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PRELIMINARY REPORT

Participation into daily life of children with cerebral palsy with multidimensional perspectives: a study protocol

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Purpose: This research study aimed to examine the relationship between participation and quality of life with impairment and environment (physical, social and attitudinal) aspects in children aged 2-18 years with cerebral palsy (CP) according to framework of International Classification of Functioning, Disability and Health.

Methods: A population-based study of children with CP sampled from 9 different districts of metropolitan area in Ankara will participate. Children were visited in special education and rehabilitation centers and inclusive schools in Ankara and totally 450 children with CP and their parents will be included. The project has two stages: translation, adaptation, validity and reliability study of Life Habits Questionnaire (LIFE-H) and determination of quality of life and participation levels and familial status. In the second stage, beside the LIFE-H, Child Health Questionnaire Parent Form-50 (CHQ-PF 50), Pediatric Disability Inventory (PEDI), Pediatric Outcomes Data Collection Instrument (PODCI), Pediatric Quality of Life Inventory (PedsQL), Impact on Family Scale (IPFAM) and Measurement Process of Care- 56 (MPOC-56) will be used.

Conclusion: This project is original in its methods by directly engaging children with CP and their families, while studying in quantitative terms the crucial outcomes of participation and quality of life.

Keywords: Cerebral palsy, Participation, Quality of life, Parents.

Çok boyutlu bakış açısıyla serebral palsili çocukların günlük yaşama katılımları: çalışma protokolü

Amaç: Projenin amacı, 2-18 yaş arası serebral palsili (SP) çocuklarda, işlevsellik, yeti yitimi ve sağlığın uluslararası sınıflandırmasına uygun olarak, katılımın ve yaşam kalitesinin bozukluk ve çevre ile (fiziksel, sosyal ve tutumsal) olan ilişkilerinin incelenmesidir.

Yöntem: Popülasyon temelli bir çalışma olarak, Ankara kent merkezindeki 9 ilçeden SP'li çocuklar katılacaktır. Ankara'da yaşayan ve özel eğitim ve rehabilitasyon merkezleri ile kaynaştırma okullarına devam eden 450 çocuk ile ebeveynleri çalışmaya dahil edilecektir. Çalışmanın, Life Habits (LIFE-H) anketinin Türkçeye çevrilmesi, uyarlanması, geçerlik ve güvenilirlik çalışmalarının yapılması ile yaşam kalitesi, katılım düzeylerinin belirlenmesi ve ailesel durumun değerlendirilmesi olmak üzere iki aşaması vardır. İkinci aşamada LIFE-H anketinin yanı sıra, Çocuk Sağlığı Anketi Ebeveyn Formu-50 (CHQ-PF-50), Pediatrik Engellilik Envanteri (PEDI), Pediatrik Veri Toplama Aracı (PODCI), Pediatrik Yaşam Kalitesi Envanteri (PedsQL), Aile Etki Ölçeği (IPFAM) ve Bakım Süreçleri Ölçeği- 56 (MPOC-56) kullanılacaktır.

Sonuç: Bu proje, doğrudan SP'li çocukları ve onların ailelerini dahil ederek, katılım ve yaşam kalitesi gibi nicel terimler ile ilgili sonuçları temel alan yöntemi açısından orijinaldir.

Anahtar kelimeler: Serebral palsi, Katılım, Yaşam kalitesi, Ebeveynler.

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Children with cerebral palsy (CP) have difficulties on problem solving, communication and socialization and spasticity, dystonia, joint contracture, abnormal bone development, poor balance, loss in selective motor control and lack of strength.[1] Health related quality of life (HRQoL) is necessary to handle together both for child and parent in children with CP. Assessment of HRQoL in children with CP includes more physical functions, activity limitation, emotional stress, communication problem between child and parent, limitation in school life and difficulties in treatment of the disease.[2-3]

According to results of a quality of life measure that patient-reported by the child with CP, children with CP have lower quality of life level than healthy peers at social support field and HRQoL level is lower in emotional state, social support and self-management fields.[4] Colver reported that changeable factors as pain, parental stress, psychological factors have positively and negatively effects on quality of life in children and young people with CP.[5] Varni reported that, HRQoL is affected by several factors like physical and psycho-social health, emotional, social and school functions according to children with CP and their parents. HRQoL become worse with decrease of motor functional level and quality of life of children with quadriplegia is lower than children with hemiplegia.[6]

