T.C.

YEDİTEPE UNIVERSITY

INSTITUTE OF HEALTH SCIENCE

DEPARTMENT OF PHYSICAL THERAPY AND REHABILITATION

INVESTIGATION OF PHYSICAL ACTIVITY LEVEL AND QUALITY OF LIFE IN PARENTS OF CHILDREN WITH VARIOUS DISABILITIES

MASTER OF PHYSIOTHERAPY AND REHABILITATION

GRETA VEGELYTE PT, MSc

ISTANBUL-2023

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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 ..... and numbered .....

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DECLARATION

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

Date

Signature

Name Surname

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LIST OF SYMBOLS AND ABBREVIATIONS

ASD -Autism spectrum disorder

A- **Autism**

B- **BMI- Body Mass Index**

C- **CP – Cerebral Palsy**

DD- Developmental disabilities

DS- Down Syndrome

HIV -Human Imuno Virus

IPAQ- International Physical Activity Questionnaire

QoF- Quality of Life

SB- Spina Bifida

SF-36- 36-Item Short Form Health Survey

WHO- World Health Organization

ABSTRACT

VEGELYTE, G. (2023). Investıgatıon of physical activity levels and quality of life in parents of children with various disabilities. Yeditepe University, Institute of Health Sciences, Department of Physiotherapy, Master Thesis. Istanbul.

This study was conducted to investigate the differences between the parents of children with various disabilities' physical activity levels and quality of life. There were 156 participants in the study. Participants were divided into four equal groups of 39 participants in each group. The groups were: Autism (A), Down Syndrome (DS), Cerebral Palsy (CP), and Spina Bifida (SB). To assess physical activity levels, the International Physical Activity Questionnaire (IPAQ) was used, and for the assessment of the quality of life, the 36-Item Short Form Health Survey (SF-36.) was used. Statistical analysis showed that there is no sıgnıfıcant difference in physical activity levels among parents of children with various disabilities ($p>0.05$). However, a statistically significant difference exists between the parents of children with various types of disabilities (A, DS, CP, SB) in quality of life. There are statistically significant differences in six out of eight domains that are included in the SF-36 questionnaire. The difference is between the parents of children with Down Syndrome and parents of children with Spina Bifida. Parents of children with Down Syndrome scored significantly better in Physical Role, Vitality, Mental Health, Social Functioning, Pain, and General Health. Parents of children with Spina Bifida also scored lower statistically significant scores than parents of children with Cerebral Palsy, in the domains of Physical Functioning, Pain, and General Health. The Spina Bifida group also reported statistically significantly lower scores than the Autism group in Physical Role. In conclusion, parents of children with Down Syndrome achieved significantly higher scores in six out of eight SF-36 questionnaire domains in comparison to Spina Bifida this is important because it shows that parents of children with Spina Bifida may need more medical professional support and care.

Keywords: Physical Activity, Quality of Life, Parents of Disabled Children.

ABSTRACT (Turkish)

VEGELYTE, G. (2023). Çeşitli yetersizlikleri olan çocukların ebeveynlerinin fiziksel aktivite düzeyleri ve yaşam kalitelerinin incelenmesi. Yeditepe Üniversitesi Sağlık Bilimleri Enstitüsü Fizyoterapi Anabilim Dalı Yüksek Lisans Tezi. İstanbul.

Bu çalışma, çeşitli engelli çocukların ebeveynleri arasındaki fiziksel aktivite düzeyleri ve yaşam kaliteleri arasındaki farklılıkları araştırmak amacıyla yapılmıştır. Araştırmaya 156 katılımcı katıldı. Katılımcılar, her grupta 39 katılımcı olacak şekilde dört eşit gruba ayrıldı. Gruplar şunlardı: Otizm (A), Down Sendromu (DS), Serebral Palsi (SP) ve Spina Bifida (SB). Fiziksel aktivite düzeylerini değerlendirmek için Uluslararası Fiziksel Aktivite Anketi (IPAQ), yaşam kalitesini değerlendirmek için 36 Maddelik Kısa Form Sağlık Anketi (SF-36.) kullanıldı. İstatistiksel analiz, çeşitli yetersizliklere sahip çocukların ebeveynleri arasında fiziksel aktivite düzeylerinde anlamlı bir fark olmadığını göstermiştir ($p>0.05$). Ancak çeşitli engel türlerine (A, DS, CP, SB) sahip çocukların ebeveynleri arasında yaşam kalitesinde istatistiksel olarak anlamlı bir fark bulunmaktadır. SF-36 anketinde yer alan sekiz alandan altısında istatistiksel olarak anlamlı farklılıklar vardır. Down Sendromlu çocukların ebeveynleri ile Spina Bifidalı çocukların ebeveynleri arasındaki fark bu kadardır. Down Sendromlu çocukların ebeveynleri, Fiziksel Rol, Canlılık, Ruh Sağlığı, Sosyal İşlevsellik, Ağrı ve Genel Sağlık alanlarında önemli ölçüde daha iyi puan aldı. Spina Bifida'lı çocukların ebeveynleri de Fiziksel İşlevsellik, Ağrı ve Genel Sağlık alanlarında Serebral Palsili çocukların ebeveynlerinden istatistiksel olarak daha düşük puanlar aldı. Spina Bifida grubu ayrıca Fiziksel Rol'de Otizm grubundan istatistiksel olarak anlamlı derecede daha düşük puanlar bildirdi. Sonuç olarak, Down Sendromlu çocukların ebeveynleri, Spina Bifida'ya kıyasla sekiz SF-36 anket alanının altısında önemli ölçüde daha yüksek puanlar elde etti, bu önemlidir çünkü Spina Bifida'lı çocukların ebeveynlerinin daha fazla tıbbi profesyonel desteğe ve bakıma ihtiyaç duyabileceğini göstermektedir.

Anahtar kelimeler: Fiziksel Aktivite, Yaşam Kalitesi, Engelli Çocuk Ebeveynleri.

1. INTRODUCTION and PURPOSE

Disability is composed of the interactions between various health conditions and can vary depending on individual and environmental factors. Disability is an inseparable part of humanity (1). The global data reveals 16% of the worldwide population experience significant disabilities, that is approximately 1,3 billion people. Out of 1,3 billion people with disabilities, 24 million are children with varying mental and physical disabilities. Due to the longer life expectancy and the increase in non-communicable diseases, the number of disabled individuals is growing. Based on the Convention on the Rights of Persons with Disabilities (CRPD), children with disabilities include those with long-term physical, mental, intellectual, or sensory impairments that, in interaction with various hurdles, may impact their full potential in participating in society as equal individuals. Various types of disabilities affect children. These types include genetic conditions that impair the child's physical, mental, or social development; previous trauma or injury. Environmental conditions such as infections or poor nutrition lead to long-term consequences. Developmental delays and learning disabilities can be caused due to exposure to the toxin in the environment. Stressful and psychologically traumatic experiences that resulted in anxiety or/and depression (1; 2).

The care for children with disabilities is challenging. The previous studies stated, that parents of disabled children, especially those with developmental disabilities face much greater caregiving demands. In comparison with parents of typically developing children, they encounter greater levels of depression and anxiety as well as stress (3;4). Unfortunately, more often than not parents of children with developmental disabilities not only experience mental distress but also physical impairments such as asthma or arthritis, including back pain and even obesity (5;6). The difficulties that parents of children with disabilities face hinder the ability to meet the needs of the child and limit the parents' physical activities and hurts the quality of life (7). Researchers confirm that physical activity is important and provides parents of children with disabilities multiple health benefits (8). Meta-analysis confirms that meeting the recommended physical activity guidelines in adults (moderate physical activities- to -vigorous of 150 mins per week) leads to a decrease in depression and anxiety. Increased physical activity levels may prevent chronic conditions such as osteoporosis and type 2 diabetes (9;10). Regardless of the significance of physical activity, parents of disabled children face obstacles that impact physical activity participation. Studies suggest that the additional care needs of a disabled

child lead to parents having less time to participate in physical activities (11). An addi Another factor that prevents parents from being physically active is the fatigue by the intensive care of the disabled child (5). Furthermore, the studies also conclude that disabled children experience more sleep disturbances through the night and this might contribute to physical inactivity among the parents (12).

Despite the studies stating that parents of disabled children are not physically active enough, some studies contradict this statement and propose that parents of disabled children are, in fact enough physically active. The contradictory research found that parents of disabled children participating in physical activity were able to meet physical activity guidelines and even surpass them by averaging 186.4 minutes of moderate-to-vigorous physical activity per week). The study conducted in Turkey among mothers with disabled children likewise confirmed the findings stating that mothers of disabled children met the physical activity guidelines by participating in an average of 199.86 minutes of moderate-to-vigorous physical activity per week (7). Similarly, conflicting data about the quality of life (QoL) of parents of disabled children were found. The research was performed during COVID-19 on parents of disabled children. The results revealed that parents of disabled children had lower scores in all of the quality of life domains including physical health, psychological health, social relationships, and environment (14). On the other hand, this year's study reported that parents of children with cerebral palsy mainly had a high quality of life. In this research, the lowest domain score was support related to disability and the highest domain score was parenting. (15). Comperasment was made between Cerebral Palsy, Aut Mental Retardation, and Autism disorder. The outcome shows that the parents whose children have Autism spectrum disorder had the lowest quality of life while the parents whose children have Mental Retardation had the highest quality of life (16).

What truly is interesting to note is that the data on the physical activity levels and quality of life in parents of disabled children seems to vary. The disability type of the child seems to be one of the contributors that may influence it.

The literature that is currently available is mainly focused on one type of disability or the various disabilities that are combined in one category and presented as such (11;12;13). There is a scarcity of literature that evaluates the physical activity levels and quality of life of parents of children with various disabilities in which the disabilities are divided into separate groups and compared amongst each other. This research focuses on investigating physical activity and quality of life in parents of children with various

disabilities. For this study, we have selected four prevalent developmental disabilities in Turkey: Autism spectrum disorder (ASD), Down syndrome (DS), Cerebral Palsy (CP), and Spina Bifida (SB) (18). The aim is to determine the differences in quality of life and physical activity in parents of disabled children between each disability separately.

Hypotheses of the Study:

H0: There is no difference between all the groups of parents of children with various disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida) physical activity levels,s and quality of life

H1: There is a difference between all the groups of parents of children with various disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida) physical activity levels, and quality of life.

2. LITERATURE REVIEW

2.1. Development of the Child

Development of the child is a growth process during which the infant evolves into an independent adult. The growth and development of the neuro-system and the human brain are referred to as psychomotor development. The development of the psychomotor system is classified into four primary categories: (19)

- Fine motor skills and gross motor skills
- Language and speech
- Activities regarding social and personal life
- Performance and cognition.

Each child goes through the same constant developmental pattern, within fairly broad limits. However, each child achieves the development goals at a different rate. Developmental goals are developed coherently, one goal follows another. The previously acquired skills in the same domain determine the subsequent development of the skills. For example, the child has to learn how to sit before the child can learn to stand or walk (20). Normal development is considered when a child can carry out a specific task at a specific age based on the accomplishment of the average child. The achievement of a particular ability during a particular age is known as a milestone. The achievement of various milestones at normal age can vary considerably. The median age is an age at which half the children's population achieve an ability. Following that, the limit age is the age at which a child should have attained the ability and is two standard deviations away from the mean age (19). Talking about a child's development it is essential to be aware of the consistency of certain milestones. An infant's ability to smile during social interactions at 8 weeks is considered to be a constant milestone. On the other hand, crawling is considered to be a very inconsistent milestone because it varies greatly over time and some children without developmental disturbances never learn how to crawl (21).

2.2. Developmental delay

As mentioned previously there are four psychomotor domains of development, when two or more of these main domains have a significant delay the "global

developmental delay" term is used (22). Severe delay is defined as the inability of a child to perform two or more tasks with a standard deviation below the mean on a standardized test suitable for his\her age (23). The delay of a child's development is categorized into three categories:

- Mild delay- when the functional age of the child is less than 33% of the child's chronological age.
- Moderate delay-when the functional age of the child is between 34%–66% of the child's chronological age.
- Severe delay- is when the functional age of the child is more than 66% of the child's chronological age.

When one or more domains of development present with abnormal patterns of progression or delay, in the early stages of life it is called developmental impairments or disorders (24)

2.3. Developmental disabilities

Developmental disorders (DDs), characterized by mental and/or physical problems affecting individuals early in life, are considered a group of permanent conditions that appear throughout life. (25). According to the Development Disability Assistance and Bill of Rights 2000, the term developmental disability is used only when there are functional problems in at least three of the following areas: economic self-sufficiency, self-direction, self-care, receptive and expressive language, mobility, learning, independence (26). Diagnosis of developmental disabilities includes neurodevelopmental disorders (such as learning disabilities, intellectual disabilities, attention-deficit/hyperactivity disorder, and Autism disorder) and other possible conditions including stuttering and blindness, hearing, loss, and even seizures (27).

2.3.1. Etiology

Currently, the researchers are certain that the etiology of these conditions is complex and that there are more than just genetic factors that determine the final diagnosis. Environmental together with genetic influences interact to cause developmental abnormalities or changes in the nervous system that lead to disability (28).

The basic developmental potential is predetermined by genetic factors, but environmental factors have very important effects on the obtained profile. Research shows that positive experiences during the early stages of childhood potentially increase brain development in areas such as social skills and language (29). Simultaneously, the brain is highly vulnerable, especially in the early embryonic stages of development and later in life (30).

Environmental factors damaging the brain development

Antenatal period:

- Infections in the early stages of pregnancy including rubella, toxoplasma, cytomegalovirus
- Infections during the late stages of pregnancy: varicella, malaria, HIV
  Exposure to toxins: radiation, pesticides, tobacco and nicotine, alcohol.
- Medications: cytotoxics, antiepileptics.

Postnatal period

- During the infancy of the child, infections such as cytomegalovirus, encephalitis, and meningitis
- During the infancy stage, exposure to the toxins such as organic compounds, lead, and mercury.
- The metabolic disorders that if left untreated can manifest further, dehydration and hypoglycemia, hypo\hypernatremia
- Domestic violence, maltreatment, severe under-stimulation, parental depression, and other mental health issues.
- Extreme malnutrition or poor dietary choices of the parents especially deficiency of iron, folate, and vitamin D (31).

Genetic factors that impact brain development:

Antenatal period:

- Prematurity of the fetus, periventricular leukomalacia and intrauterine growth retardation, and intraventricular hemorrhage (24).
- Vascular: occlusion, hemorrhage.
- The dysgenesis of the cerebral includes neuronal migration disorder, hydrocephalus, absent corpus callosum, and microcephaly.
- Genetic disorders: fragile X syndrome, chromosomal deletion or duplication, and Down syndrome (24).

2.3.2. Types of developmental disabilities

Developmental disorders is a very broad umbrella term that holds many different types of disorders (32). Developmental disorders are categorized into four main categories:

Nervous system disorders.

Neurodevelopmental disorders are generally related to birth defects that have an impact on the nervous system affecting the brain and the spinal cord. Nervous system disorders also known as (neurodevelopmental disorders), usually affect intelligence and learning abilities, in some cases, they can also have an impact on behavior, speech, and/or language skills, and can cause movement impairments (33;34;35). Neurodevelopmental disorders differ from individual to individual based on how disorders present, the symptoms that appear, complications, and outcomes of the condition (36). Unfortunately, these types of disabilities are common and include such disorders as Down syndrome, Cerebral Palsy. Fragile X syndrome, Autism.

Sensory related disorders

Another developmental disability is sensory-related disorders. Sensory impairment affects the human brain's normal and proper processing of sensory information (such as seeing, hearing, tasting, touching, and smelling). Sensory impairments such as vision and hearing impairments are often associated with other developmental disabilities. Sensory disorders are often predetermined as part of birth defects. For example in sensory disorders, children with Williams syndrome have trouble in being able to see spatial relationships between objects that are surrounding them (37). The sensitivity to the sounds is common in children with Fragile X syndrome (38). Another common disorder is Sensory Processing Disorder -which is a neurological impairment that hinders the transfer of sensory input from the body to the brain and produces appropriate motor responses

people with such disorders usually feel overstimulated and overwhelmed because the brain is unable to block unnecessary sensory information from the surrounding environment such as background noises or lights (39).

Metabolic disorders

The developmental disabilities that result from metabolic disorders are usually genetically inherited birth defects that impact the metabolism. Metabolism is an extremely important process during which the body processes all the materials needed for functioning by building up or breaking down the materials (40). One of those disorders is Phenylketonuria (PKU). Developmental delays occur due to conditions in which the issue is with a particular enzyme, a protein responsible for the speed of specific chemical reactions. Hypothyroidism is a hormonal condition that if not treated during pregnancy can lead to developmental disabilities (41).

Degenerative disorders.

Babies that are born having the degenerative disorder may appear healthy at the early stages of their life, however, as time passes they lose functioning due to the disorder. Commonly, degenerative disorders are not detectable until later on in life when the first symptoms appear. Symptoms usually include sensory and physical impairments as well as mental and behavioral disorders based on the type of defect (42). Rett syndrome is an example of the type of disorder that usually is prevalent in one gender and is caused by a very particular genetic abnormality (43). There is a huge variety of subgroups of disabilities that are associated with these four primary groups.

2.3.3. Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is an umbrella term comprising a group of neurodevelopmental conditions resulting in impaired communication and social interactions and behaviors, followed by limited interests and repetitive behaviors (44). Typically the symptoms of ASD start appearing in the early stages of childhood around 12 -18 months old and the mean age at ASD diagnosis ranges between 2 years old to 10 years old (45). Children with Autism tend to present very differently from one another, however, despite the cultural norms, the socioeconomic position of the parents, race, or ethnicity Autism Spectrum Disorder primarily depicts two different disorders in separate domains. Firstly social communication and behaviors, and secondly repetitive and restricted sensory and motor functioning. The alterations in the brain and neural rearrangement at the early

stages of the fetus's development result in Autism spectrum disorder. The diagnosis of ASD must be made based on the behavior of the child since ASD is caused by the actual changes in the brain despite that there are no reliable biomarkers to make the diagnosis. (46).

