

T.C.
YEDİTEPE UNIVERSITY
INSTITUTE OF HEALTH SCIENCES
DEPARTMENT OF PHYSIOTHERAPY AND REHABILITATION

**THE EFFECT OF MANUAL ABILITY AND UPPER
EXTREMITY FUNCTION ON PARTICIPATION
AND QUALITY OF LIFE IN CHILDREN WITH
CEREBRAL PALSY**

MASTER THESIS

BURCU KAYA, PT

İstanbul – 2022

T.C.
YEDİTEPE UNIVERSITY
INSTITUTE OF HEALTH SCIENCES
DEPARTMENT OF PHYSIOTHERAPY AND REHABILITATION

**THE EFFECT OF MANUAL ABILITY AND UPPER
EXTREMITY FUNCTION ON PARTICIPATION
AND QUALITY OF LIFE IN CHILDREN WITH
CEREBRAL PALSY**

MASTER THESIS

BURCU KAYA, PT

ADVISOR

Çiğdem YAZICI MUTLU, PT, PhD

İstanbul - 2022

THESIS APPROVAL FORM

Institute : Yeditepe University Institute of Health Sciences

Programme : Physiotherapy and Rehabilitation

Title of the Thesis : The Effect of Manual Ability and Upper Extremity Function on Participation and Quality of Life in Children with Cerebral Palsy

Owner of the Thesis : Burcu KAYA

Examination Date : 23.06.2022

This study have approved as a Master Thesis in regard to content and quality by the Jury.

	Title, Name-Surname (Institution)
Chair of the Jury:	Prof Dr Feryal SUBAŞI
Supervisor:	Dr Çiğdem YAZICI MUTLU
Member/ Examiner:	Dr Meltem YAZICI GÜLAY
Member/ Examiner:	

APPROVAL

This thesis has been deemed by the jury in accordance with the relevant articles of Yeditepe University Graduate Education and Examinations Regulation and has been approved by Administrative Board of Institute with decision dated 23.06.2022 and numbered

Prof. Dr. Bayram YILMAZ

Director of Institute of Health Sciences

DECLARATION

I hereby declare that this thesis is my own study and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which has been accepted for the award of any other degree except where due acknowledgment has been made in the text.

23.06.2022

Burcu KAYA



DEDICATION

I would like to dedicate my dissertation work to my family. A special feeling of gratitude dear parents Seval KAYA and Hacı Hüseyin KAYA and to my dear aunt Sevgi EVGİN.



ACKNOWLEDGEMENT

I would like to thank to my advisor, Prof. Dr. ıdem YAZICI MUTLU who guided and supported me in completing this scientific research, for her support. She provided me with a more comprehensive perspective throughout my dissertation process and helped me progress through the scientific foundations.

Besides, I would like to thank to Do. Dr. zgn KAYA KARA for adapting the scale which I used in my study to Turkish and for not giving up their support from me.

In addition, I would like to thank Feride BİLİR, who inspired me to progress in pediatric rehabilitation field. She was happy to share her experience and knowledge with us.

Moreover I would like to express my gratefulness to my dear mother Seval KAYA, my father Hacı Hseyin KAYA and my aunt Sevgi SEVGİN and my friends Bra Nur DERİNÖZ, Emine ZKARLIKLI and Simge YILDIZ to always support me.

TABLE OF CONTENTS

THESIS APPROVAL FORM.....	ii
DECLARATION.....	iii
DEDICATION.....	iv
ACKNOWLEDGEMENT.....	v
TABLE OF CONTENTS.....	vi
LIST OF TABLES.....	ix
LIST OF FIGURES.....	x
LIST OF SYMBOLS AND ABBREVIATIONS.....	xi
ABSTRACT.....	xiii
1.INTRODUCTION.....	1
2.THEORETICAL FRAMEWORK AND LITERATURE REVIEW.....	5
2.1. Definition And Epidemiology of CP.....	5
2.2. Etiology and Risk Factors of CP.....	6
2.3. Pathophysiology of CP.....	7
2.4. Diagnosis of CP.....	7
2.5. Classification of CP.....	8
2.5.1. Physiological Classification of CP.....	8
2.5.1.1. Spastic Cerebral Palsy.....	9
2.5.1.2. Ataxic Cerebral Palsy.....	10
2.5.1.3. Dyskinetic Cerebral Palsy.....	10
2.5.1.4. Hypotonic Cerebral Palsy.....	11
2.5.1.5. Mixed Cerebral Palsy.....	11
2.5.2. Topographical Classification of CP.....	11
2.6. Additional Problems to CP.....	13
2.6.1. Cognitive Problems.....	13
2.6.2. Musculoskeletal Problems.....	13
2.6.3. Pain.....	14
2.6.4. Epilepsy.....	14
2.6.5. Visual Problems.....	14
2.6.6. Hearing Impairments.....	14
2.6.7. Speech Problems.....	15
2.6.8. Feeding and Nutritional Problems.....	15
2.6.9. Bowel and Bladder Dysfunction.....	15

2.6.10. Respiratory Problems.....	15
2.6.12. Emotional and Behavioral Problems.....	16
2.7. Upper Extremity Functions.....	16
2.8. Manual Ability.....	17
2.9. Development of Upper Extremity Functions.....	17
2.10. Upper Extremity Functions and Manual Dexterity at Children with CP.....	19
2.11. Participation.....	20
2.12. Participation at Children with CP.....	21
2.13. Quality of Life in Children with CP.....	22
3. MATERIAL and METHOD.....	23
3.1. Participants.....	23
3.1.1. Inclusion criterias.....	23
3.1.2. Exclusion criterias.....	23
3.1.3. Flow Chart: Study Protocol.....	23
3.2. Evaluations.....	25
3.2.1. The Gross Motor Function Classification System (GMFCS).....	25
3.2.2. Manual Ability Classification Systems (MACS).....	27
3.2.3. Quality of Upper Extremity Skill Test (QUEST).....	27
3.2.4. Box Block Test.....	32
3.2.5. Participation and Environment Measure – Children and Youth.....	33
3.2.6. Cerebral Palsy Quality of Life Questionnaire.....	33
3.3 Data Analysis.....	34
4.RESULTS.....	35
4.1 Results of Manual Dexterity and Upper Extremity Functions Assessment.....	36
4.2 Results of Quality of Life Assessment.....	38
4.3 Results of Participation Assessment.....	41
4.4. Relationship Between GMFCS, MACS, BBT, QUEST and CP QOL Scores....	44
4.5 Relationship Between PEM CY Domains and GMFCS, MACS, BBT, QUEST, CP Scores.....	46
5.DISCUSSION.....	52
5.1 Quality of Life Outcomes.....	53
5.2.1 Participation Outcomes.....	56
5.2.2. Environmental Outcomes.....	58
7.REFERENCES.....	61

8.APPENDICES.....	75
8.1. Appendix 1. Workplace Approval.....	75
8.2. Appendix 2. Ethics Committee Approval.....	76
8.3. Appendix 3. Participant Information and Approval Form.....	78
8.4. Appendix 4. Sociodemographic Information Form.....	79
8.5. Appendix 5. Manual Ability Classification System.....	80
8.6. Appendix 6. Quality of Upper Extremity Skills Test.....	81
8.7. Appendix 7. Participation and Environment Measure- Children and Youth.....	99
8.8. Appendix 8. Participation and Environment Measure- Children and Youth Licence.....	102
8.9. Appendix 9. Cerebral Palsy Quality of Life Questionnaire for Children.....	105



LIST OF TABLES

Table 2.1. Risk factor for CP.....	6
Table 2.2. Physiological classification of CP.....	9
Table 2.3. Milestones of some movements	19
Table 3.1. Flow Chart of the Study.....	24
Table 3.2. GMFCS levels distinctions.....	26
Table 3.3. MACS levels distinctions.....	27
Table 3.4. The domains of the QUEST.....	29
Table 4.1. Demographic Characteristics of the Participants.....	35
Table 2 4.2. Distribution of GMFCS levels and MACS levels over topographical classes of CP.....	36
Table 4.3. Comparision of QUEST and BBT scores according to topographical classification of CP.....	37
Table 4.4. Comparision of QUEST and BBT scores according to GMFCS levels.....	38
Table 4.5. Comparison of CPQOL scores according to topographical classification.....	39
Table 4.6. Comparison of CPQOL subtest scores according to GMFCS.....	40
Table Table 4.7. Comparison of PEM CY scores according to GMFCS levels.....	43
Table 4.8. Relationship Between GMFCS, MACS, BBT, QUEST and CP QOL Scores	45
Table 4.9. Relationship Between Home Participation and GMFCS, MACS, BBT, QUEST, CP QOL Score.....	47
Table 4.10. Relationship Between School Participation and GMFCS, MACS, BBT, QUEST, CP QOL Score	48
Table 4.11. Relationship Between Community Participation and GMFCS, MACS, BBT, QUEST, CP QOL Score.....	49
Table 4.12. Relationship PEM CY environmental assessment and CPQOL.....	50

LIST OF FIGURES

Figure 2.1. Topographical classification of CP.....	12
Figure 3.1. Assessment Upper Extremity Functionality QUEST A, B and C; A)Dissociated Movements B) Grasp C)Weight bearing- prone D) Weight bearing- Sitting.....	30
Figure 3.2. Assessment Upper Extremity Functionality QUEST D; A) Protective extension – front, B) Protective extension -Sides, C)Protective Extension - Back.....	31
Figure 3.3 Box Block Test	

LIST OF SYMBOLS AND ABBREVIATIONS

AF	Average Frequency
AI	Average Involvement
BBT	Box Block Test
BBT DH	Box Block Test Dominant Hand
BBT ND	Box Block Test Non dominant Hand
BCP	Bilateral Cerebral Palsy
BMI	Body Mass Index
CP	Cerebral Palsy
CPQOL	Cerebral Palsy Quality of Life Questionnaire
DC	Desire to Change
DCP	Dyskinetic Cerebral Palsy
EH	Environmental Helpfulness
ER	Environmental Resources
GMFCS	Gross Motor Function Classification System
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
ICF	International Classification of Functioning, Disability and Health
MACS	Manual Ability Classification System
OES	Overall Environmental Helpfulness
PA	Activity Percentage
PEM CY	Participation and Environment Measurement - Child and Youth
QOL	Quality of Life
QUEST	Quality of Upper Extremity Skills Test
SCPE	The Surveillance of Cerebral Palsy in Europe

SD	Standard Deviation
UCP	Unilateral Cerebral Palsy
UEF	Upper Extremity Functions
UMN	Upper Motor Neuron
WHO	World Health Organization



ABSTRACT

KAYA, B. (2022) The Effect of Manual Ability and Upper Extremity Function on Participation and Quality of Life in Children with Spastic Cerebral Palsy Yeditepe University, Institute of Health Sciences, Department of Physiotherapy and Rehabilitation, MSc Thesis, Istanbul.

The purpose of this study was investigating the effect of manual ability and upper extremity function on participation and quality of life in children with spastic cerebral palsy (CP). 30 children with CP aged between 4 -12, have Gross Motor Function Classification System (GMFCS) 1-3 and Manual Ability Classification System (MACS) level 1-3 were included to study. Demographic information of the participants was collected by asking the family face to face. In addition to MACS, Box Block Test (BBT) was used to evaluate manual ability for both dominant and non dominant hand. Quality of Upper Extremity Skills Test (QUEST) was utilized to evaluate upper extremity functions. The Cerebral Palsy Quality of Life Questionnaire - Child Primary Caregivers (CPQOL), a disease-specific scale, was administered with the help of the family to evaluate the quality of life (QOL) in children. Participation assessment was completed with the help of the family by applying the Participation and Environment Measure - Children and Youth (PEM CY) scale. Data were analyzed using SPSS version 25. According to the results, there is no correlation between manual ability and quality of life ($p>0.05$). A correlation was found between the average frequency of home participation, the family's desire for change and manual ability, and between upper extremity skills and the family's desire to change subtest of PEM CY ($p<0.05$). In school participation there was a correlation between QUEST test and desire to change subtest of PEMCY. No relationship was found between community participation and manual ability and upper extremity functionality ($p>0.05$). There was moderate positive correlation between PEM CY and CPQOL in many subtests. To conclude, manual ability, upper extremity functions are not correlated to QOL. Manual ability and upper extremity functions are correlated with only some aspects of participation. Quality of life was found to be moderately correlated with participation in this study.

Keywords: Cerebral Palsy, Manual Ability, Upper Extremity Functions, Participation, Quality of Life

ÖZET

KAYA, B. (2022) Spastik Serebral Palsili Çocuklarda El Becerisi ve Üst Ekstremitte Fonksiyonlarının Katılım ve Yaşam Kalitesi Üzerine Etkisi Yeditepe Üniversitesi Sağlık Bilimleri Enstitüsü, Fizyoterapi ve Rehabilitasyon Bölümü, Yüksek Lisans Tezi. İstanbul.

Bu çalışmada spastik serebral palsili (SP) çocuklarda el becerisi ve üst ekstremitte fonksiyonunun katılım ve yaşam kalitesi üzerine etkisinin araştırılması amaçlanmıştır. Çalışmaya yaşları 4-12 arasında, Kaba Motor Fonksiyon Sınıflandırma Sistemi (KMFSS) 1-3 ve El Becerileri Sınıflandırma Sistemi (EBSS) düzey 1-3 olan 30 SP'li çocuk çalışmaya dahil edildi. Katılımcıların demografik bilgileri aileye sorularak temin edilmiştir. El becerilerini değerlendirmek için EBSS'ye ek olarak, hem dominant hem de dominant olmayan el için Kutu Blok Testi (KBT) kullanıldı. Üst ekstremitte fonksiyonlarını değerlendirmek için Üst Ekstremitte Becerileri Kalite Testi (QUEST) kullanıldı. Çocuklarda yaşam kalitesini değerlendirmek için, hastalığa özel bir ölçek olan Serebral Palsi Yaşam Kalitesi Anketi – Çocuk Bakımveren Formu (CPQOL) aile yardımıyla uygulandı. Katılım ve Çevre Ölçeği - Çocuk ve Gençlik (PEM CY) ölçeği aile yardımıyla uygulanarak katılım değerlendirmesi tamamlandı. Veriler SPSS versiyon 25 kullanılarak analiz edildi. Sonuçlara göre el becerisi ile yaşam kalitesi arasında ilişki bulunamamıştır ($p>0.05$). Ev katılımında el becerileri ve üst ekstremitte fonksiyonu ile ortalama katılım frekansı, ailenin değişim isteği alt testleri arasında korelasyon bulundu ($p<0.05$). Toplum katılımı ile el becerileri ve üst ekstremitte fonksiyonelliği arasında ilişki bulunamadı ($p>0.05$). Okula katılımında QUEST testi ile PEMCY'nin ainenin değişim isteği alt testi arasında bir ilişki vardı. Yaşam kalitesi ve katılım ise ilişkili bulunmuştur. Birçok alt testte PEM CY ve CPQOL arasında orta düzeyde pozitif korelasyon vardı ($p<0.05$). Sonuç olarak, el becerileri ve üst ekstremitte fonksiyonları yaşam kalitesi ile ilişkili değildir. El becerisi ve üst ekstremitte fonksiyonları, katılımın yalnızca bazı yönleriyle ilişkilidir. Bu çalışmada yaşam kalitesinin katılımı orta düzeyde ilişkili olduğu bulunmuştur.

Anahtar Kelimeler: Serebral Palsi, El Becerisi, Üst Ekstremitte Fonksiyonları, Katılım, Yaşam Kalitesi

1.INTRODUCTION

Cerebral palsy is permanent and non progressive neurodevelopmental and chronic disease (1). Cerebral palsy affects the quality of motor movement, postural control, balance as well as mental capacity. In addition, it also affects participation to life (2). Thus, cerebral palsy presents a lifelong factor that significantly affects the quality of life of children and their families (3).

According to the World Health Organization (WHO), the participation criterion, which can be defined as being included in life, is important for individuals of all ages with healthy or chronic diseases (4). Participation can be considered in a very broad perspective as participation in social life, participation in the family and home, participation in recreational activities (5). Experiencing these sub-areas of participation, especially in childhood; contributes to childrens' development by improving their self-confidence, their communication skills with the environment and their social skills (6). Children whose participation in life is supported by their family and environment, are raised as self-confident individuals by taking appropriate responsibilities for their ages in self-care and daily life activities from an early age (7). As they experience different emotional situations in communication with the environment, their capacity to regulate, solve problems and cope with the problems they may encounter increases in their future lives (8).

One of the difficulties about having CP is the problem in participation in life (9). Children with CP have less participate in life than typical developing children do (10). Factors such as spasticity, trunk hypotonia, performing movement with abnormal patterns, involuntary movements (chorea, athetosis), cognitive problems, inability in gross and fine motor movements and selective motor movements, and retardation in psychomotor development in children with CP affect the participation of these children in life. Despite the physical disability, it is aimed to increase the participation of these people in life with the various practices carried out by the family in the home in accordance with the level of the child or by the authorities in the region where the child lives, in order to facilitate the lives of disabled children and adults (11).

When the participation in life increases, the subjective well-being that the person feels apart from her current physical capacity can reach a satisfactory level (12). The approach of the family to the current situation of the child, and their attitude toward gaining the child the highest possible level of independence are important for progress both in therapy and outside of the clinic (13). Taking responsibilities appropriate to their age and level at home improves children's self-confidence and self-discipline (14).

Children with CP have a more isolated life from the society compared to typically developing children (15). However, interacting with the social environment, spending time with peers, performing activities outside the home increases the motivation of children with CP towards life (16). Children with high participation in social life have better emotional status (17). In addition, children who participate in academic life in accordance with their own mental levels develop cognitively, and their ability to concentrate increases (18). Participation in recreational activities is that children engage in hobbies and games that are appropriate for their age and support their development and perform various activities in their leisure time. Participation in recreational activities has a significant contribution to psychosocial development in children with CP, as in typically developed children (19).

According to WHO, quality of life is expressed as a way of perceiving oneself within the culture and value system of the environment where the person lives (20). According to the International Classification of Functioning, Disability and Health (ICF), biopsychosocial approach considers individuals as a whole in terms of biological, psychological and social aspects and defines well-being as well-being in all these areas. Especially in chronic diseases such as CP, psychological health and social conditions determine the patients' quality of life together with their the physical treatment within the concept of the biopsychosocial approach (21). The main purpose of physiotherapy is to enable patients to reflect what they have gained in clinic to their daily lives and to increase their quality of life by increasing their functionality. Quality of life scales usually assess the physical, mental, and social well-being of the individual, assuming that the individual is in active communication with his environment (22). In children with CP, the quality of life is measured by questioning the health-related factors such as the presence of pain, contractures, sleep quality, the use of asistive devices, the ease of access to health services, the financial and socioeconomic status of the family (23). In

addition, criterias that affect the quality of life such as the child's personality perception, feelings about living with CP, perception of life, level of worry and happiness, and anxiety for the future are also evaluated (24).

Manual ability refers to how children with CP use their hands when handling objects in daily activities. Manual ability is related to manual dexterity which is the ability to perform basic functions in daily life such as grasping and releasing objects that require coordination with gross and fine motor movements. In addition, it is a complex skill that includes not only physical factors such as range of motion and muscle strength that can be measured numerically, but also motivation, bimanual hand use level, proprioception, and tactile pressure perception (25). In children with CP, some factors such as spasticity, limitation of joint range of motion (ROM), flexion, ulnar or radial deviation at wrist joint, cortical thumb position, incorrect timing of movement, and inability to create the accurate force cause children with CP to have less dexterity (26).

In addition to decrease in manual dexterity, upper extremity (UE) involvement that encompass elbow and wrist joint problems are present in children with CP. Spasticity, decrease in ROM, kyphosis in the upper thoracic regions, internal rotation, protraction in the shoulder and flexion posture in the elbow joint can be seen. They have difficulties in also dissociated movements, weight bearing. Decreased proprioceptive information, sensitivity in tactile tissue, compensated movements, combined reactions, stereotypic movements, insufficiency in selective motor control of UE, trunk hypotonia, increased muscle tone at UE during activity, difficulty at initiating movement, and difficulty at getting out of the existing flexion and internal rotation pattern cause children with CP to have difficulty in activities that require the use of UE (27, 28).

UE functions and manual ability affects daily life skills. Children with CP may need assistance in activities that require some fine or gross motor movements, depending on the level of UE impairments and manual skills (29). UE impairment and hand skills affect the independence and functionality of the child. It affects the performance of daily living activities, participation in social, academic and home life as well as the quality of life of the child with CP. All these factors affect quality of life in children with CP (30,31, 32,).

There are many studies in the literature that research the effect of UE function and manual skills on the participation of children with CP and their quality of life (33,34,35). However, there is no consensus in the literature about participation especially since the subject of participation is detailed in current concept of the the biopsychosocial approach (33,36.)

The main purpose of this study is to investigate the effects of manual ability and upper extremity functions of children with CP on children's participation in life and their quality of life.

In this study, two hypotheses are defined:

H0: Manual ability and upper extremity functions have no effect on level of participation in life and life quality in children with CP.

H1: Manual ability and upper extremity functions have an effect on level of participation in life and life quality in children with CP.

2.THEORETICAL FRAMEWORK AND LITERATURE REVIEW

2.1. Definition And Epidemiology of CP

Cerebral Palsy which is an umbrella term encompassing various symptoms was firstly used by an English orthopaedist William Little in 1861. He defined CP via correlating neonatal hypoxia and musculoskeletal problems such as spasticity at extremities (37).

Throughout the history, the definition of CP has been updated and changed in the literature in order to increase its clinical usefulness and to reveal new focuses in diagnosis and treatment (38).

According to consensus definition in 2007 CP is a non-progressive, permanent disease of immature brain which causes activity limitation and difficulties at motor functions and posture. Also different symptoms like perceptual, cognitive, sensational, communication dysfunctions, and behavioural disorders commonly accompany with primary disorders (39). Secondary musculoskeletal disorders and neurological problems such as and epilepsy may be present. The lesion in the brain is non progressive but variety and severity of symptoms alter with age (40).

CP is one of the most common infantile diseases. The prevalence of CP varies from country to country and according to age groups (41). In 1998, The Surveillance of Cerebral Palsy in Europe (SCPE) was established to provide a general framework for CP and to standardize CP-related data (42). SCPE stated that the overall rate was 2.08/1000 live births 1980 to 1990 and according to population-based studies, the rate is currently 1.5-3 to 1000 live births (43). The prevalence of CP is 2-3/1000 in the USA, 1.5-2.5/1000 in Nordic countries and 2-3/1000 in Japan (44). The prevalence of CP in Turkey is 1.1- 4.4 /1000 live births (45).

The prevalence of CP in developed countries is decreasing over time. Technological developments and increasing health care opportunities are effective in this. In underdeveloped and developing countries, the prevalence of CP is higher due to many reasons (44).

2.2. Etiology and Risk Factors of CP

The exact underlying cause of CP remains unclear. The aetiological factors differ according to the age groups and classifications of CP. CP risk factors vary widely. Premature birth is a serious risk factor for CP. The prevalence of CP is 14.6% in extremely preterm children (born 22–27 at weeks), 6.2% in very preterm children (born at 28–31 weeks), and 0.7% in the moderate to late preterm (32–36 at weeks). However term-born children has also 0.11% risk for CP (46). Children with low birth weight have a higher risk of developing CP (47).

CP risk factors can be divided into 4 groups as pre-conceptional, prenatal, perinatal and postnatal risk factors (48). Risk factors are presented at Table 2.1.

Table 2.1. Risk factor for CP

Risk Factors of CP			
Pre-conceptional Risk Factors	Prenatal Risk Factors	Perinatal Risk Factors	Neonatal Risk Factors
• Maternal diseases (systemic diseases, hypertension ,diabetes, maternal epilepsy, immune systems disorders • Impaired fertility • Drugs and poisoning • Infections • Malnutritions • Physical and chemical factors; radiation, smoking, alcohol, environmental toxins • Socioeconomic factors	•Maternal diseases during pregnancy •Multiple pregnancy •Congenital malformations •Toxaemia, tocolytic drugs •Abnormalities of placenta •Vaginal bleeding •Hypoxia •Intrauterine suppression of development •Assistive reproductive	•Premature birth •Low birth weight •Delivery after due date •Prolonged labour •Asphyxia •Meconium aspiration	•Respiratory distress syndrome •Infections (menengitis, encephalitis) • Hyperbilirubinemia • Hypoglycemia • Hypothyroxinaemia •Intracranial hemorrhage, head traumas, cerebrovascular accidents • Cardiac arrest •Anoxia, dehydration, gastroenteritis

	technology		
--	------------	--	--

2.3. Pathophysiology of CP

Among other risk factors, perinatal hypoxia is the cause of 10% of CP cases. Likewise, in the neonatal period only 10% of CP cases occur due to infection, hypoglycaemia, stroke and trauma at neonatal period. Approximately 80% of CP is caused by brain injury in utero at prenatal period.

Before the 20th week of gestation infection, hypoxia, stroke or genetic factors and environmental factors can cause brain maldevelopment which prevent migration of cells to their final destinations. Brain malformation results in severe CP symptoms.

Hypoxia, infection, hypotension or intraventricular haemorrhage occurs at 24-32nd weeks of gestation, cause damage to periventricular white matter. Injuries in periventricular white matter results in spastic diplegia and also optic radiations affecting motor function in larger involvements.

Brain is stronger at perinatal period and injuries at this period commonly occur at basal ganglia. Damage in basal ganglia results in dyskinetic (dystonia or choreoathetoid) CP. If the brain is exposed to prolonged hypoxia, the mixed pattern with spasticity and dystonia can be seen.

Perinatal strokes mostly cause infarction in the middle cerebral artery territory. In this case, unilateral spastic CP with more upper extremity involvement occurs (49).

2.4. Diagnosis of CP

Brain development continues postnatally. Early diagnosis provides more efficient treatment by maximizes advantages from neuroplasticity of developing brain. CP or high risk of CP can be accurately predicted by experts before 6 months' corrected age.

Before 6 months' corrected age, neuroimaging and motor assessment are applied for early diagnosis and the patient's medical history is taken. In this period, the most accurate diagnosis is made by neonatal magnetic resonance imaging (MRI) and its sensitivity is 86%-89%. Prechtl Qualitative Assessment of General Movements (98% predictive of CP) is used for motor assessment. Hammersmith Infant Neurological Examination is used (96% predictive of CP).