International Classification of Functioning, Disability and Health - ICF of World Health Organization (WHO) includes the term of "participation and accepted all over the world. Assessment of activity and participation beside of bodily structure and functions became more important with ICF evaluation. Participation of children into the daily life provides to create social relationships and develop physical, cognitive and communication skills for gain adaptive behaviors.[7]

Movement capacities, educational and home life, leisure activities and social relationships of children with CP evaluated as the indicators of participation into the life.[8]The children in Level I and II (who can walk independently) of Gross Motor Function Classification System (GMFCS) have higher activity and participation into the life than children in GMFCS Level III-V (who use assistive device for walking or not able to walk). Additionally, the most important factors on participation in school and social environment are determined as GMFCS and cognitive levels.[7-9]

Rehabilitation strategies in children with CP are based on increasing activity skills by eliminating functional impairments and to increase their participation into life.[10]

Recent years, family centered therapy including hospital care is also accepted as one of the successful participation interventions.[9]

According to study of Serdaroğlu et al, prevalence of CP in Turkey is reported as 4.4 per 1000 birth.[11] Although the exact numbers of people with CP is unknown, it is estimated that 150.000 children with CP under 18 years of age live in the country, and the affected population is much higher with their families. Different measurements are used to evaluate quality of life in children with CP in Turkey, but the studies on participate into the life are still restricted.

Life Habits Questionnaire (LIFE-H) which is one of the most used scales to evaluate the participation and quality of life for CP will be adapted into the Turkish language and validation and reliability studies will be conducted.[12] Interpersonal and social relationships, focusing on social participation will be investigated in this project. It is also aimed to find out the determination of individual, familial and social barriers on participation into the life for contribution of the intervention plans in the country. One of the aims of this project is to evaluate participation in children with CP beside of motor functions, cognitive development and quality of life dimensions. In our study, participation levels of children with CP age between 2-18 years and their families living in Ankara metropolitan area in different districts will be determined.

METHODS

Our project has two stages according to our aims; the first stage is validation and reliability study of the "LIFE-H" questionnaire and the second stage is "evaluation of physical and social indicators of factors related with participation".

Ethical approval was gathered from Hacettepe University Non-invasive Clinical Researches Ethical Committee (GO 14/451-11 and GO 14/431-10). The inform consent was taken from the families. Verbal permissions were taken from Special education and rehabilitation centers in the project.

First stage: The LIFE-H Questionnaire translation, cultural adaptation, validity, and reliability

The LIFE-H Questionnaire was developed from "Disability Creation Process" model and investigates interaction of child with his environment.[10]

The LIFE-H questionnaire evaluates degree of difficulty during perform life habits and the type of aid needed (assistive device, adaptation or anyone's support). The LIFE-H has two main parts as daily activities and social roles. Questionnaire has three age group forms for 0-4 years, 5-13 years and 16 years of age and more and can be filled by the children, parents, caregivers or health professionals.[10]

The LIFE-H has three main scores as daily activities total score (mean of feeding, physical fitness, self-care, communication, shelter, movement ability dimensions); social role total score (mean of responsibilities, interpersonal relationships, social life, education, leisure activities dimensions) and the LIFE-H total score (mean of all dimensions).[10]

Each item in the questionnaire is scored between 0-9; "0" score shows *"cannot be held activity or social role or not completed"* and "9" score shows *"optimal social participation" (completing activity or social role without any difficulty and aid*).[13,14]

Satisfaction level is also scored for each item, but satisfaction scores are not added to the total score of the scale. If any item of life habits is not suitable for the person or ever tried, it will evaluate as N/A (not applicable) and will not be added to total score.[13,15]

Translation into the Turkish and cultural adaptation

The approval was received from The International Network on the Disability Creation Process (INDCP) to adapt LIFE-H questionnaire into the Turkish. Questionnaire was translated independently from English to Turkish by two physiotherapists with good level of English experienced in pediatric rehabilitation. Both translations were compared and two physiotherapists finalized the first Turkish version of the questionnaire. A native English speaker translator back translated the translated questionnaire into English, and it was checked by a linguistic expert and compared with original questionnaire.

The cultural adaptation was done and the questionnaire was reviewed by the parents have a child with CP. The questionnaire was also evaluated by five physiotherapists experienced in CP and a neuro-pediatrician for confirmation to Turkish culture.

The last version of questionnaire was used in validity and reliability study in the project.