Causes:

In current times there is no knowledge of one specific cause of Autism Spectrum Disorder, researchers and scientists are continuously working on answering this matter. Factors that have an impact on the development of the brain and are known to cause neurobiological disorders like ASD are both genetic and environmental (47). Neuropathological studies evaluating causes are scarce but reveal differences in cerebellar structure and connectivity, abnormalities in the limbic system, and cortical changes in the frontal and temporal lobes with other subtle malformations (48).

What scientists and researchers do acknowledge is the fact that genetic factors do have an impact on the susceptibility of ASD. Studies show that siblings of people with Autism Spectrum Disorder have a higher chance of the increased risk of ASD in comparison to the general population. The monozygotic twins carry a much higher probability of ASD even though it is not an absolute probability (47, 49). Besides the genetic factors, there are also environmental factors that contribute, to prenatal, perinatal, and postnatal periods during the development of the fetus (50). Investigation in this field showcases that teratogenic drugs like valproic acid and thalidomide reported to enhance the risk of Autism during parental exposure (51). Advanced parental age is also a contributor that enhances the probability of having a child with ASD (52). Some studies indicate that autoimmune diseases in mothers during pregnancy might be one of the factors that increase the possibility of ASD however, there are also studies contradicting this (53). Furthermore, recent studies are focusing more on maternal infection or immune activation during pregnancy as it has the potential of being a risk factor (54). Premature or overdue pregnancies are a risk factor for Autism Spectrum Disorder. Especially premature pregnancy seems to be the cause of other neurodevelopmental disorders like Cerebral Palsy (55).

Symptoms

Autism Spectrum disorder is a spectrum in which the individual's language skills, cognitive capabilities, and sensory impairments vary greatly on the scale (56). The most common symptoms in the early stages of childhood that cause concern include poor eye contact accompanied by poor response to the name, the lack of sharing, not attempting to

gesture by the age of 12 months as well as deficits in language and social skills. During preschool, prevalent symptoms involve obsessive interest in particular things, rigidity, and the absence of pretend games. School-age children may have a hard time understanding emotions, and humor, as well as the incapability to read the subtext. Usually, individuals with ASD possess very literal, logical thinking but have a hard time socializing with their peers.

More often than not individuals with Autism spectrum disorder have an additional developmental diagnosis.

One of the most prevalent diagnosİs is co-occurring psychiatric diagnosis. The psychiatric disorder that is predominantly prevalent and co-occurrent in people with ASD is anxiety, other disorders include disorders affecting mood (depression, dysthymia), other behavioral difficulties as well as external disorders like Attention Deficit Hyperactivity Disorder (ADHD) (57). An additional widespread disability accompanying ASD is Intellectual Disability. Estimated prevalence rates of intellectual disabilities are gradually increasing, currently being one of the most co-occurring conditions in individuals with ASD (58).

Atypical sensory experience is such a common disorder in individuals with ASD that it is depicted as a symptom of ASD and perceived in the DSM-V as hyper/hypo reactivity to sensory stimuli, exhibiting how prevalent and significant this disorder is in people with ASD. Patients with ASD experience a variety of different sensory alterations in smell, taste, auditory, vision, and tactile sensations (59). Individuals with ASD can normally detect the presented odor but tend to have impaired odor identification compared to people without ASD/60). Taste alteration is prevalent and in children with ASD, it usually manifests in children eating less various foods more often excluding vegetables, fruits, and dairy products despite the texture (61). The auditory abnormalities that patients experience usually present in an inability to identify two occurring sounds if they are presented closely (62). Individuals with Autism, vision are usually more detail-orientated leading to the conclusion that this might add to the social and communication difficulties (63). Tactile defensiveness is often occurring in children with ASD. Usually, individuals prefer to touch others rather than be touched by others, accompanied by a great preference or repulsion to specific food textures. Mouthing on nonfood objects is also a common autistic trait (59).

2.3.4. Down Syndrome

Down Syndrome is the most frequent genetic chromosomal disorder that includes a plethora of other clinical findings as well as intellectual disabilities. Individuals with Down Syndrome (DS) vary considerably depending on phenotype or intellectual disability that generally is moderate but, may differ from mild to severe (66). Social skills and functioning are commonly high in individuals with DS, on there other hand, cognitive impairments are rather severe. Ethnicity and geographical location lead to differences in the prevalence and presentation of the symptoms of individuals with Down Syndrome. DS distinguishes oneself from a weak muscle tone and very particular facial features. Generally, children with Down syndrome experience developmental delays and behavioral deficits (67). Speech and language in individuals with DS develop later than in peers without DS and even later on in life the speech might be difficult to understand (68).

Causes:

Trisomy 21 is a long-known cause of Down syndrome. The cause of the distinguishable clinical features is epigenetic factors and 200 to 300 genes on chromosome 21. Amyloid precursor protein gene, polymorphisms of Down syndrome cell-adhesion molecule (DSCAM), and multiple genes on chromosome 21 are all the causes of the different features of Down Syndrome. There are two potential ways during which trisomy 21 may occur, by translocating an additional chromosome 21 to another chromosome, or by nondisjunction with the presence of 47 chromosomes. There are no clinical characteristics or distinctions between different causes of trisomy. There are other two genetic abnormalities known as partial trisomy 21 and mosaicism of trisomy which are usually linked with reduced clinical features of DS (66).

There are known several possible causes of Down Syndrome. Advanced maternal age is one of the factors that was discovered early on. Researchers have proven that the elder age of birth givers is a risk probability for Down Syndrome primarily due to the nondisjunction errors occurring in the oocyte due to the older ovum having a greater risk of improper chromosome division (69). The fluctuation of endocrine disturbances and unbalanced chromosomes that are triggered by translocation are additional factors that might cause Down Syndrome (70).

Symptoms

Down syndrome has very distinctive clinical features and symptoms that affect the full body of people with Down Syndrome. It is essential to note that some variations exist

between individuals. The prominent features are atlantoaxial instability and hypotonia, short height, and short appendices, facial characteristics include a small mouth, head and ears, flat nose and, occiput, epicanthic folds, and up-slanting palpebral fissures (69).

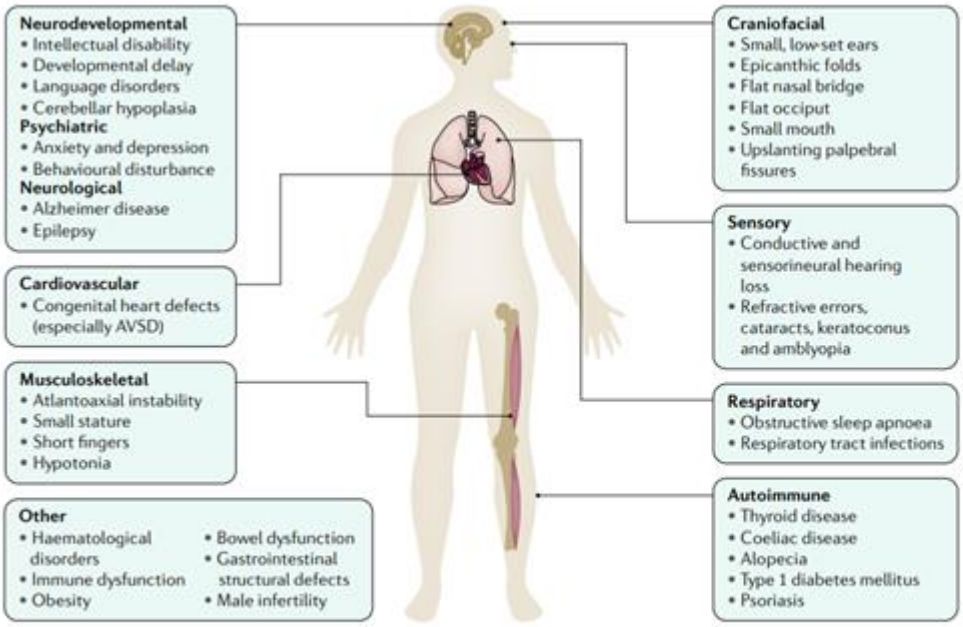

Figure 2. 1. *Features of Down Syndrome (69)*

Neurodevelopmental problems include decreased motor coordination, limited social awareness, an increased incidence of autism, as well as psychiatric problems, and later in life, dementia, impairments in language and speech, cognitive deficits, and intellectual disability (66).

There is a wide variation in IQ levels, memory, language, attention, and functional capabilities in individuals with Down Syndrome, however, usually people with DS experience difficulties in verbal memory and episodic memory, expressive language but excel at visual learning (71).

Congenital heart defects especially atrioventricular septal defect (AVSD) one of the most prevalent underlying conditions in individuals with Down Syndrome. Moreover, individuals with DS are very susceptible to other health conditions involving hypothyroidism, hematological disorders (including leukemia), epilepsy, obstructive sleep apnoea, hearing and vision problems, recurrent infections, anxiety disorders, and early-onset Alzheimer's disease (66;69).

Diagnosis:

Down Syndrome is a condition that develops during pregnancy therefore there are two main types of diagnosis. The screening tests and the diagnostic tests. Screening is a procedure by which healthcare providers identify high-risk pregnancies, preventing diagnostic procedures to be able to reduce the risk of a miscarriage. Initial screening of parents in the first trimester of pregnancy includes measurement of fetal cervical transparency and measurement of maternal serum biochemical analytes (72). First-trimester ultrasound scan of parents is done to detect characteristic signs of Down syndrome: tricuspid valve regurgitation, increased anterior maxillary angle, absence or decreased flow in the ductus venosus, absence of nasal bone, and increased NT measurement for gestational age. More invasive tests can be done in the second trimester, such as collecting amniotic fluid and measuring the amount of α-fetoprotein in maternal serum. Further testing can be done by measuring pregnancy-associated plasma protein A and inhibin A, unconjugated estriol, and β-human chorionic gonadotropin. During the second trimester, i.e. between weeks 18 and 20 of pregnancy, an ultrasound scan will usually reveal several signs, such as femur and humerus length measurements and thickened skin folds on the neck. Less prominent features include bilateral clinodactyly of the fifth toe, choroid plexus cysts, heart defects, echogenic bowel, cystic hygroma, prominent tongue, duodenal atresia, pyelectasis, a large space between the big toe and the second toe (73).

Post-test counseling and advanced diagnostic tests such as genetic analysis, amniocentesis, or chorionic villus sampling are recommended for expectant mothers with positive DS screening results. However, if signs of DS are not noticed during screening, postnatal diagnosis is made soon after birth, and healthcare professionals are trained and aware of the current clinical features of DS (66). A physical examination of an infant by an experienced physician is the most accurate primary diagnostic evaluation. The most common features of an infant suggestive of Down's Syndrome are body structure and physiognomy, often accompanied by muscle hypotonia. If DS is suspected in the postnatal period, the most appropriate genetic test is the karyotype (69).

2.3.5. Cerebral Palsy

Cerebral palsy (CP) is defined as a life-long group of neurological disorders that affect posture, limitation of movement, as well as movement and muscle tone, which are generally attributed to non-progressive disorders due to brain damage or malformation that occur while the child's brain is developing. In the fetal or infant stage (74). CP affects the movement of the body and the coordination of the muscles, followed by cognitive, behavioral, communication, sensory, disorders, perception impairments, as well as epilepsy, and secondary musculoskeletal problems (75). Each part of the human brain is responsible for different bodily functions. The brain is in control of all the voluntary movements of the human body. The motor cortex is in the human brain that controls these voluntary movements the most. The motor cortex which is responsible for the body's movements sends signals to the muscles, receiving a signal from the brain that makes the muscles tense or relax (76). Regarding this principle, a person can move freely. During CP, an impaired part of the brain is responsible for the movement of the body, the brain sends the wrong signals to the muscles, making the muscles either too tense or too relaxed. Therefore, a person cannot move normally (75;76).

Causes:

Various factors increase the risk of Cerebral Palsy. There are internal and external factors that can predetermine it. Generally, factors that determine CP are classified by the period during which damage occurred (77). Prenatal (pregnancy period up to the 7th day of the newborn's life)- this group includes various head injuries, brain deformations and anomalies (unspecified hydrocephalus and microcephaly), maternal respiratory, cardiovascular, endocrine system diseases, infections (toxoplasmosis, rubella, cytomegaly, herpes), use of alcohol or narcotic substances (medicines) (77;78). Perinatal (the period from the beginning of childbirth to the 28th day of a newborn's life) - head injuries, cerebral blood flow disorders, asphyxia - a severe disorder of the respiratory tract, blood circulation, and the heavy system caused by a lack of oxygen or its possible absence – suffocation (74).

Postnatal (from the 29th day of life to the beginning of the third year of life) - occurs after head trauma, intoxication, infection, hemolytic jaundice, and asphyxia. In the majority of children, CP infants occur during prenatal and perinatal periods (79).

The reasons for its occurrence are a very low (1.5 -2.5kg) weight at birth, and a completely premature fetus - children born before the 37th day. and especially in the 32nd

- 32nd week before the week, neonatal phalloplasty, multiple pregnancies, - twins, triplets, especially when one of the twins dies during the period or childbirth, artificial insemination and similar technologies, infection and inflammatory processes, genetic factors. Other pivotal factors depend on maternal sociodemographic characteristics and reproductive history. Maternal age contributes to the risk of having children with Cerebral Palsy. Researchers suggest that ages below 20 and above 34 years old is increasing the risk of CP (74;77;78).

Symptoms

Cerebral palsy describes a group of persistent developmental posture, movement, balance, and coordination disorders that lead to limitations in active activities (lying, sitting, rolling, walking). These disorders are caused by non-advancing damage to the brain of the fetus or newborn. Cerebral motor dysfunction (paralysis) is often accompanied by sensory, awareness, perception, cognition, communication, behavior disorders, epileptic seizures, and secondary musculoskeletal problems. Abnormal muscle tone, imbalance, muscle weakness, and loss of movement control are all manifested by the inability of muscles to stretch. Muscle weakness, spastic muscles, and contractures eventually cause bone and joint deformations (80).

In People with CP. development is delayed from childhood and postural and movement disorders are always visible. In the early months of life, infants with CP develop muscle hypotonia. Muscle tone begins to increase in those muscles that are prone to spasticity around the 6 to 18 months of a child with CP. Fluctuation of tone from hypo to hypertonus indicates the development of dyskinetic cerebral palsy. Athetosis becomes apparent between 18 and 24 months, and signs of ataxia may appear even later (81).

Early signs of CP include abnormal behavior, reduced mobility, and motor skills. The baby may be too irritable, difficult to take care of, feed poorly, sleep poorly, vomit often, do not maintain eye contact. Motor disorders are visible, the child sticks out the tongue, chews slowly, and grimaces.

Early motor signs include little to no head control and asymmetric hand fisting with hypo or hypertonic limbs. The development of movements is delayed, instead of crawling normally, the child gallops like a bunny or crawls. The clinical picture of CP is established in early childhood when movement problems become apparent (82-83).

Diagnosis

To diagnose Cerebral Palsy a combination of neurological assessments is needed. The admission of a clinical risk factor as well as neuroimaging, and physical evaluation by

the physician. This process is long and difficult resulting in late diagnosis typically by the age of 1 to 2 years or beyond (82). In current times a diagnosis of CP is attainable faster and more accurately. Caregivers of children with Cerebral Palsy prefer to have a diagnosis as early as possible to maximize long-term outcomes by leveraging neuroplasticity and brain development in early childhood (74; 84).

Diagnostic measures differ from person to person depending on identifiable factors of Cerebral Palsy in the neonatal stage which leads to closer developmental supervision and an earlier screening process. Infants that are born with detectable risk factors of Cerebral Palsy are advised to be carried out a standardized neurological assessment, motor evaluation as well as neuroimaging to obtain the diagnosis ideally before 5-month-old. The diagnosis is obtained when the newborn meets the criteria of motor impairments in addition to findings of CP during neuroimaging or a clinical history suggestive of risk (85).

Characterized by literature there are four major types of Cerebral Palsy:

Spastic

During the spastic Cerebral Palsy, the muscles are hypertonic and tense, so they cannot perform movements at the full range of motion, and are fatigued. Spasticity disrupts the normal development of movements, causes pain, disturbs sleep and feeding, possibly disrupts defecation and urination functions, and promotes the formation of contractures and deformities. Spastic CP is the most prevalent type of CP, about 70-80 percent. Spastic CP is topographical, and divided into three types (86):

- **Hemiplegia**

During hemiplegia, the upper and lower limbs of one side are affected. Seizures, decreased visual field, astereognosis, and possible loss of proprioception may occur.

- **Diplegia**

Both lower limbs are affected. Intelligence usually remains normal, and epilepsy is rare. Most people with diplegia require technical aids and various treatments to be able to walk. Spasticity and balance disorders because of talking.

- **Quadriplegia (tetraplegia)**

All four limbs are affected: usually, it includes torso muscles as well as the muscles in the mouth and even the pharynx Since almost the entire body is affected, living independently becomes impossible. Triplegia is a term used when one of the four limbs is less affected by Cerebral Palsy. Some patients may have perinatal hypoxia and ischemic encephalopathy.

Dyskinesia type:

These are involuntary, abnormal, repetitive, and sometimes stereotyped movements that occur when a person tries to perform a movement. Problems with speech, swallowing, and drooling all aggravate existing movement problems. The mental status of patients with dyskinesia is usually normal, but severe speech disturbances may mislead the observer into thinking that the patient is mentally disturbed. Existing sensorineural hearing loss also impairs the quality of communication. Muscle tone in dyskinesia is variable. At rest, muscle tone usually **remains normal, but when attempting to perform a movement, the** tone increases. Many involuntary movements are observed in this disorder (87). There are a few symptoms that are specific to dyskinesia:

• **Athetosis** - compulsory, prolonged movements of the hands and feet, face and tongue, reminiscent of the writing of the worms or snakes.