To diagnose of CP for children older than 5 months' corrected age MRI (86%-89% sensitivity), Hammersmith Infant Neurological Examination (90% sensitivity), Developmental Assessment of Young Children (83% sensitivity) are used. Also clinical findings are evaluated; asymmetry in hand functions, inability to sit without support until 9 months of age, inability to transfer weight to the plantar face of the foot are considered. In clinical assessment, whether the child has acquired the milestones such as turning, sitting and crawling on time and pathological reflexes are evaluated (50).

2.5. Classification of CP

CP includes various clinical symptoms as development of movement and posture, activity limitation, sensation, cognition, communication, perception behaviour, and seizure in different level of severity. CP is categorized and divided into subgroups to understand and describe the different levels, to provide information to healthcare professionals for current and future needs, to compare between CP cases, to evaluate and compare the same case at different periods (51). According to The SCPE, CP is classified in two groups as physiological classification and topographical classification (42).

2.5.1. Physiological Classification of CP

According to the physiological classification, CP is divided into subgroups as spastic, ataxic, dyskinetic, hypotonic and mixed CP. Abnormal patterns of motor movement and posture are found in all types of CP. While the pyramidal system (corticospinal pathways) was affected in spastic type CP, extrapyramidal system (cerebellum or basal ganglia) was damaged in ataxic and dyskinetic type CP (52).

Table 2.2. Physiological classification of CP

Type	Description
Spastic	Increased muscle tone with rapid stretching Hyperreflexia
Ataxic	Impairment at coordination, balance and stabilization
Dyskinetic	Poor control of head and trunk Wide base of support Involuntary movements Fluctuation at muscle tone
Hypotonic	Slow movement and low muscle tone Decrease in deep tendon reflexes
Mixed	Combination of other types, usually spastic and dyskinetic

2.5.1.1. Spastic Cerebral Palsy

Spastic CP, is the most common type and it consists of 85%-91% of the cases diagnosed with CP (53). Pyramidal system (corticospinal tract) is affected in spastic CP. Upper Motor Neuron impairment results in activation in pathological reflexes and hypertonia. Apart from spasticity some positive features such as clonus, static tonic stretch reflex, dyssynergic patterns at co-contractions and associated reactions can be seen because of UMN lesion.

Spasticity was defined by Lance in 1980 as an increase in stretch reflexes dependent on velocity. European Thematic Network to Develop Standardized Measures of Spasticity updated definition of CP in 2005 as disordered sensory-motor control due to UMN lesion and it results in intermittent or sustained involuntary activation of muscles (54). Spasticity is usually more severe in the lower extremities in children with bilateral

involvement whereas it may worse in the upper extremity in children with unilateral involvement. Children with spastic CP have increased tone in the lower extremities of the psoas, adductors, rectus femoris, hamstrings, gastrocnemius and soleus muscles. Also in the upper limb, the external rotators of shoulder, flexors of elbow, wrist and finger and the pronators of elbow is frequently affected by spasticity.

Spasticity reduces voluntary movement control and increases energy consumption and making it difficult for children to fulfill their daily tasks. Spasticity causes physical, emotional and behavioral handicaps. In addition, muscle and soft tissue contractures and It can cause secondary orthopedic problems such as joint contractures and skeletal deformations (55).

2.5.1.2. Ataxic Cerebral Palsy

Ataxic type CP is rare, less than 5% of all cases (56). Ataxic CP is caused by damage to the cerebellum. It is hard to generate accurate voluntary movement apart from caused by involuntary muscle activation or muscle weakness for children with ataxic CP (57).

Children with ataxic CP suffer from losing of muscular coordination, inability to appropriate force generation, rhythm, and accuracy and timing of movements and tremor (58). Children need wider base of support during movements. Additional problems such as poor eye tracking and nystagmus may also be encountered (59).

2.5.1.3. Dyskinetic Cerebral Palsy

Dyskinetic cerebral palsy (DCP) constitutes for 15% of all CP cases. Children with DCP have difficulties in motor control, coordination and muscle tone due to damage to basal ganglia or thalamus. Children with DCP have abnormal movements and postures. Uncontrolled, involuntary movements and stereotypical movements can be seen in children with CP during movements. Postural imbalance and fluctuation in muscle tone complicate fulfil their daily living activity tasks for children with DCP. Dyskinesia manifests clinically as dystonia , choreoathetosis, ballismus, tremor and rigidity.

Because of intermittent muscle contractions, children suffer from dystonia have involuntary and repetitive movements.

Choreoathetosis, which is characterized by fluctuation in muscle tone and hyperkinesia, is divided into chorea and athetosis. Rapid, jerky and involuntary movements are present at children with chorea. Children with athetosis presents different type of movement; constantly changing, slower, contorting. Both choreoathetosis and dystonia affect the whole body, but the involvement is more in the upper extremities.

Dystonia usually affects the neck, trunk and proximal extremities. There are twisting and repetitive movements. It is more severe than choreathetosis and affects children's quality of life, daily living skills and participation to life (60,61).

Ballismus are explosive swings. It is usually present with athetosis and ataxia.

Tremor is rhythmic, reciprocal movements prominent in the distal extremities.

Rigidity is the hypertonus of both gravity and antigravity muscles (61).

2.5.1.4. Hypotonic Cerebral Palsy

Children with hypotonic CP have difficulties in producing adequate muscle tone for movements. Cocontraction is insufficient, primitive reflexes are reduced. Due to hypotonia patients have floppy limbs, ligament and joint laxity. Children with hypotonic CP suffer from instability and poor head and trunk control. They move slowly and they have low tolerance to activity. Moreover they may have impairments at swallowing or chewing. Also their voice can be weak.

The clinical condition is a transitional stage before it process to spasticity (62,63).

2.5.1.5. Mixed Cerebral Palsy

Children with mixed CP have clinical features of two or more type of CP. Frequently dyskinesia and spasticity are present together (64).

2.5.2. Topographical Classification of CP

CP is classified topographically according to where the involvement is in the body. It is generally grouped as hemiplegia, diplegia and quadriplegia. According to some classifications, there are also monoplegia and triplegia (65).

Monoplegia; only one limb is affected. The affected part can be either the lower or the upper extremity. It is not very common in the clinic.

Hemiplegia; accounts for 20-30% of all spastic CP. Patients have unilateral spasticity, one upper and lower extremity are affected at one side of the body. Patients have asymmetrical movements such as asymmetrical crawling, asymmetrical hand use. Mostly they walk without assistance and their intelligence is normal. Upper extremity involvement is more severe than lower extremity involvement. They have difficulty in selective movements and fine motor movements.

Diplegia; is 30-40% of spastic CP. Primarily lower half of the body is affected. There is an increase in muscle tonus at lower extremities. Trunk is also affected. 30% of them have cognitive impairment. 80-90% of them walk with or without assistance.

Triplegia; Involvement is in bilateral lower extremities with right or left upper extremity. It is rare in clinical practice. Trunk is also affected.,

Tetraplegia; is 10%-15% of spastic type CP. Entire body including both upper and lower extremities are affected. Approximately more than half of them eventually walk with some degree of assistance. Whereas 25% of them is non ambulatory due to severe impairment. They have various additional problems such as mental retardation, epilepsy, visual and auditory impairment and communication problems (66,67).

Monoplegia and hemiplegia are classified as Unilateral Cerebral Palsy (UCP). Triplegia, diplegia and tetraplegia are classified as Bilateral Cerebral Palsy (BCP).

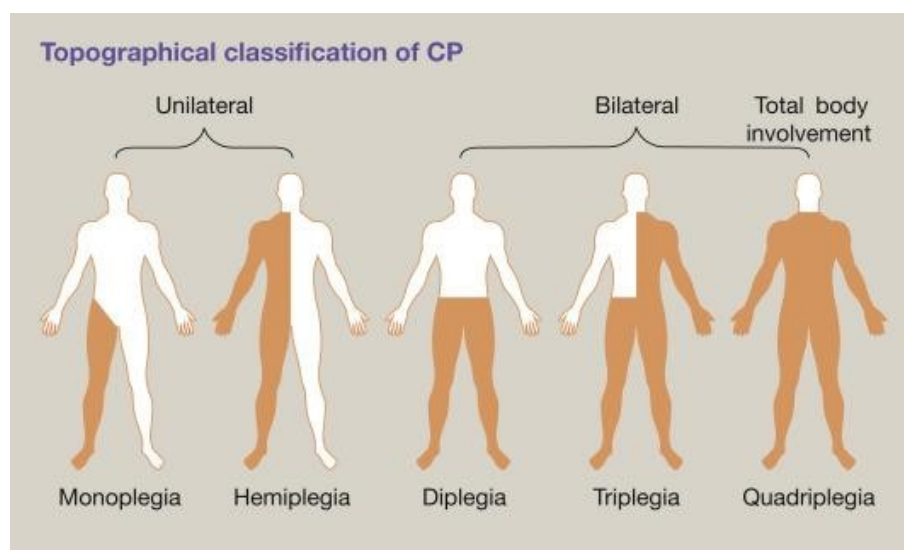


Figure 2.1. Topographical classification of CP

2.6. Additional Problems to CP

2.6.1. Cognitive Problems

Children with CP have more risk to have cognitive and mental problems compare to their peers. 30-50% Children with CP have mental retardation and even more of them have mild cognitive impairments because of brain lesion or malformation. Even though there are some severely affected quadriplegic children who has normal mental level, mental problems are more common in spastic children with severe motor involvement.

In addition, cortical abnormalities and epilepsy are associated with high risk of cognitive impairments. Except from severe mental retardation, less severe cognitive problems such as impairment in special learning, visual-spatial cognition, visual-perception, language, memory, and executive functions can be found in patients.

Moreover, speech problems can affect social interactions and this situation can interfere intellectual development of children (67, 69).

2.6.2. Musculoskeletal Problems

Some musculoskeletal problems develop over time in children with CP due to spasticity, abnormal postures and inappropriate positions. Spasticity may cause contractures, tightness at muscles, and deformities at hip and foot. Low bone density and imbalance between muscles are among the factors that cause orthopedic problems.

In hemiplegic children, leg shortening, equine deformity, and upper extremity contractures may develop.

Most of the diplegic children can walk independently and crouch gait leads tightness and contracture at gastrocnemius, hamstrings, flexor and adductor muscles of hip. There may be genu recurvatum in the knees to compensate for the shortened achilles, and hyperlordosis to compensate for the shortened hamstrings. Hip dislocation and pelvic rotation may present. Scoliosis may occur and progress over time.

In tetraplegic children hip dislocations are more common than others. Roughly 60% of children who can not walk unassisted, will have hip dislocation by age 5 years.

Scoliosis is most common in non-ambulatory children than others. It may also be accompanied by kyphosis and hyperlordosis (53, 67, 69).

2.6.3. Pain

Many children with CP experience pain as a consequence of multifactorial reasons such as spasm at muscles, hip dislocation, dystonia and gastrointestinal problems. Dislocated hip joint can include inflammatory factors and cartilage damage. Therefore there is hips joint sensitization and all of these factors cause pain. Besides, pain can arise from dental, nutrition-related and respiratory sources. Pain reduces quality of life in children (70,71).

2.6.4. Epilepsy

One of the most common comorbidities in children with CP is epilepsy. Epilepsy is more common in severely affected children and it worsens prognosis of the disease. Epilepsy is related with severe mental retardation. Epilepsy has early onset, in the first age of life and it needs to be under controlled by antiepileptic drugs to obtain an effective treatment process. Epilepsy affects children's comfort and quality of life (72).

2.6.5. Visual Problems

There is a risk of ophthalmological impairment in children with cerebral palsy. Especially in premature babies, strabismus, myopia, retinopathy of prematurity, glaucoma may present. Damage to the visual cortex leads to cortical visual impairment. Visual impairment is seen 20% to 50%, strabismus and refractive errors are seen 13% to 25%. Visual impairments affects cognitive development and reduce quality of life (73,74).

2.6.6. Hearing Impairments

In addition to other deficits, children with Cp may suffer from hearing impairments. Hearing loss rate in children with CP is 4-25%. Hearing impairments can be caused by a damage at receptors of inner ear, at neural pathway to brain and at the part of brain which receives auditory stimulations. Auditory skills are fundamental for cognitive development, communication and speech. Hearing loss may cause delay in speech acquisition and affects language skills, speech fluency, learning alterations. Hearing loss is one of the factors that make daily life difficult. It reduces the

effectiveness of therapy. Using hearing aids and cochlear implants are treatment options (75,76).

2.6.7. Speech Problems

Approximately 33 – 63 % of children with CP have speech problems. Children with CP have difficulty in producing and coordinating the oral motor movements required for speech. Speech disorders are multifaceted; articulation disorder, phonological disorder, childhood speech apraxia, and dysarthria. Because of speech problems communication is hard for children with CP. Speech impairment retards their intellectual development and reduces their participation. These children can benefit from speech therapy (77,78).

2.6.8. Feeding and Nutritional Problems

Children with CP have difficulty in swallowing during feeding (dysphagia). There is a risk of pulmonary involvement by aspiration during oral feeding. Mealtimes can be long and grueling. Many factors can affect childrens' feeding; texture of food, spoon and fork type, feeding posture, sensory problems, the caregiver who feeds the child and the environment. Feeding problems are more common at severely affected children than the others. Drooling may present because controlling muscles for swallowing is hard for patients. Feeding problems may cause nutritional inadequacy and bone mineral density reduced overtime. Children may be referred to a therapist specialized in feeding and swallowing (79).

2.6.9. Bowel and Bladder Dysfunction

Children with CP can have constipation as a consequence of inadequate gastrointestinal motility, inadequate alimentacion and reduced hydration. Also gastroesophageal reflux may been seen. Enhance water intake and diet rich in fiber can help (73,80).

Spastic CP is associated with spasticity in detrusor muscles which lead in frequent void in children. They may have irritable bladder with low capacity. Urinary incontinence is more common in children with severely affected and cognitively impairment. Neurogenic bladder syndrome is also a factor that complicates toilet habits and reduces the quality of life in children with CP (81).

2.6.10. Respiratory Problems

Respiratory problems in children with CP can cause mortality. The inability of the respiratory muscles to provide adequate inhalation and exhalation of air. Musculoskeletal system deformities such as scoliosis, the inability of the to expand and contract the rib cage, and insufficiency in diaphragm contraction create respiratory problems. Airway clearance is always a priority, providing secretions clearance and effective coughing is attempted (82).

2.6.11. Sleep Problems

Children with CP have more sleep problems than their healthy peers. 23-46% of children with CP have sleep problems such as difficult falling asleep, often waking up at night or early morning and sleep-related respiratory problems. Also their sleep quality can be reduced by muscle spasm, seizures, musculoskeletal pain. Sleep problems significantly affect quality of life (83,84).

2.6.12. Emotional and Behavioral Problems

Emotional and behavioral problems can be seen at children with CP. Multifactorial reasons leads to emotional and behavioral problems in children. Because of spasm, posture, and deformities children with CP may have chronic pain and they become sensitive to pain. They avoid movements which may cause pain. This pain-avoidance behavior limits daily functions, causes withdrawal from social life, and may result in children displaying aggressive behavior and anxiety. In addition emotional dysregulation, hyperactivity, and attentional problems can be seen. Behavioral problems are more common in children with sleep problems and chronic pain and reduce their QOL. Children should receive age-appropriate therapy and be supported in the areas of self-estimation and self-care (51, 52).

2.7. Upper Extremity Functions

Upper extremity functions (UEF) are important for performing many activities in daily living. Many factors work collaboratively during upper extremity activities performed automatically and fluently in daily life. They work in harmony to provide the appropriate range of motion, muscle strength, timing and coordination in many activities from the simplest daily life activities such as eating and combing hair to more complex functions such as sportive, artistic and occupational activities which require more strength or dexterity. Visual, auditory, tactile and proprioceptive processes, motor

planning, muscoskeletal movements and balance and coordination systems provide smoothness of movements and fluent transion between movoments. Visual, auditory, tactile and proprioceptive processes, motor planning, muscoskeletal movements and balance and coordination systems provide smoothness of movements and fluent transion between movements (87,88).

Since upper extremity functions are important in the realization of daily life activities, academic, leisure and occupational activities, they directly affect the individual's independence, participation in life and QOL (89).

2.8. Manual Ability

Manual ability refers to how the individual use their hands when handling objects in daily activities. Another term which reflects manual ability is manual dexterity. It is the skill of using hands to carry out a task resourcefully. Manual dexterity is a term that is quite closely associated with manual ability. Manual dexterity plays a role in repetitive and fluent activities such as holding and releasing objects with a meaningful goal and maintenance of activities. It is basically defined as the capability to solve a motor problem correctly, quickly, accurately, rationally and skillfully. Manual dexterity is a complex term about ingredients of task-oriented actions to elicit purposeful motor behavior. It encompasses control and coordination of finger, arm, shoulder movements, agility, grace and speed in handling objects. Also endurance and attendance at repetitive movements are important (90).

Manual dexterity is often associated with functional usage of hands. Hand functionality are stated by some intrinsic and extrinsic factors. Musculoskeletal integrity, visual and cognitive factors, and somatosensory functions can be counted as intrinsic factors. Besides extrinsic factors such as social and cultural factors determines the opportunity to experience various activity including diverse hand functions and also they affects motivation to do functional activities. Manual ability and dexterity also have effects on individuals ability to fulfill daily living tasks, participation and QOL (91,92).

2.9. Development of Upper Extremity Functions

Babies move their upper extremities to explore the environment, play and get support while moving. Environmental factors can be a source of motivation with different visual, tactile and auditory inputs for children to experience different

movements. As babies experience and practice new movements, their motor skills develop both proximally and distally. Newborn reflexes disappear over time and are replaced by voluntary movements. As the children grow, they begin to control and coordinate voluntary movements. Also, children play games using their upper extremity functions and thus their cognitive skills develop. With the development of upper extremity functions, the child acquires social skills such as playing together or academic skills such as participation in the lesson (93).

As motor development milestones; voluntary extensions, weight bearing at the upper extremities, bringing the upper extremities together in the midline, grasping releases, object manipulations, hand-to-hand object transfer, balance and protective reactions, fine motor skills, and bimanual hand use develop. In addition, visuospatial perception, hand eye coordination, visual attention develop with these motor developmental milestones (94).

Table 2.3. Milestones of some movements

Months	Movements
0-2	-Moves arms independently with random motions
3-5	-Weight bearing on forearms at prone - Reaches voluntarily - Brings both hands to the midline - Brings hands to mouth -Sustains grasp on toys with involuntary release
6-8	-Weight bearing on palms at prone -Reach for toy with one hand at prone -Brings both hands together while sitting unsupported -Uses extended arms to reach for toys - Reaching for and obtaining toys while sitting unsupported - Picks up and maintains grasp on 2 blocks - Uses a lateral grasp - Transfers toy between both hands
9-11	-Using hand support to stand up -Brings 2 blocks together at midline - Claps hands together - Releases toy with verbal command -Pincer grasp - Activates cause and effect games

2.10. Upper Extremity Functions and Manual Dexterity at Children with CP

Children with spastic CP have problems performing their upper extremity functions reaching, grasping, and manipulating objects, or performing activities of daily living. Due to spasticity, a distinct posture is usually seen in the upper extremity; shoulder adduction and internal rotation, elbow flexion, forearm pronation, wrist flexion, ulnar deviation, hands are closed and fist, and thumbs are in palm (95, 96).

Muscle strength increases while children perform movements. Difficulty in movements in children with CP causes inadequate muscle strength. Difficulties in cocontraction, muscle stiffness, restricted range of motion, pain, dominant abnormal movement patterns, difficulty in selective movements, insufficient muscle strength, inability to stabilize the proximal joints make movements complex for them.

In addition, they expend more energy while moving. Children with CP have less opportunities to explore and learn about the environment through play. Because they have difficulty in upper UEF, they are less motivated to play than typically developing children. Thus, they are adversely affected in terms of cognitive development and social interaction. Their decreased independence in daily living skills causes lower self-esteem and increased caregiver burden (97).

Children with CP have difficulties in manual dexterity because for manual dexterity proximal control, dynamic stability, ability to dissociate movements, and child's use of the upper limb to stabilization are required and they have difficulties at these.

Manual activities require the cooperation of both hands. Manipulations are done by dominant hand during the activity whereas non dominant hand is being used for stabilization. Children with CP are struggling in bimanual activities. Compensation mechanisms may develop to perform the movement. Quality of movement is reduced (98).

Influences on upper extremity and hand functions in children with CP affect children's participation in social, academic, recreational and daily life activities and eventually reduce their quality of life (99,100).

2.11. Participation

Health is described as ‘a state of complete physical, mental and social wellbeing and not merely the absence of disease by The World Health Organisation (WHO). This definition reflects the biopsychosocial model of health which considers physiological, psychological and social factors. According to this concept, besides physical and mental well-being, psychological and social factors are also emphasized. Rather than not having a disease or being alive, a state of well-being is associated to living well which highlights participation to life and to society in WHO's definition (101,102).

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) was established with the aim of observing the characteristics of the developing children and their interaction with environment and establishing a standardization for professionals. ICF defines participation as involvement in a life situation. ICF emphasizes functioning and considers participation as a social perspective of functioning (70).

Participation is a complex term which encompasses daily life, self-care activities, communication with other people, leisure activities, academic and occupation-related activities. As children grow, their participation in life also diversifies. In the beginning, contact with the caregiver, involvement in games, involvement in daily life activities are included in participation, but as the child grows, involvement fields are expanded such as involvement in school, occupational and social areas (104).

The environmental factors which is defined as the physical, social and attitudinal environment in people live also plays an important role in participation in the ICF concept. As children are exposed to different environments around them, they experience new activities and thus learn. Environmental stimuli support the musculoskeletal and cognitive development of children. Children learn communicating with their peers, motor problem solving and self-regulation. The physical facilities of the environment are effective in the participation of children.

Participation is influenced by internal factors such as the person's physical abilities, motivation and emotional state as well as environmental forces. People with higher participation in life also have higher quality of life (105).

2.12. Participation at Children with CP

Children with CP participate less in activities compared to their peers. Children with CP have less opportunities to explore the environment and experience activities by playing (106).

Physical, social and environmental barriers reduce the participation of children with CP. Physical barriers include musculoskeletal impairments, spasticity, pain, head or trunk control, inadequate hand supports, and inability in fine motor movements. The motivation of children with CP to participate in activities is lower than their age. The opportunity to meet with their peers is less. Their participation is low because they have difficulties in communicating with the people around them. Mental problems interferes socialization of children with CP with their peers.

In addition, physical conditions and socio-cultural structure of the environment and socioeconomic status of the family affect the participation of children with CP (107).

Life satisfaction decreases in children with CP who have less participation in life (108).

2.13. Quality of Life in Children with CP

WHO describes quality of life as individuals' perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (109). QOL is a multidimensional concept that includes both positive and negative aspects of individual's perception of life. QOL is affected by children's status at several domains such as physical, psychological and psychosocial. Also physical status and functional abilities, material conditions, and social interactions, health, education and literacy and participation have effects on QOL (110,111).

QOL of children with CP may decrease due to pain, discomfort, seizures, low sleep quality, inadequate communication skills, dependence on daily living activities, and lack of academic and social opportunities. In addition, difficulties in accessing health care and other social services, being accepted by other people and concerns about the future are among the factors affecting the QOL in children with CP. Besides, children's age and emotional state also affect how they perceive themselves and their lives (112). In the clinic, the QOL is evaluated to monitor the progress of the child

and the treatment plan can be revised according to the missing points. Ultimate goals of therapies are maintain or enhance QOL of children with CP and also maximizes their functioning and participation to life (113).

3. MATERIAL and METHOD

3.1. Participants

This study was conducted with children with CP who were chosen from Risky Baby Counseling Center (APPENDIX 1, page 75) to investigate the effects of manual dexterity and upper extremity functions on life participation and quality of life. The evaluations were made between July 2021 and December 2021. This study was approved by Yeditepe University Clinical Research Ethics Committee (APPENDIX 76, NO: 202108090).

30 children with CP who are complied with the following criterias were included in this study.

