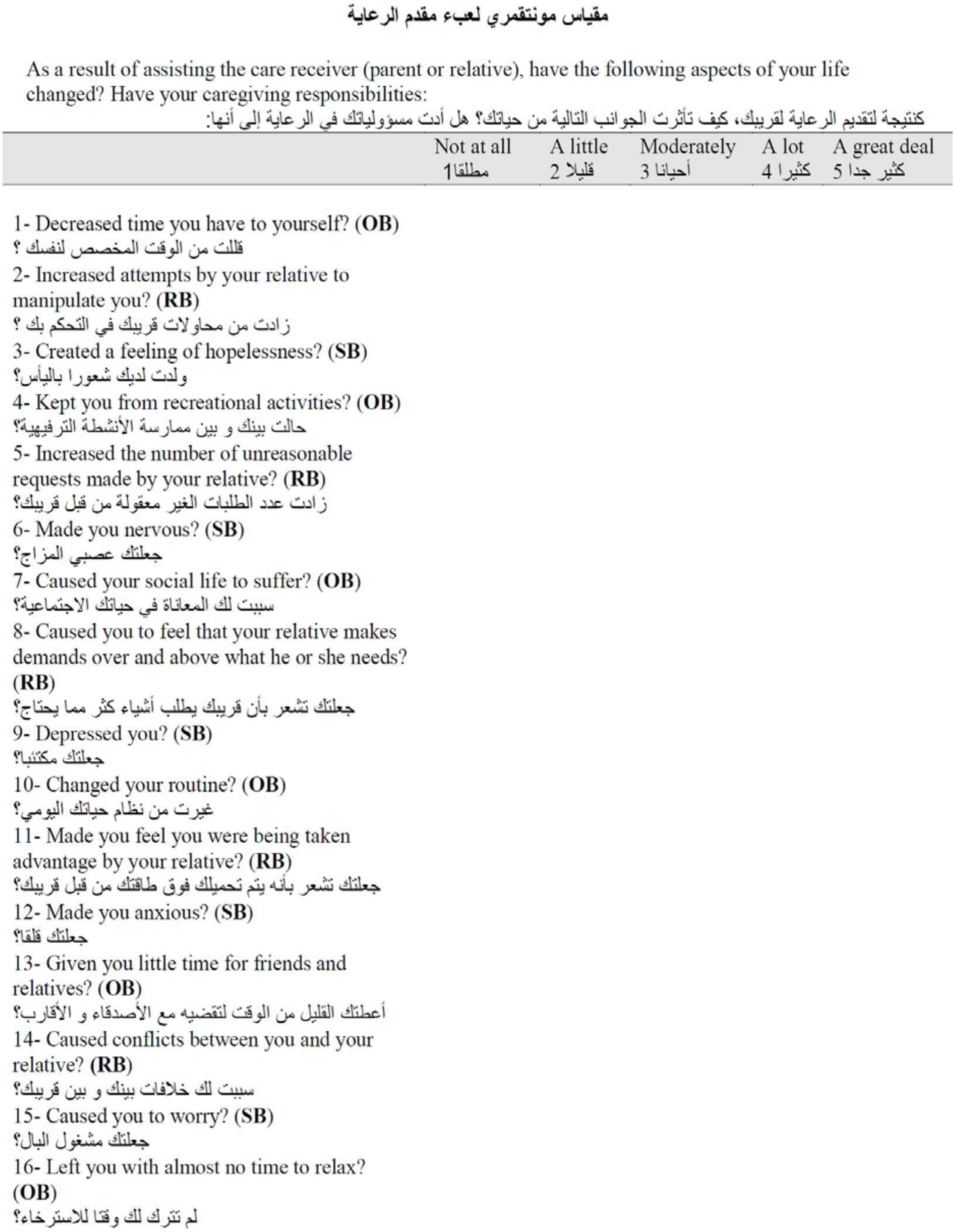
CAPE Domain Scores (*continued, page 3 of 3*)