- **Chorea -** unpredictable, multiple, fast, jerking movements in the hands or feet.

• **Choreoathetosis-** a combination of athetosis and chorea involuntary movements.

• **Dystonia –** lack of muscle control, which manifests as continuous muscle contractions or involuntary movements (87)**.**

Ataxic type:

Ataxia is a disorder of balance, coordination, and fine motor control. People with ataxia have difficulty making coordinated movements. During the first two years of their life, the muscles are weak and hypotonic. Muscle tone normalizes, and signs of ataxia appear at the end of the second to the beginning the f the third year of life. People who can walk with their feet wide apart, swaying, are at risk of falling, and their gait is often accompanied by a low-intensity tremor. Disorders of mental development are possible, cases of epilepsy are increasing, and pronounced speech disorders are visible. Comparing CP types with spastic and dyskinesia, the ataxic type is distinguished by the fact that the joints are often hypermobile, and children are very flexible (89).

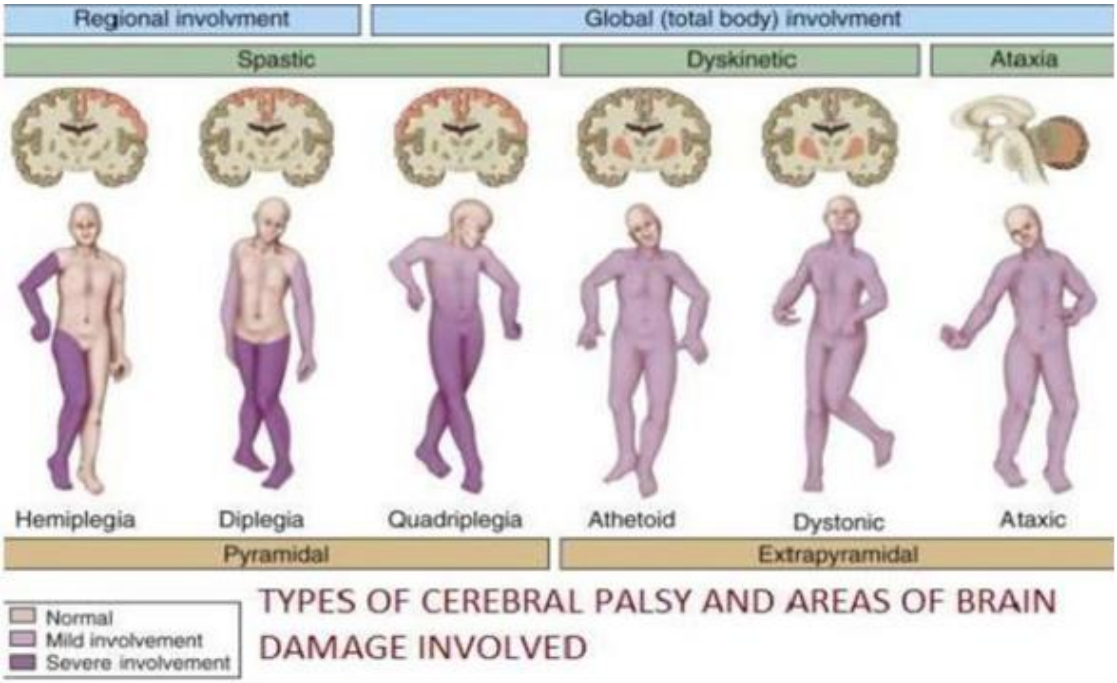

Figure 2. 2. Types of Cerebral Palsy (81)

Mixed

Individuals with mixed CP have dystonia, mild spasticity, and/or athetoid movements. An additional motor impairment that is prevalent in this type of CP is ataxia. In mixed Cerebral Palsy, spastic ataxic diplegia is prevalent and it is caused by hydranencephaly (90).

Exceptions

Sometimes people with CP are not included in these CP types because they have many different disorders. Dystonia may be observed in the spastic type of cerebral palsy, but may not correspond to its anatomical classification, as the clinical findings may overlap. A good example of this is whole-body hypotonia, which occurs in infancy and persists throughout childhood (90).

2.3.6. Spina Bifida

Spina bifida (SB) is a vastly prevalent birth defect that is characterized as highly complicated and fatal. SB affects the central nervous system due to the incompletion of the growth of the neural tube (91). Spina Bifida is a type of neural tube defect (NTD). Any

degree of neural tube closure is called a neural tube defect. Due to the complications caused by SB, the diagnosis of infants with SB begins even before birth and continues throughout the lifetime including multiple disciplines. SB results in many different neurological defects as well as impaired development depending on the degree of neutralization. Spina bifida is a condition that requires an individual medical care plan to achieve survival and positive outcomes (92).

Cause:

Spina Bifida is a neurogenetic disorder that is composed of both genetics as well as environmental factors. The most prevalent cases of environmental factors are caused by the deficiency of folate acid as most Spina Bifida causes are regarded as "folic acid-sensitive" (93). Obesity and diabetes in mothers are considered possible risk factors for Spina Bifida (91). Additional environmental factors include exposure to teratogens such as valproic acid, which is highly associated with neural tube defects that increases the risk of Spina Bifida about ten times (94).

Genetic factors of Spina Bifida include chromosomal syndromes as well as genetic polymorphism that results in poor neutralization (95). The research concluded that polymorphism of the gene encoding the MTHFR enzyme involved in folate metabolism is a very likely genetic factor (96). Generally speaking, neural tube deformities are isolated defects some of which are linked with chromosomal syndromes, most commonly Trisome of 13 and 18 (95). Many possible factors may cause Spina bifida however there are also a few factors that may cause the reoccurrence of Spina Bifida. These include the history of the family's health, the severity of the defect, and geographic location. Studies state that recurrence risk increases by about 3 to 8% if there were previously born infants with Spina Bifida defect or if family history from the mother side has any Spina Bifida affected relatives. The risk of Spina Bifida recurrence worsens with an increasing number of individuals with Spina Bifida (93).

Symptoms:

Spina Bifida means split spine and is not a consistent spinal disorder. Spinal dysraphism can occur in different locations and sizes, the following types are: Myelomeningocele is the most common type of Spina Bifida and affects about 90% of people with SB and is the most severe, the others being meningocele, lipomyelomeningocele. As the fetus develops, the spinal canal remains open along several vertebrae, causing the spinal cord and surrounding protective membranes to come out and form a sac on the baby's back (93; 94; 98).

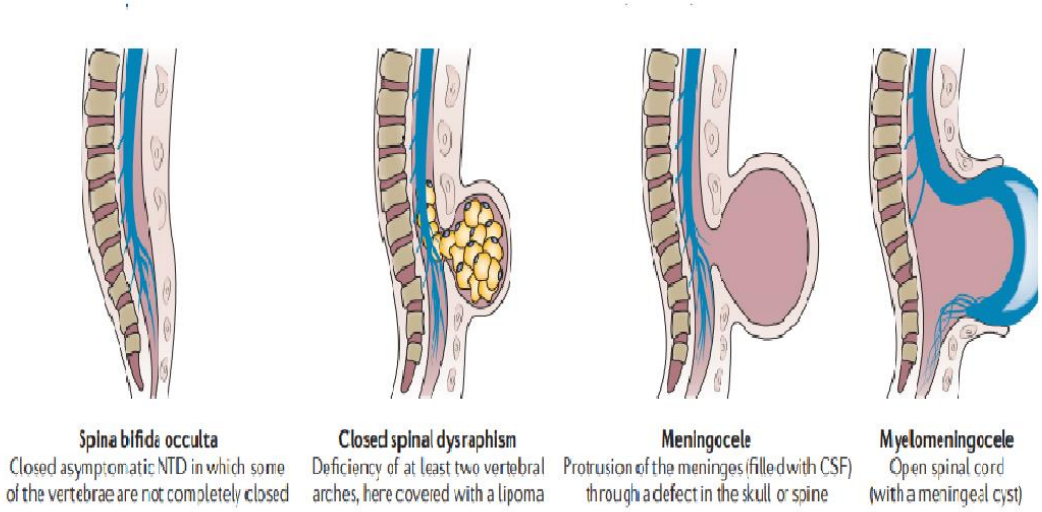

Figure 2. 3. Types of Spina Bifida (94)

The presentation of myelomeningocele is typically but not always neurological. It affects the brain and portrays phenotypic features causing dysfunction in cognition, behavior, and adaptation, accompanied by common complicated effects of neurological impairments on several organ systems. Despite a large number of similarities that spina bifida myelomeningocele poses with other neurogenetic disorders involving genetics, behavior, and brain development, Spina Bifida myelomeningocele is not considered to be one (97). Spina Bifida myelomeningocele like many other neurological conditions affects the ability to read and comprehend, logical thinking like math skills, and language. But individuals with Spina Bifida myelomeningocele can hypersociolize and have some sort of speech and language characteristics. Nevertheless, these skills and features vary greatly from person to person. Less common is intellectual disabilities, on the other hand, the most prevailing strengths and weaknesses are adaptive skills followed by academics and cognitive abilities. Individuals with Spina Bifida also encounter other types of dysfunctions in their daily lives (99). Bowel and urinary incontinence is unfortunately frequent dysfunction that affects individuals with Spina Bifida (100). Movement disorders are also common and typically affect lower limbs, weakness or total paralysis of the legs are characteristic of Spina Bifida. Additionally, sensation loss in the lower bottom of the body contributes to the symptoms of SB (98).

Diagnosis:

In the countries where national screening programs exist the Spina Bifida can be detected in the prenatal period. Ultrasound is the most commonly used screening tool as it is safe, inexpensive, and non-invasive. Ultrasound is also considered to be more specific and reliable than biochemical screening tools, to detect anatomical abnormalities (101). Clinical signs of Spina Bifida can be seen on sonographic images during the second trimester: "lemon sign" flat temporal bones with abnormal skull shape, ventriculomegaly, and posterior fossa changes can also be seen on the scan. As well as abnormal features of the ventricles of the brain. (102). However, closed spinal abnormalities are not detectable before birth because they are not visible within skull signs. Later in the pregnancy indicators suggesting Spina Bifida include the absence of lower extremities movement or deficit of it, non-typical positioning of infants feet may also be a sign. Currently, new ultrasound markers were discovered providing an opportunity for open Spina Bifida to be found as early in the pregnancy as in the first trimester. Intracranial translucency, the sonographic equivalent of the fourth ventricle, can be evident during the screening (103). However, some types of closed Spina Bifida can be undetectable during the first trimester of pregnancy. The outcomes and implications in such cases may differ highly so the proper diagnosis and differentiation of such cases are significant.
If Spina Bifida is suspected regarding the screening finding in the early semester the parents are further sent to the tertiary care center for thorough assessment and parental counseling. To make sure there are no associated abnormalities a detailed anatomic survey is completed (102). The level of the spinal defect and the appearance of secondary findings will be evaluated using neuro sonography, three-dimensional ultrasound, or Magnetic Resonance Imaging (104).

2.4. How child's disability affects parents?

The birth of a disabled child is a devastating discovery to the parents. In many cases, these parents' lives change drastically because caring for a disabled child affects all aspects of life. The care of a disabled child is demanding and affects parents' employment status, especially women. Unfortunately, despite the attempts for gender equality for the past two decades, women are still maintaining their primary caregiver status. That results in women facing difficulties and hardships in handling their occupational duties as well as the care of the disabled child. A study done in Norway showed that caring for a disabled

child hurts the mother's labor market participation as well as a decrease in working hours and income. It was concluded that as the severity of a child's-disability increases the likelihood of the mother's income suffering due to decreased working hours or that the mother has to give up work completely increases as well. Further investigation revealed that as a child approaches school age the difference in income between mothers with and without disabled children increased as well as the participation in the labor market. However, caring for children with disabilities reduces the labor income of the father but had no effect on hours worked or participation in the labor market (105).

Socioeconomic status is not the only change that parents with disabled children face. Many parents experience stress related to the disability of their child, as it requires additional care tasks like medical care, behavior management, equipment management necessary for the child, and service navigation (106). Additional roles are placed upon the shoulders of the mother as a therapist and teacher, case manager. Studies disclosed that the physical and mental health status of mothers of disabled children has significant differences in comparison to the mothers of healthy children (107). Recent research has concluded that parents of disabled children tend to experience mental health problems in comparison to other parents. The probability of having depression or anxiety was about three times higher for mothers of disabled children and more than twice for fathers (108). Increased stress and anxiety during the care of a disabled child are depicted in the quality and quantity of sleep during the night. While sleep deprivation varies from diagnosis to diagnosis, the key factor remains the same the necessity for parents to stay alert through the night. Sleep deprivation is relentless and draining affecting the parents as well as their relationship and physical health (109). Previous studies reveal that parents of disabled children showed a significantly higher chance of developing chronic diseases (such as back pain, obesity. chronic bronchitis, asthma. heart disease, and migraines,), as well as significantly increased smoking and unhealthy sleep (5)

2.5. Quality of Life in Parents of Children with Disabilities

The definition of Quality of life has evolved as originally referred to the overall well-being of a person's various aspects of day-to-day life. The purpose of life, standards, aspirations, and living situation, all of this constitute the quality of life by which a person perceives his life situation.”. However, QoL is a complicated notion construed and determined miscellaneously within and between various disciplines. Therefore there are

plenty of different instruments to measure QoL. Since QoL may be seen as a very subjective area, the instruments designed to evaluate the QoL were based mainly on empirical data rather than conceptual models or definitions. Physical functioning, psychological, emotional, and social well-being are the main areas of quality of life. Families of individuals with neurodevelopmental disorders are evaluated according to these areas of quality of life (110).

Children with developmental disorders frequently experience multiple complicated physical, mental, and behavioral impairments and have highly demanding healthcare needs (25). A study that evaluated the quality of life of Turkish mothers of disabled children stated, that as the care burden of the mothers increases the quality of life decreases (7). Research shows that social relations, environment, and physical and psychological health are all domains of the quality of life that are affected by the child's disability (111). The study that used the SF-36 questionnaire to evaluate the life quality of mothers whose children have CP, showed that out of 8 quality of life domains, 6 domains scored significantly lower than the control group whose children had no disabilities. The domains of physical role, emotional role, mental health, general health, vitality, and social functioning were decreased in the parents who have disabled children, in comparison to the control group (112). An in-depth analysis of life quality in parents with disabled children was conducted. The research concluded that not only do the carers of children with CP experience poor life quality when compared to healthy kids but it also found how different types of Cerebral Palsy affect life quality. Interestingly enough during the study the parents whose kids had hemiplegia experienced more psychological problems and had poorer psychological health than the primary carers of children with diplegia or quadriplegia.

The findings can be considered to be controversial as individuals with hemiplegia tend to experience milder motor dysfunction than individuals with quadriplegia or diplegia. However, the carers of individuals with diplegia and tetraplegia reported lower scores in physical health (15).

Another study evaluated the life quality of parents of disabled children during the COVID-19 pandemic and found that the overall life quality scores of parents of disabled children were significantly poorer than in the control group. While there was a statistically significant difference in two of the four domains, physical and environmental, in the evaluation of the quality of life, no difference was observed in the other two social and

psychological domains. Although the COVID-19 pandemic affected the overall quality of life scores in the control and study groups, scores were lower in the study group (14).

2.6. Physical Activity in Parents of Children with Disabilities

Physical inactivity is a considerable threat to society today as it is a major risk factor for mortality and morbidity worldwide. In 2020 the World Health Organization released new physical activity guidelines. It is recommended that adults engage in a combination of at least 150-300 minutes of moderate-intensity physical activity, 75-150 minutes of high-intensity physical activity, or equivalent aerobic physical activity each week. Regular physical activity is a highly effective primary as well as a secondary prevention method against at least 25 chronic conditions as well as reducing the risk of these chronic conditions by about 20% to 30 % (9).

However, a systematic review concluded that only 16.7% of parents of children with disabilities met physical activity recommendations and 50% of parents were not active enough. (113) A study comparing the physical activity of children with developmental disabilities, children with Down syndrome, and parents of healthy children found that parents of children with developmental disabilities were less likely to participate in regular physical activity than parents of healthy children. However, parents of children with Down syndrome are the least likely to engage in regular physical activity (45% less than typical children, 8-37% less in other groups). (11th). Contrary to a previous study, a study conducted on mothers of disabled mothers in Turkey found that mothers met the physical activity guidelines, but their physical activity levels were insufficient (7). Another Bourke-Taylor et al. The study found that parents of children with disabilities engaged in approximately 186.4 minutes of moderate to vigorous physical activity per week and met current physical activity guidelines. The study also found that improved physical activity was positively associated with positive well-being among mothers of children with disabilities (13).

3. MATERIALS AND METHODS

3.1. The subjects of the thesis

The research was conducted in the special education center "Özel Işıl Özel Eğitim Merkezi" in Istanbul/Turkey. Between 2022 December and 2023 February. Parents at first were asked to sign the voluntary consent form (Appendix 3) stating that they are participating in the study voluntarily and that they can withdraw from the study whenever they want without any repercussions. Also, the consent form ensures parents' complete anonymity.

The ethical committee board of Yeditepe University approved the study protocol on December 16, 2022, with issue number 202211Y0316 (Appendix 1). The study began to conduct on the 19th of December of 2022. Permission from the special education school center "Özel Işıl Özel Eğitim Merkezi" was also taken (Appendix 2). The surveys that were used in the study 36-Item Short Form Health Survey (SF-36). (Appendix 4) and the International Physical Activity Questionnaire (IPAQ) Turkish form was authorized. (Appendix 5).