3.1.1. Inclusion criterias

- Having diagnosis of CP
- Being between the ages of 4-12
- Having level I, II or III according to GMFCS
- Having upper extremity impairments and having MACS 1, 2, 3 level
- Adequate mental level and compliance with the therapist to be able to follow simple instructions

3.1.2. Exclusion criterias

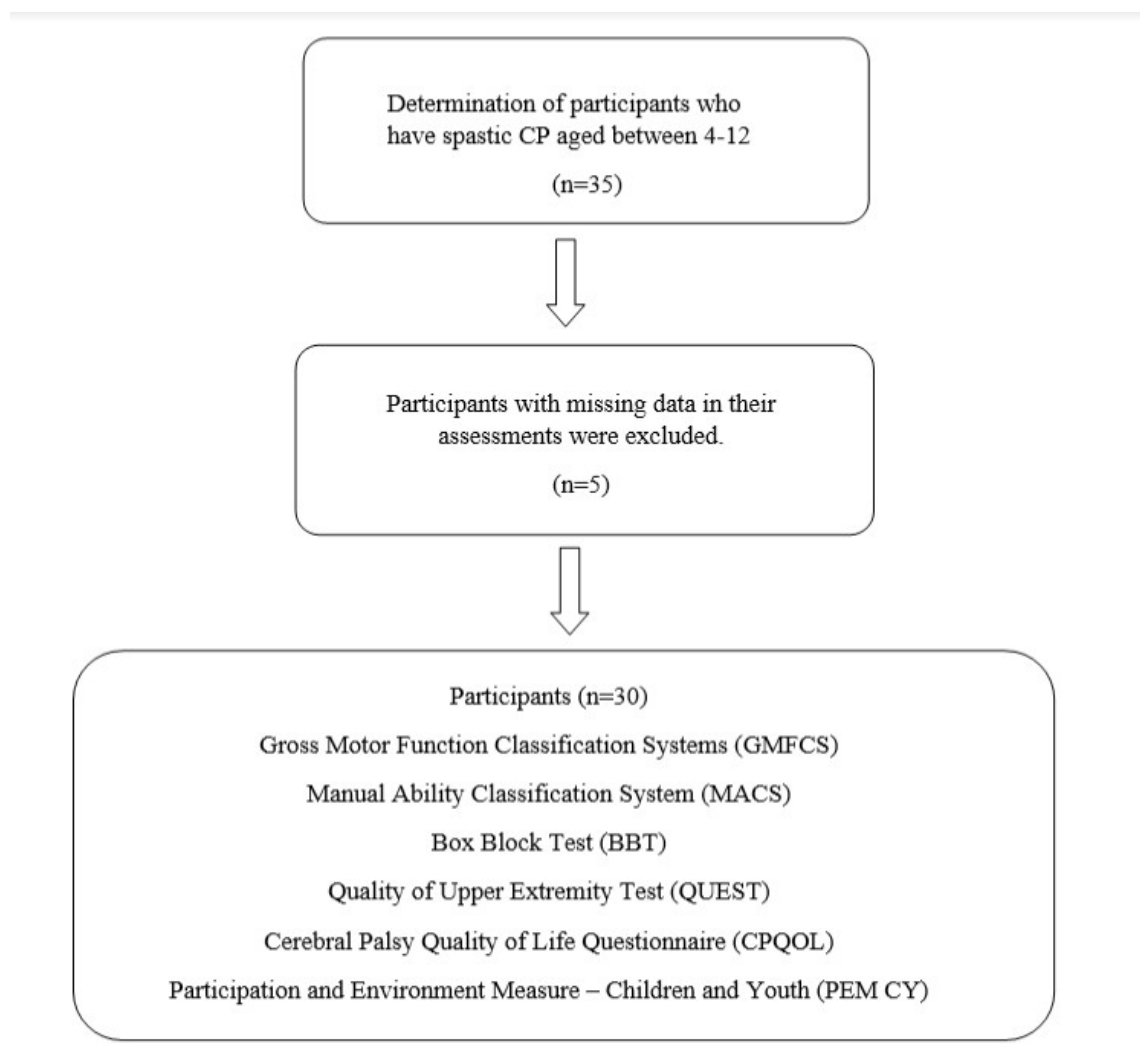
- Children with dystonia and ataxia and children with having other movement disorders in addition to CP (choera, athetosis)
- Children with uncontrolled epilepsy and vision problems
- Children who had botox or surgery in the last 6 months

3.1.3. Flow Chart: Study Protocol (Table 3.1)

The purpose of study and the details about evaluations which are included in the study were explained to the families and the caregivers of the children who were selected to participate to the study. Participant Information and Approval Form (APPENDIX 3, page 78) were signed by the families and caregivers to demonstrate that participant agreed to participate the study voluntarily. General informations as current physical features and medical status of the child were gathered with the help of the Socio-Demographic Information Form (APPENDIX 4, page 79).

Evaluations were included Gross Motor Function Classification System, Manual Ability Classification Systems (APPENDIX 5, page 80), Quality of Upper Extremity Skill Test (QUEST) (APPENDIX 6, page 81), Box Block Test, Participation and Environment Measure – Children and Youth (APPENDIX 7, page 99), and Cerebral Palsy Quality of Life Questionnaire (APPENDIX 9, page 105).

Table 3.1. Flow Chart of the Study



3.2. Evaluations

3.2.1. The Gross Motor Function Classification System (GMFCS)

GMFCS is a performance based clinical tool to classify the motor functions of children with cerebral palsy at sitting, transferring and mobility. GMFCS is composed of five levels; level I represents highest motor functions and level V represents lowest motor functions. The differences between levels are based on functional limitations, the need for hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility (114).

GMFCS level of participants is decided via clinical observation and examination

General headings for each level :

LEVEL I - Walks without limitations

LEVEL II - Walks with limitations

LEVEL III - Walks Using a hand-held mobility device

LEVEL IV - Self-mobility with limitations, may use powered mobility

LEVEL V - Transported in a manual wheelchair

The distinctions between levels vary according to the age of the child (Table 3.2).

Table 3.2. GMFCS levels distinctions

GMFCS	0-2 Age
Level I :	Infants can sit, crawl, use hands to manipulate objects, after transfer sitting to standing with hand support and walk between 18 months to 2 years
Level II :	Infants can sit but use hands for balance, can crawl and take steps holding on furniture
Level III :	Infant can sit with low and back support, can creep and roll
Level IV :	Infant can control head, sit with trunk support, roll to supine, may roll to prone
Level V :	Infants have limited voluntary movement control and can not control head and trunk against gravity
	2-4 Age
Level I :	Children can sit with hands free, can transfer sitting to standing and walk without assistance
Level II :	Children can sit with both hands free but have balance problem. They can stand up holding furniture, can crawl and walk with an assistive device
Level III :	Children can sit in W-sitting and may with support. They can creep and crawl without reciprocal pattern, may stand holding furniture and can walk with hand held assistive device indoor
Level IV :	Children can sit with support, stand with support and have mobility as rolling, creeping, and crawling
Level V :	Children have no means of independent movement and head, trunk control. They are transported
	4-6 Age
Level I :	Children can sit and stand, walk outdoor and stairs. Emerging ability to run and jump.
Level II :	Children can sit with hands free, can stand up holding a stable surface, walk indoor without assistance, climb stairs holding the railing but can not jump or run
Level III :	Children can sit with support to maximize hand function, can stand up holding a surface, walk with hand held device, climb stairs with assistance and transported at outside long distance
Level IV :	Children sit with adaptive equipment, can stand and sit with pulling himself or assistance, walk with walker in a short distance but have difficulty at turning and transported at community
Level V :	Children have extremely limited voluntary movement control and they are transported at the community
	6-12 Age
Level I :	Children can walk outside, climb stairs, run and jump but coordination and balance are limited.
Level II :	Children have difficulties at walking at crowded place or inclined surface. They can climb with holding railing, may use hand held device at community, have limitations at running and jumping
Level III :	Children can roll, creep, crawl, sit with support, walk with hand held device in indoor, sit and stand up with assistance or support. They use wheelchair at long distance
Level IV :	They use wheelchair, body supported wheelchair, equipment for sitting. They can walk with assistance in short distance, transported at long distance.
Level V :	Children are transported at manual wheelchair. They have limitation at head and trunk control and at voluntary movements. They use assistive equipment for maintain position and alignment
	12-18 Age
Level I :	They can walk outside, climb stairs, run and jump but coordination and balance are limited.
Level II :	They have difficulties at walking at long distance or at inclined surface. They can climb with holding railing, may use hand held mobility device at community.
Level III :	They may walk with hand held mobility device and can use wheelchair himself at community. They can stand up with support.
Level IV :	They use wheelchair, body supported wheelchair, equipment for sitting. They can walk with assistance in short distance, transported at long distance.
Level V :	They are transported at manual wheelchair. They have limitation at head and trunk control and at voluntary

	movements. They use assistive equipment at maintain position and alignment
--	--

3.2.2. Manual Ability Classification Systems (MACS)

MACS aims to evaluate how children with CP use their hands to handle objects in daily activities. MACS is valid for 4-18 years old children who have CP diagnosis. The levels are based on the children's self-initiated ability to handle objects and their need for assistance or adaptation to perform manual activities at daily life. MACS is consist of five levels. MACS levels of participants are decided via clinical observation and gathering informations about children's' hand ability by asking his caregiver. While Level I represents minor limitations, level V represents most severe limitations (115). The distinctions between MACS level are revealed at Table 3.3

Table 3.3. MACS levels distinctions

MACS Level	
Level I :	Children handle objects easily and successfully. Daily living are not affected. They have limitations at coordination, at handling small objects require very detailed fine motor control.
Level II :	Children handle most objects but with somewhat reduced quality and/or speed of achievement. They may use compensations and daily living are not affected.
Level III :	Children handle objects with difficulty; needs help to prepare and/or modify activities. Activities are completed with limited success. They need help to prepare/adjust the activity. Their degree of independence is related to the supportiveness of the environmental context.
Level IV :	Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.
Level V :	Does not handle objects and has severely limited ability to perform even simple actions. They might at best participate with a simple movement in special situations, e.g. by pushing a button.

3.2.3. Quality of Upper Extremity Skill Test (QUEST):

The QUEST is a clinical scale for measuring upper extremity movement patterns and hand functions in children. It is a valid test that measures upper extremity function in children with cerebral palsy (116). QUEST is a reliable test for children with CP up to age 12 (117). It evaluates hand spasticity, grasping and object manipulations, hand function, dissociative normal joint movements in shoulder, elbow, wrist and fingers, protective extensions and weight transfer to UE in different positions.

There are 33 items in total. Right and left upper extremities are scored separately. Hand preference of the child is noted. It is scored in four different sub-areas with its own scoring system. 0 indicates the least skill and 100 indicates the highest skill (118). Initially QUEST Test is explained to participant, Then, movements which will be tested are demonstrated to children. Children perform the movement first with dominant side, then non dominant side. The score is noted.

The different domains which are evaluated at QUEST are shown at the Table 3. 4.



Table 3.4. The domains of the QUEST

Domains of QUEST			
<i>A. Dissociated Movements</i>			
Shoulder	Elbow	Wrist	Independent Movements
-Flexion -Flexion with fingers extended -Abduction -Abduction with fingers extended	-Flexion with supination -Extension with supination -Flexion with pronation -Extension with pronation	-Extension with elbow extension -Extension with elbow flexion -Extension with pronation -Extension with supination -Flexion with supination	-Independent finger wiggling -Independent thumb movement
<i>B. Grasp</i>	<i>C. Weight Bearing</i>		<i>D. Protective Extension</i>
-Grasp of cube -Grasp of cereal -Grasp of pencil	-Weight bearing in prone -Weight bearing in prone with reach -Weight bearing in sitting with hands forward -Weight bearing in sitting with hands by side -Weight bearing in sitting with hands behind		-Protective extension forward -Protective--extension forward -Protective extension backward

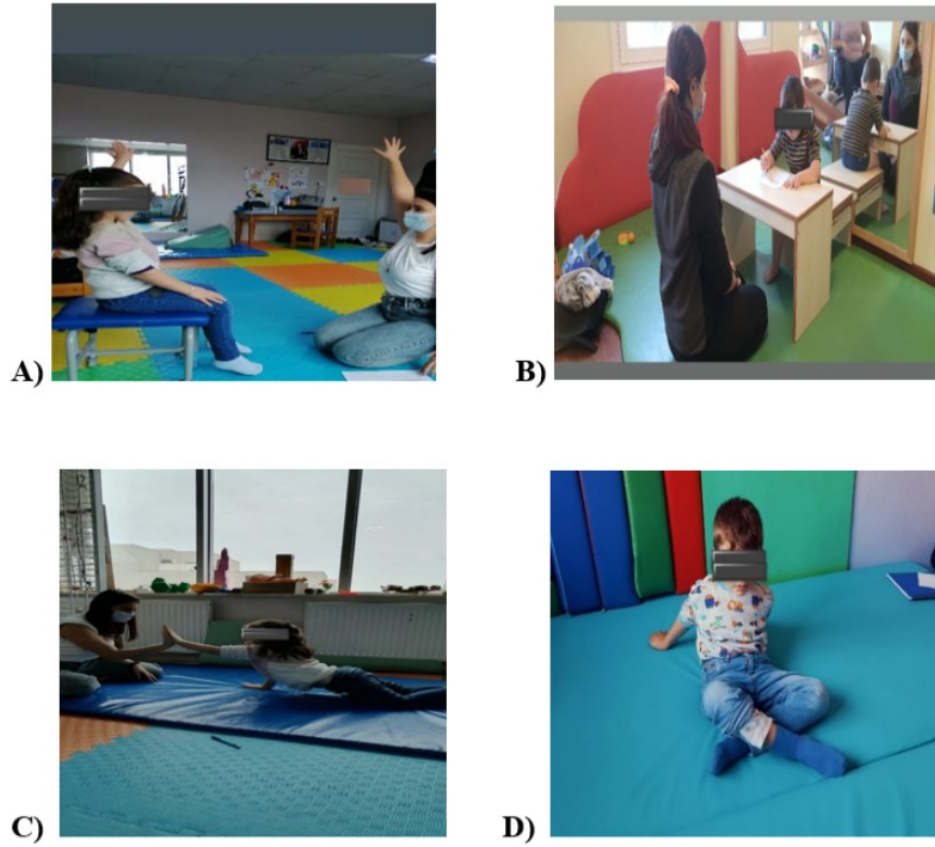


Figure 3.1. Assessment Upper Extremity Functionality QUEST A, B and C A) Dissociated Movements
B) Grasp C) Weight bearing- prone D) Weight bearing-Sitting

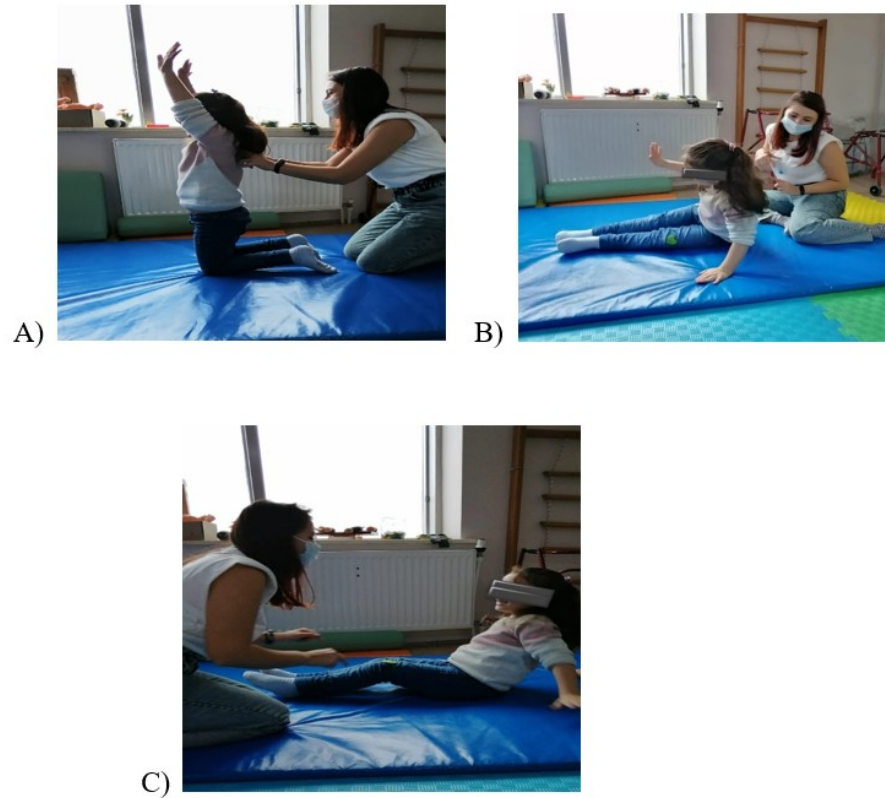


Figure 3.2. Assessment Upper Extremity Functionality QUEST D, A) Protective extension – front, B) Protective extension -Sides, C)Protective Extension - Back

3.2.4. Box Block Test

The Box and Block Test (BBT) is a functional outcome measure that is used to evaluate manual dexterity and hand function. BTT comprises grasping, releasing of cubs, transporting objects, coordination, proper timing, repetitive movements, ability to control upper extremity and thorax during the test (119). BBT is valid and reliable test which is used in various patient population as stroke, traumatic brain injury, neuromuscular disorders. BBT is also valid and reliable functional test for hand dexterity among children with cerebral palsy (120). The BBT composes of a wooden box (53.7 cm x 25.4 cm x 8.5 cm size) and 150 colorful cubs (2.5 cm x 2.5 cm 2.5 cm size). The box is divided in two equal parts and 150 cubes are placed in ona part.

The patient has appropriate sitting position with the feet on the ground, thorax at upright position and the box is placed in front of the patient at a table which has appropriate height. The patient is asked to take the cubs from one side of the box one by one with one hand and throw them from the other side of the box. The patient is allowed a 15-second trial period prior to testing. The patient can choose which upper extremity he starts. The preference of extremity side is noted by the therapist. Patient keeps transferring the cubes to other side of the box during 1 minute. Verbal encouragement is allowed. The number of the cubes transferred at the end of the 1 minute is counted. Patient repeats the test with other upper extremity. High number of cubes indicates higher manual dexterity and functionality while lower number of cubes indicate lower functionality.



Figure 3.3. Box Block Test

3.2.5. Participation and Environment Measure – Children and Youth

PEM-CY is a clinical tool to measure participation of children ages 5 to 17. PEM-CY is a parent-report comprehensive measurement includes home participation, school participation and social participation. The scale consists of 3 domains; participation frequency, extent of involvement, and desire for change in activities. Families choose the frequency of participation to determined activity among to the options daily, several times a week, several times a month, once a month, several times in the last 4 months, once in the last 4 months, and never. They evaluate how their child participate to the activity within minimal to maximal range. In the last part they evaluate if they want to change the participation of children or not. 8 points reflects maximum frequency and maximum involvement and 1 points reflects the minimum. Desire to change in participation reflects the percentage of activity which parents would like to alter in terms of participation frequency or how much the child participate.

In accordance with the ICF concept, environmental factors are also evaluated in the participation perspective. The sensory quality of the environment, physical conditions and facilitating possibilities are asked. PEM CY is used for both typically developed children and children with various disabilities such as cerebral palsy, acquired brain injury, asperger and down syndrome (121).

In 2020, the translation study of PEM CY was carried out by Kara Kaya et al. and it is reliable and validated in Turkish language (122).

Parents are asked to fulfill the PEM CY Turkish questionnaire while their children's upper extremity is being evaluated. Questions which parents can not understand clearly are explained to them face to face.

3.2.6. Cerebral Palsy Quality of Life Questionnaire

CPQOL is a disease specific clinical tool enables healthcare professionals and researchers evaluate quality of life of patients with cerebral palsy. It is valid and reliable measurement. Two different versions of CPQOL are developed. CP QOL-Child is developed to evaluate quality of life at children with CP with age 4-12. This scale is applied with the help of the primary caregiver of children. CPQOL - Teen version is developed to assess quality of life of adolescents with CP age 13-18. CP QOL-Teen can be applied both self report and with the help of the caregiver (123). Turkish validation study is conducted by Atasavun et al. in 2016 and as a result of study

Turkish version of CPQOL is valid and reliable tool to evaluate quality of life of children with CP (124).

In our study CPQOL-Child form is used. The primary caregivers of children are asked to rate the scale. The scale is based on what do caregivers think about feelings of children about relative activities, rather than what the children exactly can. Caregivers score the questions with 1 being the lowest level of happiness and 9 the highest level of happiness. Evaluations include how the child feels in the family and friend environment, how he feels about participation, communication, his health, his special equipment, his pain, access to services, and opinion of caregiver about their health of caregiver. Scores are calculated as percentage of how much happy about the related item.

3.3 Data Analysis

Correlation between upper extremity function, manual ability and participation, quality of life is calculated by Statistical Package Analyze for Social Sciences (SPSS) version 25.0 program. According to Shapiro-Wilk test, it was decided whether the data were normally distributed or not. If the data were normally distributed, the Independent Samples T-test was used to compare the quantitative data between two groups, and if the data were not normally distributed, the Mann-Whitney U test was used to compare the quantitative data between two groups. One-way ANOVA was used to compare normally distributed data between the 3 groups, and the Kruskal-Wallis test was used to compare non-parametric data. Bonferroni and Mann-Whitney U tests were used to find the source of the difference between the groups. Spearman Correlation Analysis was used to correlate the data. $p < 0,05$ was accepted as statistically significant.

4.RESULTS

Demographic features were evaluated by divided participant into two groups as UCP and BCP according to topographic classification. The UCP group consists of hemiplegic CP and monoplegic CP and includes 14 participants. The BCP group includes diplegic CP, tetraplegic CP and includes 16 participants. The mean age, height, weight and body mass index (BMI) of the UCP and BCP groups are shown in Table 4,1 and there was no statistically significant difference between the groups in terms of these data ($p>0.05$).

Table 4.1. Demographic Characteristics of the Participants

	UCP mean±sd N=14	BCP mean±sd N=16	t/U	p
Age (years)	6,07±2,30	6,37±1,41	U=85,000	0,248
Height (cm)	113,21±15,46	112,94±10,01	t=0,058	0,954
Weight (kg)	21,10±8,03	21,98±5,42	U=92,500	0,417
BMI (kg/cm²)	15,94±2,10	16,87±2,65	t=-1,058	0,299

UCP: Unilateral Cerebral Palsy, BCP: Bilateral Cerebral Palsy, sd: Standard Deviation, BMI: Body Mass Index, t= Independent Samples T-test, U=Mann Whitney-U test

GMFCS levels, MACS levels and gender by UCP and BCP groups are shown in Table 4.2. In the UCP group, there were 11 participants (78.6%) at GMFCS level 1 and 3 participants (21.4%) at level 2. In the BCP group, there were 3 participants (18.8%) at GMFCS level 1 and level 2, and 10 participants (62.5%) at level 3. In the UCP group, there were 8 participants (57.1%) at MACS level 1 and 3 participants (21.4) at levels 2 and 3. In the BCP group, there were 5 participants (31.3%) at MACS level 1, 6 participants (37.5%) at level 2, and 7 participants (31.3%) at level 3. In the UCP group, 57,1% of the participants were male (n=8) and 42.9% were female (n=6). In the BCP group, 43.8% of the participants were male (n=7), 56.3% were female (n=9).

Table 1 4.2. Distribution of GMFCS levels and MACS levels over topographical classes of CP

		UCP		BCP	
		mean±sd		mean±sd	
		n	%	n	%
GMFCS	Level 1	11	78,6	3	18,8
	Level 2	3	21,4	3	18,8
	Level 3	0	0,0	10	62,5
MACS	Level 1	8	57,1	5	31,3
	Level 2	3	21,4	6	37,5
	Level 3	3	21,4	5	31,3
Gender	Male	8	57,1	7	43,8
	Female	6	42,9	9	56,3

UCP: Unilateral Cerebral Palsy, BCP: Bilateral Cerebral Palsy, sd: Standard Deviation, GMFCS : Gross Motor Function Classification System, MACS: Manual Ability Classification System

4.1 Results of Manual Dexterity and Upper Extremity Functions Assessment

Manual dexterity assessment was performed with BBT. According to UCP and BCP group, results for the dominant and non-dominant hand of BBT and subtests of QUEST assessment are shown in Table 4.3. In all subtests of the QUEST, the UCP group scored statistically significantly higher than the BCP group.

There was a statistically significant difference between the groups in all subtests of the QUEST. The UCP group had a statistically significant higher score than the BCP group in Dissociated Movements assessment ($p=0,047$), Grasp assessment ($p=0,15$), Weight Bearing assessment ($p=0,04$), Protective Extension assessment ($p=0,000$), and the Total QUEST score ($p=0,002$).

While there was no statistically difference between groups in terms of non-dominant hand assessment of BBT, UCP group had significantly higher score in terms of dominant hand assessment of BBT ($p=0,031$).

Table 4.3. Comparison of QUEST and BBT scores according to topographical classification of CP

		UCP mean±sd	BCP mean±sd	t/U	p
	Dissociated Movements	85,66±12,05	70,00±20,98	U=64,500	0,047*
	Grasp	78,57±17,20	59,38±22,39	t=2,603	0,015*
	Weight bearing	91,51±8,53	73,97±19,07	t=3,169	0,04*
	Protective Extension	78,77±14,36	54,46±18,07	t=4,037	0,000*
	Total QUEST	83,66±10,96	64,92±17,84	t=3,404	0,002*
	BBT DH	28,07±10,37	20,56±7,68	t=2,273	0,031*
	BBT ND	20,00±12,41	14,50±8,16	t=1,452	0,158

UCP: Unilateral Cerebral Palsy, BCP: Bilateral Cerebral Palsy, sd: Standard Deviation, QUEST: Quality of Upper Extremity Skills Test, BBT DH: Box Block Test Dominant Hand, BBT ND: Box Block Test Non-dominant Hand, t= Independent Samples T-test, U=Mann Whitney-U test, * $p<0.05$

Table 4.4 shows the QUEST subtests and BBT scores by GMFCS levels. There was significant difference between groups in all subtests of QUEST when compared according to GMFCS levels.

There was a significant difference between GMFCS level 1-3 ($p=0,000$ $U=13,000$) and level 2-3 ($p=0,007$, $U=6,500$) in dissociated movements. There was a significant difference between GMFCS levels 1-3 in Grasp subtest according to Bonferroni ($p=0.000$). There is a significant difference between GMFCS level 1-3 ($p=0,000$, $U=7,500$) and level 2-3 ($p=0,008$, $U=5,500$) in the Weight Bearing test. According to Bonferroni, there was a significant difference between GMFCS level 1-3 ($p=0,000$) and level 2-3 ($p=0,003$) in the Protective Extension subtest. In QUEST Total

score, there was a significant difference between GMFCS level 1-3 ($p=0.000$) and level 2-3 ($p=0.002$).

While there is was a significant difference between the groups in the dominant hand according to the GMFCS level in the BBT score, there were no significant difference between the groups in the non-dominant hand. There was a significant difference between GMFCS level 1-2 ($p=0.006$, $U=10.50$) and level 1-3 ($p=0.001$, $U=18,000$) in BBT dominant hand score.

Table 4.4. Comparision of QUEST and BBT scores according to GMFCS levels

GMFCS	Level 1	Level 2	Level 3	F/Z	p
Dissociated Movements	87,11±10,66	85,12±12,85	58,91±18,01	Z=2,691	0,002*
Grasp	82,80±15,89	66,99±13,88	48,89±18,70	F=12,275	0,000*
Weight Bearing	93,44±6,53	86,67±11,69	63,65±15,41	Z=15,363	0,000*
Protective Extension	79,17±12,07	68,81±14,35	45,30±16,00	F=17,450	0,000*
QUEST Total	85,66±8,57	76,89±11,69	54,93±13,88	F=22,361	0,000*
BBT DH	30,14±8,05	19,67±6,15	18,20±8,78	Z=12,251	0,002*
BBT ND	22,07±10,84	13,00±9,63	12,50±7,99	Z=5,648	0,059

QUEST: Quality of Upper Extremity Skills Test, BBT DH: Box Block Test Dominant Hand, BBT ND: Box Block Test Non-dominant Hand GMFCS : Gross Motor Function Classification System, sd: Standard Deviation, * $p<0.05$

4.2 Results of Quality of Life Assessment

The mean percentage scores of the subtests of the QOL assessment according to the UCP and BCP groups are shown in Table 4.5. There were no significant difference between groups in Social wellbeing and acceptance, Feelings about functioning, Participation and physical health, Emotional wellbeing and self esteem, Pain and impact of disability, Family Health and CPQOL Total evaluations.