Validity study

Pediatric Outcome Data Inventory (PODCI) was used as valid and reliable gold standard measurement that is adapted by Dilbay Keskin and Kerem Gunel to assess criterion-dependent validity of Life-H.[16,17]Spearmen's rho correlation coefficient was used for validity analysis.

Reliability study

In this stage, 89 children with CP and their parents were included and 47 of the children were boys (52.8%) and 42 of them were girls (47.2%). Three age groups were identified according to LIFE-H as 2-4, 5-13 and 14-18 years of age and age distribution was 25 (28.1%), 42 (47.2%) and 22 (24.7%) respectively. Only one child with CP per family was included for reliability study. The retest questionnaire was applied after 15 days after the first application of the test. Internal consistency was analyzed with Cronbach's alpha coefficient and Spearman's rho correlation coefficient was used for test-retest analyzes.

Second stage: Evaluation of physical and social indicators of quality of life and participation in children with CP

In the second stage, it is planned to reach children with CP in special education and rehabilitation centers and special education schools in Ankara metropolitan area. According to power analyzes, it was planned to reach 450 children with CP and their parents within 95% confidence interval.

Ten different measurements involved in four different fields were applied beside the questionnaire form including sociodemographic properties, service and care requirements questions for children with CP and their parents. Each scale has questions to evaluate different aspects of quality of life, participation into the life, social and interpersonal relations and motor functions.

The measurements were given in detail below:

1. Disability level and classifications

Pediatric Evaluation of Disability Inventory-PEDI

Pediatric Evaluation of Disability Inventory (PEDI) is used to evaluate the level of disability in the children with disability. PEDI is a comprehensive and discriminative clinical measurement for functional ability and performance of children with disability, developed for especially evaluate the children's functions who are younger than 7.5 years of age. PEDI consists of three main section as functional skills, aids of caregivers and modifications. Functional skills part evaluates child's functional abilities in three sub-parts as self-care, mobility and social functions Caregivers evaluates according to disability condition of the child and their needs. Modifications part evaluates environmental modifications and devices child uses in daily life skills. The original test was developed by Haley et al[18,19] and validity and reliability of the Turkish PEDI was showed by Erkin et al. and high Cronbach's alpha coefficients (> or =0.98), high ICC values (> or =0.96) and high Spearman correlation coefficients (> or =0.86) were found.[20]

Gross Motor Function Classification System- GMFCS

Functional status of individual is determined by using standardized classification systems. Expended and revised Gross Motor Function Classification System GMFCS will be used to classify gross motor functions of children. GMFCS was developed by Palisano et al for children with CP and based on child's self-initiated movements as sitting or walking. GMFCS has five levels and the differences between levels are meaningful for daily life and based on functional limitations, necessity of handhold assistive devices (walker, crutches or walking stick) or wheeled mobility devices and quality of movement as less. Expended and revised version of GMFCS includes young people age between 12-18 and emphasis ICF terms.[21] The Turkish version of GMFCS will use in project that was adapted by Kerem Gunel et al, the validity and reliability of this version was showed in children with CP by El et al and the ICC between two physicians was 0.97 and the total agreement was 89%; the overall weighted μ was 0.86. High test-retest reliability was found (ICC: 0.94) and the total agreement was 75% for test-retest reliability.[21]

Manual Ability Classification System-MACS

Manual Ability Classification System (MACS) is used to determine hand functions. MACS was developed by Eliasson et al in 2006 for children with CP aged 4 years and above and was developed to classify how children with CP use their hands when handling objects in daily activities. The MACS has five levels and levels based on ability of grasping objects of the child and necessity of aid or adaptation during perform hand activities in daily life.[22] MACS was adapted into the Turkish and validity and reliability of this version was showed by Akpınar et al. The inter-rater reliability of the Turkish version was high; the ICC ranged from 0.89 to 0.96 among different professionals and parents. Between two persons of the same profession it ranged from 0.97 to 0.98. For the test-retest reliability it ranged from 0.91 to 0.98.[23]

Communication Function Classification System-CFCS

Communication function of children with CP is classified with Communication Function Classification System (CFCS) within project. Hidecker et al. developed CFCS in 2011 as a valid and reliable system.[24] The CFCS has five levels which classify daily communication performance in individuals with CP and mainly focused activity and participation levels of ICF. Each CFCS level determine all communication performance rather than communication ways.[24] In this project, the Turkish version of CFCS that was adapted into the Turkish by Mutlu et al, will use.