The anonymous survey was designed (Appendix 6) and parents of children with disabilities were asked to fill out the questionnaire regarding the demographics, child's disability type, physical activity questionnaires, and quality of life.

3.2. The objects of the study

Participants:

There are a total of 156 participants in the study. There were 31 (19,9%) male participants and 125 (80,1%) females. The participants were split into four equal groups based on the type of the child's disability so each group had 39 participants.

Inclusion criteria:

- Is a primary caregiver (either the father or mother of a family)

- One parent represents one child (both parents of the same child cannot participate)
- Has a child (ages between 1 and 17) with a disability.
- The child's disability falls into one of these diagnoses: Autism, Downs syndrome, Cerebral palsy, and Spina bifida.

3. 3. Sample size calculation

Yamane's (1967) formula: n = N/(1+N(e)2) is going to be used to calculate the sample size of this thesis. The variables in this formula are:
n = the sample size
N = the population of the study
e = the margin error in the calculation
Calculation:
Population size N=258 students in the special education center
e =0.05 -the margin error in the calculation
Sample size n= 258/ 1+258(0.05) ^2
=258/1+258(0.0025)
=258/1+0,65 =258/1,65 =156,36
The sample size in the study was used as 156. Following the condition that the population size is 258 in which the margin of error is 0.05.
The power analysis was made by utilizing the G Power 3.1 program. The G Power analysis showed an estimate of the smallest sample size needed for an experiment was 140 participants. The Power of the thesis was 80% to increase the power and complete the equal groups, 156 participants were used in the study (APPENDIX 9.)

- **Sampling methods**

For this thesis, we used the controlled quota sampling method. To determine the differences between parents of children with Autism, Down Syndrome, Cerebral Palsy, and Spina Bifida we have selected 156 participants based on the sample size calculation and power analysis. We divided these participants into four equal groups of 39 participants. To ensure the equal number of participants in each group.

3.4. Study Protocol

The research was conducted using in-person filling physical surveys. Totally 156 parents of children with various disabilities participated in the study. They were four groups of parents of children with various disabilities. Each group had 39 parents of: Autism, Down Syndrome, Cerebral Palsy, and Spina Bifida. In this study the mean age of participants was 37,4 ±2.7, there were 31 males (19,9%) and 125 females (80,1%)

1. The demographic survey was used to determine the participant's age as well as gender and child's disability type.
2. The Physical activity levels were concluded using The International Physical Activity Questionnaires (IPAQ).
3. The Quality of Life was measured using a 36-Item Short Form Health Survey 36 (SF-36) questionnaire.
4. After the survey is completed the questionnaires are to be evaluated and the results are to be presented.

3.5. Data Collection Methods

Data collection includes questionnaires and surveys:

1. Demographic survey.

This includes information about the gender, age, marital status, education, and employment status, the number of children in the family, the disability type of the child, and the age of the disabled child. The demographic survey was designed by the Researcher Investigator the a of the thesis based on another demographic survey available on the internet (Appendix 6).

2. The International Physical Activity Questionnaires (IPAQ)

The IPAQ was used to assess the physical activity of the participants. The purpose of this survey is to provide simple and essential tools used for internationally comparable data on physical activity for health. This tool evaluates the intensity of physical activity and measures the amount of sitting time people spend in their daily lives, including total physical activity in MET-min per week. The long and short Turkish IPAQ forms both proved to be valid to assess the physical activity levels in both women and men of Turkey. The Turkish version of the IPAQ was almost

identical to the original English version in terms of test-retest reliability and very good concurrent validity (114). Short IPAQ is composed of 7 items.

The short form of IPAQ is composed of four main domains:

- Vigorous activities
- Moderate activities
- Walking
- Time sitting

The website of IPAQ provides an automatic report in Excel to conclude the total score and determine the activity level. The results can be categorized as high activity l, moderate activity, or low activity) and also can be used as a continuous variable (MET minutes a week) It requires the duration in minutes and frequency by days of vigorous and moderate activities as well as walking and sitting time. To calculate each category's minutes per week as a continuous score the Metabolic Equivalent (MET; multiples of resting energy expenditure) was used. The continuous score is calculated by this formula, The MET-min per week: MET level x minutes of activity/day x days/week (Appendix 4).

3. 36-Item Short Form Health Survey (SF-36) for the assessment of the caregivers' quality of life. The SF-36 questionnaire is most commonly used in the clinical setting and studies, general population surveys. The questionnaire composes of a multi-item scale that evaluates eight domains of health.

1) Physical Functioning- evaluates the limitations occurring in physical activities because of health problems;

2) Physical Role-assessees the limitations in usual role activities caused by physical health problems;

3)Emotional Role- evaluates the limitations in usual role activities caused by emotional problems;

4) Vitality- evaluates the energy and fatigue

5) Social Functioning- evaluates limitations in social activities because of physical or emotional problems;

6) Mental Health -assesses the psychological distress and well-being

7) Pain- evaluates the bodily pain

8) General Health- evaluates the overall health

Scoring: Each domain of the SF-36 is evaluated separately. The scores of each domain are sums of the questions in each section. The minimum score of each domain is 0

and the maximum is 100. The higher the scores of the domain the lower the disability in that domain.

The study was done to evaluate the reliability of the SF-36 Turkish version. The study was performed on 63 participants whose reported conditions did not change in 3 months. The results showed that when comparing results between such individuals from before and after the was no statistically significant difference between them. The Turkish version of SF-36 was concluded to be reliable and valid (115). (Appendix 5).

3.6. Statistical analysis

The analysis of the data was carried out by using SPSS-Statistics 29 software. The frequency distribution among the data variables was implemented as well as descriptive statistic analysis for continuous variables. The significance level in this study was accepted as $p \leq 0.05$. A data normality test (Kolmogorov-Smirnov test) was used, and the results of the normality test showed that data variables are not normally distributed. Since the data were not normally distributed non-parametric tests were used. To perform statistical hypothesis testing Kruskal-Wallis analysis method as well as the Mann-Whitney U analysis method was used for the comparison of continuous data scores. Since the categorical variables have more than two categories Kruskal-Wallis analysis method was used to measure physical activity level and life quality among parents of children with various types of disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida), post hoc Dunn's explanatory analysis was used to supplement the Kruskal-Wallis test. To determine from which groups the difference arises the variables should be compared in pairs by two categories separately, for this Mann-Whitney U analysis method was performed.

The correlation between the numeric variables among all groups of parents of children with various disabilities was investigated using Spearman's correlation analysis. The direction and strength of the relationship between the two ranked variables are measured by Spearman's rank coefficient. Spearman's p-value can range from +1 to -1, values are considered positive when positive and negative when p is negative. A ρ value of 0 means no ranking, so the closer the p-value is to 0, the weaker the relationship between the variables.

For further investigation, multiple linear regression analysis was performed to analyze the relationship between the disability type of the child and the parental physical

activity and life quality and variables. The purpose of multiple regression analysis is to use independent variables whose values are known to estimate the value of a dependent variable. For this reason, independent variables cannot be more than two groups, therefore analysis was made using dummy variables separately for each dependent variable.

4. RESULTS

4.1. Results of demographic data

4.1.1. Demographic data results in all participants

The demographic data consists of the mean values of the participant's age and frequencies of gender, education level, marital status, employment, and type of the child's disability.

Table 4. 1. The features of participants

Features of participants	**Minimum**	**Maximum**	**Mean (±sd)**
Age of Parent	18	65	37.4 ±2.7,
Height (m)	1.47	1.83	1.63 ± 0.078
Weight (kg)	45	97	66.68 ±11.47
BMI	17.4	37.6	25.1 ±3.90
Age of Child	1	17	8.3 ± 4.8
Total			156

The mean age of participants is 37.6 ± 2.5 years, with 18 being the minimum and 65 being the maximum. The mean height of participants is 1.63± 0.078 m and the mean weight is 66.68±11.47 kg the mean BMI (Body Mass Index) is 25.1 ±3.90.

Table 4. 2. General characteristics of all respondents

Demographic Questionnaire		**Frequencies**	**Percentage**
Gender	Male	31	19.9%
	Female	125	80.1%
Education Level	Middle school	30	19.2%
	High school	58	37.2%
	Bachelor degree	20	12.8%
	Master degree	1	0.6%
	Doctorate and higher	0	0.0%

	Trade school	9	5.8%
	I don't want to say	38	24.4%
Marital Status	Married	140	89.7%
	Single	2	1.3%
	Divorced	8	5.1%
	I don’t want to say	6	3.8%
	Other	0	0.0%
Employment	Full-time job	29	18.6%
	Part-time or casual job	15	9.6%
	Not working	9	5.8%
	Stay-at-home mom	92	59.0%
	Voluntary work	0	0.0%
	Studying	3	1.9%
	Retired and other	8	5.1%
Disability of Child	Autism	39	25.0%
	Down Syndrome	39	25.0%
	Cerebral Palsy	39	25.0%
	Spina Bifida	39	25.0%
Age of Diagnosis	From Birth	101	64.7%
	1 year	23	14.7%
	2-6 years	24	15.4%
	7-10 years	7	4.5%
	1-15 years	1	0.6%
Total		**156**	**100%**

In the study, a total of 156 parents of children with various disabilities were participating. The distribution of the participants' gender was 19.9% males and 80.1% Females. The education level among the participants was as follows: the majority of participants had high school education 37.2%, and second after was the population that didn't want to say 24.4%, a good percentage of participants had middle school education 19.2%, following, participants that had Bachelor degree 12.8%, trade school education had 5.8%. The marital status showed that a large number of the participants 89.7% are married, in furtherance, divorced 5.1%, don’t want to say 3.8%, single 1.3%. The data on employment revealed that: predominantly participants are "stays at home moms" 59%, 18.6% of the participants had full-time jobs, several participants had part-time or casual jobs 9.6% not working 5.8%, retired and other 5.1% a small percentage was studying

1.9%, non of the participants did any voluntary work. Types the disabilities were distributed evenly: Autism, Down Syndrome, Cerebral Palsy, and Spina Bifida 25% each. Correspondents disclosed that regarding the age of diagnosis, a vast majority of 64.7% of children of parents with various disabilities were diagnosed from birth.15,4% of the children were diagnosed by 2-6 years old, and 14.7% were diagnosed by 1 year. 4.5% of children were diagnosed from ages 7 to 10 years old. And finally, 0.6% of the children were diagnosed by the age of 11 to 15 years old.

4.1.2. Demographic results according to the different types of the child's-disability

Table 4. 3. Anthropometric data according to the child's disability type

		Age of Parent		Age of the child		Height		Weight		BMI	
Disability type	**N**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD (±)**	**Mean**	**SD (±)**	**Mean**	**SD (±)**
Autism	39	35.60	5.53	7.92	4.84	161.95	7.16	65.89	11.96	24.97	4.51
Down Syndrome	39	37.91	5.29	8.33	4.71	164.28	7.45	69.56	11.42	25.80	4.14
Cerebral Plasy	39	38.39	5.26	8.72	4.39	163.48	8.42	65.97	12.24	24.62	3.65
Spina Bifida	39	38.52	5.33	8.38	5.26	161.77	8.11	65.26	10.09	24.99	3.80

The mean scores of participants' anthropometric data according to the child's disability type. The highest age mean score is of the parents of children with Spina Bifida 38.52 the lowest age mean is of the parents of children with Autism 35.60. The lowest BMI score is of the parents of children with Cerebral Palsy 24.62 and the highest mean score is of the parents of children with Down Syndrome 25.80. According to the Centers for Disease Control and Prevention (CDC), BMI status is as follows:

- Below 18.5- underweight
- Between 18.5–24.9- healthy
- Between 25.0–29.9- overweight
- 30.0 and above- obese

The parents of children with Down Syndrome fall under the overweight category according to the BMI mean score.

Table 4. 4. Kruskal-Wallis test to compare means of anthropometric data among all four groups

Test Statistics	Age of Parent	Height	Weight	BMI	Age of the Child
Kruskal-Wallis H	1.769	2.98	3.76	1.74	0.73
P=	0.622	0.394	0.288	0.628	0.866

Analysis shows that there are no significant differences between the means of participants' age, age of the child, weight, height, and BMI.

4.2. Results of physical activity levels

4.2.1. Results of physical activity levels of all participants

Table 4. 5. Frequencies of Physical Activity levels of all participants

Activity Level	Frequencies (N)	Percentage (%)
High activity level	17	10.9%
Moderate activity level	72	46.2%
Low activity level	67	42.9%
Total	**156**	**100%**

As seen in the table above the lowest number of participants 10.9% scored high activity levels and is sufficiently physically active. The second comes low activity level with 42.9% of the participants being physically inactive, the highest number of participants scored moderate activity level 46. 2% that shows insufficient physical activity (115).

Table 4. 6. Frequencies of METs and Mins of IPAQ

	METS	Mins
Median	**795**	**240**
Mean	**1363.17**	**366.03**

Std. Deviation ±	±1462.022	± 375.575
Minimum	0	0
Maximum	7545	1860

IPAQ scale can measure both the categorical and continuous results of physical activity among parents. The categorical data means the activity level i.e. low, moderate, and high activity levels. While the continuous data are the MET minutes active. However, continuous data presents a non-normal distribution of energy expenditure in many populations including this one.

4.2.2. Results of physical activity levels according to the type of child's disability

Table 4. 7. IPAQ results according to different types of disabilities

				Frequencies (n)	Percentage (%)
Disability of Child	**Autism**	Physical Activity Level	High activity level	5	12.8%
			Moderate activity level	18	46.2%
			Low activity level	16	41.0%
	Down Syndrome	Physical Activity Level	High activity level	3	7.7%
			Moderate activity level	18	46.2%
			Low activity level	18	46.2%
	Cerebral Palsy	Physical Activity Level	High activity level	4	10.3%
			Moderate activity level	21	53.8%
			Low activity level	14	35.9%
	Spina Bifida	Physical Activity Level	High activity level	5	12.8%
			Moderate activity level	15	38.5%
			Low activity level	19	48.7%

In the table above (table 7), we see that the mean distribution of physical activity levels among the types of disabilities falls into these categories: Autism group, a large number of participants 46.2%are in the moderate activity level category. Second, in the low activity level category 41.0% of participants, and lastly, high activity levels reached 12.8% of participants. Regarding Down Syndrome, both low and moderate activity level categories have the same number of participants 46.2%. In the high activity level category, were 6 15.4% participants. In the Cerebral Palsy group, the majority of the parents

participating achieved moderate activity levels of 53.8% of participants, the low activity level category was reached by 35.9%, high activity level was scored by 10.3%. And lastly, for Spina Bifida a great number of participants scored a low activity level of 48.7%, this is the highest number of low-activity participants among all four groups. A moderate activity level was scored by 38.5%, and high activity level was achieved by 12.8%.

Table 4. 8. METs and Mins active per week according to the child's disability type

	Autism	**Down Syndrome**	**Cerebral Palsy**	**Spina Bifida**		
	Mean (±sd)				**Kruskal-Wallis H**	**P**
METs	1470.28± 1492.28	**1057.67±1 139.71**	1370.97± 1340.25	**1553.77±1 803.27**	1.929	0.587
Mins	384.23 ±350.56	**305.90 ±327.50**	376.79 ±386.24	**397.18 ±436.88**	0.587	0.499

This table shows the means of METs per week and Mins per week active. The highest number of METs/week active is of parents of children with Spina Bifida. The parents of children with Down Syndrome have the lowest number of METs/week active. Including the lowest Mins/week active whilst, parents of children with Spina Bifida have the highest number of Mins/week active.

To evaluate the difference in physical activity levels across four different groups of parents of children with varying types of disabilities (Autism, Down Syndrome, Cerebral Palsy, and Spina Bifida), the Kruskal Wallis Test was used. The Kruskal Wallis Test revealed insignificant differences between the four groups of parents of children with different disabilities regarding the METs\week p=0.587) and Mins\week p=0.499). To supplement the Kruskal-Wallis test results the post hoc Dunn's exploratory analysis was used. The null hypothesis stating that there are no significant differences between parents of children with various disabilities in physical activity regarding METs per week and Mins per week active was retained

4.3. Results of quality of life

4.3.1. Results of quality of life of all participants

Table 4. 9.SF-36 results of the whole population

Domains	Minimum	Maximum	Mean (±SD)
Physical functioning	0	100	**60.5** ± 28.6
Physical Role	0	100	**50.9** ± 35.9
Emotional Role	0	100	**54.9** ± 39.7
Social Functioning	0	100	**60** ± 21
Pain	0	100	**60** ± 26.2
Vitality	0	85	**47.3** ± 18.2
Mental Health	16	96	**56.3** ± 16.3
General Health	0	100	**54.3** ± 20

The 36-item Short Form Health Questionnaire (SF-36) consists of 8 fields related to patient-reported patient health questionnaires. Each scale is converted directly to a 0-100 scale, assuming that each question carries equal weight. The lower the score, the more disabilities there are. The higher the score, the less disability there is, that is, zero score is equivalent to maximum disability and 100 points is equivalent to no disability.

The results show that regarding the score of physical functioning, the mean is 60.5± 28.6 where the minimum score is 0 and the maximum is 100. Regarding physical roles where the minimum is 0 and maximum 100 the mean score is 50.9± 35.9. The emotional role seems to score slightly better than the physical role where 0 is minimum, 100 is maximum and 54.9± 39.7 is the mean score. Social functioning scored second best after physical functioning where 0 is minimum and 100 is maximum, the mean is 60± 21. Pain scores mean 60± 26.2 where o is minimum and 100 is maximum. Vitality, where 0 is minimum and 85, is maximum, the mean score is 47.3± 18.2. In mental health where 16 is the minimum score and 96 is the maximum, the mean value is 56.3± 16.3. General health where 0 is the minimum and 100 is the maximum, 54.3± 20 is the mean score.