The UCP group had a statistically significantly higher score in the Access to Services evaluation than the BCP group ($p=0,022$).

Table 4.5. Comparison of CPQOL scores according to topographical classification

%	UCP mean±sd	BCP mean±sd	t/U	p
Social wellbeing and acceptance	86,19±8,03	83,55±9,84	t=0,797	0,432
Feelings about functioning	77,80±12,23	74,67±15,74	t=,808	0,426
Participation and physical health	76,53±13,06	68,67±14,84	t=1,529	0,137
Emotional wellbeing and self esteem	91,00±9,02	85,80±12,27	U=90,500	0,370
Access to Services	79,49±17,43	63,46±18,66	t=2,419	0,022*
Pain and impact of disability	65,01±17,20	65,57±14,45	t=-,097	0,923
Family Health	76,25±24,94	69,67±23,19	t=0,745	0,463
CPQOL Total	75,11±18,29	73,39±8,65	U=76,500	0,140

UCP: Unilateral Cerebral Palsy, BCP: Bilateral Cerebral Palsy, sd: Standard Deviation, CP QOL; Quality of Life Questionnaire, t= Independent Samples T-test, U=Mann Whitney-U test, * $p<0.05$

Table 4.6. Comparison of CPQOL subtest scores according to GMFCS

GMFCS	Level 1 mean±sd	Level 2 mean±sd	Level 3 mean±sd	F/Z	P
Social wellbeing and acceptance	83,78±7,13	89,55±8,47	83,32±11,31	F=1,071	0,357
Feelings about functioning	73,11±16,13	83,00±9,81	76,24±12,75	Z=2,063	0,356
Participation and physical health	69,55±13,92	76,29±17,34	73,88±13,87	F=0,532	0,593
Emotional wellbeing and self esteem	88,88±9,59	89,20±11,14	86,74±13,60	Z=0,356	0,939
Access to Services	72,08±17,91	84,15±20,82	61,42±17,57	F=6,273	0,043
Pain and impact of disability	66,84±18,56	66,90±8,33	62,22±14,96	F=0,283	0,756
Family Health	72,09±26,83	81,02±29,31	68,70±15,79	Z=3,665	0,160
CPQL Total	75,71±10,10	72,32±25,47	73,19±9,76	Z=1,369	0,504

GMFCS: Gross Motor Function Classification Systems, CP QOL; Cerebral Palsy Quality of Life Questionnaire, sd: Standard Deviation

Among the GMFCS levels, there was a statistically significant difference only in the Access to Services evaluation from the CPQOL subtests ($p=0.043$). There was a difference between GMFCS level 2 -3 in the service access test ($p=0.022$, $U=9000$).

There were no statistically significant difference between MACS levels in terms of CPQOL.

4.3 Results of Participation Assessment

Participation of children with CP was evaluated in three domains; participation at home, participation at school and participation at community and results of all domains are presented at Table 4.7. Children's participation was compared according to GMFCS Levels in three domains.

There were statistically significant difference at Average Frequency(AF) ($p=0,019$) and at Desire to Change (DC) ($p=0,038$) subtest in home participation domain. When Post Hoc Bonferroni analysis was applied to find the source of the significant difference in AF, the difference was found to be between GMFCS level 2-3 ($p=0.025$). When the source of the difference in the DC subtest is examined with the Mann Whitney-U test, between level 1-3 ($U=36.500$, $p= 0.047$) and between level 2-3 ($U=10.500$, $p=0.033$), the desire for change score at level 3 was statistically higher than level 2 and 1.

No significant difference was found between GMFCS levels in the Participated Activity Percentage (PA), Average Involvement(AI), Supports, Barriers, Environmental Helpfulness (EH), Environmental Resources (ER) and Overall Environmental Support (OES) subtests in the home participation domain.

There was a significant difference between the groups in the DC subtest in school participation ($p=0.020$). When the source of the significant difference was examined by Post hoc Bonferroni analysis, DC score of level 3 was found to be statistically higher between level 2 and 3 ($p=0.019$).

There were no significant difference between GMFCS levels in terms of AF, PA, AI, Supports, Barriers, EH, ER and OES subtests in the school participation domain.

There was a statistically significant difference at AI subtest in community participation domain ($p=0,006$). According to the Mann Whitney-U test, there were significant difference between level 1-2 ($U=2,000$, $p=0.001$) and level 2-3 ($U=9,000$, $p=0.022$).

There were no significant difference between GMFCS levels in terms of AF, PA, DC, Supports, Barriers, EH, ER and OES subtests in the community participation domain.



Table Table 4.7. Comparison of PEM CY scores according to GMFCS levels

	GMFCS	AF mean±sd	PA mean±sd	AI mean±sd	DC mean±sd	Supports mean±sd	Barriers mean±sd	EH mean±sd	ER mean±sd	OES mean±sd
HOME	Level1	6,63±0,83	91,42±8,64	4,17±0,52	57,86±21,19	47,07±28,67	8,21±15,25	91,36±11,01	82,78±18,07	86,92±11,66
	Level2	7,07±0,59	96,67±5,16	4,37±20,48	48,33±14,72	50,83±19,35	1,33±3,26	97,50±4,18	91,00±11,76	94,66±6,86
	Level3	5,85±0,93	81,00±15,24	3,96±0,55	76,00±24,13	58,80±26,54	4,40±7,59	89,60±12,31	86,10±10,91	87,95±8,48
	F/Z	F=4,635	Z=5,895	F=1,175	Z=3,687	Z=1,754	Z=1,198	Z=2,259	Z=1,136	F=1,338
	p	0,019	0,052	0,324	0,038	0,416	0,549	0,323	0,567	0,279
SCHOOL	Level1	4,17±0,88	58,46±17,25	4,33±0,43	60,00±23,09	34,46±17,44	12,92±14,03	84,08±13,80	82,31±12,69	83,46±11,23
	Level2	4,40±1,78	60,00±20,00	4,89±0,17	33,33±11,58	38,33±23,67	5,67±9,81	76,33±15,01	82,67±11,15	80,00±13,87
	Level3	4,71±0,85	77,14±13,80	4,06±1,03	77,14±17,99	52,28±23,13	20,14±19,27	86,28±10,98	79,43±16,01	83,00±12,48
	F/Z	F=0,681	Z=4,807	Z=3,480	F=4,786	F=1,829	Z=1,680	Z=2,259	Z=1,076	F=0,104
	p	0,517	0,090	0,176	0,020	0,186	0,432	0,323	0,584	0,902
COMMUNITY	Level1	3,69±0,90	61,72±17,91	4,20±0,53	45,15±23,38	33,07±22,51	13,64±16,65	83,43±14,99	76,57±15,89	80,50±13,68
	Level2	4,70±1,30	65,37±6,18	6,03±1,49	42,88±20,37	37,67±9,69	13,17±10,67	79,50±14,05	86,83±10,50	82,67±10,32
	Level3	4,01±0,80	61,00±7,38	4,46±1,24	50,22±22,29	23,40±10,97	22,20±14,64	76,10±17,28	76,00±12,57	76,20±13,26
	F/Z	F=2,325	F=0,216	Z=10,072	F=14,02	F=1,497	Z=3,182	F=,649	F=1,365	F=0,544
	p	0,117	0,807	0,006	0,786	0,242	0,204	0,531	0,272	0,587

AF: Average Frequency, PA : Participated Activity Percentage, AI: Average Involvement, EH: Environmental Helpfulness, ER: Environmental Resources, OES: Overall Environmental Support, GMFCS : Gross Motor Function Classification System, sd: Standard Deviation, * p<0.0

There was no difference between MACS levels in terms of PEM CY score.

4.4. Relationship Between GMFCS, MACS, BBT, QUEST and CP QOL Scores

Table 4.8 indicates the relationship between GMFCS, MACS, BBT, QUEST and CPQOL.

There was a positive moderate correlation between GMFCS level and MACS level (Pearson $r=0.567$, $p=0.001$). GMFCS level had a moderate negative correlation with BBT DH (Pearson $r=-0.571$, $p=0.001$), moderate negative correlation with BBT ND (Pearson $r=-0.421$, $p=0.021$) and a strong negative correlation was found with the QUEST total score (Pearson $r=-0.775$, $p=0.000$).

MACS level had a strong negative correlation with BBT DH (Pearson $r=-0.744$, $p=0.000$), a negative strong correlation with BBT ND (Pearson $r=-0.795$, $p=0.021$), and a strong negative correlation with QUEST total score (Pearson $r=-0.861$, $p=0.000$).

There was a strong positive correlation (Pearson $r=0.853$, $p=0.000$) between BBT DH and BBT ND, and a strong positive correlation between BBT DH and QUEST total score (Pearson $r=0.696$, $p=0.000$).

There was a moderate positive correlation between BBT ND score and QUEST total score (Pearson $r=0.696$, $p=0.000$).

No statistically significant correlation was found between CPQOL and other evaluation results.

Table 4.8. Relationship Between GMFCS, MACS, BBT, QUEST and CP QOL Scores

		GMFCS	MACS	BBT DH	BBT ND	QUEST TOTAL	CP QOL TOTAL
GMFCS	r	1	0,567**	-0,571**	-0,421*	-0,775**	-0,087
	p		0,001	0,001	0,021	0,000	0,647
MACS	r		1	-0,744**	-0,795**	-0,861**	-0,009
	p			0,000	0,021	0,000	0,961
BBT DH	r			1	0,853**	0,696**	0,150
	p				0,000	0,000	0,428
BBT ND	r				1	0,696**	0,066
	p					0,000	0,728
QUEST TOTAL	r					1	0,045
	p						0,814
CPQL TOTAL	r						1
	p						

GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System, BBT DH: Box Block Test Dominant Hand, BBT ND: Box Block Test Non-dominant Hand, QUEST: Quality of Upper Extremity Skills Test, CP QOL; Quality of Life Questionnaire, r= correlation coefficient, *p<0.05, **p<0.01

4.5 Relationship Between PEM CY Domains and GMFCS, MACS, BBT, QUEST, CP QL Scores

The relationship between GMFC level, MACS level, BBT score, QUEST total score and CP QOL score and the participation subtests of children with CP in the home, school and community domains were analyzed separately.

The relationship of the subtests of the home participation domain with the GMFCS level, MACS level, BBT score, QUEST total score and CP QOL score is presented in Table 4.9.

In the home participation domain, a positive weak correlation was found between the AF subtest and BBT DH (Pearson $r = 0.377$, $p = 0.040$). In addition, there was a moderate positive correlation between AF subtest and CP QOL (Pearson $r = 0.402$, $p=0.028$).

There was moderate positive correlation between PA subtest and CP QOL (Pearson $r=0.367$, $p=0.046$).

There were a positive moderate correlation between DC and MACS levels (Pearson $r=0,390$, $p=0,033$). DC subtest had a negative moderate correlation with BBT ND (Pearson $r = -0,387$, $p=0,034$) Also there was moderate negative correlation between DC and QUEST total score (Pearson $r = -0.455$, $p=0,012$). In addition DC had a negative moderate correlation with CP QOL (Pearson $r=-0,423$, $p=0,020$).

Table 4.9. Relationship Between Home Participation and GMFCS, MACS, BBT, QUEST, CP QOL Score

HOME		GMFCS	MACS	BBT DH	BBT NDH	QUEST	CP QL
AF	r	-0,326	-0,296	0,377*	0,211	0,322	0,402*
	p	0,079	0,133	0,040	0,263	0,082	0,028
PA	r	-0,268	-0,166	0,285	0,071	0,197	0,367*
	p	0,152	0,381	0,126	0,710	0,296	0,046
AI	r	-0,149	-0,350	0,303	0,280	0,330	-0,055
	p	0,431	0,058	0,104	0,134	0,075	0,773
DC	r	0,309	0,390*	-0,387*	-0,278	-0,455*	-0,423*
	p	0,097	0,033	0,034	0,137	0,012	0,020

AF: Average Frequency, PA : Participated Activity Percentage, AI:Average Involvement, GMFCS : Gross Motor Function Classification System, MACS: Manual Ability Classification System, BBT DH: Box Block Test Dominant Hand, BBT ND: Box Block Test Non-dominant Hand, QUEST: Quality of Upper Extremity Skills Test, CP QOL; Quality of Life Questionnaire, r= correlation coefficient,*p<0.05, **p<0.01

The relationship of the subtests of the school participation domain with the GMFCS level, MACS level, BBT score, QUEST total score and CP QOL score is presented in Table 4.10.

There was a moderate negative correlation between school participation subtests PA and GMFCS level (Pearson $r=-0,431$, $p=0,040$).

DC negatively and moderately correlated with QUEST total score (Pearson $r=0,458$, $p=0,028$).

Table 4.10. Relationship Between School Participation and GMFCS, MACS, BBT, QUEST, CP QOL Score

SCHOOL		GMFCS	MACS	BBT DH	BBT NDH	QUEST	CP QL
AF	r	0,210	-0,173	0,155	0,130	-0,082	0,283
	p	0,336	0,431	0,479	0,555	0,708	0,191
PA	r	-0,431*	0,044	-0,007	0,142	-0,248	0,137
	p	0,040	0,841	0,974	0,519	0,253	0,534
AI	r	0,049	-0,278	0,221	0,345	0,180	0,188
	p	0,845	0,185	0,311	0,107	0,411	0,592
DC	r	0,223	0,302	-0,148	-0,323	-0,458*	-0,087
	p	0,305	0,161	0,501	0,133	0,028	0,693

AF: Average Frequency, PA : Participated Activity Percentage, AI:Average Involvement, GMFCS : Gross Motor Function Classification System, MACS: Manual Ability Classification System, BBT DH: Box Block Test Dominant Hand, BBT ND: Box Block Test Non-dominant Hand, QUEST: Quality of Upper Extremity Skills Test, CP QOL; Quality of Life Questionnaire, r= correlation coefficient,*p<0.05, **p<0.01

The relationships between Community participation domain of PEM CY assessment with the GMFCS levels, MACS levels, BBT score, QUEST total score and CP QOL score were presented in Table 4.11.

Also, there was a positive moderate correlation between AI subtest and CPQOL (Pearson $r=0,371$, $p=0,044$).

Table 4.11. Relationship Between Community Participation and GMFCS, MACS, BBT, QUEST, CP QOL Score

COMMUNITY		GMFCS	MACS	BBT DH	BBT NDH	QUEST	CP QL
AF	r	0,183	-0,027	0,017	-0,061	-0,071	0,002
	p	0,334	0,886	0,929	0,748	0,709	0,993
PA	r	-0,085	-0,119	0,222	0,013	0,062	-0,017
	p	0,654	0,532	0,238	0,947	0,744	0,928
AI	r	0,108	0,061	-0,133	-0,080	0,003	0,371*
	p	0,572	0,750	0,483	0,675	0,989	0,044
DC	r	0,061	0,191	-0,263	-0,183	-0,258	-0,271
	p	0,747	0,312	0,160	0,333	0,168	0,147

AF: Average Frequency, PA : Participated Activity Percentage, AI:Average Involvement, GMFCS : Gross Motor Function Classification System, MACS: Manual Ability Classification System, BBT DH: Box Block Test Dominant Hand, BBT ND: Box Block Test Non-dominant Hand, QUEST: Quality of Upper Extremity Skills Test, CP QOL; Quality of Life Questionnaire, r= correlation coefficient,*p<0.05, **p<0.01

Table 4.12 presents the relationship between PEM CY Environment score and CPQOL. Accordingly, there is a moderate positive correlation ($r=0.447$) between home Feeling about Functioning and Home EH, Participation and physical health and EV EH, Access to Service and home EH, and CPQOL total and home EH. There is a moderate positive correlation between Access to service and Home ER, and between Family health and ER. There are positive moderate correlations between Feelings about Functioning and OES, Participation and Physical health and OES, Emotional Wellbeing and OES, Access to Services and OES, Family health and OES.

There are moderate correlations between Feeling Functioning and EH, between Family health and EH, and between CPQOL total score and EH in school domain. There is a strong correlation between Access to Service and EH. There is moderate correlation between Access to Service and ER in school domain. There is a strong correlation between Access to Service and OES in school domain. There is moderate correlation between Family Health and OES in school attendance, and between CPQOL total score and OES.

There is no relationship between EH and CPQOL in community participation. There are moderate correlations between Emotional Wellbeing and ER, Access to Service and ER, Pain and ER, Family health and ER, and CPQOL total score and ER. There is moderate correlation between Access to Service and OES, Family health and OES, and CPQOL total score and OES.

Table 4.12. Relationship PEM CY environmental assessment and CPQOL

		HOME			SCHOOL			ENVIRONMENT		
	p/r	EH	ER	OES	EH	ER	OES	EH	ER	OES
SWA	r	0,166	0,159	0,300	0,022	-0,178	-0,015	0,136	0,102	-0,060
mean±sd	p	0,382	0,402	0,107	0,921	0,415	0,946	0,474	0,592	0,754
FF	r	0,447*	0,342	0,535**	0,423*	0,169	0,402	0,317	0,333	0,356
mean±sd	p	0,013	0,065	,002	0,044	0,441	0,057	0,088	0,072	0,053
PPH	r	0,414*	0,210	0,430*	0,379	0,033	0,230	0,088	0,168	0,097
mean±sd	p	0,023	0,266	0,018	0,074	0,882	0,291	0,642	0,376	0,609
EWS	r	0,250	0,319	0,387*	0,310	0,220	0,324	0,027	0,407*	0,163
mean±sd	p	0,182	0,086	0,035	0,151	0,313	0,132	0,888	0,026	0,390
AC	r	0,548**	0,607**	0,646**	0,744**	0,524*	0,738**	0,290	0,543**	0,462*
mean±sd	p	0,002	0,000	0,000	0,000	0,010	0,000	0,120	0,002	0,010
PID	r	0,049	0,052	-0,013	0,062	0,069	0,081	0,070	0,414*	0,184
mean±sd	p	0,797	0,786	0,944	0,778	0,755	0,714	0,713	0,023	0,330
FH	r	0,557**	0,529**	0,597**	0,596**	0,487*	0,630**	0,226	0,612**	0,445*
mean±sd	p	0,001	0,003	0,001	0,003	0,018	0,001	0,229	0,000	0,014
CPQOL	r	0,478**	0,303	0,489**	0,531**	0,227	0,468*	0,313	0,512**	0,453*
Total	p	0,008	0,104	0,006	0,009	0,297	0,024	0,092	0,004	0,012
mean±sd										

SWA=Social wellbeing and acceptance, FF= Feelings about functioning, PPH=Participation and Physical Health, EWS= Emotional wellbeing and self esteem, AC= Access to Services, PID= Pain and impact of disability, FH= Family Health, EH=Environmental Helpfulness, ER= Environmental Resources, OES=Overall Environmental Support, r= correlation coefficient , p<0.05, **p<0.01

5.DISCUSSION

This study aimed to investigate the effect of upper extremity functions and manual dexterity on participation and quality of life in children with CP. To investigate this, we used GMFCS to assess general physical motor capacity, MACS to assess manual ability, BBT to evaluate manual dexterity, QUEST to upper extremity function, PEM CY to assess participation and CPQOL to assess quality of life. All participants were divided into two groups as children with monoparetic and hemiparetic CP in UCP, diparetic and tetraparetic children in BCP (125). There was no significant difference between the UCP and BCP groups in terms of age, height, weight, BMI and gender.

In our study UCP groups are composed of mostly GMFCS Level 1-2 and MACS level 1-2. According to the literature, most of the children with UCP have MACS level 1-2 and GMFCS level 1-2. (126)

In our study, we found a relationship between motor functions and manual dexterity. There was a correlation between GMFCS level and MACS level of children with CP in our study. In the literature, it has been revealed that as the GMFCS level increases, there is a decrease in manual ability. Unes S. et al found a strong correlation between GMFCS level and MACS level in their study (127).

According to our study there was a strong negative correlation between motor functions and upper extremity functions. GMFCS level and QUEST score were negatively correlated. Current literature stated that upper extremity functions decrease as CP severity increases justlike our results (128).

Also, in our study a correlation was found between upper extremity functions and manual dexterity. QUEST is correlated with both dominant and non dominant hand assessment o BBT. In the literature, a relationship has been found between manual dexterity including grip release and QUEST (129).

Results of our study indicates that UCP group has a statistically higher QUEST score than BCP. In the literature, the upper extremity scores of children with bilateral involvement were found to be lower (130, 131). In addition, the QUEST includes the total result of bilateral upper extremity assessment. All these may explain the higher score of the UCP group according to the QUEST result in our study.

A strong negative correlation between upper extremity function and manual ability was found in this study. QUEST and MACS were negatively and strongly correlated. Loewen P. et al found a relationship between upper extremity performance and the severity of hand impairment (132).

In our study, dexterity was found to be significantly higher in the UCP group in the dominant hand compared to the BCP group. On the other hand, there was no difference between the UCP and BCP groups in the non-dominant hand BBT test. Similar to our results, Golubović Š et al found a difference in manual dexterity between CP subgroups. Hemiparesis has a higher score on the BBT test than diparesis and quadriplegia. (25). This can be explained by the fact that some participants in the UCP group had a more severe impairment at their non-dominant hand than the impairment of the non-dominant hand in the BCP group.

In addition, there is a significant difference between BBT Dominant hand scores according to GMFCS levels in our study. GMFCS level 1 has higher scores than 2 and 3. Moreover, a moderate negative correlation was found with GMFCS in both the dominant and non-dominant hands. The literature supports this conclusion (25).

In our study, a strong negative correlation was found between manual ability and manual dexterity. We found that MACS levels are negatively and strongly correlated to both dominant and non dominant hand of BBT score. According to the literature, manual dexterity and manual ability are parameters that affect each other. Similar to our study, Ohrvall A. M. et al examined the relationship between manual ability and manual dexterity and found a strong negative correlation between BBT and MACS levels (26).

5.1 Quality of Life Outcomes

In our study, it was found that the scores of all CPQOL subtests in the UCP group were higher than those in the BCP group, except for the Access to Service assessment, but the difference was not statistically significant. In addition, when the scores of the CPQOL subtests were compared according to the GMFCS levels, no significant difference was found between the groups except Access to Service subtest. Although there are many studies in the literature supporting that quality of life decreases as the level of GMFCS increases, there are also other studies which found no difference between the subtests of the CPQOL score according to the GMFCS levels, as in our

study. In the study of Marxsis T. et al, no relationship was found between the degree of physical involvement and quality of life in children with CP (133). Soleimani F. et al found that children with high motor function and mobility achieved higher scores in the Functioning, Participation and Physical Health and Emotional Well-being subtests in CPQOL, but there was no difference in the remaining scores. In another study, a correlation was found with the GMCS level in the Feelings about Functioning, Participation and Physical health subtests, but not with other subtests (134).

We consider that there may be some reasons for the direct correlation was not found between GMFCS levels and quality of life. QOL is a multidimensional term, functional level is only one of the factors that affects QOL.

Initially, the CPQOL is a subjective questionnaire and parents' answers about how the child is feeling may not directly reflect the truth. According to some studies, the answers of the parents are not correlated with the answers of the children (135). Expectations of families from children may affect the CPQOL score. Families' expectations in children with high GMFCS levels may be higher and CPQOL responses were low as they compared their children with typically developing children (136). According to the study of Bendixen et al., while families focus on what children cannot do and negativities, children focus on activities they can do and positive thinking. Families underestimate and ignore their children's happiness in life (137). Especially in non-observable items such as feelings and stress, families have difficulty in scoring (138). Consistent with the study of Kołtuniuk A. Et al found that physical capacity is not correlated with in emotional and social dimensions, as in our study (139). Some authors have described this situation as the disability paradox. According to Rosenbaum and Landfeldt, some children with higher physical involvement have better QOL than other children who have less physically involved. (140, 141).

Another disadvantage of caregiver scoring is that the acceptance of families about children's situation. This factor affects the child's acceptance of their situation and his capacity to cope with the disease. Thus acceptance of families affect childrens' quality of life (142).

The subtest of pain and quality of life was not correlated accorging to our results. On the contrary, studies revealed that there is a negative correlation between

pain dimension and quality of life in literature (139). This may be explained by the fact that our study did not include GMFCS levels 4 and 5 which have more pain. Also we excluded children who had surgery or botox in the last 6 months. For this reason, a correlation between pain and QOL could not be found determined according to the GMFCS level.

There was no relationship between physical capacity of children and family health in our study. Similar to our study, Park ET et al stated that the happiness level of the family is not related to GMFCS level or MACS level (143).

According to our study, it was found that children with GMFCS level 3 had lower score in Accessing Services subtest than the others. This can be explained by the fact that children at level 3 attend more frequently pediatric examination, physiotherapy and occupational therapy or other services relative to others. There are studies in the literature that support the same conclusion (19, 145). In addition, the rate of accessing to service differs in children with CP, depending on the financial situation of the family, the welfare of the country and the opportunities it provides to the patients (146,147,148).

In our study, no significant correlation was found between MACS level, BBT score and CPQOL score. On the other hand, most studies in the literature revealed that there is a positive correlation between hand functions and QOL (149, 125, 150). In studies that found correlations between manual skill and quality of life, MACS levels 1-5 were included (125). Since our study included children with MACS level 1-3, there may not be a relationship between MACS level and CPQOL.

Upper extremity functions and quality of life is not directly related according to our study. However, in the literature, quality of life in children with CP increases as upper extremity functionality increases (132, 151).

These studies emphasized that upper extremity functions are especially important in ADL (Activity of Daily Living) and fulfilling daily life tasks affects the quality of life of children with CP (152). The lack of correlation between manual ability and QOL in our study may be explained by the fact that CPQOL does not directly assess the ADL. In addition, although there is a correlation between UE functionality and the total score of the QOL assessment in the literature, no correlation was found in all QOL subtests (100).

Moreover, the fact that we did not find correlation between MACS, BBT QUEST and CP QL in our study may be explained by psychological and motivational factors. Emotional factors may be more determinant than physical abilities in quality of life (133).