2. Quality of life measurements

Pediatric Outcome Data Collection Instrument -PODCI

The Pediatric Outcome Data Collection Instrument (PODCI) was developed by Pediatric Outcome Data developing group (American Orthopedic Surgeons Academy, North America Pediatric Orthopedia Association, American Academy of Pediatrics and Shriner Hospitals). PODCI consists from five dimensions; upper limb function, physical function and sport, transfer and basic mobility, pain and happiness/satisfaction; additionally, there is an expectation dimension evaluates expectation from treatment only for children.[25] The validity and reliability study were done by Daltroy et al. and internal reliability of the PODCI is good to excellent (Cronbach's alpha=0.82-0.95), test-retest reliability is good to excellent (Pearson correlation coefficient=0.71-0.97).[25] Internal consistency of the Turkish version of the PODCI was reported as acceptable (alpha=0.93) and test-retest reliability is quite high (ICC=0.992).[17]

PODCI has three forms according to age groups; 2-10 years old age group child form filled by parents of children with CP, 11-18 years old age group adolescent parent form filled by parents and adolescent form filled by adolescent by themselves. Scores of the PODCI are calculated for each dimension separately and scores change between 0-100, higher score reflects better health condition (Daltroy, Liang et al. 1998) and measure has its own calculation tool.[25]

Child Health Questionnaire Parent Form-CHQ PF-50

Child Health Questionnaire Parent Form (CHQ PF-50) was developed by Landgraf et al. in Boston University for parents of children and adolescents 5 to 18 years of age. The questionnaire contains 50 questions and consists of 14 subscales that are role functioning: emotional/behavior, role functioning: physical, bodily pain, general behavior, mental health, self-esteem, general health perception, parental impact: emotional, parental impact: time, family activities, family cohesion, change in health.[26]

The change in health condition of child is categorical, compare the health state with a year ago and is not included into the analysis. Subscales standardized scores changes between 0 to 100 and higher scores reflect better health condition.[26] The questionnaire was adapted into the Turkish by Özdoğan et al. and validity and reliability study was shown in children with rheumatoid arthritis in 2001.[27] For the Turkish CHQ PF-50, Pearson items correlations with its scale were greater by at least 1 SE for 92% of the items (62% by 2 SE; Cronbach's alpha was 0.7 for 10/11 (91%) measurable health concepts (i.e. Health concepts with more than 1 item) of the CHQ (overall 0.97; range 0.66-0.96) with the exception being BE (0.66). Also the 15 CHQ health concepts showed a poor reproducibility with a median of 0.1 (range -0.4 to 0.6).[27]

Pediatric Quality of Life (PedsQL)

Pediatric Quality of Life (PedsQL) was developed by Varni et al. to measure HRQoL in children and adolescents from 2 to 18 years of age in 1999 and evaluates physical health, emotional functioning and social functioning dimensions. Scoring is done at three fields; measure total score, physical health total score and psychosocial health score that is calculated from emotional, social and school functioning item scores and consists of 23 items. PedsQL is one of the general quality of life measurements that can be used in large populations as school and hospital settings and suitable both children and adolescents with any disease and healthy. In scoring, higher scores reflect better HRQoL.[28] The reliability and validity of the Turkish test was reported by Çakın Memik (2005) for from 13 to18 years of age and according to their study, the internal consistency of the scale (Cronbach's alpha coefficient) was 0.82 for the child self-report and 0.87 for the parent proxy report. The PedsQL scores of both the child self-report and parent proxy report showed a statistically significant low to medium level of inversely proportional correlation with many indicators of morbidity and illness burden. Üneri (2005) et al. were reported the reliability and validity of the Turkish test for from 2 to 7 years of age.[29,30]

3. Impact on the family

Measure of Processes of Care- MPOC

The Measure of Processes of Care (MPOC) is the most widely used to measure evaluation of the experience of the family based on their own notifications and related to rehabilitation centers and service providers; developed by King et al. in 1995 in children with different kinds of disability.[31] MPOC is a questionnaire published in two different versions to assess how parents with disabilities have an impact on their children's psychosocial status. MPOC-56 consists of 56 questions evaluating the institutions where the child receives service and the employees in these institutions. MPOC-20 is a shortened and simplified version of the MPOC-56 and consists of 20 selected questions.[32,33]

MPOC assesses the services offered in five areas: competence and co-operation providing general information, providing child-specific information, coordinated and comprehensive care, and respectful and supportive care. The Turkish translation was done by Turker et al. and the Turkish form will be used.