4.3.2. Results of quality of life according to the disability type of the child

Table 4. 10. SF-36 Results according to the different types of disabilities

	Autism	**Down Syndrome**	**Cerebral Palsy**	**Spina Bifida**		
		Mean ± SD			**Kruskal-Wallis**	**P**
Physical functioning	57± 30.4	65.5± 23.8	**66.5± 30.8**	**52.9± 27.55**	6.782	0.079
Physical Role	55.1 ± 35.44	**60.3 ± 34.28**	50.6 ± 39.52	**37.8 ± 31.35**	8.667	**0.034***
Emotional Role	53.85 ± 39.46	**58.98 ± 41.51**	55.56 ± 42.12	**51.28 ± 36.56**	0.983	0.805
Vitality	47.18 ± 16.42	**54.23 ± 14.89**	45.13 ± 20.66	**42.95 ± 19.25**	9.836	**0.020***
Mental Health	56.31 ± 14.95	**62.56 ± 17.23**	56.62 ± 15.48	**50.10 ± 15.98**	9.839	**0.020***
Social Functioning	57.69 ± 21.19	**66.42 ± 20.10**	61.41 ± 20.53	**54.49 ± 21.36**	6.959	0.073
Pain	55.64 ±26.73	65.31 ± 28	**66.15 ± 25.10**	**53.21 ± 23.47**	8.573	**0.036***
General Health	53.08 ± 22.29	**59.10 ± 18.56**	57.56 ± 18.17	**47.69 ± 19.66**	10.923	**0.012***

This table shows the mean scores of all SF-36 domain scores according to the different types of disabilities. Physical Functioning The highest mean score is in the Cerebral Palsy group 66.5 ± 30.8 and the lowest in Spina Bifida 52.9 ± 27.55. in the Physical Role, the highest means score is in the Down Syndrome group 60.3 ± 34.28, and lowest in the Spina Bifida group 37.8 ± 31.35. In regards to all further domains, the Down Syndrome group has the highest mean scores while the Spina Bifida group has the lowest mean scores.

To evaluate the differences between all four groups the Kruskal-Wallis test was used. The test revealed an insignificant difference (p=0.079) between four groups of parents of children with varying types of disabilities, regarding Physical Functioning, the test of Physical Role showed significant differences between the four groups (p=0.034). There was no significant difference between all four groups regarding Emotional Role (p=0.805), however, there was a significant difference between groups regarding the domains of Vitality (p=0.020) and Mental Health (p=0.020). The test showed that there was also a significant difference in groups among Pain (p=0.036) and General Health

(p=0.012). The post-hoc Dunn's exploratory analysis was used to ensure the results of Kruskal- Wallis. The post-hoc Dunn's exploratory analysis rejected the null hypothesis regarding the SF-36 questionnaire domains of Physical Role, Vitality, Mental Health, Pain, and General Health and retained the hypothesis concerning Physical Functioning, Emotional role, and Social Functioning.

Table 4. 11. SF-36 domains significant values between child's disability type

SF-36 Domains	**Groups mean scores**		**Comparing disability types**	**P**
Physical Role	Autism Down Syndrome Spina Bifida	**55.1** **60.3** **37.8**	Autism/ Spina Bifida Down Syndrome /Spina Bifida	**0.026*** **0.003***
Vitality	Autism Down Syndrome Cerebral Palsy Spina Bifida	**47.2** **54.2** **45.1** **42.9**	Autism/Down Syndrome Down Syndrome/ Cerebral Palsy Down Syndrome/ Spina Bifida	**0.033*** **0.018*** **0.005****
Mental Health	Down Syndrome Spina Bifida	**62.6** **50.1**	Down Syndrome/ Spina Bifida	**0.003****
Social Functioning	Down Syndrome Spina Bifida	66.42 54.49	Down syndrome\Spina Bifida	**0.047***
Pain	Down Syndrome Cerebral Palsy Spina Bifida	**65.3** **66.2** **53.2**	Down Syndrome/ Spina BifidaCerebral palsy/ Spina Bifida	**0.033*** **0.014***
General Health	Autism Down Syndrome Spina Bifida Cerebral Palsy	**53.1** **59.1** **47.7** **57.6**	Autism/ Down Syndrome Down Syndrome/ Spina Bifida Cerebral palsy/ Spina Bifida	**0.021*** **0.004**** **0.032***

***P ≤ 0.05**
****P≤ 0.01**

The table exhibits the differences between each group of disability separately according to the domains of the SF-36 questionnaire in which the Kruskal Wallis test was used to find the significance. To differentiate the exact groups that were statistically significantly different from one another the Mann-Whitney U test was used. Mann-Whitney U test revealed that there is one more domain of SF-36 in which there is a significant difference between the parents of children with various disabilities. In the

domain of Social Functioning, there is a significant difference between the parents of children with Down Syndrome and parents of children with Spina Bifida.

In Physical Role, two statistically significant differences were found between Autism/ Spina Bifida (p=0.026*) and Down Syndrome /Spina Bifida (p=0.003*. According to, the table, scores are significantly different with Spina Bifida being the lowest mean score compared to Autism and Down Syndrome. Regarding the domain of Vitality, significant differences were founded among the three groups, Autism/ Down Syndrome (p=0.033*), Down Syndrome/ Cerebral Palsy (p =0.018*), and Down Syndrome/ Spina Bifida (p= 0.005*). In Table (14) we can see the significant difference between Down Syndrome and the other three groups because Down Syndrome has the highest mean score compared to others. The domain of Mental Health had only one significant group difference in Down Syndrome/ Spina Bifida (p =0.003*), in which the significant difference between the two mean scores with Down Syndrome having the higher mean score. Social Functioning significant difference between Down Syndrome\Spina Bifida, (p=0.047*) and the Pain domain had two statistically significant group differences between Down Syndrome/ Spina Bifida (p=0.033*) and Cerebral palsy/ Spina Bifida (p=0.014*), a significant difference between Down Syndrome and Spina Bifida as well as Spina Bifida and Cerebral Palsy due to the fact group had the lowest mean score. The General Health domain has the most statistically significant difference among all the groups (p=0.012), there are three groups of statistically significant differences Autism/ Down Syndrome (p =0.021) Down Syndrome/ Spina Bifida (p =0.004*) and Cerebral palsy/ Spina Bifida (p=0.032*). The significant difference between Spina Bifida is due to the reason that Spina Bifida had the lowest mean score among the groups.

4.4. Relationship between the variables

4.4.1. Correlation analysis

Table 4. 12. Relationship between IPAQ and SF-36 scores

Variables	**1.**	**2.**	**3.**	**4.**	**5.**	**6.**	**7.**	**8.**	**9.**	**10.**
1. METs\week	**1**									
2.Mins\week	R=.944 **P<0.01**	**1**								

3. Physical functioning	R=.176 **P=0.028**	R=.167 **P=0.037**	**1**							
4. Physical Role	R=.133 P=0.098	R=.111 P=0.165	R=.483 **P<0.01**	**1**						
5. Emotional Role	R=.068 P=0.397	R=.022 P=0.784	R=.401 **P<0.01**	R=.548 **P<0.01**	**1**					
6. Vitality	R=.114 P=0.157	R=.128 P=0.112	R=.363 **P<0.01**	R=.405 **P<0.01**	R=.274 **P<0.01**	**1**				
7. Social functioning	R=-.043 P=0.695	R=.034 P=0.673	R=.449 **P<0.01**	R=.396 **P<0.01**	R=.233 **P<0.01**	R=.304 **P<0.01**	**1**			
8. Mental Health	R=.032 P=0.591	R=.020 P=0.805	R=.414 **P<0.01**	R=.429 **P<0.01**	R=.275 **P<0.01**	R=.393 **P<0.01**	R=.373 **P<0.01**	**1**		
9. Pain	R=.193 **P=0.016**	R=.161 **P=0.044**	R=.534 **P<0.01**	R=.496 **P<0.01**	R=.461 **P<0.01**	R=.335 **P<0.01**	R=.413 **P<0.01**	R=.405 **P<0.01**	**1**	
10. General Health	R=.133 P=0.098	R=.157 P=0.050	R=.496 **P<0.01**	R=.489 **P<0.01**	R=.292 **P<0.01**	R=.358 **P<0.01**	R=.279 **P<0.01**	R=.479 **P<0.01**	R=.466 **P<0.01**	**1**

Spearman correlation analysis showed the relationship among all the variable scores. As expected there is a statistically significant, strong positive relationship between METs\week and Mins\week r=.944 (p<0.01). There is a statistically significant, but weak positive relationship between Physical functioning and Mets\week r=.176, (p=0.028), also there is a significant, positive weak relationship between Physical Functioning and Mins\week r=.167*(p=0.037) Among the domains of the SF-36 questionnaire, the correlations are seen: significant moderately positive relationship between Physical Functioning and Physical Role r=.484 (p>0.01), Physical functioning and Emotional Role have a moderately positive statistically significant relationship r=.401 (p>0.01), as well as a strong positive significant relationship between Physical Role and Emotional Role r=.548, (p<0.01). There is also a statistically significant positive weak correlation between Physical functioning and Vitality r=.364 (p>0.01), a positive moderate correlation between Physical Role and Vitality r=.405 (p>0.01), and again the weak positive correlation between Emotional Role and Vitality r=.274 (p<0.01). Social Functioning and Physical Functioning have a positive moderate statistically significant correlation r=.449(p<0.01), Social Functioning and Physical Role have a weak positive correlation r=.396 p>0.01, as well as, Social Functioning and Emotional Role r=233 (p<0.01), and Social Functioning and Vitality r=.304(p<0.01). Mental Health has two statistically significant, moderate positive correlations with Physical Functioning r=.414(p<0.01) and Physical Role r=,429 (p>.01) and other statistically significant but weak positive correlations with Emotional Role r=.275, (p>.01), Vitality r=.393, (p>.01), and Social Functioning r=.373(p<0.01).

Pain has correlations not only with other domains of SF-36 but also with IPAQ Mets\week statistically significant, weak positive relationship r=.193 (p=0.016), and Mins\ active r=.161, (p=0.044). Pain and Physical Functioning has a statistically significant, strong positive relationship r=.534 (p>0.01), and Pain and Physical Role has a moderate positive relationship r=.496 (p<0.01). Pain also has moderate positive relationships with Physical Role r=.496, Emotional Role r=.461, (p>0.01), Vitality r=.335 (p>0.01), Social Functioning r=.413 (p<0.01), and Mental Health r=.405 (p<0.01).

General Health has statistically significant, moderate positive relationships with five other domains: Physical Functioning r=.496 (p<0.01), Physical Role r=.489 (p<0.01), Vitality r=.358 (p<0.01), Mental Health r=.479 (p<0.01), and Pain r=.466 (p<0.01). Moreover, it has statistically significant, weak positive relationships with Emotional Role r=.292 (p>0.01) and Social Functioning r=.279 (p>0.01).

Table 4. 13. Correlation of the type of the disability of the child and IPAQ and SF-36

Variables	**METs**	**Mins**	**PhF**	**PhR**	**PhE**	**V**	**SF**	**MH**	**P**	**GH**
Disability of the child	R=-.009 P=0.912	R=-.045 P=0.576	R=-.037 P=0.646	**R=.196 P=0.014**	R=-.042 P=0.603	R=-.137 P=0.089	R=-.062 P=0.503	R=-.152 P=0.059	R=-.025 P=0.749	R=-.062 P=0.442

* PhF= Physical Functioning, *PhR= Physical Role. *ER= Emotional Role. *V= Vitality, *MH= Mental Health, *SF= Social Functioning, *P= Pain, *GH= General Health

In regards to the disability type and METs, Mins per week active the analysis showed no relationship. Spearman's correlation analysis showed a statistically significant (p=0.014) correlation between the disability of the child and the Physical Role domain. However, the correlation was negative, and weak (r=-.196).

4.4.2. Regression analysis

Table 4. 14. Regression analysis according to the disability type

Dependent variables											
About Spina Bifida											
Independent Variables		**METs**	**Mins**	**PhF**	**PhR**	**ER**	**V**	**SF**	**MH**	**P**	**GH**
Au	**B= P= T=**	-83.4 0.807	-12.9 0.880	8.4 0.189	**17.3 0.032* 2.167**	2.5 0.777	4.2 0.300	3.2 0.497	6.2 0.087	2.4 0.678	5.3 0.230
DS		-496.1 0.107	-91.2 0.287	9.4 0.141	**22.4 0.006* 2.809**	7.6 0.397	**11.2 0.006* 2.775**	**11.9 0.012* 2.534**	**12.4 <0.001** 3.454**	**12.1 0.041* 2.066**	**11.4 0.012* 2.553**
CP		-182.7 0.582	-20.3 0.812	**13.5 0.036* 2.121**	12.8 0.111	4.2 0.673	2.1 0.593	6.9 0.144	6.5 0.073	**12.9 0.029* 2.209**	**9.8 0.029* 2.209**
About Cerebral Palsy											
Au	**B P= T=**	99.3 0.765	7.4 0.931	-9.4 0.141	4.4 0.575	-1.7 0.850	2 0.615	-3.7 0.431	0 0.932	-10.5 0.075	-4.4 0.0317
DS		-313.3 0.346	-70.8 0.408	-1.1 0.873	9.6 0.230	3.4 0.706	**9.1 0.027* 2.239**	5 0.289	5.9 0.101	0 0.886	1.5 0.731
About Down Syndrome											
Au	**B P=**	412.6 0.215	78.3 0.361	-8.4 0.189	-5.1 0.522	-5.1 0.572	-7 0.085	-8.7 0.066	-6.2 0.085	-9.6 0.101	-6 0.180

*Au=Autism, *DS= Down Syndrome, *CP=Cerebral Palsy, *SB= Spina Bifida *PhF= Physical Functioning, *PhR= Physical Role. *ER= Emotional Role. *V= Vitality, *MH= Mental Health, *SF= Social Functioning, *P= Pain, *GH= General Health

Linear regression models were also used to quantify the possible association between IPAQ scores and SF-36 scores with the child's disability type. The dependent variables (METs\week, Mins\week, Physical functioning, Physical Role, Emotional Role, Vitality, Social Functioning, Mental Health, Pain, and General Health) were regressed on independent variables (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida). The independent variables predicted there is no significant difference between all independent groups regarding such dependent variables as METs\week and Mins\week. Thus rejecting the alternative hypothesis that different types of child's disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida) had an impact on parents' physical activity regarding METs\week and Mins\week.

In regards to Quality of life, the SF-36 questionnaire revealed that out of eight domains, six of those had significant differences between the groups of parents of children with various disabilities. The analysis showed that there is a significant and positive impact on Physical Functioning concerning Spina Bifida compared with Cerebral Palsy B=13.5, t=2.121, p=0.036*. Regression in the regards of Spina Bifida group with the Autism group showed that there is a significant and positive impact on Physical Role B=17.3, t=2.167, p=0.032*, also regression showed that there is a significant and positive impact of Physical Role in regards to Spina bifida with Down Syndrome B= 22.4, t=2.809, p=0.006*. The domain of Vitality showed a strong significant and positive impact

regarding the difference between Spina Bifida and Down Syndrome groups B= 11.2, t=2.775, p=0.006. Positive and significant impact was also found between the groups of Cerebral Palsy and Down Syndrome B=9.1, t=2.239, p=0.027. Social Functioning and Mental Health domains both showed similar results when regression analysis was performed. A positive and significant impact B=11.9 t= 2.534, p=0.012 between Spina Bifida and Down syndrome regarding Social Functioning was found, on the other hand in consideration of Mental Health a strong significant and positive impact was established between Spina Bifida and Down Syndrome Groups B=12.4, t=3.454, p<0.001. Regression analysis on Pain showed that there are significant and positive impacts between Spina Bifida and Down Syndrome B=12.1, t=2.066, p=0.041*. The same analysis showed that there is a significant and positive impact on the Pain domain between Spina Bifida and Cerebral Palsy B=12.9, t= 2.209, p=0.029* General Health domain regression analysis showed that the two groups have a statistically significant and positive impact compared to one another, Spina Bifida with Down Syndrome B=11.4, t=2.553, p=0.012* and Spina bifida with Cerebral Palsy B=9.8, t=2.209, p=0.029*

5. DISCUSSION AND CONCLUSION

This thesis aimed to investigate the physical activity level and quality of life in parents of children with various disabilities. This study has two hypotheses. Firstly, we hypothesized that there is a difference between parents of children with various disabilities (Autism, Down Syndrome, Cerebral palsy, Spina Bifida) in physical activity levels and quality of life. Secondly, we hypothesized that there is no difference between parents of children with various disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida) in physical activity levels and quality of life.

Statistical analysis has demonstrated that there is no difference between parents of children with various disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida) in physical activity levels. The physical activity levels between all four groups were not statistically significantly different (p=0.765). There was also no significant difference among all four groups regarding METs per week and Mins per week active. Of the whole 156 participants only 10.9% obtained high activity levels and were sufficiently active, 46.2% scored moderate activity levels and were insufficiently active, and a large portion of participants 42.9% reported low activity levels along with inactivity. The results of our findings comply with other literature. The study conducted by Yilmaz & Küçük Alemdar (7), found that for mothers of children with various disabilities, physical activity was determined to be insufficient. Among all four groups, the parents of children with various disabilities mostly reported low activity (inactive) or moderate (insufficient) physical activity levels.