Furthermore, the fact that our study was conducted at a period which corona restrictions were mild to moderate may have affected the QOL score. In the literature, it has been stated that the Covid 19 pandemic reduces participation in school and therapy, and increases stress and depression in children with CP (153).

5.2.1 Participation Outcomes

In our study, it was found that GMFCS level 3 participated more frequently than level 2 in home participation and score of desire to change is higher at children with GMFCS level 3 both in home and school participation. There are studies that support children have higher participation at lower GMFCS levels (154,155).

There were no differences between GMFCS levels in community participation in our study. Regardless of GMFCS levels, families rated community participation lower than school and home participation. This may caused by community participation requires more effort and less preferred by females. Also Covid 19 restrictions may have effect on this result.

In terms of Average Involvement, while there was no difference between GMFCS levels in school participation and home participation, it was found that level 2 had higher score at community participation.

While there was no difference between the GMFCS levels of the Percentage of participated activity, a negative moderate correlation was found between the number of activities attended at school and the GMFCS level in our study. Just like in literature, children with high functionality participate in more activities at school than those with low functionality (156).

We found that percentage of activities attended does not differ according to the GMFCS level in home participation and it may be due to the fact that the questions evaluating home participation in the PEM CY test composed of generally questions about sedentary participation. Questions such as playing computer, watching TV, socializing using technology assess domestic sedentary participation and regardless of

GMFCS level, children's sedentary participation is high. Vila-Nova et al found similarly high levels of sedentary participation in the home, independent of physical capacity (107). In another study conducted in 2019, no relationship was found between the percentage of activity and the GMFCS level (157).

The community participation, the participation of children at all GMFCS levels was generally found to be low compared to activities at school and at home in our study. This can be explained by the fact that the effort to be provided by both children and caregivers for home and school participation is easier than community participation. Justlike our results there are also studies in literature showing that home participation is higher than other domains (158).

In terms of participation frequency, there was no difference between GMFCS levels in the school and community areas. Similar to our study, Alghamdi et al found no difference between GMFCS level 2-3 in their study (159).

In our study, the fact that there is no difference between GMFCS levels and MACS levels in the average involvement subtest, which measures how willingly children participate during the activity, can be explained by motivational factors. Children's motivation and willingness to participate during activity are more determinative than physical capacity in involvement. There are studies in the literature that support this argument (107, 160).

A correlation was found between family's desire for change, which is a subtest of PEM CY, and MACS, BBT in our study. Likewise, when the relationship between manual ability, gross manual dexterity and participation is examined, there are studies in the literature that support that there is a correlation between them (161,162).

On the other hand, no correlation was found between manual dexterity and participation in other subtests of PEM CY in our study. Similar to this results there are also studies in the literature that do not find a relationship between participation and manual ability and dexterity (36,163, 164).

We also found that upper extremity function is correlated to one of the subtests of participation, desire to change domain in both home and school. Similarly, most of the studies in the literature found a relationship between UE function and participation (25, 2). This results may be due to the fact that children's motivation was unstable both

during the assessment and participation in daily life and their motivation and emotional status were not directly dependent on their physical capacity and skills (164, 167). Earde, P. emphasized the importance of emotional factors in participation in his study (167).

In our study there were no correlation between physical capacity, manual ability and participation except a few subtests. According to some studies, such as Vila-Nova F. et al's study, a relationship was found between children's physical levels and participation were found in only some subtest (107). Similar to our study, especially in the Enjoyment evaluation there were no difference between GMFCS and MACS level. Also, studies that found correlations between dexterity and participation were included up to MACS level 5, as in Pashmdarfard M.'s study (8). In our study, onlyn MACS level 1-3included. For this reason, the difference between levels may not be significant and there may not be a correlation between MACS levels and participation.

No relationship was found between school participation and quality of life in our study. We consider that this conclusion may caused by the effect of Covid 19 restrictions.

In the home domain, it was observed that the quality of life increased as the percentage of children's participation and the frequency of participation increased.

Community participation was correlated with avarage involvement and quality of life. The fact that children who happily participate in social activities has higher quality of life can be explained by motivational factors. Children who participate activities happily also see life more positively than others and feel more satisfied with their lives.

5.2.2. Environmental Outcomes

The environmental assessment of PEM CY includes the physical conditions of the environment in home, school and community environments, the participants' perception of environmental opportunities as a barrier or support, and the resources of families such as time and money.

We have found the highest correlations were found between PEM CY score and CPQOL. Most of the subtests of quality of life assessment were related to environment assessment results in our study. Justlike our study, literature states that environmental

conditions affect children's participation in life (163). Environmental regulations are important for the participation of children with CP in life (168). Wheelchair-friendly roads, facilitations at transportation, and specially arranged classrooms are required for school (169). Lack of environmental regulations are perceived as barriers to the participation of children with CP and reduce their participation (170). Governments are supposed to provide environmental regulations for people with disabilities (171). Since the government support is higher in countries with high levels of welfare, there is also a difference between countries in participation (172). Alemdar et al emphasized in their study that the participation of Turkish children is low (173). In developed countries, community participation is supported as well as school participation (173).

In our study, it was found that children had difficulties especially in Access to Service. As in developed countries, children with CP need support in school participation, transportation, social activities and especially access to the health system, access to physiotherapy, occupational therapy and doctor control (174,113). Even if the participation of children in school and society is regulated by the government within the framework of certain rules, problems arise in terms of acceptance and support of children in practice, and this affects children emotionally (175).

Besides, assistive devices are also important for the active participation of children in daily life, and participation may decrease when they cannot be obtain due to financial reasons (173,176).

According to our study financial problems can also restrict participation of children. There are also other studies in literature that revealed the importance of financial factors in participation of children (177, 170). Caregiving for a child with CP is more demanding if families are not financially supported by the governments (170). Children's participation in life may be restricted due to their family's financial situation (177).

Moreover, the fact that the family does not have enough time to support the child's participation can also be counted as a barrier. Children's participation in life changes according to the family's preference for using time and financial resources (179).

Limitations of this study; Restriction of school and community activities due to Covid 19 during the study period may affect the study. The socio-economic information

of the families which may affect the participation of the children with CP was not questioned in this study.

6.CONCLUSION

No correlation was found between manual ability, upper extremity function, and quality of life in this study.

Moderate correlation was found between manual ability, upper extremity function, and some of participation.

Also there was a correlation between quality of life and participation.

This study revealed that environmental factors have an important effect on participation.

7. REFERENCES

1. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006 [published correction appears in *Dev Med Child Neurol*. 2007 Jun;49(6):480]. *Dev Med Child Neurol Suppl*. 2007;109:8-14.
2. Ko EJ, Sung IY, Moon HJ, Yuk JS, Kim HS, Lee NH. Effect of Group-Task-Oriented Training on Gross and Fine Motor Function, and Activities of Daily Living in Children with Spastic Cerebral Palsy. *Phys Occup Ther Pediatr*. 2020;40(1):18-30.
3. Şahin S, Köse B, Aran OT, Bahadır Ağce Z, Kayıhan H. The Effects of Virtual Reality on Motor Functions and Daily Life Activities in Unilateral Spastic Cerebral Palsy: A Single-Blind Randomized Controlled Trial. *Games Health J*. 2020;9(1):45-52.
4. Resch C, Van Kruijsbergen M, Ketelaar M, et al. Assessing participation of children with acquired brain injury and cerebral palsy: a systematic review of measurement properties. *Dev Med Child Neurol*. 2020;62(4):434-444. doi:10.1111/dmcn.14465
5. Cameron D, Willoughby C, Messer D, Lux M, Aitken M, Getz K. Assessing Participation Burden in Clinical Trials: Introducing the Patient Friction Coefficient. *Clin Ther*. 2020;42(8):e150-e159.
6. Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol*. 2017;59(1):16-25.
7. Drummond AF, Coster WJ, Gomes AMR, Mancini MC. Children's Participation in Household Tasks: Caregiver Importance and Satisfaction. *OTJR (Thorofare N J)*. 2019;39(3):151-158.
8. Pashmdarfard M, Amini M, Hassani Mehraban A. Participation of Iranian Cerebral Palsy Children in Life Areas: A Systematic Review Article. *Iran J Child Neurol*. 2017;11(1):1-12.
9. Longo E, Badia M, Orgaz BM. Patterns and predictors of participation in leisure activities outside of school in children and adolescents with Cerebral Palsy. *Res Dev Disabil*. 2013;34(1):266-275.

10. Abu-Dahab SMN, Alheresh RA, Malkawi SH, Saleh M, Wong J. Participation patterns and determinants of participation of young children with cerebral palsy. *Aust Occup Ther J*. 2021;68(3):195-204. doi:10.1111/1440-1630.12714
11. Friedman SL, Norwood KW Jr; COUNCIL ON CHILDREN WITH DISABILITIES. Out-of-Home Placement for Children and Adolescents With Disabilities-Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity. *Pediatrics*. 2016;138(6):e20163216.
12. Whitney DG, Peterson MD, Warschausky SA. Mental health disorders, participation, and bullying in children with cerebral palsy. *Dev Med Child Neurol*. 2019;61(8):937-942.
13. Alghamdi MS, Chiarello LA, Palisano RJ, McCoy SW. Understanding participation of children with cerebral palsy in family and recreational activities. *Res Dev Disabil*. 2017;69:96-104.
14. Milićević M. Home participation of children with and without cerebral palsy in Serbia: an exploratory study. *Disabil Rehabil*. 2020;42(25):3696-3706.
15. Amini M, Saneii SH, Pashmdarfard M. Factors affecting social participation of Iranian children with cerebral palsy. *Occup Ther Health Care*. 2018;32(3):290-305.
16. Mei C, Reilly S, Reddihough D, et al. Activities and participation of children with cerebral palsy: parent perspectives. *Disabil Rehabil*. 2015;37(23):2164-2173.
17. Adegboye D, Sterr A, Lin JP, Owen TJ. Theory of mind, emotional and social functioning, and motor severity in children and adolescents with dystonic cerebral palsy. *Eur J Paediatr Neurol*. 2017;21(3):549-556. doi:10.1016/j.ejpn.2017.01.013
18. Lindsay S, McPherson AC. Experiences of social exclusion and bullying at school among children and youth with cerebral palsy. *Disabil Rehabil*. 2012;34(2):101-109.
19. Alghamdi MS, Chiarello LA, Palisano RJ, McCoy SW. Understanding participation of children with cerebral palsy in family and recreational activities. *Res Dev Disabil*. 2017;69:96-104.
20. Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. (1998). *Psychological medicine*, 28(3), 551–558.
21. DA Fonseca Filho GG, Lopes AC, Bezerra RB, et al. Assessment of child development in premature babies based on the ICF biopsychosocial model. *Eur J Phys Rehabil Med*. 2021;57(4):585-592.
22. Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. *Arch Dis Child*. 2001;84(3):205-211.
23. Houlihan CM, O'Donnell M, Conaway M, Stevenson RD. Bodily pain and health-related quality of life in children with cerebral palsy. *Dev Med Child Neurol*. 2004;46(5):305-310.

24. Chen KL, Tseng MH, Shieh JY, Lu L, Huang CY. Determinants of quality of life in children with cerebral palsy: a comprehensive biopsychosocial approach. *Res Dev Disabil.* 2014;35(2):520-528.
25. Golubović Š, Slavković S. Manual ability and manual dexterity in children with cerebral palsy. *Hippokratia.* 2014;18(4):310-314.
26. Burtner PA, Poole JL, Torres T, et al. Effect of wrist hand splints on grip, pinch, manual dexterity, and muscle activation in children with spastic hemiplegia: a preliminary study. *J Hand Ther.* 2008;21(1):36-43.
27. Koman LA, Gelberman RH, Toby EB, Poehling GG. Cerebral palsy. Management of the upper extremity. *Clin Orthop Relat Res.* 1990;(253):62-74.
28. Bonnefoy-Mazure A, Sagawa Y Jr, Lascombes P, De Coulon G, Armand S. A descriptive analysis of the upper limb patterns during gait in individuals with cerebral palsy. *Res Dev Disabil.* 2014;35(11):2756-2765.
29. Russo RN, Skuza PP, Sandelance M, Flett P. Upper limb impairments, process skills, and outcome in children with unilateral cerebral palsy. *Dev Med Child Neurol.* 2019;61(9):1080-1086.
30. Sakzewski L, Ziviani J, Boyd RN. Efficacy of upper limb therapies for unilateral cerebral palsy: a meta-analysis. *Pediatrics.* 2014;133(1):e175-e204.
31. Schmidt AK, van Gorp M, van Wely L, et al. Autonomy in participation in cerebral palsy from childhood to adulthood. *Dev Med Child Neurol.* 2020;62(3):363-371.
32. Tonmukayakul U, Imms C, Mihalopoulos C, et al. Health-related quality of life and upper-limb impairment in children with cerebral palsy: developing a mapping algorithm. *Dev Med Child Neurol.* 2020;62(7):854-860.
33. Pashmdarfard M, Shervin Badv R. The Impact of Manual Ability Level on Participation of Children with Cerebral Palsy in Life Areas: A Cross-Sectional Study. *Iran J Child Neurol.* 2019;13(3):83-91.
34. Almasri NA, Saleh M, Abu-Dahab S, Malkawi SH, Nordmark E. Functional profiles of children with cerebral palsy in Jordan based on the association between gross motor function and manual ability. *BMC Pediatr.* 2018;18(1):276. Published 2018 Aug 21.
35. Kachmar O, Kushnir A, Matiushenko O, Hasiuk M. Influence of Spinal Manipulation on Muscle Spasticity and Manual Dexterity in Participants With Cerebral Palsy: Randomized Controlled Trial. *J Chiropr Med.* 2018;17(3):141-150.
36. Angelin AC, Sposito AM, Pfeifer LI. Influence of functional mobility and manual function on play in preschool children with cerebral palsy. *Hong Kong J Occup Ther.* 2018;31(1):46-53.
37. Vitrikas K, Dalton H, Breish D. Cerebral Palsy: An Overview. *Am Fam Physician.* 2020;101(4):213-220.
38. Ruiz Brunner MM, Cuestas E. La construcción de la definición parálisis cerebral: un recorrido histórico hasta la actualidad. [The construction of cerebral palsy definition: a

historical journey to the present]. *Rev Fac Cien Med Univ Nac Cordoba*. 2019;76(2):113-117. Published 2019 Jun 19.

39. Tomás CC, Oliveira E, Sousa D, et al. Proceedings of the 3rd IPLeiria's International Health Congress : Leiria, Portugal. 6-7 May 2016. *BMC Health Serv Res*. 2016;16 Suppl 3(Suppl 3):200. Published 2016 Jul 6.

40. Graham HK, Rosenbaum P, Paneth N, et al. Cerebral palsy. *Nat Rev Dis Primers*. 2016;2:15082. Published 2016 Jan 7. Michael-Asalu A, Taylor G, Campbell H, Lelea LL, Kirby RS. Cerebral Palsy: Diagnosis, Epidemiology, Genetics, and Clinical Update. *Adv Pediatr*. 2019;66:189-208. doi:10.1016/j.yapd.2019.04.002

41. Michael-Asalu A, Taylor G, Campbell H, Lelea LL, Kirby RS. Cerebral Palsy: Diagnosis, Epidemiology, Genetics, and Clinical Update. *Adv Pediatr*. 2019;66:189-208.

42. Christine C, Dolk H, Platt MJ, et al. Recommendations from the SCPE collaborative group for defining and classifying cerebral palsy. *Dev Med Child Neurol Suppl*. 2007;109:35-38.

43. Prevalence and characteristics of children with cerebral palsy in Europe. *Dev Med Child Neurol*. 2002;44(9):633-640.

44. Korzeniewski SJ, Slaughter J, Lenski M, Haak P, Paneth N. The complex aetiology of cerebral palsy. *Nat Rev Neurol*. 2018;14(9):528-543. doi:10.1038/s41582-018-0043-6

45. Serdaroglu A, Cansu A, Ozkan S, Tezcan S. Prevalence of cerebral palsy in Turkish children between the ages of 2 and 16 years. *Dev Med Child Neurol*. 2006;48(6):413-416. doi:10.1017/S0012162206000910

46. Spittle AJ, Morgan C, Olsen JE, Novak I, Cheong JLY. Early Diagnosis and Treatment of Cerebral Palsy in Children with a History of Preterm Birth. *Clin Perinatol*. 2018;45(3):409-420.

47. Chee YY, Wong RMS, Wong MSC, Tso WWY, Wong WHS, Lee SL. Changes in Mortality and Cerebral Palsy in Extremely Low-Birth-Weight Infants in a Tertiary Center in Hong Kong. *Glob Pediatr Health*. 2020;7:2333794X20901932. Published 2020 Jan 22.

48. Sadowska M, Sarecka-Hujar B, Kopyta I. Cerebral Palsy: Current Opinions on Definition, Epidemiology, Risk Factors, Classification and Treatment Options. *Neuropsychiatr Dis Treat*. 2020;16:1505-1518. Published 2020 Jun 12.

49. Wimalasundera N, Stevenson VL. Cerebral palsy. *Pract Neurol*. 2016;16(3):184-194. doi:10.1136/practneurol-2015-001184

50. te Velde A, Morgan C, Novak I, Tantsis E, Badawi N. Early Diagnosis and Classification of Cerebral Palsy: An Historical Perspective and Barriers to an Early Diagnosis. *J Clin Med*. 2019;8(10):1599. Published 2019 Oct 3. doi:10.3390/jcm8101599

51. Bax M, Goldstein M, Rosenbaum P, et al. Proposed definition and classification of cerebral palsy, April 2005. *Dev Med Child Neurol*. 2005;47(8):571-576. doi:10.1017/s001216220500112x
52. Christine C, Dolk H, Platt MJ, et al. Recommendations from the SCPE collaborative group for defining and classifying cerebral palsy. *Dev Med Child Neurol Suppl*. 2007;109:35-38. doi:10.1111/j.1469-8749.2007.tb12626.x
53. Aisen ML, Kerkovich D, Mast J, et al. Cerebral palsy: clinical care and neurological rehabilitation. *Lancet Neurol*. 2011;10(9):844-852. doi:10.1016/S1474-4422(11)70176-4
54. Pandyan AD, Gregoric M, Barnes MP, et al. Spasticity: clinical perceptions, neurological realities and meaningful measurement. *Disabil Rehabil*. 2005;27(1-2):2-6.
55. Bar-On L, Molenaers G, Aertbeliën E, et al. Spasticity and its contribution to hypertonia in cerebral palsy. *Biomed Res Int*. 2015;2015:317047.
56. Levy, J. P., Oskoui, M., Ng, P., Andersen, J., Buckley, D., Fehlings, D., ... Shevell, M. (2019). *Ataxic-hypotonic cerebral palsy in a cerebral palsy registry. Neurology: Clinical Practice*, 10.1212/CPJ.0000000000000713.
57. Johari R, Maheshwari S, Thomason P, Khot A. Musculoskeletal Evaluation of Children with Cerebral Palsy. *Indian J Pediatr*. 2016;83(11):1280-1288.
58. Seyyar GK, Aras B, Aras O. Trunk Control in Children With Ataxic Cerebral Palsy. *Percept Mot Skills*. 2019;126(5):815-827.
59. Sendinç B, Özgüzel MH, Güzelalan AY, Konuralp N. Serebral palsy: epidemiology, clinic bulgular, sınıflandırma. *Hipokrat Lokomotor* 2005;33(6):239-43. KİTAP
60. Monbaliu E, Himmelmann K, Lin JP, et al. Clinical presentation and management of dyskinetic cerebral palsy. *Lancet Neurol*. 2017;16(9):741-749. doi:10.1016/S1474-4422(17)30252-1
61. Pharoah PO. Dyskinetic cerebral palsy in Europe: trends in prevalence and severity, on behalf of the SCPE Collaboration. *Arch Dis Child*. 2009;94(12):917-918.
62. Livanelioğlu A, Kerem M. *Serebral Palside Fizyoterapi*. Ankara: Pelikan Kitabevi; 2009.
63. Sankar C, Mundkur N. Cerebral palsy-definition, classification, etiology and early diagnosis. *Indian J Pediatr*. 2005;72(10):865-868.
64. Brandenburg JE, Fogarty MJ, Sieck GC. A Critical Evaluation of Current Concepts in Cerebral Palsy. *Physiology (Bethesda)*. 2019;34(3):216-229.
65. Reid SM, Carlin JB, Reddiough DS. Classification of topographical pattern of spasticity in cerebral palsy: a registry perspective. *Res Dev Disabil*. 2011;32(6):2909-2915.
66. Jones MW, Morgan E, Shelton JE, Thorogood C. Cerebral palsy: introduction and diagnosis (part I). *J Pediatr Health Care*. 2007;21(3):146-152.

67. Pountney, T., *Physiotherapy for Children*. New York: Butterworth-Heinemann; 2007
68. Green LB, Hurvitz EA. Cerebral palsy. *Phys Med Rehabil Clin N Am*. 2007;18(4):859-vii.
69. Stadsleiv K. Cognitive functioning in children with cerebral palsy. *Dev Med Child Neurol*. 2020;62(3):283-289. doi:10.1111/dmcn.14463
70. Berker AN, Yalçın MS. Cerebral palsy: orthopedic aspects and rehabilitation. *Pediatr Clin North Am*. 2008;55(5):1209-ix.
71. Blackman JA, Svensson CI, Marchand S. Pathophysiology of chronic pain in cerebral palsy: implications for pharmacological treatment and research. *Dev Med Child Neurol*. 2018;60(9):861-865.
72. Chiang KL, Kuo FC, Cheng CY, Chang KP. Prevalence and demographic characteristics of comorbid epilepsy in children and adolescents with cerebral palsy: a nationwide population-based study. *Childs Nerv Syst*. 2019;35(1):149-156. doi:10.1007/s00381-018-3920-9
73. Jan MM. Cerebral palsy: comprehensive review and update. *Ann Saudi Med*. 2006;26(2):123-132.
74. Duke R, Eyong K, Burton K, et al. The effect of visual support strategies on the quality of life of children with cerebral palsy and cerebral visual impairment/perceptual visual dysfunction in Nigeria: study protocol for a randomized controlled trial. *Trials*. 2019;20(1):417. Published 2019 Jul 10. doi:10.1186/s13063-019-3527-9
75. Hilgenberg AM, Cardoso CC, Caldas FF, Tschiedel Rde S, Deperon TM, Bahmad F Jr. Hearing rehabilitation in cerebral palsy: development of language and hearing after cochlear implantation. *Braz J Otorhinolaryngol*. 2015;81(3):240-247.
76. Jibril YN, Shamsu KA, Muhammad NB, Hasheem MG, Tukur AR, Salisu AD. Determinants of hearing loss in children with cerebral palsy in Kano, Nigeria. *Niger J Clin Pract*. 2021;24(6):802-807.
77. Mei C, Reilly S, Bickerton M, et al. Speech in children with cerebral palsy. *Dev Med Child Neurol*. 2020;62(12):1374-1382.
78. Pennington L, Goldbart J, Marshall J. Speech and language therapy to improve the communication skills of children with cerebral palsy. *Cochrane Database Syst Rev*. 2004;2004(2):CD003466.
79. Arvedson JC. Feeding children with cerebral palsy and swallowing difficulties. *Eur J Clin Nutr*. 2013;67 Suppl 2:S9-S12.
80. Wright AJ, Fletcher O, Scrutton D, Baird G. Bladder and bowel continence in bilateral cerebral palsy: A population study. *J Pediatr Urol*. 2016;12(6):383.e1-383.e8. doi:10.1016/j.jpuro.2016.05.027

81. Ozturk M, Oktem F, Kisioglu N, et al. Bladder and bowel control in children with cerebral palsy: case-control study. *Croat Med J.* 2006;47(2):264-270.
82. Marpole R, Blackmore AM, Gibson N, Cooper MS, Langdon K, Wilson AC. Evaluation and Management of Respiratory Illness in Children With Cerebral Palsy. *Front Pediatr.* 2020;8:333. Published 2020 Jun 24. doi:10.3389/fped.2020.00333
83. Hulst RY, Gorter JW, Voorman JM, et al. Sleep problems in children with cerebral palsy and their parents. *Dev Med Child Neurol.* 2021;63(11):1344-1350.
84. Blackmer AB, Feinstein JA. Management of Sleep Disorders in Children With Neurodevelopmental Disorders: A Review. *Pharmacotherapy.* 2016;36(1):84-98.
85. Milićević M, Weber P, Bolli P, Heimgartner N, Merlo P, Zehnder T, Kätterer C. Behavioral and emotional problems in children and adults with cerebral palsy. *Eur J Paediatr Neurol.* 2016;20(2):270-274.
86. Yamaguchi R, Nicholson Perry K, Hines M. Pain, pain anxiety and emotional and behavioural problems in children with cerebral palsy. *Disabil Rehabil.* 2014;36(2):125-130. doi:10.3109/09638288.2013.782356
87. Braito I, Maselli M, Sgandurra G, et al. Assessment of upper limb use in children with typical development and neurodevelopmental disorders by inertial sensors: a systematic review. *J Neuroeng Rehabil.* 2018;15(1):94. Published 2018 Nov 6. doi:10.1186/s12984-018-0447-y
88. Hadders-Algra M. Early human motor development: From variation to the ability to vary and adapt. *Neurosci Biobehav Rev.* 2018;90:411-427. doi:10.1016/j.neubiorev.2018.05.009
89. Sidiropoulos A, Magill R, Gordon A. Coordination of the upper and lower extremities during walking in children with cerebral palsy. *Gait Posture.* 2021;86:251-255.
90. Abu-Dahab SMN, Almasri NA, Saleh M, Malkawi SH. Determinants of Manual Abilities of Children with Cerebral Palsy: A National Registry-Based Study [published online ahead of print, 2021 Apr 14]. *Dev Neurorehabil.* 2021;1-6. Darian-Smith I, Galea MP,
91. Darian-Smith C. Manual dexterity: how does the cerebral cortex contribute?. *Clin Exp Pharmacol Physiol.* 1996;23(10-11):948-956.
92. Wiesendanger M. Manual dexterity and the making of tools - an introduction from an evolutionary perspective. *Exp Brain Res.* 1999;128(1-2):1-5.
93. Hadders-Algra M. Early human motor development: From variation to the ability to vary and adapt. *Neurosci Biobehav Rev.* 2018;90:411-427.