Impact on Family Scale- IPFAM

Impact on Family Scale (IPFAM) was developed in 1980 by Stein and Riessman to evaluate the effects of pediatric chronic health conditions on patients and their families. In their research, the "effect" is defined as the effect of the child's disease on the family system. The scale consists of 27 items and consists of five areas: Economic impact, social impact, familial impact, personal difficulties and coping strategies.[34] The Turkish validity and reliability study was conducted by Bek et al. in 2009 in children with developmental disabilities.[35]

Test-retest reliability of the Turkish IPFAM was found to be ICC = 0.953 for total impact, 0.843 for financial support, 0.940 for general impact, 0.871 for disruption of social relations and 0.787 for coping. Internal consistency was tested using Cronbach's alpha and was found to be 0.902 for total impact of IPFAM. For construct validity the correlation between total impact score of IPFAM and WeeFIM was $r=-0.532$ ($p<0.001$) and the correlation between total impact score of IPFAM and the physiotherapist's evaluation was $r=0.519$ ($p<0.001$).[35]

DATA COLLECTION

The questionnaire consisting of sociodemographic characteristics of children and families and 10 different scales were applied face to face by physiotherapists working with cerebral palsy cases. Children with CP who are registered to Guidance and Research Centres in Ankara metropolitan area, Çankaya, Yenimahalle, Altındağ, Mamak, Keçiören, Sincan, Etimesgut, Pursaklar, Gölbaşı districts and attending special education and rehabilitation centers are reached in the project. The interviews with the families in the physiotherapy sessions of the children in special education and rehabilitation centers lasted from 60 to 90 minutes. Children who are diagnosed with CP between the ages of 2-18 were included to the project.

ANALYSIS PLAN

At this stage, the following questions are sought under a structural modeling design (Figure 1).

1. How is motor level, quality of life and participation affected in children with CP?

The effects of level of disability of children with CP on (disability scale, gross motor functions classification system levels, manual abilities classification system, and communication functions classification), quality of life (PedsQL, PODCI, CHQ-PF50) will be evaluated. It is aimed to determine the different aspects of the quality of life in children with CP by using more than one scale.

Participation into life (measured with PODCI and LIFE-H) will be analyzed with the level of disease (by using PEDI, GMFCS level, MACS Level, CFCS level) in the children with CP. As a result of these analyzes, the effect of child's disability type on quality of life and participation into life will be examined in depth and it is aimed to determine needed intervention areas to increase quality of life and participation into life.

2. Is there a significant difference between the service and care needs of children with CP with different motor effect level and type? How are the age, clinical type, body distribution, accompanying problems, educational levels, and distribution of daily living activities in children with CP?

The association will be analyzed between the service and maintenance requirements and with the level of disease (measured with PEDI, GMFCS, MACS, CFCS) in the children with CP. The questions in the questionnaire will be evaluated in order to determine the service and care needs of children; additionally, the necessities will be determined according to the sociodemographic characteristics of children and families.