Analysis according to the child's disability type revealed that only 7.7 % of parents of children with Down syndrome reported high (sufficient) activity levels and the majority of parents of children with Down Syndrome reported moderate (insufficient) or low activity levels (inactivity). The research conducted by Diaz (11) showcases similar results. It was concluded that parents whose children have Down Syndrome are more likely to be physically inactive, not only when compared with parents of normally developing children, but also when compared with parents with other developmentally disabled children or special health care needs, including Cerebral Palsy (11). In our study, we found that a higher percentage of parents of children with Cerebral palsy reported high activity levels 10.3%, and a lower percentage of parents reported low activity (inactivity) levels 35.9% than parents of children with Down Syndrome. 46.2% of parents of children with Down Syndrome reported low activity levels. The highest number of parents that reported

high activity levels were the parents of children with Spina Bifida 12.8% and the parents of children with Autism 12.8%. Despite the highest number of high (sufficient) physically active parents in the Autism group, many parents have reported moderate and low activity, which shows that parents of children with Autism are not sufficiently active. Research by Haegele et al. investigated the parents of children with Autism physical activity levels had found that parents of children with Autism were not able to meet physical activity guidelines for adults (2 days of muscle-strengthening activity and 150 minutes of moderate-intensity physical activity) (116). The parents of children with Spina Bifida also reported the highest number of high activity levels, in addition to that, the Spina Bifida group reported the highest number of low activity levels 48.7% which is the largest number of low activity levels among all the four groups. Even though there is no statistically significant difference between the activity levels of parents of children with various disabilities it is apparent that there are some differences in physical activity of parents of children with various disabilities. The findings of this research comply with previous studies stating that parents of children with disabilities largely engage with insufficient activity levels or are inactive (7; 11; 116).

Research showed that there is a statistically significant difference between parents of children with various disabilities (Autism, Down Syndrome, Cerebral Palsy, Spina Bifida) in quality of life. In regards to the quality of life, each domain of the SF-36 scale was evaluated separately from the others. A significant difference was discovered between these domains: Physical Role, Vitality, Mental Health, Pain, and General Health ($p<0.05$) among all four groups. A study conducted by Ljubičić et al. investigated the family and individual quality of life in parents of children with developmental disorders, the outcome of the study showed that parents of children with different types of disorders reported reduced quality of life in different domains when compared with typically developing children's parents. Parents of children with Autism and Down syndrome were more likely to report reduced family quality of life in all domains. The parents of children with Autism and Cerebral Palsy reported the lowest perception of physical health. Psychological well-being and social relationships were the lowest in parents of children with Autism. Parents of children with Down syndrome on the other hand reported a lower result in the social relationship domain (117).

Statistical analysis of this study showed which groups exactly, had the most significant difference from each other. Regarding the Physical Role domain, the data analysis showed that there is a significant difference between parents of children with

Autism and Spina Bifida, as well as, between Down Syndrome and Spina Bifida groups. Parents of children with Down syndrome scored significantly higher ($p<0.01$) scores than parents of children with Spina Bifida. Additionally, parents of children with Autism also scored significantly higher ($p<0.05$) scores than parents of children with Spina Bifida. The study conducted by Civilibal et al. investigated the quality of life of mothers of children with Spina Bifida using SF-36 domains and found that mothers of children with Spina Bifida had significantly lower scores in regards to the majority of domains including Physical Roles except the Social Functioning and Mental Health than the control group (118).

In the domain of Vitality, the parents of children with Down syndrome scored significantly higher scores than any other group. Significant differences were seen between Down Syndrome and Autism, Down Syndrome and Cerebral Palsy ($p<0.05$), and finally between Down Syndrome and Spina Bifida groups ($p<0.01$). The Mental Health domain had only one group of significant differences between them, Down Syndrome scored significantly higher than the Spina Bifida group ($p<0.01$). In the domain of Pain parents of children with Down syndrome scored significantly higher than the parents of children with Cerebral palsy ($p<0.05$) and higher than parents of children with Spina Bifida ($p>0.05$). The General Health domain of SF-36 had significant differences between the Down Syndrome group that scored significantly higher than the Autism group ($p<0.05$), Down Syndrome group also scored significantly higher scores in comparison with Spina Bifida ($p<0.01$). The Cerebral Palsy group scored significantly higher scores than the Spina bifida group ($p<0.05$).

When compared between the four groups, Down Syndrome scored highest in quality of life domains, while parents of children with Spina Bifida scored the lowest in quality of life domains. Similarly, previous research comparing the quality of life between different types of disability has found that parents of children with Down's Syndrome have a better quality of life than parents of children with other developmental disabilities (119). In a study by Tekinarslan in which he compared depression and quality of life of Turkish mothers with children with Autism, Down Syndrome, and Cerebral Palsy, a significant difference was found in the mean quality of life scores of mothers with children with Down syndrome, Cerebral Palsy, and Autism. Environment and National Environment areas. Mothers of children with Down Syndrome scored significantly higher than mothers of children with Cerebral Palsy or mothers of children with Autism (120). This phenomenon has been mentioned before in the literature and has been called the “Down

syndrome advantage". This is because parents of children with Down Syndrome have almost no psychiatric problems, experience less stress, or are generally better off compared to parents of children with other disabilities (121; 122; 123; 124). Christodoulou et al. investigated the quality of life of parents with different disabilities and discovered that parents with children with Down Syndrome had better psychological health than parents whose children had Autism. In addition, it was revealed that parents of children with Down Syndrome performed better in environmental parameters than parents of children with Autism (125).

On the other hand, research by Haimour & Radi investigated parents of children with learning difficulties (Metal Disabilities, Autism, Learning Disabilities) and various types of disabilities. The results of the study revealed that the severity of the child's diagnosis as well as the type of the child's diagnosis has a significant impact on the life quality of the parents. Mental Retardation and Physical Disabilities of the Child lowered the parent's life quality significantly when compared with parents of children with learning difficulties (126). In Tekinarslan's study, it was concluded that the quality of life scores of parents with children with DS was higher, while parents with children with CP had lower scores than parents of children with Autism and Down syndrome (120). A previous study by Wiley and Renk found that the main factor for the low quality of life of parents of children with Cerebral palsy might be the physical incapability of children with Cerebral Palsy. Problems with mobility, or neurological issues caused by Cerebral palsy, result in children being more dependent on their parents and increasing the care burden (127). Previous research done by Javalkar et al investigated the mothers of children with chronic conditions such as cerebral palsy, Down syndrome, spina bifida, and physical disability, and found that the burden of care in mothers who had a physically disabled child was statistically significantly higher than those who did not have a disabled child (128). The study by Yılmaz and Alemdar discovered that the life quality and burden of care in the mothers had a significant correlation. The correlation showed that as the life quality lowers, the burden of care increases (7).

The same assumption might be made in the current research when talking about the parents of children with Spina Bifida. Common symptoms of Spina Bifida include some degree of lower body paralysis affecting the child's motility as well as bladder and bowel control (98; 99; 100). This has an impact on day-to-day life and socialization. The study conducted in Uganda by Bannink et al. analyzed the stress that parents of children with Spina Bifida experience and found that Parental Stress Index scores were high. More than

half of the participants scored above the Parental Stress Index cut-off point for clinically significant stress levels (129). It was also discovered that the outcomes of the stress were related to the child's incontinence problems, bowel movement management, and inability to walk. The study by Civilibal discovered that mothers of children with Spina Bifida not only scored significantly lower scores than a control group in quality of life but also scored higher scores in the scales assessing anxiety and depression indicating that mothers of children with Spina Bifida are more likely to experience depression and anxiety (118).

Correlation analysis between the IPAQ evaluating physical activity levels and SF-36 scores showed that there is a significant correlation between the domain of Physical Functioning and METs\week as well as Mins\week active ($p<0.05$). The more Mins and METs per week of physical activity the better the Physical Functioning scores. The Pain domain of the SF-36 questionnaire also has a significant positive correlation with the IPAQ questionnaire METs\week active and Mins\week active. In regards to the Pain domain, the more METs\week and Mins\week parents of children with various disabilities are physically active the higher the Pain domain score gets meaning that the less pain parents of children with various disabilities are experiencing. A last year's study conducted by Andrieieva et al. investigated the relationship between the quality of life and physical activity levels and family well beingsThe study results were able to prove the relationship between life quality and physical activity. The life quality of participants who performed low physical activity was determined to be significantly lower than those who performed moderate levels of physical activity in all the aspects and domains of life quality. Physical Functioning, Physical Role, Vitality, and Mental Health domains correlated significantly with physical activity (130).

Among the domains of the SF-36 questionnaire, statistically significant ($p<0.05$), positive correlations are seen between all of the domains. Physical Functioning and: Physical Role, Emotional Role, Vitality, Social Functioning, Mental Health, Pain, and General Health. This suggests that the higher the score of Physical Functioning the higher and better quality of life in other domains of SF-36 gets.

Correlation between the disability type of the child and IPAQ showed no significant correlations. The correlation between SF=36 domains showed that there is a significant correlation between the type of the child's disability and Physical Role.
In this research, we aimed to determine if the type of disability has any impact on physical activity levels and quality of life. There was no significant difference among parents of children with various disabilities in physical activity levels. However, as previously

mentioned parents of children with Down Syndrome achieved significantly higher scores in six out of eight SF-36 questionnaire domains (Physical Role, Vitality, Mental Health, Social Functioning, Pain, and General Health) in comparison to Spina Bifida. Parents of children with Spina Bifida also scored statistically significantly lower scores than parents of children with Cerebral Palsy, in the domains of Physical Functioning, Pain, and General Health. The Spina Bifida group also reported statistically significantly lower scores than the Autism group in Physical Role. Previous studies suggest that parents of children with Spina Bifida experience high levels of stress, anxiety, depression, and poor quality of life. (118; 129). And finally, the Cerebral Palsy group scored significantly lower than the Down Syndrome group compared to the Vitality domain. According to the researchers, multiple various factors can influence the quality of life of parents of children with disabilities, parental age, sex, employment status, socioeconomic status, marital status, number of children in the family as well as health-related parental problems (121).

Overall, there is a lack of research that focuses on and evaluates the parents of children with Spina Bifida quality of life. The results of this thesis show that parents of children with Spina Bifida have the lowest out of the four types of disabilities quality of life. Six out of eight domains are statistically significantly different in comparison with Down Syndrome. This is important because it shows that parents of children with Spina Bifida may need more medical professional support and care. Another interesting finding is the high quality of life of parents of children with Down Syndrome adding to the "Down syndrome advantage" that was discussed previously.

In conclusion, there is no difference in physical activity levels among parents of children with various disabilities. There is a difference between the quality of life of parents of children with various disabilities.

This study has potential limitations. The research was a self-reported survey, a comparative research design to investigate the parents of children with different types of disabilities' physical activity levels and quality of life. Self-reporting bias is a common issue that many researchers face. There are several regards of bias that come along with self-reported data. Bias can emerge from social desirability, recall period, sampling approach, or selective recall. In this particular research, the recall bias, as well as social desirability bias, pose limitations on the research. One of the limitations is recalled bias when talking about the IPAQ questionnaire. This subject bias may influence the results of our research. For future studies investigating physical activity levels and quality of life of parents of children with various disabilities, more exact tests could be used to prevent the

limitations such as recall bias as well as exaggerations of the time spent actively. More objective physical activity measurements should be used (heart rate monitors, pedometers, accelerometers, or even direct observation)

Another limitation is the small sample size. Although the sample size was determined by power analysis, it is relatively small. The study was conducted in one of Turkiye's special education centers and does not reflect the whole population. The disabilities that were chosen in this study are the most common ones in Turkiye however, there are so many other types of disabilities that were not taken into consideration. For further research, a greater sample size should be used as well as the inclusion of a greater variety of disabilities. Additionally, the already selected disabilities should be distinguished further. Cerebral Palsy should be specified based on Gross Motor Function Classification System (GMFCS) levels. Spina Bifida should also be further separated according to the different types.

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7. APPENDİX

7.1. Ethical Committee Approval

YEDITEPE UNIVERSITY

No : E.83321821-805.02.03-94
Subject : Non Interventional Clinical Research Ethics Board Decision

To Prof. Dr. Rasmi Muammer

Yeditepe University Non-Interventional Clinical Research Ethics Board has reviewed the research proposal placed upon ethical approval for the project as the research title, the researchers, the application number, the ethics board meeting details, and the provided documents have been outlined below. This research proposal has been evaluated by the members of the ethics board and full ethical **APPROVAL** has been granted.

Research Title:	Investigation of physical activity level and quality of life in parents of children with various disabilities.
Researchers:	Greta VEGELYTE, Prof. Dr. Rasmi MUAMMER
Application Number:	202211Y0316

ETHICS BOARD MEETING DETAILS			
Meeting Date:	16 December 2022	**Meeting Place:**	Online (Google Meet)

PROVIDED DOCUMENTS
Wet signed application file, file uploaded to a CD or USB media, and electronic submission
Title of research and the names of the researchers
Letter of application
Application Form
Nature of the Research;
• Type
• Significance and distinctive value
• Aims and objectives
• Method
• Management of the research
• Widespread impact
• Pertinence of the budget and reason (if applicable)
• Timeframe and convenience
• References
Informed consent form (uniquely prepared for the research)
Letter of Undertaking-1 A commitment to undertake the responsibility of obtaining institutions permission from where the data collection will be made
Letter of Undertaking-2 A commitment to read the latest version of the World Medical Association Declaration of Helsinki and all relevant guidelines of the Ministry of Health

True copy by e-signature.
Document Tracking Address : http://belgedogrulama.yeditepe.edu.tr/bg.aspx?id=CA8449C2-6D15-4A89-8A9D-73734A26D058

Yeditepe Üniversitesi 26 Ağustos Yerleşimi, İnönü Mahallesi Kayışdağı Caddesi 34755
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For Info: Sevgi BAYRAKTAR
Profession: Uzman Yardımcısı
Phone Number:

Letter of Undertaking-3 A commitment on whether there are previous ethical board applications
Letter of Undertaking-4 A commitment that no action will be taken during the research that is not included in the research budget and that will bring additional burden to the volunteer or the Social Security Institution
Letter of Undertaking-5 A commitment to reading the circular on treatment approaches and scientific research in COVID-19 patients
Letter of Undertaking-6 A commitment to reading the document of Research Application Permissions that is published by Ministry of Education
'Resume Forms' filled separately by all the researchers and signed
Additional documents (Scale permissions used, if any, etc.)

Prof. Dr. Didem ÖZDEMİR ÖZENEN
Chair

Assoc. Prof. Dr. Gökhan ERTAŞ
Deputy Chair

Assoc. Prof. Dr. Elif SUNGURTEKİN EKÇİ
Reporter

Prof. Dr. Feryal SUBAŞI
Member

Assoc. Prof. Dr. Binnur OKAN BAKIR
Member

Assist. Prof. Dr. Emine Nur ÖZDAMAR
Member

Assist. Prof. Dr. Sevim ŞEN
Member

7.2. Permission from the special education school center "Özel Işıl Özel Eğitim Merkezi"

T.C. YEDİTEPE ÜNİVERSİTESİ
GİRİŞİMSEL OLMAYAN KLİNİK ARAŞTIRMALAR
KURUMSAL İZİN

Çeşitli yetersizlikleri olan çocukların ebeveynlerinde fiziksel aktivite düzeyi ve yaşam kalitelerinin incelenmesi

Araştırmacı: Greta Vegelyte

Sorumlu Araştırmacı: Prof. Dr. Rami Muammer

Araştırmanın adı: Çeşitli yetersizlikleri olan çocukların ebeveynlerinde fiziksel aktivite düzeyi ve yaşam kalitelerinin incelenmesi

Çalışmanın bir araştırma olduğu: Araştırma, Yeditepe Üniversitesi Fizyoterapi ve Rehabilitasyon Yüksek Lisans öğrencisi Greta Vegelyte tarafından yürütülen bir yüksek lisans tezidir. Sorumlu araştırmacı Yeditepe Üniversitesi Prof. Dr. Rasmi Muammer'dir. Çalışma sadece eğitim amaçlıdır.

Araştırmanın amacı: Bu tezin amacı, çeşitli yetersizlikleri olan çocukların ebeveynlerinin fiziksel aktivite düzeylerini ve yaşam kalitelerini değerlendirmek ve araştırmaktır Bu tezin konusu, çeşitli yetersizlikleri olan çocukların ebeveynleridir. Araştırmanın sorusu: Farklı engellilik türlerinin, çeşitli engelli çocukların ebeveynlerinde yaşam kalitesi ve fiziksel aktivite üzerinde farklı bir etkisi var mıdır?

Gönüllünün araştırmaya devam etmesi için öngörülen süre: Araştırma, İstanbul'da Aralık 2022 - Şubat 2023 tarihleri arasında "Özel Işıl Özel Eğitim Merkezi"nde gerçekleştirilecek.

Araştırmaya katılması beklenen tahmini gönüllü sayısı:

Tahmini gönüllü sayısı çeşitli engelleri olan çocuğu olan 152 ebeveyndir.

Araştırmada uygulanacak yöntemler:

Prosedür: Araştırma özel eğitim okulu merkezi "Özel Işıl Özel Eğitim Merkezi"nde yapılacaktır. 2022 Aralık ile 2023 Şubat arasında.

Ebeveynlerden öncelikle araştırmaya gönüllü olarak katıldıklarına ve herhangi bir olumsuzluk yaşamadan istedikleri zaman çalışmadan çekilebileceklerine dair gönüllü olur formunu imzalamaları istenecektir. Ayrıca onay formu, ebeveynlerin tam bir anonimlik sağlamasını sağlar. Anonim anket tasarlandı ve engelli çocukların ebeveynlerinden demografik bilgiler, çocuk sağlığı, yaşam kalitesi ve fiziksel aktivite anketlerini doldurmaları istendi.

1/3

Ebeveynler daha sonra çocuğun engeline göre 4 gruba ayrılacaktır. Sonuçlar, hangi ebeveyn grubunun yaşam kalitesi ve fiziksel aktivitenin çocuğun engel türünden daha fazla etkilendiğini görmek için kendi aralarında karşılaştırılacaktır.