94. Machado LR, Heathcock J, Carvalho RP, Pereira ND, Tudella E. Kinematic characteristics of arm and trunk when drinking from a glass in children with and without cerebral palsy. *Clin Biomech (Bristol, Avon)*. 2019;63:201-206. d
95. Louwers, Annoek; Warnink-Kavelaars, Jessica; Obdeijn, Miryam; Kreulen, Mick; Nollet, Frans; Beelen, Anita (2018). *Effects of Upper-Extremity Surgery on Manual Performance of Children and Adolescents with Cerebral Palsy*. *The Journal of Bone and Joint Surgery*, 100(16), 1416–1422.
96. Dekkers KJFM, Smeets RJEM, Janssen-Potten YJM, Gordon AM, Speth LAWM, Rameckers EAA. Psychometric Evaluation of 2 New Upper Extremity Functional Strength Tests in Children With Cerebral Palsy. *Phys Ther*. 2019;99(8):1107-1115.
97. Raouafi S, Achiche S, Begon M, Sarcher A, Raison M. Classification of upper limb disability levels of children with spastic unilateral cerebral palsy using K-means algorithm. *Med Biol Eng Comput*. 2018;56(1):49-59.
98. Burgess A, Boyd RN, Ziviani J, Ware RS, Sakzewski L. Self-care and manual ability in preschool children with cerebral palsy: a longitudinal study. *Dev Med Child Neurol*. 2019;61(5):570-578.
99. Kavlak E, Altuğ F, Büker N, Şenol H. Musculoskeletal system problems and quality of life of mothers of children with cerebral palsy with different levels of disability. *J Back Musculoskelet Rehabil*. 2015;28(4):803-810.
100. Bingol H, Kerem Gunel M. The effects of hand deformity on upper-limb function and health-related quality of life in children with spastic hemiplegic cerebral palsy. *Hand Surg Rehabil*. 2021;40(6):722-728.
101. Nobile M. THE WHO DEFINITION OF HEALTH: A CRITICAL READING. *Med Law*. 2014;33(2):33-40.
102. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry*. 1980;137(5):535-544.
103. Perenboom RJ, Chorus AM. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disabil Rehabil*. 2003;25(11-12):577-587.
104. Reedman S, Boyd RN, Sakzewski L. The efficacy of interventions to increase physical activity participation of children with cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol*. 2017;59(10):1011-1018.
105. Frisch D, Msall ME. Health, functioning, and participation of adolescents and adults with cerebral palsy: a review of outcomes research. *Dev Disabil Res Rev*. 2013;18(1):84-94.
106. Shikako-Thomas K, Majnemer A, Law M, Lach L. Determinants of participation in leisure activities in children and youth with cerebral palsy: systematic review. *Phys Occup Ther Pediatr*. 2008;28(2):155-169. doi:10.1080/01942630802031834

107. Vila-Nova F, Dos Santos Cardoso de Sá C, Oliveira R, Cordovil R. Differences in Leisure Physical Activity Participation in Children with Typical Development and Cerebral Palsy. *Dev Neurorehabil*. 2021;24(3):180-186.
108. Omura J, Fuentes M, Bjornson K. Participation in Daily Life: Influence on Quality of Life in Ambulatory Children with Cerebral Palsy. *PM R*. 2018;10(11):1185-1191.
109. Felce D, Perry J. Quality of life: its definition and measurement. *Res Dev Disabil*. 1995;16(1):51-74.
110. Gilson KM, Davis E, Reddihough D, Graham K, Waters E. Quality of life in children with cerebral palsy: implications for practice. *J Child Neurol*. 2014;29(8):1134-1140.
111. Tsoi WS, Zhang LA, Wang WY, Tsang KL, Lo SK. Improving quality of life of children with cerebral palsy: a systematic review of clinical trials. *Child Care Health Dev*. 2012;38(1):21-31.
112. Opheim A, Jahnsen R, Olsson E, Stanghelle JK. Physical and mental components of health-related quality of life and musculoskeletal pain sites over seven years in adults with spastic cerebral palsy. *J Rehabil Med*. 2011;43(5):382-387.
113. Kobylańska M, Kowalska J, Neustein J, et al. The role of biopsychosocial factors in the rehabilitation process of individuals with a stroke. *Work*. 2018;61(4):523-535.
114. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*. 1997;39(4):214-223
115. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurol*. 2006;48(7):549-554.
116. Rosa-Rizzotto M, Visonà Dalla Pozza L, Corlatti A, et al. A new scale for the assessment of performance and capacity of hand function in children with hemiplegic cerebral palsy: reliability and validity studies. *Eur J Phys Rehabil Med*. 2014;50(5):543-556.
117. Thorley M, Lannin N, Cusick A, Novak I, Boyd R. Reliability of the quality of upper extremity skills test for children with cerebral palsy aged 2 to 12 years. *Phys Occup Ther Pediatr*. 2012;32(1):4-21.
118. Thorley, M., Lannin, N., Cusick, A., Novak, I., & Boyd, R. (2012). Construct validity of the Quality of Upper Extremity Skills Test for children with cerebral palsy. *Developmental medicine and child neurology*, 54(11), 1037–1043.
119. Platz T, Pinkowski C, van Wijck F, Kim IH, di Bella P, Johnson G. Reliability and validity of arm function assessment with standardized guidelines for the Fugl-Meyer Test, Action Research Arm Test and Box and Block Test: a multicentre study. *Clin Rehabil*. 2005;19(4):404-411.

120. Araneda R, Ebner-Karestinos D, Paradis J, et al. Reliability and responsiveness of the Jebsen-Taylor Test of Hand Function and the Box and Block Test for children with cerebral palsy. *Dev Med Child Neurol*. 2019;61(10):1182-1188.
121. Coster W, Bedell G, Law M, et al. Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Dev Med Child Neurol*. 2011;53(11):1030-1037.
122. Kaya Kara O, Turker D, Kara K, Yardimci-Lokmanoglu BN. Psychometric properties of the Turkish version of Participation and Environment Measure for Children and Youth. *Child Care Health Dev*. 2020;46(6):711-722.
123. Waters E, Davis E, Mackinnon A, et al. Psychometric properties of the quality of life questionnaire for children with CP. *Dev Med Child Neurol*. 2007;49(1):49-55.
124. Atasavun Uysal S, Düger T, Elbasan B, Karabulut E, Toylan İ. Reliability and Validity of The Cerebral Palsy Quality of Life Questionnaire in The Turkish Population. *Percept Mot Skills*. 2016;122(1):150-164.
125. Trabacca A, Vespino T, Di Liddo A, Russo L. Multidisciplinary rehabilitation for patients with cerebral palsy: improving long-term care. *J Multidiscip Healthc*. 2016;9:455-462. Published 2016 Sep 22.
126. Fehlings D, Krishnan P, Ragguett RM, et al. Neurodevelopmental profiles of children with unilateral cerebral palsy associated with middle cerebral artery and periventricular venous infarctions. *Dev Med Child Neurol*. 2021;63(6):729-735.
127. Unes S, Tuncdemir M, Ozal C, et al. Relationship among four functional classification systems and parent interpredicted intelligence level in children with different clinical types of cerebral palsy [published online ahead of print, 2022 Mar 18]. *Dev Neurorehabil*. 2022;1-7.
128. Boyaci, A., Akal, A., Tutoglu, A., Kandemir, H., Koca, I., Boyraz, I., ... Ozkan, U. (2014). *Relationship among Ocular Diseases, Developmental Levels, and Clinical Characteristics of Children with Diplegic Cerebral Palsy*. *Journal of Physical Therapy Science*, 26(11), 1679–1684.
129. Decraene L, Feys H, Klingels K, et al. Tyneside Pegboard Test for unimanual and bimanual dexterity in unilateral cerebral palsy: association with sensorimotor impairment. *Dev Med Child Neurol*. 2021;63(7):874-882.
130. Guedin, N., Fluss, J., & Thevenot, C. (2018). *Dexterity and Finger Sense: A Possible Dissociation in Children With Cerebral Palsy*. *Perceptual and Motor Skills*, 125(4), 718–731.
131. Park ES, Sim EG, Rha DW. Effect of upper limb deformities on gross motor and upper limb functions in children with spastic cerebral palsy. *Res Dev Disabil*. 2011;32(6):2389-2397.
132. Loewen, P., Steinbok, P., Holsti, L., & MacKay, M. (1998). Upper Extremity Performance and Self-Care Skill Changes in Children with Spastic Cerebral Palsy following Selective Posterior Rhizotomy. *Pediatric Neurosurgery*, 29(4), 191–198.

133. Makris T, Dorstyn D, Crettenden A. Quality of life in children and adolescents with cerebral palsy: a systematic review with meta-analysis. *Disabil Rehabil.* 2021;43(3):299-308.
134. Keawutan, P., Bell, K. L., Oftedal, S., Davies, P. S. W., Ware, R. S., & Boyd, R. N. (2018). *Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: A cross-sectional study. Research in Developmental Disabilities, 74, 139–145.*
135. Longo, E., Badia, M., Begoña Orgaz, M., & Gómez-Vela, M. (2017). *Comparing parent and child reports of health-related quality of life and their relationship with leisure participation in children and adolescents with Cerebral Palsy. Research in Developmental Disabilities, 71, 214–222.*
136. Piazza B, Hennrikus W, Schell R, et al. The factors most important for quality of life in children and adolescents with cerebral palsy. *J Pediatr Neurol Med.* 2016;1:1–4.
137. Bendixen RM, Fairman AD, Karavolis M, Sullivan C, Parmanto B. A User-Centered Approach: Understanding Client and Caregiver Needs and Preferences in the Development of mHealth Apps for Self-Management. *JMIR Mhealth Uhealth.* 2017;5(9):e141. Published 2017 Sep 26. doi:10.2196/mhealth.7136
138. Jardine J, Glinianaia SV, McConachie H, et al. Self-Reported quality of life of young children with conditions from early infancy: a systematic review. *Pediatrics.* 2014;134: e1129–e1.
139. Kołtuniuk A, Rozensztrauch A, Budzińska P, Rosińczuk J. The Quality of Life of Polish Children with Cerebral Palsy and the Impact of the Disease on the Family Functioning. *J Pediatr Nurs.* 2019;47:e75-e82.
140. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med.* 1999;48(8):977-988.
141. Rosenbaum P. Cerebral palsy in the 21st century: is there anything left to say?. *Neuropediatrics.* 2009;40(2):56-60.
142. Basińska MA, Woźniewicz A. Psychologiczne czynniki oddziałujące na stan somatyczny--metoda pomiaru [Psychological factors affecting medical conditions--a method of measurement]. *Przegl Lek.* 2014;71(6):328-333.
143. Park EY, Kim JH. Activity limitation in children with cerebral palsy and parenting stress, depression, and self-esteem: A structural equation model. *Pediatr Int.* 2020;62(4):459-466.
144. McDowell, B. C.; Duffy, C.; Parkes, J. (2015). *Service use and family-centred care in young people with severe cerebral palsy: a population-based, cross-sectional clinical survey. Disability and Rehabilitation, (), 1–6.*
145. Jain A, Sponseller PD, Shah SA, et al. Subclassification of GMFCS Level-5 Cerebral Palsy as a Predictor of Complications and Health-Related Quality of Life After Spinal Arthrodesis. *J Bone Joint Surg Am.* 2016;98(21):1821-1828.

146. Power, R., King, C., Muhit, M., Heanoy, E., Galea, C., Jones, C., ... Khandaker, G. (2018). *Health-related quality of life of children and adolescents with cerebral palsy in low- and middle-income countries: a systematic review*. *Developmental Medicine & Child Neurology*, 60(5), 469–479.
147. Bian C, Peng F, Guo H, Chen K. Investigation on Quality of Life and Economic Burden of Children with Cerebral Palsy in Changzhou. *J Healthc Eng*. 2022;2022:1519689. Published 2022 Jan 4.
148. Nicolson A, Moir L, Millsteed J. Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review. *Disabil Rehabil Assist Technol*. 2012;7(5):345 –9
149. Kusumoto Y, Takaki K, Matsuda T, Nitta O. Relevant factors of self-care in children and adolescents with spastic cerebral palsy. *PLoS One*. 2021;16(7):e0254899. Published 2021 Jul 21.
150. Arnould C, Bleyenheuft Y, Thonnard JL. Hand functioning in children with cerebral palsy. *Front Neurol*. 2014;5:48. Published 2014 Apr 9. doi:10.3389/fneur.2014.00048
151. Wallen M, Stewart K. Upper limb function in everyday life of children with cerebral palsy: description and review of parent report measures. *Disabil Rehabil*. 2015;37(15):1353-1361. doi:10.3109/09638288.2014.963704
152. Chang HJ, Ku KH, Park YS, et al. Effects of Virtual Reality-Based Rehabilitation on Upper Extremity Function among Children with Cerebral Palsy. *Healthcare (Basel)*. 2020;8(4):391. Published 2020 Oct 10.
153. Cankurtaran, D., Tezel, N., Yildiz, S. Y., Celik, G., & Unlu Akyuz, E. (2021). *Evaluation of the effects of the COVID-19 pandemic on children with cerebral palsy, caregivers' quality of life, and caregivers' fear of COVID-19 with telemedicine*. *Irish Journal of Medical Science (1971 -)*.
154. Palisano RJ, Copeland WP, Galuppi BE. Performance of physical activities by adolescents with cerebral palsy. *Phys Ther*. 2007;87:77–87. 2006/ 12/21.
155. van Schie, Petra E.M.; Siebes, Renate C.; Dallmeijer, Annet J.; Schuengel, Carlo; Smits, Dirk-Wouter; Gorter, Jan Willem; Becher, Jules G. (2013). *Development of social functioning and communication in school-aged (5–9years) children with cerebral palsy*. *Research in Developmental Disabilities*, 34(12), 4485–4494. 033
156. Grbovic A, Dimoski S, Stojkovic I, et al. Ucestvovanje mladih sa cerebralnom paralizom u slobodnim aktivnostima [Participation of young people with cerebral palsy in leisure activities]. In: Dopsaj M, Juhas I, Kasum G, editors. Medunarodna naucna konferencija Efekti primene fizicke aktivnosti na antropoloski status dece, omladine i odraslih, Beograd, 11-12 decembar 2012. Beograd: Fakultet sporta i fizickog vaspitanja; 2012. p. 441–452

157. Sienko S. Understanding the factors that impact the participation in physical activity and recreation in young adults with cerebral palsy (CP). *Disabil Health J.* 2019;12(3):467-472.
158. Milićević M, Nedović G. Comparative study of home and community participation among children with and without cerebral palsy. *Res Dev Disabil.* 2018;80:74-83. doi:10.1016/j.ridd.2018.06.010
159. Zeidan J, Joseph L, Camden C, et al. Look Around Me: Environmental and Socio-Economic Factors Related to Community Participation for Children with Cerebral Palsy in Québec. *Phys Occup Ther Pediatr.* 2021;41(4):429-446.
160. Lauruschkus K, Nordmark E, Hallström I. "It's fun, but ..." Children with cerebral palsy and their experiences of participation in physical activities. *Disabil Rehabil.* 2015;37(4):283-289.
161. Angelin AC, Sposito AM, Pfeifer LI. Influence of functional mobility and manual function on play in preschool children with cerebral palsy. *Hong Kong J Occup Ther.* 2018;31(1):46-53.
162. Zapata-Figueroa V, Ortiz-Corredor F. Assessment of Manual Abilities Using the Box and Block Test in Children with Bilateral Cerebral Palsy. *Occup Ther Int.* 2022;2022:9980523. Published 2022 Feb 22.
163. Burak, M., & Kavlak, E. (2019). *Investigation of the relationship between quality of life, activity participation and environmental factors in adolescents with cerebral palsy. NeuroRehabilitation, 45(4), 555–565.*
164. Tan, S. S., van der Slot, W. M. A., Ketelaar, M., Becher, J. G., Dallmeijer, A. J., Smits, D.-W., & Roebroeck, M. E. (2016). *Factors contributing to the longitudinal development of social participation in individuals with cerebral palsy. Research in Developmental Disabilities, 57, 125–135.*
165. Harvey, A., Robin, J., Morris, M. E., Graham, H. K., & Baker, R. (2008). *A systematic review of measures of activity limitation for children with cerebral palsy. Developmental Medicine & Child Neurology, 50(3), 190–198.*
166. McConnell K, Johnston L, Kerr C. Upper limb function and deformity in cerebral palsy: a review of classification systems. *Dev Med Child Neurol.* 2011;53(9):799-805.
167. Zvolanek KM, Goyal V, Hruby A, Ingo C, Sukal-Moulton T. Motivators and barriers to research participation for individuals with cerebral palsy and their families. *PLoS One.* 2022;17(1):e0262153. Published 2022 Jan 26.
168. da Silva AP, Bulle Oliveira AS, Pinheiro Bezerra IM, et al. Low cost assistive technology to support educational activities for adolescents with cerebral palsy. *Disabil Rehabil Assist Technol.* 2018;13(7):676-682.
169. Verschuren O, Wiart L, Hermans D, Ketelaar M. Identification of facilitators and barriers to physical activity in children and adolescents with cerebral palsy. *J Pediatr.* 2012;161(3):488-494.

170. Bourke-Taylor HM, Cotter C, Lalor A, Johnson L. School success and participation for students with cerebral palsy: a qualitative study exploring multiple perspectives. *Disabil Rehabil*. 2018;40(18):2163-2171.
171. Pérez-Ardanaz B, Morales-Asencio JM, León-Campos Á, et al. Quality of Life and Health Services Utilization for Spanish Children With Cerebral Palsy. *J Pediatr Nurs*. 2020;53:e121-e128.
172. King G, Imms C, Palisano R, et al. Geographical patterns in the recreation and leisure participation of children and youth with cerebral palsy: a CAPE international collaborative network study. *Dev Neurorehabil*. 2013;16(3):196-206.
173. Alemdaroğlu-Gürbüz İ, Karakuş AB. Examining mobility, independence, motor function, participation, and parental stress in a school-aged Turkish cerebral palsy population: a cross-sectional study. *Neurol Sci*. 2019;40(12):2493-2500.
174. Michelsen SI, Flachs EM, Uldall P, et al. Frequency of participation of 8-12-year-old children with cerebral palsy: a multi-centre cross-sectional European study. *Eur J Paediatr Neurol*. 2009;13(2):165-177.
175. Earde, P. T., Praipruk, A., Rodpradit, P., & Seanjumla, P. (2018). *Facilitators and Barriers to Performing Activities and Participation in Children With Cerebral Palsy*. *Pediatric Physical Therapy*, 30(1), 27–32. doi:10.1097/pep.0000000000000459
176. Nicolson y A, Moir L, Millstead J. Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review. *Disabil Rehabil Assist Technol*. 2012;7(5):345 –9
177. Abdullahi A, Isah A. Caregiver's perspectives on facilitators and barriers of active participation in cerebral palsy rehabilitation in North West Nigeria: a qualitative study. *BMC Health Serv Res*. 2020;20(1):615. Published 2020 Jul 6.
178. Hammal D, Jarvis SN, Colver AF. Participation of children with cerebral palsy is influenced by where they live. *Dev Med Child Neurol*. 2004;46(5):292-298.
179. Wright A, Roberts R, Bowman G, Crettenden A. Barriers and facilitators to physical activity participation for children with physical disability: comparing and contrasting the views of children, young people, and their clinicians. *Disabil Rehabil*. 2019;41(13):1499-1507.



8.APPENDICES

8.1. Appendix 1. Workplace Approval

03.06.2021

YEDİTEPE ÜNİVERSİTESİ REKTÖRLÜĞÜ'NE
(SAĞLIK BİLİMLERİ ENSTİTÜ MÜDÜRLÜĞÜ)

Enstitünüzün Fizyoterapi ve Rehabilitasyon Yüksek Lisans Programı öğrencisi Burcu Kaya'nın Serebral Palsili Çocuklarda 'El Becerisi ve Üst Ekstremité Fonksiyonunun Katılım ve Yaşam Kalitesi Üzerine Etkisi' isimli yüksek lisans tez çalışması kapsamındaki araştırmalarını 18.06.2021 – 29.11.2021 tarihleri arasında merkezimizde yapması uygun bulunmuştur.

Bilgilerinize arz ederim.

Saygılarımla

Uzm. Fzt. Feride BİLİR

8.2. Appendix 2. Ethics Committee Approval



YEDİTEPE ÜNİVERSİTESİ
GİRİŞİMSEL OLMAYAN KLİNİK ARAŞTIRMALAR
ETİK KURULU

Versiyon No 2.0
13.02.2022
Sayfa 1 / 2

KARAR FORMU

14.03.2022

ETİK KURUL BİLGİLERİ	Etik Kurulun Adı	Yeditepe Üniversitesi Girişimsel Olmayan Klinik Araştırmalar Etik Kurulu
	Açık Adres	Yeditepe Üniversitesi Kayışdağı Kampüsü, Tıp-Mühendislik Binası, Sağlık Bilimleri Enstitüsü, İnönü Mah. Kayışdağı Cad. 326A, 26 Ağustos Yerleşimi 34755 Ataşehir, İstanbul
	İnternet Sayfası	http://goetik.yeditepe.edu.tr/
	Telefon	0216 578 00 00
	E-posta	goetik@yeditepe.edu.tr

DEĞERLENDİRİLEN BELGELER	Islak imzalı başvuru dosyası, CD'si ve elektronik başvuru	☒
	Araştırma başlığı ve araştırmacıların isimleri	☒
	Başvuru dilekçesi	☒
	Başvuru Formu- Araştırmanın;	☒
	• Niteliği	☒
	• Önemi ve özgün değeri	☒
	• Amaç ve hedefleri	☒
	• Yöntemi	☒
	• Yönetimi	☒
	• Yaygın etkisi	☒
	• Araştırma bütçesi (Mevcutsa)	☒
	• Süresi ve uygunluğu (Zaman cetveli)	☒
	• Kaynakları	☒
	Bilgilendirilmiş Gönüllü Olur Formu (yapılan araştırmaya özel olarak hazırlanmış)	☒
	Taahhütname-1	☒
	Araştırmanın yapılacağı kurumdan izin alma sorumluluğunun araştırmacılara ait olduğuna dair taahhüt	☒
	Taahhütname-2	☒
	Dünya Tıp Birliği Helsinki Bildirgesinin son versiyonunun ve Sağlık Bakanlığı'nın ilgili tüm kılavuzlarının okunmasına dair taahhüt	☒
	Taahhütname-3	☒
	Daha önce yapılmış etik kurul başvuruları mevcut olup olmadığına dair taahhüt	☒
	Taahhütname-4	☒
	Araştırma sırasında araştırma bütçesinde yer almayan ve gönüllünün kendisine veya Sosyal Güvenlik Kurumuna ek yük getirecek hiçbir işlem uygulanmayacağına dair taahhüt	☒
	Taahhütname-5	☒
	COVID-19 hastalarında tedavi yaklaşımları ve bilimsel araştırmalar genelgesi okunmasına dair taahhüt	☒
	Taahhütname-6	☒
	Milli Eğitim Bakanlığı Araştırma Uygulama İzinleri konulu yazının okunmasına dair taahhüt	☒
	Araştırmacıların her birisine ait özgeçmiş formu	☒
	Ek belgeler (Varsa kullanılan ölçek izinleri vb.)	☒

KARAR BİLGİLERİ	Başvuru Numarası	202108090
	Toplantı Tarihi	15.10.2021
	Toplantı Yeri	Çevirim içi (Google Meet)
	Karar No	7

Araştırmanın Başlığı: Spastik Serebral Palsili Çocuklarda El Becerisi ve Üst Ekstremitate Fonksiyonunun Katılım ve Yaşam Kalitesi Üzerine Etkisi
Araştırmacılar: Burcu Kaya, Çiğdem Yazıcı Mutlu



BAŞVURU NUMARASI: 202108090

14.03.2022

KARAR

☒ KABUL	☐ RET ☐ KAPSAM DIŞI (GİRİŞİMSEL) ☐ BİLİMSEL VE/VEYA ETİK KURALLARA AYKIRI ☐ BİR SORUMLU ARAŞTIRMACININ (TEZ İŞE TEZ DANIŞMANI), BİR TOPLANTIYA İKİ (2) ADETTE FAZLA ÇALIŞMA BAŞVURUSUNDA BULUNMASI ☐ KURUM İÇİ BAŞVURULARINDA KURUMSAL E-POSTA HESABI İLE GİRİŞ YAPILMAMIŞ OLMASI ☐ ŞARTLI KABULDE BELİRTİLEN REVİZYONLARIN ZAMANINDA VE/VEYA İSTENİLDİĞİ ŞEKİLDE YAPILMAMIŞ OLMASI
--	---

Yeditepe Üniversitesi Girişimsel Olmayan Klinik Araştırmalar Etik Kurulu adına
Prof.Dr.Didem Özdemir ÖZENEN
Başkan

8. 3. Appendix 3. Participant Information and Approval Form

BİLGİLENDİRİLMİŞ GÖNÜLLÜ OLUR FORMU (BGOF)

‘Spastik Serebral Palsili Çocuklarda El Becerisi ve Üst Ekstremitte Fonksiyonunun Katılım ve Yaşam Kalitesi Üzerine Etkisi’ adlı bu bilimsel araştırmanın amacı serebral palsili çocukların kavrama, bırakma gibi ince motor hareketleri içeren el becerilerinin ve omuz, dirsek ve el bileği eklemlerinin eklem hareket açıklığı, ağırlık aktarma gibi fonksiyonel becerilerinin çocukların hayata katılımı ve hayat kaliteleri üzerine etkisini araştırmaktır. Bu çalışmada kaba motor seviyesini belirlemek amacıyla Kaba Motor Fonksiyon Sınıflama Sistemi (KMFSS), el becerilerini ölçmek için El Becerileri Sınıflandırma Sistemi (MACS) ve Tahta Kutu Blok Testi (BBT), üst ekstremitte fonksiyonelliğini ölçmek için Üst Ekstremitte Beceri Kalitesi Testi (QUEST), çocukların hayata katılımını ölçmek için Katılım ve Çevre Ölçeği-Çocuk ve Ergenler için (PEM CY), ve çocukların yaşam kalitesini ölçmek için Serebral Palsili Çocuklar için Yaşam Kalitesi Ölçeği (CPQOL) kullanılacaktır. Sosyodemografik bilgiler formu aile yardımıyla doldurulduktan sonra bahsi geçen ölçümler fizyoterapist tarafından yapılacaktır. Gerekli görülmesi halinde testler tekrarlanacaktır. Test sonuçları bilgisayar ortamına geçirilerek analiz edilecektir. Çalışmaya serebral palsi tanılı 30 çocuk katılacaktır. Katılımcıya yapılacak değerlendirmeler ve yasal temsilcisinin dolduracağı ölçekler yaklaşık olarak yarım saat ila bir saat arasında zaman alacaktır. RİBEM Riskli Bebek Danışma Merkezi’nden çalışmayı yürütmek için izin alınmıştır

Çalışma kapsamında yapılacak olan değerlendirme yöntemlerinin tıbben bilinen hiçbir zararı yoktur. Çalışma sırasında beklenmeyen herhangi bir sorunla karşılaşılması halinde gerekli müdahalenin tutarı araştırmacı tarafından karşılanacaktır.