Child's name ______________________________ Date ______________

Formal Domain

CAPE Item Number	Item Description	⓿ No ❶ Yes **Diversity**	❶ 1 time in past 4 months ❷ 2 times in past 4 months ❸ 1 time a month ❹ 2–3 times a month ❺ 1 time a week ❻ 2–3 times a week ❼ 1 time a day or more **Intensity**	❶ Alone ❷ With family ❸ With other relatives ❹ With friends ❺ With others **With Whom**	❶ Home ❷ Relative's home ❸ In your neighborhood ❹ At school (but **not** during classes) ❺ In your community ❻ Beyond your community **Where**	❶ Not at all ❷ Somewhat; sort of ❸ Pretty much ❹ Very much ❺ Love it **Enjoyment**
16	Doing martial arts					
17	Swimming					
18	Doing gymnastics					
19	Horseback riding					
20	Racing or track and field					
21	Doing team sports					
22	Learning to sing (choir or individual lessons)					
23	Taking art lessons					
24	Learning to dance					
25	Getting extra help for schoolwork from a tutor					
26	Playing a musical instrument					
27	Taking music lessons					
28	Participating in community organizations					
29	Doing a religious activity					
30	Participating in school clubs					
	Totals for each dimension Follow the directions provided in each column to calculate the Formal Domain Score for each dimension.	**Diversity**	**Intensity**	**With Whom**	**Where**	**Enjoyment**
	Formal Domain Sums		÷ 15 Write total in box below	÷ Formal Diversity Score Write total in box below	÷ Formal Diversity Score Write total in box below	÷ Formal Diversity Score Write total in box below
		Write sum in box below				
	Formal Domain Scores	**Diversity Score**	**Intensity Score**	**With Whom Score**	**Where Score**	**Enjoyment Score**

Appendix J: Caregiver Disability Burden (Modified Montgomery Borgatta Caregiver Burden Scale (MBCBS)) Arabic Version:



مقياس مونتقمري لعبء مقدم الرعاية

As a result of assisting the care receiver (parent or relative), have the following aspects of your life changed? Have your caregiving responsibilities:

كنتيجة لتقديم الرعاية لقريبك، كيف تأثرت الجوانب التالية من حياتك؟ هل أدت مسؤولياتك في الرعاية إلى أنها:

	Not at all مطلقا1	A little قليلا 2	Moderately أحيانا 3	A lot كثيرا 4	A great deal كثير جدا 5

1- Decreased time you have to yourself? (**OB**)
قللت من الوقت المخصص لنفسك ؟

2- Increased attempts by your relative to manipulate you? (**RB**)
زادت من محاولات قريبك في التحكم بك ؟

3- Created a feeling of hopelessness? (**SB**)
ولدت لديك شعورا باليأس؟

4- Kept you from recreational activities? (**OB**)
حالت بينك و بين ممارسة الأنشطة الترفيهية؟

5- Increased the number of unreasonable requests made by your relative? (**RB**)
زادت عدد الطلبات الغير معقولة من قبل قريبك؟

6- Made you nervous? (**SB**)
جعلتك عصبي المزاج؟

7- Caused your social life to suffer? (**OB**)
سببت لك المعاناة في حياتك الاجتماعية؟

8- Caused you to feel that your relative makes demands over and above what he or she needs? (**RB**)
جعلتك تشعر بأن قريبك يطلب أشياء كثر مما يحتاج؟

9- Depressed you? (**SB**)
جعلتك مكتئبا؟

10- Changed your routine? (**OB**)
غيرت من نظام حياتك اليومي؟

11- Made you feel you were being taken advantage by your relative? (**RB**)
جعلتك تشعر بأنه يتم تحميلك فوق طاقتك من قبل قريبك؟

12- Made you anxious? (**SB**)
جعلتك قلقا؟

13- Given you little time for friends and relatives? (**OB**)
أعطتك القليل من الوقت لتقضيه مع الأصدقاء و الأقارب؟

14- Caused conflicts between you and your relative? (**RB**)
سببت لك خلافات بينك و بين قريبك؟

15- Caused you to worry? (**SB**)
جعلتك مشغول البال؟

16- Left you with almost no time to relax? (**OB**)
لم تترك لك وقتا للاسترخاء؟

ENGLISH ABSTRACT

Title: Assessment of Functional Independence and Community Participation in Children with Cerebral Palsy: The Caregiver Disability Burden

Background: Cerebral Palsy (CP) is one of the most common disabilities encountered in the practice of Physical Therapy. Many children are affected by this disorder in the Kingdom of Saudi Arabia. Knowing the functional capacity, community participation and caregiver burden among these children will enhance the planning of care for them and provides more knowledge to the policymakers related to these individuals.