Katılımcılar:

- Down sendromlu çocukların ebeveynleri
- Serebral palsili çocukların ebeveynleri
- Otizmli çocukların ebeveynleri
- Spina Bifidalı çocukların ebeveynleri

Dahil edilme kriterleri:

- Birincil bakıcıdır (bir ailenin babası veya annesi). engelli bir çocuğun (1-18 yaş arası)
- Çocuğun engeli şu tanılardan birine girer:
  - Otizm,
  - Downs sendromu,
  - Serebral palsi,
  - Spina bifida.

Yöntemler:

1. **Bakım verenlerin yaşam kalitesinin değerlendirilmesi için Tıbbi Sonuç Çalışması 36 (SF-36).** SF-36, klinik uygulama ve araştırmalarda, sağlık politikası değerlendirmelerinde ve genel nüfus anketlerinde kullanılmak üzere tasarlanmıştır. SF-36, sekiz sağlık kavramını değerlendiren çok maddeli bir ölçek içerir: 1) sağlık sorunları nedeniyle fiziksel aktivitelerde kısıtlamalar; 2) fiziksel veya duygusal problemler nedeniyle sosyal aktivitelerde kısıtlamalar; 3) fiziksel sağlık sorunları nedeniyle olağan rol faaliyetlerinde kısıtlamalar; 4) bedensel ağrı; 5) genel ruh sağlığı (psikolojik sıkıntı ve esenlik); 6) duygusal problemler nedeniyle olağan rol faaliyetlerinde kısıtlamalar; 7) canlılık (enerji ve yorgunluk); ve 8) genel sağlık algıları.
2. **Uluslararası Fiziksel Aktivite Anketleri (IPAQ)** Fiziksel aktiviteyi değerlendirmek için. Bu anket 4 anketten oluşmaktadır. Telefonla veya kendi kendine uygulanan yöntemlerle kullanım için uzun (5 etkinlik alanı bağımsız olarak sorulur) ve kısa (4 genel öğe) versiyonları mevcuttur. Anketlerin amacı, sağlıkla ilgili fiziksel aktivite hakkında uluslararası olarak karşılaştırılabilir veriler elde etmek için kullanılabilecek ortak araçlar sağlamaktır. IPAQ uzun ve kısa formları, bir Türk erkek ve kadın örneğinde toplam fiziksel aktivitenin değerlendirilmesi için güvenilir ve geçerlidir. IPAQ Türkçe versiyonu, test-tekrar test güvenilirliği ve oldukça iyi eşzamanlı geçerlilik açısından orijinal İngilizce versiyonla neredeyse aynı bulunmuştur. Spesifik aktivite maddeleri için test-tekrar test güvenilirlik katsayıları IPAQ'nun her iki Türkçe formu için de en yüksek yürüme aktivitesi için ve en düşük orta şiddetteki aktivite içindi.
3. **Demografik anket -** yaş ve cinsiyet, medeni durum gibi soruları yanıtlamak için.

Yeditepe Üniversitesi Fizyoterapi ve Rehabilitasyon Bölümü öğrencisi Greta Vegelyte, "Özel Işıl Özel Eğitim Merkezi" kullanımının yüksek lisans tezi olarak yapılması için izin vermek istiyorum. **Araştırmanın adı:** Çeşitli yetersizlikleri olan çocukların ebeveynlerinde fiziksel aktivite düzeyi ve yaşam kalitelerinin incelenmesi

Araştırmacı: Greta Vegelyte

Sorumlu Araştırmacı: Prof. Dr. Rami Muammer

Kurumun adı: IŞIL ÖZEL EĞİTİM MERKEZİ

Kurum Müdürü: Canan SEPETCİ

İmza **Tarihi**

21.11.2022

7.3. Voluntary consent form

T.C. YEDİTEPE ÜNİVERSİTESİ
GİRİŞİMSEL OLMAYAN KLİNİK ARAŞTIRMALAR
ETİK KURULU

BİLGİLENDİRİLMİŞ GÖNÜLLÜ OLUR FORMU (BGOF) – YETİŞKİN

Araştırmanın adı: Çeşitli yetersizlikleri olan çocukların ebeveynlerinde fiziksel aktivite düzeyi ve yaşam kalitelerinin incelenmesi

Çalışmanın bir araştırma olduğu: Araştırma, Yeditepe Üniversitesi Fizyoterapi ve Rehabilitasyon Yüksek Lisans öğrencisi Greta Vegelyte tarafından yürütülen bir yüksek lisans tezidir. Sorumlu araştırmacı Yeditepe Üniversitesi Prof. Dr. Rasmi Muammer'dir. Çalışma sadece eğitim amaçlıdır.

Araştırmanın amacı: Bu tezin konusu, çeşitli yetersizlikleri olan çocukların ebeveynleridir. Bu tezin amacı, çeşitli yetersizlikleri olan çocukların ebeveynlerinin fiziksel aktivite düzeylerini ve yaşam kalitelerini değerlendirmek ve araştırmaktır. Farklı engel türleri, çeşitli engelleri olan çocukların ebeveynlerinde yaşam kalitesi ve fiziksel aktivite üzerinde farklı bir etkiye sahip midir?

Gönüllünün araştırmaya devam etmesi için öngörülen süre: Araştırma, İstanbul'da Aralık 2022 - Şubat 2023 tarihleri arasında "Özel Işıl Özel Eğitim Merkezi"nde gerçekleştirilecek.

Araştırmaya katılması beklenen tahmini gönüllü sayısı: Tahmini gönüllü sayısı, engelli çocuğu olan 152 ebeveyndir.

Araştırmada uygulanacak yöntemler:

Prosedür:

Ebeveynlerden öncelikle araştırmaya gönüllü olarak katıldıklarına ve herhangi bir olumsuzluk yaşamadan istedikleri zaman çalışmadan çekilebileceklerine dair gönüllü olur formunu imzalamaları istenecektir. Ayrıca onay formu, ebeveynlerin tam bir anonimlik sağlamasını sağlar. Anonim anket tasarlandı ve engelli çocukların ebeveynlerinden demografik bilgiler, çocuk sağlığı, yaşam kalitesi ve fiziksel aktivite anketlerini doldurmaları istendi.

Ebeveynler daha sonra çocuğun engeline göre 4 gruba ayrılacaktır. Sonuçlar, hangi ebeveyn grubunun yaşam kalitesi ve fiziksel aktivitenin çocuğun engel türünden daha fazla etkilendiğini görmek için kendi aralarında karşılaştırılacaktır.

Katılımcılar:

- Down sendromlu çocukların ebeveynleri
- Serebral palsili çocukların ebeveynleri
- Otizmli çocukların ebeveynleri
- Spina Bifidalı çocukların ebeveynleri

Dahil edilme kriterleri:

- Birincil bakıcıdır (bir ailenin babası veya annesi). engelli bir çocuğun (1-18 yaş arası)

1/4

- Çocuğun engeli şu tanılardan birine girer:
  - Otizm,
  - Downs sendromu,
  - Serebral palsi,
  - Spina bifida.

Yöntemler:

1. **Bakım verenlerin yaşam kalitesinin değerlendirilmesi için Tıbbi Sonuç Çalışması 36 (SF-36).** SF-36, klinik uygulama ve araştırmalarda, sağlık politikası değerlendirmelerinde ve genel nüfus anketlerinde kullanılmak üzere tasarlanmıştır. SF-36, sekiz sağlık kavramını değerlendiren çok maddeli bir ölçek içerir: 1) sağlık sorunları nedeniyle fiziksel aktivitelerde kısıtlamalar; 2) fiziksel veya duygusal problemler nedeniyle sosyal aktivitelerde kısıtlamalar; 3) fiziksel sağlık sorunları nedeniyle olağan rol faaliyetlerinde kısıtlamalar; 4) bedensel ağrı; 5) genel ruh sağlığı (psikolojik sıkıntı ve esenlik); 6) duygusal problemler nedeniyle olağan rol faaliyetlerinde kısıtlamalar; 7) canlılık (enerji ve yorgunluk); ve 8) genel sağlık algıları.
2. **Uluslararası Fiziksel Aktivite Anketleri (IPAQ)** Fiziksel aktiviteyi değerlendirmek için. Bu anket 4 anketten oluşmaktadır. Telefonla veya kendi kendine uygulanan yöntemlerle kullanım için uzun (5 etkinlik alanı bağımsız olarak sorulur) ve kısa (4 genel öğe) versiyonları mevcuttur. Anketlerin amacı, sağlıkla ilgili fiziksel aktivite hakkında uluslararası olarak karşılaştırılabilir veriler elde etmek için kullanılabilecek ortak araçlar sağlamaktır. IPAQ uzun ve kısa formları, bir Türk erkek ve kadın örneğinde toplam fiziksel aktivitenin değerlendirilmesi için güvenilir ve geçerlidir. IPAQ Türkçe versiyonu, test-tekrar test güvenilirliği ve oldukça iyi eşzamanlı geçerlilik açısından orijinal İngilizce versiyonla neredeyse aynı bulunmuştur. Spesifik aktivite maddeleri için test-tekrar test güvenilirlik katsayıları IPAQ'nun her iki Türkçe formu için de en yüksek yürüme aktivitesi için ve en düşük orta şiddetteki aktivite içindi.
3. **Demografik anket** - yaş ve cinsiyet, medeni durum gibi soruları yanıtlamak için.

Gönüllülerin sorumlulukları:

- Gönüllüler Bilgilendirilmiş Onam Formunu baştan sona okumaktan sorumludur. Formu imzaladıktan sonra, gönüllüler çalışma hakkında tam olarak bilgilendirilir ve araştırmacıların anketleri ve anket sonuçlarını kamuya açık olarak paylaşımları için tam onay verirler.
- Anketlerin mümkün olduğunca doğru bir şekilde yanıtlanmasını sağlamaktan gönüllüler sorumludur.
- Anketlerin araştırmacı araştırmacıya geri dönmesi durumunda gönüllüler sorumludur.

Gönüllülerin hakları:

- Gönüllünün araştırmaya katılımının isteğe bağlı olduğu ve gönüllünün istediği zaman, herhangi bir cezaya veya yaptırıma maruz kalmaksızın, hiçbir hakkını kaybetmeksizin araştırmaya katılmayı reddedebileceği veya araştırmadan çekilebileceği.
- Gönüllünün çalışmaya katılmakla parasal yük altına girmeyeceği ve herhangi bir ödeme de yapılmayacağı.

- Gönüllünün kimliğini ortaya çıkaracak kayıtların gizli tutulacağı, kamuoyuna açıklanamayacağı; araştırma sonuçlarının yayımlanması halinde dahi gönüllünün kimliğinin gizli kalacağı.
- İzleyiciler, yoklama yapan kişiler, etik kurul, kurum ve diğer ilgili sağlık otoritelerinin gönüllünün orijinal tıbbi kayıtlarına doğrudan erişimlerinin bulunabileceği, ancak bu bilgilerin gizli tutulacağı, yazılı bilgilendirilmiş gönüllü olur formunun imzalanmasıyla gönüllü veya kanuni temsilcisinin söz konusu erişime izin vermiş olacağı.
- Araştırma konusuyla ilgili ve gönüllünün araştırmaya katılmaya devam etme isteğini etkileyebilecek yeni bilgiler elde edildiğinde gönüllünün veya kanuni temsilcisinin zamanında bilgilendirileceği.
- Gönüllünün; araştırma, kendi hakları veya araştırmayla ilgili herhangi bir advers olay hakkında daha fazla bilgi temin edebilmesi için temasa geçebileceği kişiler ile bu kişilere ait günün 24 saatinde erişebileceği telefon numaraları.

Araştırmacı araştırmacı:	Telefon numarası:
GRETA VEGELYTE	05455350856

Gönüllünün araştırmaya katılımının sona erdirilmesini gerektirecek durumlar veya nedenler:

- Gönüllü, anketin tamamına uyamaz.
- Gönüllü fikrini değiştirdi ve araştırmaya katılmaya devam etmek istemiyor.

Gönüllü:

Bilgilendirilmiş gönüllü olur formundaki tüm açıklamaları okudum. Bana yukarıda konusu ve amacı belirtilen araştırma ile ilgili yazılı ve sözlü açıklama aşağıda adı belirtilen araştırmacı tarafından yapıldı. Araştırmaya gönüllü olarak katıldığımı, istediğim zaman gerekçeli veya gerekçesiz olarak araştırmadan ayrılabileceğimi biliyorum.

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

Gönüllünün:

Adı, soyadı: **İmzası:** **Tarih:**

Adresi:

Telefon numarası:

Araştırmacı araştırmacı:

Adı, soyadı: Greta Vegelyte **İmzası:** **Tarih:**

Adresi: İstanbul Bahçelievler Mah çalışlar cad. ressam namık ismail sok murat apt no 9 daire 8.

Telefon numarası: 05455350856

7.4. SF -36 questionnaire (Turkish version)

Hastanın adı-soyadı:
Tarih:

SF-36 (Kısa Formu)

Aşağıdaki sorular sizin kendi sağlığınız hakkındaki görüşünüzü, kendinizi nasıl hissettiğinizi ve günlük aktivitelerinizi ne kadar yerine getirebildiğinizi öğrenmek amacındadır.

Size en uygun yanıtı veriniz.

1. Genel olarak sağlığınız için aşağıdakilerden hangisini söyleyebilirsiniz?

Mükemmel	Çok iyi	İyi	Orta	Kötü
❑1	❑2	❑3	❑4	❑5

2. Bir yıl öncesi ile karşılaştırdığınızda şu anki genel sağlık durumunuzu nasıl değerlendirirsiniz?

Çok daha iyi	Biraz iyi	Hemen hemen aynı	Biraz daha kötü	Çok daha kötü
❑1	❑2	❑3	❑4	❑5

Aşağıdaki sorular bir gün içinde yapabileceğiniz işlerle (aktivitelerle) ilgilidir. Sağlığınız bu aktiviteleri kısıtlıyor mu? Eğer kısıtlıyorsa, ne kadar?

	Evet,çok kısıtlı	Evet,biraz kısıtlı	Hayır,hiç kısıtlı değil
3. Koşmak, ağır kaldırmak, ağır sporlara katılmak gibi ağır etkinlikler	❑1	❑2	❑3
4. Bir masayı çekmek, elektrik süpürgesini itmek ve ağır olmayan sporları yapmak gibi orta dereceli etkinlikler	❑1	❑2	❑3
5. Market poşetlerini kaldırmak veya taşımak	❑1	❑2	❑3
6. Birkaç kat merdiven çıkmak	❑1	❑2	❑3
7. Bir kat merdiven çıkmak	❑1	❑2	❑3
8. Eğilmek, diz çökmek, çömelmek, diz çökmek	❑1	❑2	❑3
9. Bir kilometreden fazla yürümek	❑1	❑2	❑3
10. Birkaç yüz metre yürümek	❑1	❑2	❑3
11. Yüz metre yürümek	❑1	❑2	❑3
12. Kendi başına banyo yapmak ve giyinmek	❑1	❑2	❑3

Son 4 hafta boyunca bedensel sağlığınızın sonucu olarak, işiniz veya diğer günlük etkinliklerinizde, aşağıdaki sorunlardan biriyle karşılaştınız mı?

	Evet	Hayır
13. Çalışma yaşamınızda veya diğer aktivitelerinizde geçirdiğiniz zamanı kısalttınız mı?	❑1	❑2
14. Arzu ettiğinizden daha az şeyi mi tamamlayabildiniz?	❑1	❑2
15. Çalışma veya diğer yaptığınız işlerin çeşidinde kısıtlama yaptınız mı?	❑1	❑2
16. Çalışma yaşamınızda veya diğer aktivitelerinizi yapmakta güçlük çektiniz mi? (Aşırı efor - çaba sarf ettiniz mi?)	❑1	❑2

Son 4 hafta boyunca, duygusal sorunlarınızın (örneğin çökkünlük veya kaygı) sonucu olarak işiniz veya diğer günlük etkinliklerinizle ilgili aşağıdaki sorunlarla karşılaştınız mı?

	Evet	Hayır
17. Çalışma yaşamınızda veya diğer aktivitelerinizde geçirdiğiniz zamanı kısalttınız mı?	❑1	❑2
18. Arzu ettiğinizden daha az işi mi tamamlayabildiniz?	❑1	❑2
19. İşinizle veya diğer aktivitelerinizle ilgili işleri her zamanki kadar dikkat vererek yapamadınız mı?	❑1	❑2

20. Son 4 hafta boyunca bedensel sağlığınız veya duygusal sorunlarınız, aileniz, arkadaş veya komşularınızla olan olağan sosyal etkinliklerinizi ne kadar etkiledi?

Hiç etkilemedi	Çok Az	Orta Derecede	Epeyce	Çok fazla
❑1	❑2	❑3	❑4	❑5

21. Son 4 hafta içinde vücudunuzda ne kadar ağrı oldu?

Hiç olmadı	Çok Az	Hafif	Orta	Çok	Pek çok
❑1	❑2	❑3	❑4	❑5	❑6

22. Son 4 hafta boyunca ağrınız, normal işinizi (hem ev işlerinizi hem ev dışı işinizi düşününüz) ne kadar etkiledi?

Hiç Etkilemedi	Biraz Etkiledi	Orta Derecede	Epey Etkiledi	Çok Etkiledi
❑1	❑2	❑3	❑4	❑5	❑6

Aşağıdaki sorular sizin son 4 hafta boyunca neler hissettiğinizle ilgilidir. Her soru için, sizin duygularınızı en iyi karşılayan yanıtı, son 4 haftadaki sıklığını göz önüne alarak seçiniz.