Bu çalışma için sizden herhangi bir ücret talep edilmeyecektir. Çalışmanın size kısa süreli ve derhal bir yarar sağlamak yerine, serebral palsili çocukların rehabilitasyonu ile alakadar olan organizasyonlara, topluluklara ve bilimsel literatüre katkı sağlaması beklenmektedir.

Gönüllünün kimliğini ortaya çıkaracak kayıtlar gizli tutulacaktır. Araştırmayla ilgili olarak gerek duyulması halinde gönüllü veya kanuni temsilcisi ile tekrar iletişime geçirebilir.

Katılımcının Onayı

Bilgilendirilmiş gönüllü olur formundaki tüm açıklamaları okudum. Fzt. Burcu Kaya’nın başlattığı bilimsel araştırmanın detayları tarafıma açıklanmıştır.

Araştırmaya gönüllü olarak katıldığımı, istediğim zaman gerekçeli veya gerekçesiz olarak araştırmadan ayrılabilceğimi biliyorum. Çalışmaya katılmak için herhangi bir zorlamaya maruz kalmadık. Araştırmaya katılmayı reddetmemiz halinde bunun medikal tedavimizi ve fizyoterapistimiz ile ilişkimizi bozmayacağını biliyorum. Bu çalışma sonuçlarının kullanılmasını kısıtlamamayı, yayın, rapor ve benzeri bilimsel dokümanlarda kullanılmasını kabul ediyorum.

Söz konusu araştırmaya, hiçbir baskı ve zorlama olmaksızın kendi rızamla katılmayı kabul ediyorum

Gönüllünün Adı Soyadı :

Kanuni temsilcisinin/ebeveyninin Adı Soyadı:

İmzası:

Tarih:

Adresi:

Telefon numarası:

Araştırmacı : Fizyoterapist Burcu Kaya

Adres :

Telefon:

Email:

Tarih:

İmza:

8.4. Appendix 4. Sociodemographic Information Form

SOSYODEMOGRAFİK BİLGİLER FORMU

1.Katılımcının adı soyadı :

2.Doğum tarihi:

3.Tanısı:

4.Cinsiyet:

5.Kullandığı taraf eli : Sağ / Sol

6.Nörolojik problemi var mı? Varsa nedir? (Mikrosefali,hidrocefali, epilepsi vb) :

7.Görme problemi var mı? Gözlük kullanıyor mu?

8.İşitme problemi ve işitme cihazı var mı?

9.Fizyoterapiye başlama tarihi nedir?

10.Ne sıklıkla terapi alıyor? (Haftada kaç gün ? veya ayda kaç gün?)

11.Anaokuluna / Okula devamı :

12.Ambulasyon için kullandığı yardımcı cihazlar ? (kanedyen, walker, tekerlekli sandalye) :

13.Ortez / tabanlık varlığı/ el splinti/ dirsek ateli varlığı :

14. Düzenli kullandığı ilaçlar var mı? Varsa neler?

15. Daha önce geçirdiği müdahaleler ve bunların tarihi (botox, kas ya da kemik ameliyatı):

8.5. Appendix 5 Manual Ability Classification System

Manual Ability Classification System (MACS)

Serebral Palsili Çocuklarda El Becerileri Sınıflandırma Sistemi (4-18 yaş)

Hastanın Adı Soyadı: _____ Tarih: ____/____/____

MACS serebral palsili çocukların günlük faaliyetleri sırasında nesneleri tutmak için ellerini nasıl kullandıklarını sınıflandırır. MACS çocukların en iyi kapasitelerini değil, evde, okulda, toplumda nesneleri tutmak için genellikle ellerini nasıl kullandıklarını (ne yaptıklarını) belirler. Çocuğun, çeşitli gündelik nesneleri nasıl tuttuğu hakkında bilgi edinmek için, özel bir test yolu ile değil, çocuğu iyi bilen birisine sorular sormak gereklidir. Çocuğun tuttuğu nesneler yaşla ilişkili olarak değerlendirilmelidir. MACS, her eli ayrı ayrı değil, çocuğun nesneleri genel tutma becerisini sınıflandırır.

MACS'ı kullanmak için neleri bilmeliyiz?

Çocuğun önemli günlük faaliyetleri sırasında nesneleri tutma yeteneğini, örn. b oyun, boş vakitleri değerlendirme, yemek yeme, giyinme... Çocuğun hangi durumlarda bağımsız olduğu ve ne dereceye kadar destek ve uyarlamaya ihtiyaç duyduğu.

MACS Düzeyleri

- 1** Nesneleri kolaylıkla ve başarıyla tutup kullanabiliyor.
☐ En fazla hız ve dikkat gerektiren el işlerini yaparken güçlüklerle karşılaşır. Ancak el becerilerindeki herhangi bir kısıtlanma günlük faaliyetlerdeki bağımsızlığı sınırlandırmıyor.
- 2** Çoğu nesneyi tutup kullanabiliyor fakat başarma hızı ve/veya kalitesinde biraz azalma var.
☐ Bazı faaliyetleri yapmaktan kaçınabiliyor veya bunları bazı zorluklarla başarabiliyor, yapılmak istenilenler için alternatif yollar kullanılabilir ama el becerileri günlük faaliyetlerdeki bağımsızlığı çoğunlukla sınırlandırmıyor.
- 3** Nesneleri zorlukla tutup kullanabiliyor; faaliyetleri hazırlaması ve/veya değiştirmesinde yardıma ihtiyaçları vardır.
☐ Faaliyetlerin yapılması yavaş, nitelik ve nicelik açısından başarı sınırlıdır. Eğer önceden hazırlanmışsa veya uyarlanmışsa faaliyetleri bağımsız olarak gerçekleştirebiliyor.
- 4** Uyarlanmış durumlarda sınırlı sayıda kolaylıkla kullanılan nesneyi tutup kullanabiliyor.
☐ Faaliyetlerin bir kısmını çaba göstererek ve sınırlı başarıyla gerçekleştiriyor. Faaliyetin kısmen başarılması için bile sürekli desteğe ve yardıma ve/veya uyarlanmış ortama ihtiyaç duyuyor.
- 5** Nesneleri tutup kullanamıyor ve basit faaliyetleri bile gerçekleştirmek için ileri derecede kısıtlı beceriye sahip.
☐ Tamamen yardıma ihtiyaç duyuyor.

Düzeyler Arasında Dikkat Edilecek Farklar:

Düzey 1 ve 2 arasındaki farklar

1. düzeydeki çocuklar, ayrıntılı ince motor kontrol veya eller arasında etkin koordinasyon gerektiren çok küçük, ağır veya kırılabilen nesneleri tutmada zorluklar yaşayabilir. Yeni ve alışık olmadıkları durumlarda zorluklar başarıyı etkileyebilir. II. düzeydeki çocuklar, I. düzeydeki çocuklarla hemen hemen aynı faaliyetleri yaparlar ama başarının kalitesi düşüktür veya yavaştır. Eller arasındaki işlevsel farklılıklar başarının etkinliğini sınırlandırabilir. II. düzeydeki çocuklar genellikle nesneleri tutmayı basitleştirmeye çalışırlar; örneğin nesneyi iki elle tutmak yerine bir yüzey kullanarak desteklerler.

Düzey 2 ve 3 arasındaki farklar

II. düzeydeki çocuklar yavaş veya düşük kalitede başarıyla da olsa çoğu nesneyi tutabilir. III. düzeydeki çocuklar faaliyeti hazırlamak için genellikle yardıma ihtiyaç duyar ve/veya nesnelere ulaşma veya tutma becerileri sınırlı olduğu için bulundukları ortamda değişiklikler yapılması gerekebilir. Belirli faaliyetleri gerçekleştiremezler ve bağımsızlıklarının derecesi bulundukları ortamdaki desteğin düzeyine bağlıdır.

Düzey 3 ve 4 arasındaki farklar

III. düzeydeki çocuklar, durum önceden ayarlanmışsa ve bir yetişkinin gözetimi altında işler ve yeterince zamanları varsa seçilmiş faaliyetleri gerçekleştirebilirler. IV. düzeydeki çocuklar faaliyet süresince sürekli yardıma ihtiyaç duyarlar ve en iyi ihtimalle faaliyetin sadece bazı bölümlerine anlamlı olarak katılabilirler.

Düzey 4 ve 5 arasındaki farklar

4. düzeydeki çocuklar faaliyetin bir bölümünü gerçekleştirebilir; ancak sürekli yardıma ihtiyaç duyarlar. 5. düzeydeki çocuklar özel durumlarda en iyi ihtimalle basit bir hareketle faaliyete katılabilirler, örnek olarak, basit bir düğmeye basmak veya bazen basit nesneleri tutmak.

Bjasson AC, Krumlinde Sundholm L (2006) Dev Med Child Neurol. 2006 48:549-554

8.6. Appendix 6: Quality of Upper Extremity Skills Test



Quality of Upper Extremity Skills Test

Carol DeMatteo, Mary Law, Dianne Russell, Nancy Pollock, Peter Rosenbaum, Stephen Walter

Child's Name: _____ Date: _____ Time of Day: _____
year/month/day

Evaluator: _____ Age: _____ years _____ months

Testing Conditions:

Room _____

Seating
(e.g., insert) _____

Table
(e.g., cutout) _____

Orthotics
(e.g., splints/AFOs) _____

Others Present
(e.g., parent) _____

Score Key

- ✓ = Yes (able to complete item according to specification)
- ✗ = No (can not or will not complete item)
- NT = Not Tested (not able to administer item)

If a complete section is not tested, insert NT in summary score

MAKE SURE THERE IS A SCORE ENTERED IN EVERY SCORING BOX

SUMMARY SCORE (transfer from QUEST Scoring Sheet)

A:	DISSOCIATED MOVEMENTS	
B:	GRASPS	
C:	WEIGHT BEARING	
D:	PROTECTIVE EXTENSION	

TOTAL SCORE = $\frac{\text{SUM OF SCORES FOR EACH SECTION TESTED}}{\text{TOTAL \# OF SECTIONS TESTED}}$

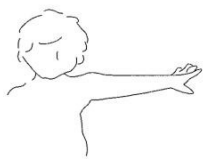
= _____

© 1992 DeMatteo, Law, Russell, Pollock, Rosenbaum, Walter

A. DISSOCIATED MOVEMENTS

Shoulder Items

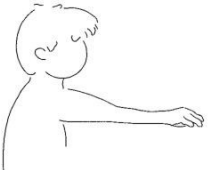
Start Position: sitting in chair no table hands on lap

ITEM	SCORE				CRITERIA
"SHOULDER"	L		R		
	<90	≥90	<90	≥90	
1. Flexion 	☐	☐	☐	☐	elbow: complete extension wrist: neutral to extension
2. Flexion with Fingers Extended 	☐	☐	☐	☐	elbow: complete extension wrist: neutral to extension
3. Abduction 	☐	☐	☐	☐	elbow: complete extension wrist: neutral to extension
4. Abduction with Fingers Extended 	☐	☐	☐	☐	elbow: complete extension wrist: neutral to extension

✓ ☐
 x ☐
 NT ☐
 2.

A. DISSOCIATED MOVEMENTS continued
Elbow Items

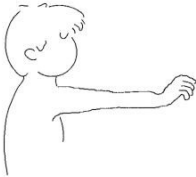
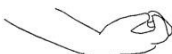
Start Position: sitting in chair no table hands on lap

ITEM "ELBOW"	SCORE				CRITERIA
	L		R		
	half <range	half ≥range	half <range	half ≥range	
1. Flexion 	☐	☐	☐	☐	forearm: <u>complete</u> supination
2. Extension 	☐	☐	☐	☐	forearm: <u>complete</u> supination
3. Flexion 	☐	☐	☐	☐	forearm: <u>complete</u> pronation
4. Extension 	☐	☐	☐	☐	forearm: <u>complete</u> pronation

✓ ☐ x ☐ NT ☐ 3.

A. DISSOCIATED MOVEMENTS continued
Wrist Items

Start Position: sitting at table forearms may be on table

ITEM	SCORE				CRITERIA
"WRIST"	L		R		
	half <range	half ≥range	half <range	half ≥range	
1. Extension	☐	☐	☐	☐	elbow: <u>complete</u> extension*
					<i>*see manual for definition of complete extension</i>
2. Extension	☐	☐	☐	☐	elbow: at least 10° flexion
					
3. Extension	☐	☐	☐	☐	forearm: <u>complete</u> pronation
					
4. Extension	☐	☐	☐	☐	forearm: <u>complete</u> supination
					
5. Flexion	☐	☐	☐	☐	forearm: <u>complete</u> supination
					

✓ ☐ x ☐ NT ☐ 4.

A. DISSOCIATED MOVEMENTS continued
Finger Items

Start Position: sitting at table forearms must rest on table

ITEM	L	SCORE	R	CRITERIA
1. Independent Finger Wiggling	☐		☐	dissociation of all fingers no associated reactions



2. Independent Thumb Movement	☐		☐	no associated reactions
-------------------------------	--------------------------	--	--------------------------	-------------------------

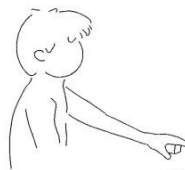


Grasp of 1" Cube

Start Position: sitting at table cube at distance requiring elbow extension

Note: If Item 1 is performed, then Item 2 should also be scored YES

ITEM	L	SCORE	R	CRITERIA
1. Grasp Using Thumb	☐		☐	shoulder: neutral elbow: extension wrist: neutral to extension
2. Grasp Using Palm	☐		☐	shoulder: neutral elbow: extension wrist: neutral to extension



✓ ☐ x ☐ NT ☐ 5.

A. DISSOCIATED MOVEMENTS continued
Release of 1" Cube

Start Position: sitting at table cube in child's hand *

* Allowable to put cube in child's hand if he/she can't actively grasp
Note: If Item 1 is performed, then Item 2 should also be scored YES

ITEM	SCORE		CRITERIA
	L	R	
1. Release from Thumb and Fingers 	☐	☐	shoulder: neutral elbow: extension wrist: neutral to extension
2. Release from Palm 	☐	☐	shoulder: neutral elbow: extension wrist: neutral to extension
✓ ☐ ✗ ☐ NT ☐			

Scoring for Part A: DISSOCIATED MOVEMENTS (pages 2-6)

Total ✓ : = a

Total ✗ : = b

Total NT : = c

TRANSFER TO QUEST SCORING SHEET ON PAGE **i**

B. GRASPS
Sitting Posture *during grasps*

Note: Observations for scoring this item should be made while administering the grasp items in the following section.

ITEM	SCORE			
	NORMAL	ATYPICAL		
Head	☐	☐	☐	☐
		Left	Right	Flexion Extension
		<i>circle atypical posture</i>		
Trunk	☐	☐	☐	
		Forward	Lateral	
		<i>check off position</i>		
Shoulders	☐	☐	☐	
		Retracted	Elevated	
		<i>check off position</i>		

Scoring for Part B1: GRASPS - Sitting Posture (page 7 only)

Total Normal (max. = 3) : = d

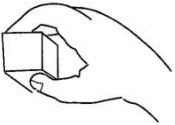
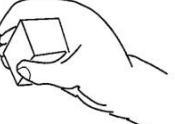
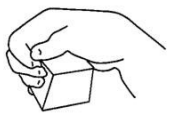
Total Atypical (max. = 5) : = e

TRANSFER TO QUEST SCORING SHEET ON PAGE ii

B. GRASPS continued
Grasp of 1" Cube

Start Position: sitting at table cube on table within comfortable reach

Note: Once a grasp has been performed, give a YES score for all those below it.
 If grasp observed is not listed, then score NO in all boxes and describe it under
 "Other" below.

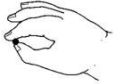
ITEM	SCORE		CRITERIA
	L	R	
1. Radial Digital 	☐	☐	wrist: neutral to extension
2. Radial Palmar 	☐	☐	wrist: neutral to extension
3. Palmar 	☐	☐	
Other:			

✓ ☐ x ☐ NT ☐ 8.

B. GRASPS continued
Grasp of Cereal

Start Position: sitting at table

Note: Once a grasp has been performed, give a YES score for all those below it.
 If grasp observed is not listed, then score NO in all boxes and describe it under
 "Other" below.

ITEM	SCORE		CRITERIA
	L	R	
1. Fine Pincer 	☐	☐	wrist: neutral to extension
2. Pincer 	☐	☐	wrist: neutral to extension
3. Inferior Pincer 	☐	☐	
4. Scissor 	☐	☐	
5. Inferior Scissor 	☐	☐	

Other:

✓ ☐ x ☐ NT ☐ 9.

B. GRASPS continued
Grasp of Pencil or Crayon

Start Position: sitting at table pencil placed midline vertical with point facing child

Note: Child must pick up pencil on his/her own.

Once a grasp has been performed, give a YES score for all those below it.

Circle one of:	L Dominance	R Dominance	L Preference	R Preference
Circle one of:	grasp of Pencil		grasp of Crayon	

ITEM	SCORE		
	L	R	
1. Dynamic Tripod (pencil, grasped distally - precise opposition of thumb, index & middle finger)	☐	☐	
2. Static Tripod (pencil grasped proximally - crude approximation of thumb, index & middle finger)	☐	☐	
3. Digital Pronate	☐	☐	
4. Palmar Supinate	☐	☐	

Other: _____

✓ ☐ ✗ ☐ NT ☐

<i>Scoring for Part B: GRASPS (pages 8-10)</i>		
Total ✓ :		= f
Total ✗ :		= g
Total NT :		= h
TRANSFER TO QUEST SCORING SHEET ON PAGE ii		

C. WEIGHT BEARING

Start Position: prone or 4 point

Note: Once a position is scored, give a YES score for all those below it

	ITEM	SCORE		CRITERIA
Circle test position:	prone	4 point		
1. Weight Bearing		L	R	
	a) elbow extended, hand open	☐	☐	Thumb must be out of palm for all weight bearing items or they are scored "NO".
	b) elbow extended, fingers flexed	☐	☐	
	c) elbow extended, hand fisted	☐	☐	
	d) elbow flexed, hand open	☐	☐	
	e) elbow flexed, fingers flexed	☐	☐	
	f) elbow flexed, hand fisted	☐	☐	

	ITEM	SCORE
2. Weight Bearing with Reach		
	a) Bears weight on LEFT hand with LEFT elbow completely extended and reaches with other arm.	☐
	b) Bears weight on RIGHT hand with RIGHT elbow completely extended and reaches with other arm.	☐

✓ ☐ x ☐ NT ☐ 11.

C: WEIGHT BEARING continued
Sitting

Start position: sitting on floor preferably cross-legged

	ITEM	SCORE	L	R	CRITERIA
1. Hands forward - circle test position: <u>cross-legged</u> <u>ring</u> <u>other</u> _____					
	a) elbow extended, hand open		☐	☐	Thumb must be out of palm for all items.
	b) elbow extended, fingers flexed		☐	☐	
	c) elbow extended, hand fisted		☐	☐	
	d) elbow flexed, hand open		☐	☐	
	e) elbow flexed, fingers flexed		☐	☐	
	f) elbow flexed, hand fisted		☐	☐	
2. Hands by side - circle test position: <u>cross-legged</u> <u>ring</u> <u>other</u> _____					
	a) elbow extended, hand open		☐	☐	Thumb must be out of palm for all items.
	b) elbow extended, fingers flexed		☐	☐	
	c) elbow extended, hand fisted		☐	☐	
	d) elbow flexed, hand open		☐	☐	
	e) elbow flexed, fingers flexed		☐	☐	
	f) elbow flexed, hand fisted		☐	☐	
3. Hands behind - circle test position: <u>cross-legged</u> <u>ring</u> <u>other</u> _____					
	a) elbow extended, hand open		☐	☐	Thumb must be out of palm for all items.
	b) elbow extended, fingers flexed		☐	☐	
	c) elbow extended, hand fisted		☐	☐	
	d) elbow flexed, hand open		☐	☐	
	e) elbow flexed, fingers flexed		☐	☐	
	f) elbow flexed, hand fisted		☐	☐	
☒ ☐ ☒ ☐ NT ☐					

Scoring for Part C: WEIGHT BEARING (pages 11-12)

Total ✓ : = i

Total ✗ : = j

Total NT : = k

TRANSFER TO QUEST SCORING SHEET ON PAGE iii

12.

D: PROTECTIVE EXTENSION

Start position: preferably ring sitting or kneeling

Note: Once a position is scored, give a YES score for all those below it.

ITEM	SCORE		
	L	R	
1. Protective Extension - Forward - circle start position:	ring sit	kneeling	other _____
a) elbow extended, hand open	☐	☐	
b) elbow extended, fingers flexed	☐	☐	
c) elbow extended, hand fisted	☐	☐	
d) elbow flexed, hand open	☐	☐	
e) elbow flexed, fingers flexed	☐	☐	
f) elbow flexed, hand fisted	☐	☐	
2. Protective Extension - Side - circle start position:	ring sit	kneeling	other _____
a) elbow extended, hand open	☐	☐	
b) elbow extended, fingers flexed	☐	☐	
c) elbow extended, hand fisted	☐	☐	
d) elbow flexed, hand open	☐	☐	
e) elbow flexed, fingers flexed	☐	☐	
f) elbow flexed, hand fisted	☐	☐	
3. Protective Extension - Backward - circle start position:	ring sit	kneeling	other _____
a) elbow extended, hand open	☐	☐	
b) elbow extended, fingers flexed	☐	☐	
c) elbow extended, hand fisted	☐	☐	
d) elbow flexed, hand open	☐	☐	
e) elbow flexed, fingers flexed	☐	☐	
f) elbow flexed, hand fisted	☐	☐	
✓ ✗ NT			

<i>Scoring for Part D: PROTECTIVE EXTENSION (page 13 only)</i>		
Total ✓ :		= l
Total ✗ :		= m
Total NT :		= n
TRANSFER TO QUEST SCORING SHEET ON PAGE iv		

E: HAND FUNCTION RATING

Please rate this child's hand function (circle a number)

Guidelines for scoring hand function:

POOR: minimal independent hand grasps, no active release, unable to combine reach and grasp

GOOD: spontaneous reach, grasp and release, good eye-hand coordination

	POOR										GOOD
Left Hand	0	1	2	3	4	5	6	7	8	9	10
Right Hand	0	1	2	3	4	5	6	7	8	9	10
Bilateral	0	1	2	3	4	5	6	7	8	9	10

F: SPASTICITY RATING

Please rate this child's spasticity

Guidelines for scoring spasticity:

MILD: good spontaneous movement, normal tone at rest, associated reactions present

MODERATE: tone interferes with spontaneous movement, may be present at rest

SEVERE: minimal spontaneous movement, stiff limbs, tone present at rest

	NONE	MILD	MODERATE	SEVERE
Left Hand	☐	☐	☐	☐
Right Hand	☐	☐	☐	☐

G: COOPERATIVENESS RATING

Please rate this child's level of cooperation during this assessment.

NOT cooperative	SOMEWHAT cooperative	VERY cooperative
☐	☐	☐

QUEST *Scoring Sheet*.....



DISSOCIATED MOVEMENTS

1. Transfer score information from page 6 of QUEST.

$$\text{Total } \checkmark = \boxed{} = a$$

$$\text{Total } \times = \boxed{} = b$$

$$\text{Total NT} = \boxed{} \times 2 = c$$

2. Calculate unstandardized score.

$$\text{Score A} = \frac{2(a) + b}{128 - c} \times 100$$

c a is multiplied by 2 because each $\checkmark$ scores 2 points.

$$\text{Score A} = \frac{2() + ()}{128 - ()} \times 100$$

c The **128 - c** calculation adjusts the score for any items not tested.

$$\text{Score A} = \boxed{}$$

c Round to two decimal points.

3. Obtain a standardized score ranging from zero to 100.

$$(\text{Score A} - 50) \times 2 = (- 50) \times 2 =$$

This is the dissociated movements score and can be transferred to the front page of the QUEST.

i.



1. Transfer score information on sitting posture from page 7.

$$\text{Total Normal} = \boxed{} \times 2 = d$$

$$\text{Total Atypical} = \boxed{} \times (-1) = e$$

$$\text{Score B1} = d + e = \boxed{}$$

2. Transfer score information on grasps from page 10.

$$\text{Total } \checkmark = \boxed{} = f$$

$$\text{Total } \times = \boxed{} = g$$

$$\text{Total NT} = \boxed{} \times 2 = h$$

3. Calculate unstandardized score.

$$\text{Score B} = \frac{\text{Score B1} + 2(f) + g}{54 - h} \times 100$$

c The **54 - h** calculation adjusts the score for any items not tested.

$$\text{Score B} = \frac{() + 2() + ()}{54 - ()} \times 100$$

$$\text{Score B} = \boxed{}$$

c Round to two decimal points.

4. Obtain a standardized score ranging from below zero (if a child scores $\times$ on all items and has atypical posture) to 100.

$$(\text{Score B} - 50) \times 2 = (- 50) \times 2 = \boxed{}$$

This is the grasps score and can be transferred to the front page of the QUEST.

ii.