Study Aims: The primary aim of the current study was to examine the functional status and the community participation in children with cerebral palsy and to examine the possible disability burden on the caregivers of children with cerebral palsy. The secondary aim was to determine any possible association between the clinical characteristics of cerebral palsy, functional impairments, community participation, and the caregiver disability burden.

Material and methods: In this cross-sectional study, we included fifty children with cerebral palsy aged 6-12 years and their caregivers. The children’s demographic details were obtained, and they were undergone functional assessment by Functional Assessment of children (WeeFIM); community participation was examined by Children’s Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC). While the caregiver's burden was analyzed using Modified Montgomery Borgatta Caregiver Burden Scale (MBCBS). Once the interviewer assessed the children and caregivers, their details were computed to obtain meaningful results.

Results: The involved participants consisted of 50 children with CP, with a mean age of 8.5 (SD = 2.1) years. There were 34 males (68%) and 16 females (32%), all from the spastic type of CP (100%). The total mean ± SD for Wee FIM scores, CAPE, PAC, and MBCBS for the sample were 92.9 ± 18.4, 31.0 ± 5.2, 2.4 ± 0.2, and 39 ± 12.3. There was a perfect correlation between WeeFIM and CAPE with an r-value of 0.83 ($p<0.001$). Good correlation between MBCBS and CAPE with an r-value of - 0.69 ($p<0.001$). A moderate correlation between GMFCS, paralysis distribution, ambulation capacity, and hours of caregiving with CAPE overall scores. However, the regression analysis showed a good influence of only GMFCS levels, ambulation capacity, and WeeFIM self-care scores on community participation of children with CP, which CAPE assesses. In comparison, there was a good correlation between WeeFIM total scores with MBCBS total scores with an r-value of - 0.62 ($p<0.001$) and a moderate correlation between GMFCS, paralysis distribution, BMI, hours of caregiving with MBCBS overall scores. However, the further regression analysis showed a good influence of only BMI and CAPE diversity scores on MBCBS.

Conclusion: The current study could establish functional capacity, community participation, and caregivers' burden of spastic children in the Kingdom of Saudi Arabia. The Functional capacity and community participation were better, and the caregiver burden was less among children with CP compared to various studies conducted in other parts of the world. In addition, there was a strong relation between GMFCS levels, ambulation capacity, and WeeFIM self-care scores on community participation. Moreover, BMI and CAPE diversity scores can influence the caregiver's burden.

Keywords: cerebral palsy, children, function, participation, and caregiver burden

ARABIC ABSTRACT

العنوان: تقييم الاستقلال الوظيفي والمشاركة المجتمعية لدى الأطفال المصابين بالشلل الدماغي: عبء الإعاقة على مقدم الرعاية

المقدمة: يعد الشلل الدماغي أحد أكثر الإعاقات شيوعا في عيادات العلاج الطبيعي ويصاب العديد من الأطفال بهذا الاضطراب في المملكة العربية السعودية. كما أن معرفة القدرة الوظيفية ومشاركة المجتمع وعبء مقدم الرعاية بين هؤلاء الأطفال ومرافقيهم سيعزز توفير الرعاية لهم ويوفر المزيد من المعرفة لصانعي السياسات المتعلقة بهؤلاء الأفراد.

أهداف الدراسة: الهدف الأساسي من الدراسة الحالية هو فحص الوضع الوظيفي ومستوى مشاركة المجتمع لدى الأطفال المصابين بالشلل الدماغي وفحص عبء الإعاقة المحتمل على مقدمي الرعاية للأطفال المصابين بالشلل الدماغي. بينما الهدف الثانوي من الدراسة هو تحديد أي ارتباط محتمل بين الخصائص السريرية للشلل الدماغي والضعف الوظيفي ومستوى مشاركة المجتمع وعبء مقدم الرعاية.