	Sürekli	Çoğu Zaman	Epey Zaman	Bazen	Ara Sıra	Hiçbir zaman
23. Kendinizi yaşam dolu olarak hissettiniz mi?	❑1	❑2	❑3	❑4	❑5	❑6
24. Çok sinirli biri oldunuz mu?	❑1	❑2	❑3	❑4	❑5	❑6
25. Hiçbir şeyin size neşelendiremeyeceği kadar moraliniz bozuk ve kötü oldu mu?	❑1	❑2	❑3	❑4	❑5	❑6
26. Kendinizi sakin ve huzurlu hissettiniz mi?	❑1	❑2	❑3	❑4	❑5	❑6
27. Çok enerjik oldunuz mu?	❑1	❑2	❑3	❑4	❑5	❑6
28. Kendinizi kalbi kırık ve üzgün hissettiniz mi?	❑1	❑2	❑3	❑4	❑5	❑6
29. Kendinizi yıpranmış, bitkin hissettiniz mi?	❑1	❑2	❑3	❑4	❑5	❑6
30. Mutlu, sevinçli bir insan oldunuz mu?	❑1	❑2	❑3	❑4	❑5	❑6
31. Yorgunluk hissettiniz mi?	❑1	❑2	❑3	❑4	❑5	❑6

32. Son 4 hafta boyunca bedensel sağlığınız veya duygusal sorunlarınız sosyal etkinliklerinizi (arkadaş veya akrabalarınızı ziyaret etmek gibi) ne sıklıkta etkiledi?

Sürekli	Çoğu zaman	Bazen	Ara Sıra	Hiçbir zaman
❑1	❑2	❑3	❑4	❑5

Aşağıdaki her bir ifade sizin için ne kadar doğru veya yanlıştır? Her bir ifade için en uygun olanını işaretleyiniz.

	Kesinlikle doğru	Çoğunlukla doğru	Emin değilim	Çoğunlukla yanlış	Kesinlikle yanlış
33. Ben diğer insanlara göre daha kolay hastalanıyorum.	❑1	❑2	❑3	❑4	❑5
34. Tanıdığım kişiler kadar sağlıklıyım.	❑1	❑2	❑3	❑4	❑5
35. Sağlığımın kötüleşmekte olduğunu sanıyorum.	❑1	❑2	❑3	❑4	❑5
36. Sağlığım mükemmeldir.	❑1	❑2	❑3	❑4	❑5

13, 14, 15, 16, 17, 18, 19 numaralı maddeler için aşağıdaki değiştirme yönergesini kullanın.

1	0 puan
2	100 puan

21, 23, 26, 27, 30 numaralı maddeler için aşağıdaki değiştirme yönergesini kullanın.

1	100 puan
2	80 puan
3	60 puan
4	40 puan
5	20 puan
6	0 puan

24, 25, 28, 29, 31 numaralı maddeler için aşağıdaki değiştirme yönergesini kullanın.

1	0 puan
2	20 puan
3	40 puan
4	60 puan
5	80 puan
6	100 puan

32, 33, 35 numaralı maddeler için aşağıdaki değiştirme yönergesini kullanın.

1	0 puan
2	25 puan
3	50 puan
4	75 puan
5	100 puan

Toplam SF-36 skoru:

Alt parametrelere ait değerleri bulmak için formül:

Fiziksel Fonksiyon	(3+4+5+6+7+8+9+10+11+12) / 10
Fiziksel Rol Güçlüğü	(13+14+15+16) / 4
Emosyonel Rol Güçlüğü	(17+18+19) / 3
Enerji/ Canlılık/ Vitalite	(23+27+29+31) / 4
Ruhsal Sağlık	(24+25+26+28+30) / 5
Sosyal İşlevsellik	(20+32) / 2
Ağrı	(21+ 22) / 2
Genel Sağlık	(1+33+34+35+36) / 5

Türk Toplumu için SF-36 'nın Norm Değerleri

	Kadın (±Standart Sapma)	Erkek(±Standart Sapma)
Fiziksel Fonksiyon	80.6 ± 21.7	87.2 ± 17.1
Fiziksel Rol Güçlüğü	82.9 ± 28.6	89.8 ± 19.3
Ağrı	81.0 ± 20.2	85.1 ± 16.4
Genel Sağlık	69.1 ± 16.9	73.6 ± 14.9
Enerji/ Canlılık/ Vitalite	63.4 ± 13.7	65.7 ± 11.9
Sosyal İşlevsellik	90.1 ± 12.9	91.7 ± 12.8
Emosyonel Rol Güçlüğü	89.0 ± 22.5	92.8 ± 15.1
Ruhsal Sağlık	70.1 ± 11.4	71.0 ± 10.6

Kaynakça:

1. *Demiral, Y., Ergor, G., Unal, B., Semin, S., Akvardar, Y., Kivircik, B., & Alptekin, K. (2006). Normative data and discriminative properties of short form 36 (SF-36) in Turkish urban population. BMC public health, 6, 247. https://doi.org/10.1186/1471-2458-6-247*

7.5. IPAQ Questionnaire

ULUSLARARASI FİZİKSEL AKTİVİTE ANKETİ (KISA)

İnsanların günlük hayatlarının bir parçası olarak yaptıkları fiziksel aktivite tiplerini bulmayla ilgileniyoruz. Sorular son 7 gün içerisinde fiziksel olarak harcanan zamanla ilgili olarak sorulacaktır. Lütfen yaptığımız aktiviteleri düşünün; işte, evde, bir yerden bir yere giderken, boş zamanlarımızda yaptığımız spor, egzersiz veya eğlence aktiviteleri.

Son 7 günde yaptığınız şiddetli aktiviteleri düşünün. Şiddetli fiziksel aktiviteler zor fiziksel efor yapıldığını ve nefes almanın normalden çok daha fazla olduğu aktiviteleri ifade eder. Sadece herhangi bir zamanda en az 10 dakika yaptığınız bu aktiviteleri düşünün.

1. Geçen 7 gün içerisinde kaç gün ağır kaldırma, kazma, aerobik, basketbol, futbol veya hızlı bisiklet çevirme gibi şiddetli fiziksel aktivitelerden yaptınız?

Haftada___gün
□ Şiddetli fiziksel aktivite yapmadım. → (3.soruya gidin.)

2. Bu günlerin birinde şiddetli fiziksel aktivite yaparak genellikle ne kadar zaman harcadınız?

Günde ___ saat
Günde ___ dakika
□ Bilmiyorum/Emin değilim

Geçen 7 günde yaptığınız orta dereceli fiziksel aktiviteleri düşünün. Orta dereceli aktivite orta derece fiziksel güç gerektiren ve normalden biraz sık nefes almaya neden olan aktivitelerdir. Yalnız bir seferde en az 10 dakika boyunca yaptığınız fiziksel aktiviteleri düşünün.

3. Geçen 7 gün içerisinde kaç gün hafif yük taşıma, normal hızda bisiklet çevirme, halk oyunları, dans, bowling veya çiftler tenis oyunu gibi orta dereceli fiziksel aktivitelerden yaptınız?Yürüme hariç.

Haftada___gün
□ Orta dereceli fiziksel aktivite yapmadım. → (5.soruya gidin.)

4. Bu günlerin birinde orta dereceli fiziksel aktivite yaparak genellikle ne kadar zaman harcadınız?

Günde ___ saat
Günde ___ dakika
□ Bilmiyorum/Emin değilim

Geçen 7 günde yürüyerek geçirdiğiniz zamanı düşünün. Bu işyerinde, evde, bir yerden bir yere ulaşım amacıyla veya sadece dinlenme, spor, egzersiz veya hobi amacıyla yaptığınız yürüyüş olabilir.

5. Geçen 7 gün içerisinde, bir seferde en az 10 dakika yürüdüğünüz gün sayısı kaçtır?

Haftada___gün
□ Yürümedim. → (7.soruya gidin.)

6. Bu günlerden birinde yürüyerek genellikle ne kadar zaman geçirdiniz?

Günde ___ saat
Günde ___ dakika
□ Bilmiyorum/Emin değilim

Son soru, geçen 7 günde hafta içinde otururak geçirdiğiniz zamanlarla ilgilidir. İşte, evde, çalışırken ya da dinlenirken geçirdiğiniz zamanlar dahildir. Bu masanızda, arkadaşınızı ziyaret ederken, okurken, otururken veya yatarak televizyon seyrettiğinizde oturarak geçirdiğiniz zamanları kapsamaktadır.

7. Geçen 7 gün içerisinde,günde oturarak ne kadar zaman harcadınız?

Günde ___ saat
Günde ___ dakika
□ Bilmiyorum/Emin değilim

SORULARIMIZ SONA ERMİŞTİR.KATILIMINIZ İÇİN TEŞEKKÜRLER.

İletişim adresi: ptmeldaozturk@yahoo.com

7.6. Demographic survey

Çeşitli yetersizlikleri olan çocukların ebeveynlerinde aktivite düzeyi ve yaşam kalitelerinin incelenmesi

Bu anket, çeşitli engelleri olan çocukların ebeveynlerinin fiziksel aktivite düzey yaşam kalitelerini değerlendirmek için tasarlanmıştır. Bölüm 1, nüfusu daha iyi anlamamıza yardımcı olan demografik sorulardan oluşmaktadır.

1. Yaş
   - ☐ 18- 25
   - ☐ 26-36
   - ☐ 36-45
   - ☐ 46-55
   - ☐ 56- 70
   - ☐ 70+

2. Cinsiyeti
   - ☐ Erkek
   - ☐ Kadın

3. Tamamladığınız en yüksek derece veya eğitim seviyesi nedir?
   - ☐ Bazı liseler
   - ☐ Lise
   - ☐ Lisans
   - ☐ Yüksek lisans
   - ☐ Doktora veya daha yüksek
   - ☐ Ticaret Okulu
   - ☐ Söylememeyi tercih etmek

4. Medeni Durum
   - ☐ Evli
   - ☐ Bekar
   - ☐ Boşanmış
   - ☐ Söylememeyi tercih etmek
   - ☐ Başka:

5. İş durumu
   - ☐ Tam zamanlı iş
   - ☐ Yarı zamanlı veya gündelik iş
   - ☐ Çalışmıyor (iş arıyor / aramıyor)
   - ☐ Ev hanımı
   - ☐ Gönüllü çalışma

- ☐ 18 eğitim sonrası tam veya yarı zamanlı (kolej)
- ☐ Emekli ve diğer

6. Hanenizde 18 yaşından küçük kaç çocuk yaşıyor?

- ☐ 1 çocuk
- ☐ 2 çocuk
- ☐ 3 çocuk
- ☐ 4 çocuk
- ☐ 5 çocuk
- ☐ 6 +

7. Hanenizde 18 yaş altı engelli kaç çocuk yaşıyor?

- ☐ 1 çocuk
- ☐ 2 çocuk
- ☐ 3 çocuk
- ☐ 4 çocuk
- ☐ 5 çocuk
- ☐ 6 +

8. Çocuğunuzun/çocuklarınızın ne tür bir engeli var?

- ☐ Otizm
- ☐ Down Sendromu
- ☐ Serebral palsi
- ☐ Spina bifida

9. Çocuğunuz/çocuklarınız kaç yaşında?

10. Çocuğunuza ne kadar süre önce teşhis konuldu?

11. Doğumdan beri

- ☐ 1 yıl
- ☐ 2-6 yıl
- ☐ 6-10 yıl
- ☐ 10-15 yıl
- ☐ 15-18 yaş

12. Çocuğunuzun engeli ne kadar şiddetli?

- ☐ Severe
- ☐ Moderate
- ☐ Mild

7.7. Permission to use SF-36 (Kisa)

Gmail

Greta V <vegreta@gmail.com>

Kısa Form-36
2 messages

28 November 2022 at 12:52

Tünaydın, Yeditepe Üniversitesi Fizik Tedavi ve Rehabilitasyon Yüksek Lisans öğrencisiyim "Çeşitli engelleri olan çocukların anne babalarında fiziksel aktivite düzeyi ve yaşam kalitesinin araştırılması" konulu tez yazıyorum. Bu Kisa-36 formunu engelli çocuğu olan anne babaların yaşam kalitesini değerlendirmek için kullanmak için izninizi rica ediyorum.
Saygılarımla Greta Vegelyte.

2 December 2022 at 14:16

Tabiki kullanabilirsiniz
İyi çalışmalar dilerim

28 Kas 2022 Pzt, saat 13:53 tarihinde Greta V <vegreta@gmail.com> şunu yazdı:
[Quoted text hidden]

7.8. Permission to use IPAQ

Gmail

Greta V <vegreta@gmail.com>

(no subject)
2 messages

28 November 2022 at 13:14

Good afternoon Professor MELDA SAĞLAM,

I am a Yeditepe University Physical Therapy and Rehabilitation Master's student. I am writing a thesis on "Investigation of physical activity level and quality of life in parents of children with various disabilities". I request your permission to use this Physical Activity Questionnaire to evaluate the physical activity level of parents with disabled children.
Best regards Greta Vegelyte.

8 December 2022 at 19:15

Dear Greta Vegelyte,

You can use the IPAQ Turkish form in your research.

Sincerely,

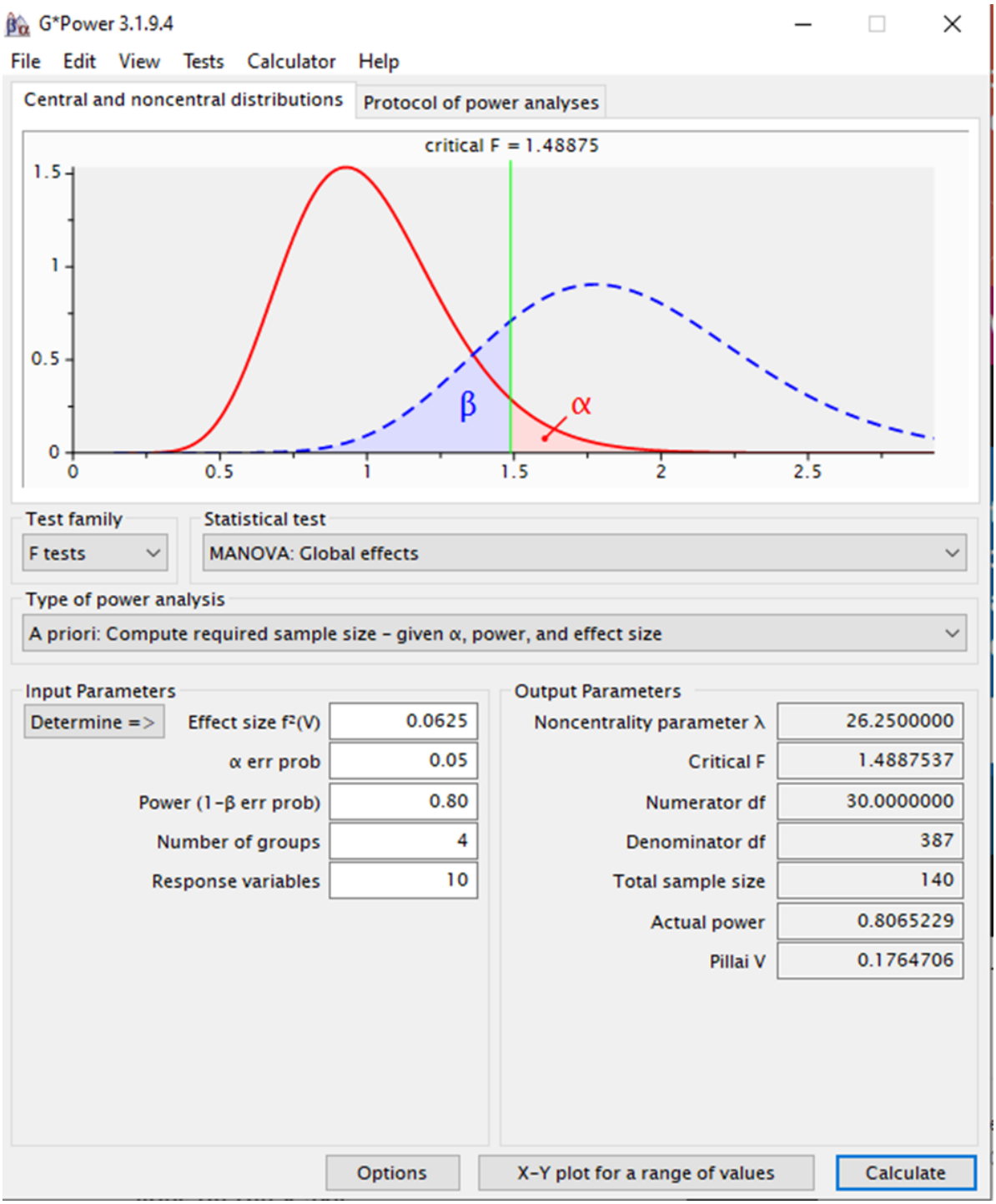
Prof. Dr. Melda Sağlam

Hacettepe Üniversitesi

Fizik Tedavi ve Rehabilitasyon Fakültesi

Kalp ve Solunum Fizyoterapisi ve Rehabilitasyon Ana Bilim Dalı

7.9. G Power analysis



7.10 Curriculum Vitae

Personal Information

Name		**Surname**	
Place of Birth		**Date of Birth**	
Nationality		**TR ID Number**	
E-mail		**Phone number**	

Education

Degree	Department	The name of the Institution Graduated From	Graduation year
Doctorate			
Master			
University			
High school	-		

Languages	Grades (#))

All the grades must be listed if there is more than one (KPDS, ÜDS, TOEFL; IELTS vs),

Work Experience (Sort from present to past)

Position	Institute	Duration (Year - Year)
		-
		-

Computer Skills

Program	Level

***Excellent, good, average, or basic**

Scientific works

The articles published in the journals indexed by SCI, SSCI, AHCI

Articles published in other journals

Proceedings presented in international scientific meetings and published in the proceedings book.

Journals in the proceedings book of the refereed conference/symposium

Others (Projects / Certificates / Rewards)