3. How do the families of children with CP affect with different motor influence levels and type?

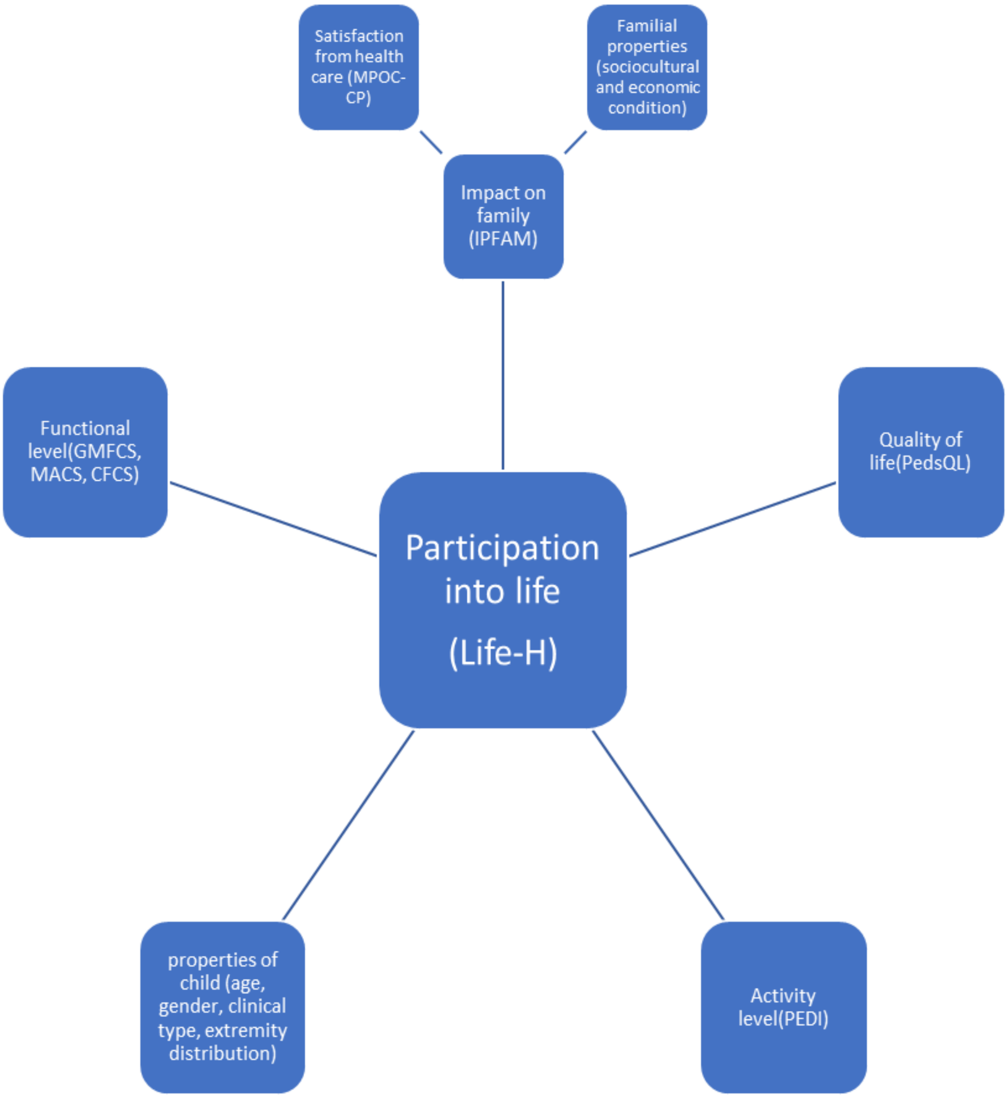

Figure 1. Structural modeling design.

Effects of disease levels of children with CP (PEDI, GMFCS, MACS, CFCS) on the family (MPOC and IPFAM) will be evaluated. As a result of this analysis, it is aimed to define the needs of the families according to their children's disease level. This analysis will provide the priority intervention areas to support both the children and their families.

4. Is there a significant relationship between participation level in children with CP and activity, communication, motor effect, hand skills, quality of life and care processes?

It is aimed to identify the factors related to the participation of children with CP. In advanced analysis in which life-H scale is defined as dependent variable, independent variables are determined as sociodemographic characteristics, disability levels and quality of life of children. Further analyses will be conducted after bivariate analyses. This analyses will be conducted in three age group according to LIFE-H Scale. It is aimed to define the most priority areas affecting the participation in life in children with CP.

Contribution of the Project to the Field

In our country, children with SP can participate in inclusive education in normal schools under the Provincial Directorate of National Education, or they can continue their education and training in special primary schools and high schools designed for people with disabilities. The number of students attending to formal education in special education institutions where special education personnel are employed, where specially trained personnel are employed, is indicated as 306.205 (http://www.tuik.gov.tr/PreHaberBultenleri.do?id=24645). Depending on the severity of disability (percentage of disability report), one or more sessions per week can take individual training and physiotherapy sessions in special education and rehabilitation centers. Additionally, at the public hospitals or private medical cents, at least 30 physiotherapy and rehabilitation and occupational therapy sessions per year or in addition to the second public hospital and university hospital reports up to 90 sessions of services can be used.

In order to increase the quality of life and participation of children with CP, with this project, contribution will be made to identify specific areas of intervention for the development of health and education services. A proposal package will be prepared for the priority intervention areas of the child regarding the level of disability or the care process in order to take part in education and health services. In addition, the development of specific recommendations on family support will be another important contribution.

This is the first extended study covering the different aspects of participation in evaluation of children with CP in our country. The results of the research will give the important evidence to improve the quality of life in children with CPs and support to the families.

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