الأساليب والإجراءات: في هذه الدراسة المقطعية قمنا بتضمين خمسين طفلا تتراوح أعمارهم بين ٦ -١٢ عاما تم تشخيصهم بالشلل الدماغي وكذلك مقدمي الرعاية لهم. تم الحصول على التفاصيل الديموغرافية للأطفال وخضعوا للتقييم الوظيفي من خلال استخدام مقاس الاستقلال الوظيفي للأطفال

(WeeFIM) كما تم فحص مشاركة المجتمع عن طريق تقييم مشاركة واستمتاع الأطفال باستخدام (CAPE) وتفضيلات أنشطة الأطفال (PAC)، بينما تم تحليل عبء مقدم الرعاية باستخدام مقاس (مونتغمري بورجاتا عبء مقدم الرعاية المعدل) (MBCBS). بمجرد تقييم الأطفال ومقدمي الرعاية، تم حساب تفاصيلهم للحصول على نتائج ذات مغزى.

النتائج: يتألف المشاركون من ٥٠ طفلا مصابا بالشلل الدماغي بمتوسط عمر ٨ سنوات ونصف. كان هناك ٣٤ ذكر (٦٨٪) و١٦ أنثى (٣٢٪)، جميعهم من النوع التشنجي للشلل الدماغي (١٠٠٪). كان المتوسط الإجمالي والانحراف المعياري لدرجات Wee FIM وCAPE وPAC وMBCBS للعينة ٩٢.٩ ± ١٨.٤ و٣١.٠ ± ٥.٢ و٢.٤ ± ٠.٢ و٣٩ ± ١٢.٣ على التوالي. كان هناك ارتباط قوي بين القدرة الوظيفية (WeeFIM) والمشاركة المجتمعية (CAPE) بقيمة r ٠.٨٣ (p<0.001). كما أوجدت الدراسة علاقة جيدة بين مقاس (مونتغمري بورجاتا عبء مقدم الرعاية المعدل) (MBCBS) والمشاركة المجتمعية للأطفال (CAPE) بقيمة r -٠.٦٩ (p<0.001). وعلاقة متوسطة بين (GMFCS) ونوع الأجزاء المصابة في جسم الطفل وقدرة المشي وكذلك عدد ساعات الرعاية مع النتائج الإجمالية للمشاركة المجتمعية للأطفال (CAPE). ومع ذلك، أظهر تحليل الانحدار تأثيرًا جيدًا لمستويات GMFCS، وقدرة المشي، ونتائج القدرة الوظيفية في الرعاية الشخصية (WeeFIM Self-care) على مشاركة المجتمع للأطفال المصابين بالشلل الدماغي والتي يقيمها CAPE. بالمقارنة، كان هناك ارتباط قوي بين مجموع الدرجات الاستقلال الوظيفي WeeFIM مع مجموع درجات عبء مقدم الرعاية MBCBS بقيمة r -٠.٦٢ (p<0.001).

وارتباط متوسط بين GMFCS وتوزيع الشلل ومؤشر كتلة الجسم وساعات تقديم الرعاية مع درجات MBCBS الإجمالية. ومع ذلك، أظهر تحليل الانحدار الإضافي تأثيرًا جيدًا لنتائج تنوع مؤشر كتلة الجسم وCAPE فقط على MBCBS.

الخلاصة: الدراسة الحالية أوجدت القدرة الوظيفية والمشاركة المجتمعية للأطفال المصابين بالشلل الدماغي وعبء مقدمي الرعاية لهم في المملكة العربية السعودية. كانت القدرة الوظيفية والمشاركة المجتمعية للأطفال أفضل وكان عبء مقدم الرعاية أقل بين الأطفال المصابين بالشلل الدماغي مقارنة بالدراسات المختلفة التي أجريت في أجزاء أخرى من العالم. بالإضافة إلى ذلك كانت هناك علاقة قوية بين مستويات (GMFCS) وقدرة المشي ونتائج القدرة الوظيفية في الرعاية الشخصية (WeeFIM Self-care) على مشاركة المجتمع. علاوة على ذلك يمكن أن يؤثر مؤشر كتلة الجسم والمشاركة المجتمعية للأطفال على عبء مقدم الرعاية.

الكلمات الدالة: الشلل الدماغي، الأطفال، المشاركة، عبء مقدم الرعاية، الاستقلال الوظيفي