WEIGHT BEARING

1. Transfer score information from page 12 of QUEST.

Total ✓ = = i
Total ✗ = = j
Total NT = x 2 = k

2. Calculate unstandardized score.

$$\text{Score C} = \frac{2(i) + j}{100 - k} \times 100$$

c The **100 - k** calculation adjusts the score for any items not tested.

$$\text{Score C} = \frac{2(\quad) + (\quad)}{100 - (\quad)} \times 100$$

Score C =

c Round to two decimal points.

3. Obtain a standardized score ranging from zero to 100.

$$(\text{Score C} - 50) \times 2 = (\quad - 50) \times 2 =$$

This is the weight bearing score and can be transferred to the front page of the QUEST.

iii.



PROTECTIVE EXTENSION

1. Transfer score information from page 13 of QUEST.

Total ✓ = = l
Total ✗ = = m
Total NT = x 2 = n

2. Calculate unstandardized score.

$$\text{Score D} = \frac{2(l) + m}{72 - n} \times 100$$

c The **72 - n** calculation adjusts the score for any items not tested.

$$\text{Score D} = \frac{2(\quad) + (\quad)}{72 - (\quad)} \times 100$$

Score D =

c Round to two decimal points.

3. Obtain a standardized score ranging from zero to 100.

$$(\text{Score D} - 50) \times 2 = (\quad - 50) \times 2 =$$

This is the protective extension score and can be transferred to the front page of the QUEST.

iv.

8.7. Appendix 7. Participation and Environment Measure- Children and Youth

Katılım ve Çevre Ölçeği – Çocuklar ve Gençler®

Wendy Coster, Mary Law, Gary Bedell

Türkeçe çevirisi (2014) Uzm. Fzt. Özgün Kaya Kara (ozgun.kaya@hacettepe.edu.tr),

Uzm. Fzt. Duygu Türker ve Doç. Dr. Akmer Mutlu tarafından yapılmıştır.

Hacettepe Üniversitesi, Ankara, Türkiye.

Katılım ve Çevre Ölçeği-Çocuklar ve Gençler (PEM-CY)'in kullanımı için izin, lisanslı kullanıcılara verilmektedir ("Kullanım Şartlarını" tamamlamak için bu sayfayı ziyaret ediniz: <http://canchild.ca/en/resourcesGeneral/TermsOfUse.pdf>). Lisanslı kullanıcılar kendi araştırmaları ve klinik uygulamaları için Katılım ve Çevre Ölçeği-Çocuklar ve Gençler (PEM-CY)'in tüm sayfalarını, telif hakkı bildirimi ile çoğaltılabilirler ancak yeniden satış amaçlı çoğaltamazlar. PEM-CY'nin maddelerinde veya yapısında değişiklik yapılması ve yabancı bir dile çevrilmesi, yazarlardan yazılı izin alınmaksızın yapılamaz.

PEM-CY, "CanChild Centre for Childhood Disability Research – <https://public.canchild.ca/Inventory>" adresinden satın alınabilir. Daha fazla bilgi için "www.canchild.ca" sayfasını ziyaret ediniz.

© Copyright 2010 Trustees of Boston University



ANKET TALİMATLARI

Katılım, çocuğun toplumdaki, okuldaki ve evdeki önemli günlük aktivitelere dahil olmasını ifade eder. Katılımın anlamı çocuğun aktiviteleri **ne sıklıkla** yaptığını ve bu aktiviteleri yaparken **nasıl dahil olduğunu** içerir.

Anket çocuğun katılımı ile ilgili 3 alanda (ev, okul, toplum) meydana gelen 25 tip aktiviteye katılımı ile ilgili bir grup soru sorar. Herbir aktivite tipini açıklamak için birkaç örnek veriyoruz. Ancak, soruları cevaplarken uygun kategorideki aktivitelerin tümünü düşünmelisiniz.

Her aktivite tipi için şunları soruyoruz:

1. Son 4 ayda çocuğunuz **ne sıklıkla** katılımında bulundu
2. Çocuğunuz en sık yaptığı 1 veya 2 aktiviteye katılırken, bu aktivitelere **nasıl dahil oluyor?**
3. Çocuğunuzun katılımını **değiştirmek** veya **değiştirmemek** istermiydiniz, eğer öyleyse nasıl değiştirmek isterdiniz

ÖNEMLİ

Bu anket, çocuğunuzun aktivitelere katıldığı zamanki bağımsızlık seviyesini sorgulamamaktadır. "Katılım", çocuğunuzun rutin olarak kullandığı veya kullanılabilir her türlü yardımı, desteği veya diğer yöntemleri kullanarak aktiviteyle nasıl uğraştığını ifade eder.

Yanıtınızı seçerken lütfen, çocuğunuzun dikkat, konsantrasyon, duygusal sorumluluk veya memnuniyet seviyesini düşününüz. (genellikle kullandığı her türlü destekler veya yardımcıları).

Çok katılım = Genelde, çocuk aktivite boyunca katılım gösterir. Aktivite sırasında onun ve diğerlerinin ne yaptığına bir çok girişim ve/veya ilgi ve dikkat gösterir.

Kısmen katılım = Çocuk zamanın bir kısmında aktiviteye katılım gösterir. Aktivite sırasında onun ve diğerlerinin ne yaptığına biraz girişim ve/veya ilgi ve dikkat gösterir.

Minimal katılım= Çocuk aktivitenin küçük bir bölümüne katılım gösterir . Aktivite sırasında onun ve diğerlerinin ne yaptığına çok az girişim ve/veya ilgi ve dikkat gösterir.

Çocuğunuzun katılımını zorlaştıran veya katılımına yardım eden şeyler varsa, örneğin ekipmanlar veya diğerlerinin desteği gibi, bu anketin ev, okul ve toplum ortamı bölümlerinde bunların etkilerini belirtebilirsiniz.



EVDE KATILIM		A) Genellikle, çocuğunuz bu tip aktivitelerden 1 veya daha fazla aktiviteye ne sıklıkla katılır?										B) Çocuğunuzun en sık katıldığı bu tip aktivitelerden 1 veya 2 aktiviteyi düşünün. Genellikle, çocuğunuz bu aktiviteleri yaparken nasıl katılım gösterir?					C) Bu tip aktivitelere çocuğunuzun katılımını değiştirmek istersiniz?					
		BİR YANIT SEÇİNİZ ☒										BİR YANIT SEÇİNİZ ☒					EĞER EVETSE, UYGULAMALARIN HEPSİNİ KONTROL EDİNİZ ☒					
		Her gün	Haftada birkaç kez	Haftada bir kez	Ayda birkaç kez	Ayda bir kez	Son 4 ay içinde birkaç kez	Son 4 ay içinde bir kez	Hiçbir zaman	5 Çok katılım gösterir	4	3	2	1	Minimal katılım gösterir	Değişim gösteriyor	Evet, daha sık yapar	Evet, daha nadir yapar	Evet, daha fazla katılım gösteren	Evet, daha az katılım gösteren	Evet, daha geniş kapsamlı aktivitelerle katılım gösteren	Evet, daha az katılım gösteren
1) Bilgisayar ve video oyunları																						
2) Ev içi oyunlar (ör: oyuncaklar ile oynama, yapbozlar, masa oyunları, mutfak veya giyinme oyunları)																						
3) Sanatlar, el işleri, müzik ve hobiler (ör: resim ve el işleri yapma, müzik dinleme, enstrüman çalma, koleksiyon, boş vakitlerinde okuma, eğlence amaçlı yemek pişirme)																						
4) TV, videolar ve DVDler izleme																						
5) Diğer insanlar ile birarada olma (ör: yaşlılarıyla, aile ve diğer misafirler ile etkileşim)																						
6) Teknoloji kullanarak sosyalleşme (ör: telefon, bilgisayar)																						
7) Ev işleri (ör: bulaşık makinesini boşatma/doldurma, odasını veya evin diğer alanlarını temizleme, yemek pişirme, çöpü dışarı çıkarma, masayı hazırlama, evcil hayvana bakma)																						
8) Kişisel bakım (ör: giyinme, elbiselerini seçme, saçlarını tarama veya dişlerini fırçalama, makyaj yapma)																						
9) Okul hazırlıkları (ev ödevi değil) (ör: eşyaları toplama, okul çantasını hazırlama, öğe yemeğini paketlenme, program gözden geçirme)																						
10) Ev ödevi (ör: okuma, ev ödevleri, okul projeleri)																						

8.8. Appendix 8. Participation and Environment Measure- Children and Youth Licence

PEM-CY - PARTICIPATION AND ENVIRONMENT MEASURE - CHILDREN AND YOUTH (the "Measure") LICENSE

IMPORTANT - PLEASE READ CAREFULLY: This license to use the Measure ("License") for 1 - 2 users is a legally binding License between you ("You") and McMaster University ("McMaster").

By using the Measure, you agree to be bound by the terms of this License. If you do not agree to the terms of this License, you are not authorized to use the Measure and must not install, copy, or use the Measure.

TERMS OF USE

1. PARTIES

This is a License between McMaster and You personally. By agreeing to the terms of this License, You indicate that You agree to be bound by the terms of this License and You represent and warrant that You have the legal authority to enter into this License.

2. PRODUCT

This License is for the specific use of the Measure in its printed form only.

3. OWNERSHIP OF THE MEASURE

You acknowledge that McMaster owns all right, title and interest in the copyright and all other intellectual property rights to the Measure. McMaster does not grant You any ownership interest in the Measure and only licenses You to use the Measure in accordance with the terms of this License. No rights, title or interest in or to any official mark, trade-mark, service mark, logo or trade name of McMaster is granted to You under this License.

4. AUTHORIZED USES

Provided You comply with all the terms and conditions of this License, McMaster grants You a non-exclusive, non-transferable, revocable, license for use of the Measure for personal, research, non-commercial purposes only.

5. AUTHORIZED USERS

McMaster licenses the Measure to You for your use by You only. You must not make Measure available to any other person or entity or allow any other person or entity to use the Measure.

6. PROHIBITED USES

You must not:

1. sell, sublicense, rent, loan or otherwise distribute copies of the Measure;
2. duplicate, create, or include the Measure in any digital format;
3. include the Measure as a component of a commercial product or use the Measure for performing commercial research or other non-personal uses;
4. publicly perform or display the Measure, including making the Measure available for download to anyone else on any computer system or network; or
5. remove or obscure any copyright, trade-mark or other proprietary notices from Measure.

7. DISCLAIMER OF WARRANTIES

The Measure has been developed as part of research conducted at McMaster. McMaster is providing you the Measure "as is" with all faults and without warranty of any kind, either express or implied.

McMaster expressly disclaims and excludes all warranties and representations expressed or implied, including but not limited to, any implied warranties that the Measure is merchantable, accurate or fit for a particular purpose. McMaster does not warrant that the Measure will meet Your requirements or that the use of the Measure will produce a desired result, or that the Measure will operate uninterrupted, or error free or that any defects in the Measure will be corrected. McMaster does not warrant that the use of the Measure will not infringe any patent, copyright or trade-mark or other rights.

8. ASSUMPTION OF RISK

You assume all risk and responsibility for the selection, installation, use, quality, performance and results obtained from the Measure.

9. LIMITATION OF LIABILITY

In no event will McMaster be liable to You or any other person or entity, for any damages of any kind, including lost profits, data, business interruption or special, incidental or consequential damages, in any way arising out of or in connection with the Measure, its use or performance or this License, even if McMaster has been advised of the possibility of such damages.

10. INDEMNITY

In consideration for the benefit obtained under this License, You will indemnify and hold harmless McMaster against any claims, liability, loss, damage, costs or expenses, including reasonable legal costs, resulting from your possession and or use of the Measure.

11. THIRD PARTY RIGHTS

The Measure may be dependent on programs, operating systems or other intellectual property of third parties which may require third party licenses. Compliance to terms and payment of fees associated with these third party Licenses are the sole responsibility of You and are not included in this License.

12. SUPPORT

McMaster will not provide any support or assistance to you in relation to the use and/or installation of the Measure.

13. ACKNOWLEDGMENT OF MCMASTER

If You use or reference the Measure in any publication (including scientific publications, electronic documents and/or websites) You must include appropriate acknowledgment of McMaster.

14. TERM AND TERMINATION

This License commences on the date that it is electronically delivered to You and continues in effect unless it is terminated earlier by McMaster. It may be terminated by McMaster immediately without notice if You fail to comply with any of the terms and conditions of this License. Upon termination of this License, Your rights to use You terminate and You must immediately stop using the Measure, uninstall and return to McMaster all copies of the Measure and any user documentation in Your possession or control.

15. REPRESENTATION OF AUTHORITY

You represent and warrant that you possess the legal authority to enter into this License and that You will be financially responsible for Your use of the Measure You are responsible for supplying any hardware, or software necessary to use the Measure.

16. NO ASSIGNMENT

You must not assign, sublicense or otherwise transfer this License or any rights granted by this License without the prior written consent of McMaster and any attempt to do so without the consent of McMaster will be void.

17. FORCE MAJEURE

Neither party to this License will be liable for delay or failure to perform their respective obligations this License if such delay or failure arises from any cause beyond the reasonable control of the party ('**Force Majeure**') provided such party gives the other party written notice of the Force Majeure. Force Majeure includes, without limitation: labour disputes, strikes, other labour or industrial disturbances and any act of God, fire, natural disaster, power failures, accidents, act of government, shortages of materials or supplies and failure of contractors to perform. If a party is temporarily excused from performing its obligations under this License because of Force Majeure, it must promptly resume performance when such Force Majeure is cured or removed.

18. COMPLETE LICENSE

This License contains the entire agreement between You and McMaster relating to the Measure, and supersedes any prior understandings, arrangements, commitments, communications or agreements, oral or written, between You and McMaster with respect to the Measure. You should print out and/or download a copy of this License and retain it for Your records. McMaster reserves the right to make changes to this License without notice.

19. SEVERABILITY

If any provision of this License becomes void, invalid, illegal or unenforceable, the remaining provisions will not be affected and will continue in effect as though the unenforceable provision(s) were deleted.

20. WAIVER

If either party omits or delays to require the other party to punctually fulfill any of its obligations under this License, this omission or delay will not operate as a waiver by that party of its rights under this License.

21. SURVIVAL

Clauses 3 (Ownership), 7 (Disclaimer of Warranties), 8 (Assumption of Risk), 9 (Limitation of Liability), 10 (Indemnity), 13 (Acknowledgment of McMaster), and 16 – 24 (General provisions) survive termination of this License.

22. GOVERNING LAW

This License will be interpreted in accordance with the laws of the Province of Ontario, Canada. Any suit, action, or proceeding arising out of or relating to this License must be brought in Hamilton, Ontario and You submit to the exclusive jurisdiction of the Courts of Hamilton, Ontario. Use of the Measure is prohibited in any jurisdiction which does not give effect to the terms of this License.

8.9. Appendix 9. Cerebral Palsy Quality of Life Questionnaire for Children

Serebral Palsi Yaşam Kalitesi Ölçeği- Bakım Veren Formu

Size , çocuğunuzun hayatı (aile, arkadaşlar, sağlık ve okul gibi) hakkında ne hissettiği ile ilgili bazı sorular sormak istiyoruz. **Her soru "... hakkında sizce çocuğunuz ne hissetmektedir" şeklinde bitmektedir.** Her sorunun cevabı olarak, çocuğunuzun ne hissettiğini düşünüyorsanız karşılayan rakamı seçmenizi istiyoruz. **1 (çok mutsuz) ve 9 (çok mutlu)** arasından istediğiniz rakamı seçebilirsiniz.

Bu anket, serebral palsinin her türüne sahip gençlere göre hazırlandığı için bazı soruları cevaplamak zor olabilir. Lütfen tüm soruları cevaplamaya çalışınız. Bu anket, çocuğunuzun neleri yapabildiğini değil nasıl hissettiğini ölçmektedir. Örneğin:

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Sizce çocuğunuz genel olarak insanlarla geçinmesi konusunda ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz genel olarak hayatı konusunda ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz bir bütün olarak hayatı hakkında ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz yaşam kalitesi konusunda ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz ne kadar mutlu?	1	2	3	4	5	6	7	8	9

1. ARKADAŞLAR VE AİLE

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Sizce genel olarak insanlarla geçinme konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizinle geçinme konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce ailesinden gördüğü destek hakkında çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce kardeşleriyle geçinmesi konusunda çocuğunuz ne hissetmektedir ? veya □ (Kardeşi yok)	1	2	3	4	5	6	7	8	9
Sizce okul dışından diğer gençlerle geçinmesi(Okuldan arkadaşlar dışında) konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce yetişkinler ile geçinmesi konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9

Sizce kendi kendine vakit geçirmesi hakkında çocuğunuz ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce arkadaşları ile vakit geçirme konusunda çocuğunuz ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce ailesiyle gezmeye gitme konusunda çocuğunuz ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz ailesi tarafından kabullenilmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okul dışından gençler tarafından kabullenilmesi (okul arkadaşları dışında) konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce yetişkinler tarafından kabullenilmesi konusunda çocuğunuz ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz genel olarak insanlar tarafından kabullenilmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce yapmak istediği şeyleri yapabilme (Yapmaya izin verilen değil,yapabildiği) konusunda çocuğunuz ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce girişimde bulunma ve yeni şeyler deneme konusunda çocuğunuz ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz kendisi hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz olumlu tavır ve düşünceleri hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz geleceği hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz hayattaki imkanları konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

2. OKUL

Sizce çocuğunuz okuldaki diğer gençlerle geçinmesi konusunda ne hissetmektedir ? (Birden fazla okula devam ediyorsa, en çok vakit geçirdiği okulu düşünün)

Çok mutsuz Mutsuz Ne mutlu ne mutsuz Mutlu Çok mutlu
1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okulundaki diğer öğrenciler arasına karışması konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz öğretmenleriyle geçinmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okuldaki bakıcılarıyla geçinmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

o veya (Okulda bakıcısı yok)

Sizce çocuğunuz okuldaki diğer öğrenciler tarafından kabullenilmesi konusunda ne hissetmektedir ? (Birden fazla okula devam ediyorsa , en çok vakit geçirdiği okulu düşünün)

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okuldaki öğretmen ve çalışanlar tarafından kabullenilmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okulda başkalarıyla aynı muameleyi görüp gömeme konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz derslerde yaşitlarına ayak uydurabilme konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz fiziksel olarak yaşitlarına ayak uydurabilme konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okuldaki katılımı konusunda ne hissetmektedir ? (Birden fazla okula devam ediyorsa, en çok vakit geçirdiği okulu düşünün)

1 2 3 4 5 6 7 8 9

3.KATILIM

Çok mutsuz Mutsuz Ne mutlu ne mutsuz Mutlu Çok mutlu
1 2 3 4 5 6 7 8 9

Sizce çocuğunuz boş zamanını değerlendirme ve hobileriyle ilgilenmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz sportif aktivitelere katılabilmesi (Spor yapıp yapmadığınız değil, spor yapmak hakkındaki hislerinizi soruyoruz) konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz okul dışında sosyal etkinliklere katılabilmesi konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz topluma karışabilmesi hakkında ne hissetmektedir ?

4.İLETİŞİM

Çok mutsuz Mutsuz Ne mutlu ne mutsuz Mutlu Çok mutlu
1 2 3 4 5 6 7 8 9

Sizce çocuğunuz tanıdığı insanlarla iletişim kurması (herhangi bir yolla) konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz tanımadığı insanlarla iletişim kurması(herhangi bir yolla)

konusunda ne hissetmektedir ?

Sizce çocuğunuz başkalarının
onunla iletişim kurması
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz insanlarla teknoloji yoluyla
iletişim kurması (internet, kısa mesaj)
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

5.SAĞLIK

Çok mutsuz Mutsuz Ne mutlu ne mutsuz Mutlu Çok mutlu

Sizce çocuğunuz genel olarak sağlığı
hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz beden sağlığı
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz etrafta hareket edebilmesi
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz uykuları
hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz görünümü
hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz ergenlikle birlikte
vücudundaki değişiklikler
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz başkalarına ihtiyaç
duymadan işlerini yapabilmesi
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz gelecekte ona olabilecekler
konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz hayatta başardıkları
hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz iyi olmak istediği şeylerdeki
başarısı hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz yaşadığınız çevrede
dolaşabilmesi hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz bir yerden bir yere gidebilme
(örn. ulaşım) konusunda ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Sizce çocuğunuz gelecekle ilgili planları
hakkında ne hissetmektedir ?

1 2 3 4 5 6 7 8 9

Aşağıdaki soruların cevapları "Hiç Önemsemiyorum" ile "Çok Önemişiyorum" arasında değişmektedir.

Hiç Önemsemiyor Çok Önemişiyorum

Sizce çocuğunuz Serebral palsili olmasını
önemişiyor mu?

1 2 3 4 5 6 7 8 9 10

Aşağıdaki iki soru, bedeni kullanma hakkında nasıl hissettiğini sormaktadır, o kısımları kullanıp kullanamadığını değil.

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Sizce çocuğunuz kollarını ve ellerini kullanması hakkında ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz bacaklarını kullanması hakkında ne hissetmektedir ?	1	2	3	4	5	6	7	8	9

Aşağıdaki 3 soru, günlük işlerini tamamlayabilmesi ile ilgili hislerini sormaktadır, tamamlayıp tamamlayamadığını değil.

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Sizce kendi kendine giyinebilmesi konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce yardımsız yiyip içebilmesi konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce tuvaleti kendi başına kullanabilmesi konusunda çocuğunuz ne hissetmektedir ?	1	2	3	4	5	6	7	8	9

6. ÖZEL EKİPMAN

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Sizce çocuğunuz evde ona ait özel ekipmanlar (Özel sandalyeler, destek barları, tekerlekli sandalye, yürüteç, AFO, görme cihazı, iletişim cihazı) veya ☐ (Evde özel ekipman kullanmıyor) konusunda ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz okulda ona ait özel ekipmanlar (not alma aletleri, özel sandalyeler, destek barları tekerlekli sandalye, yürüteç, dizüstü bilgisayar, görmeye yardımcı cihaz, işitme cihazı, iletişim aletleri) veya ☐ (Okulda özel ekipman kullanmıyor) konusunda ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz yaşadığı toplumda mevcut olan özel ekipmanlar (rampalar, asansörler, tekerlekli sandalyeye erişim) veya ☐ (Toplumda özel ekipmana ihtiyacı yok) konusunda ne hissetmektedir ?	1	2	3	4	5	6	7	8	9
Sizce çocuğunuz yaşadığı toplumda mevcut olan özel hizmetlere erişimi (İş bulma , özel araçla evden alınma) konusunda ne hissetmektedir ? veya ☐ (Toplumda özel hizmetlere ihtiyacım yok)	1	2	3	4	5	6	7	8	9

7.AĞRI VE SIKINTI

	Hiç ağrısı yok	1	2	3	4	5	6	7	8	9	Çok fazla ağrısı var
Sizce çocuğunuzun ne kadar ağrısı var?											

Eğer hiç ağrısı yoksa 7.sayfaya geçin, varsa 6. sayfaya geçiniz.

	Hiç üzülmüyor	1	2	3	4	5	6	7	8	9	Çok üzülmüyor
Sizce çocuğunuz yaşadığı ağrının şiddeti konusunda ne hissetmektedir ?											
Sizce çocuğunuz hissettiği rahatsızlığın derecesi hakkında ne hissetmektedir ?											
Sizce çocuğunuz ağrıyla başedebilmesi hakkında ne hissetmektedir ?											
Sizce çocuğunuz ağrısını kontrol edebilmesi hakkında ne hissetmektedir ?											
Sizce çocuğunuz ağrısının hayatını engellemesi hakkında ne hissetmektedir ?											
Sizce ağrısı çocuğunuzun kendisi gibi olmasını engelliyor mu? Bu konuda ne hissetmektedir ?											
Sizce çocuğunuz ağrının günlük keyiflerine (resim yapmak ,müzik dinlemek , film izlemek vb.) engel olması konusunda ne hissetmektedir ?											

Aşağıdaki sorular, SİZİN hakkınızda, hizmetlere erişiminiz ile ilgili ne hissettiğiniz hakkında

Aşağıdaki sorular, bu hizmetlere erişiminiz ile ilgili ,hizmetleri kullanıp kullanmadığınızla değil.

8. Hizmetlere Erişim

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Çocuğunuzun tedaviye erişimi konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Çocuğunuzun fizyoterapiye erişimi konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Çocuğunuzun konuşma terapisine erişimi konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Çocuğunuzun iş – uğraş terapisine erişimi konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Çocuğunuzun hastalığına özgü tıbbi ve cerrahi bakıma erişimi konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Bir çocuk doktorundan tavsiye alabilmeniz konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Toplumda mevcut olan özel hizmetlere erişiminiz (iş bulma taşınma gibi yardımcı hizmetler) konusunda ne hissediyorsunuz ? veya ☐ Bu hizmetlere erişmeyi hiç denemedim	1	2	3	4	5	6	7	8	9
Geçici bakım hizmetlerine erişiminiz konusunda ne hissediyorsunuz ? veya ☐ Geçici bakım hizmetlerine erişmeyi hiç denemedim (Bu kutuyu işaretlediyseniz lütfen sıradaki iki soruyu atlayın)	1	2	3	4	5	6	7	8	9
Aldığınız yardımcı bakım hizmetinin miktarı konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Geçici bakım hizmetine erişiminizin kolaylığı konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Çocuğunuzun toplumdaki hizmet ve olanaklara erişmesi (okul sonrası programları, tatil programları, izcilik vb. gruplar) konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Çocuğunuzun okuldaki öğrenimine ek yardıma erişimi konusunda ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9

Sizinle ilgili birkaç soru...

	Çok mutsuz	Mutsuz	Ne mutlu ne mutsuz	Mutlu	Çok mutlu				
Ne kadar mutlusunuz ?	1	2	3	4	5	6	7	8	9
Beden sağlığınız hakkında ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Bakıcılık işi (Ücretli/ücretsiz) hakkında ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9
Ailenizin parasal durumu hakkında ne hissediyorsunuz ?	1	2	3	4	5	6	7	8	9

Aşağıdaki soruya, çok eminim ile hiç emin değilim arasında bir cevap veriniz

	Hiç emin değilim	çok eminim							
Çocuğunuzun hissettiklerini anlatabildiğinize ne kadar eminsiniz ?	1	2	3	4	5	6	7	8	9