

Is There any Difference in Health Related Quality of Life, Self Care and Social Function in Children with Different Disabilities Living in Turkey?

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Abstract

Objective: The aim of this study was to examine the differences in the health related quality of life and the self care and social function in daily life of children with different disabilities.

Methods: One hundred and two children with physical, emotional and cognitive disabilities (cerebral palsy, mental retardation, and hearing loss) and 28 children age matched as a control group were included in this study for the comparison. The Pediatric Evaluation of Disability Inventory (PEDI) was used to evaluate the independence and participation of children in daily life activities. The Turkish version of the Child Health Questionnaire-Parent form (CHQ - PF50) was used to evaluate the health related quality of life.

Findings: All 3 groups were different from the control group in terms of self-care and the social domains according to the PEDI results ($P < 0.05$). Children with cerebral palsy (CP) were more dependent in the areas of self-care and mobility activities ($P < 0.05$). The main difference was found in global general health (GGH), physical functioning (PF), the emotional impact on the parent (PE) subsections of the CHQ-PF50 between the CP and the hearing loss groups; the role of the physical (RP) and emotional behavior (BE) subsections between the mental retardation (MR) and the CP groups, and the BE and mental health (MH) subsections between the MR and the hearing loss (HL) groups ($P < 0.05$).

Conclusion: All the children with disabilities were different from the control group in their quality of life, self care and social function. However the status of the children with MR and HL were parallel between each other in their health related quality of life, self care and social function. On the other hand, the most affected and dependent group was children with CP. The results will provide guidelines for healthcare professionals in implementing effective rehabilitation programs, especially to those with cerebral palsy, to reduce the level of strain and increase the health related quality of life, self care and social function of children with different disabilities.

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Introduction

Many neurodevelopmental diseases which cause disability in individuals, such as cerebral palsy (CP), mental retardation (MR), spina bifida, Down

syndrome, hearing loss (HL), and speech disorders, are congenital and affect physical, cognitive, sensory and adaptive functions during the developmental process. Moreover, the severity of disease causes variations in the daily needs of

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individuals and their families even in the same disability group. These disabilities cause limitations in activities and participation in adolescence and adulthood and affect the quality of life (QoL) and wellbeing in negative ways^[1,2]. Disability in children leads to inadequacy in different areas such as self-care, speech, communication, learning, mobility, independent living and financial adequacy. Therefore, individuals with chronic disabilities need long-term care, treatment and rehabilitation^[3,4]. This progression causes a decrease in the QoL of both individuals with disability and their care providers who also must worry about the future and continuous health care provision^[3,5-7]. Parameters needed for improving their quality of life, self care and social function should be assessed in details, which is the main aim of our study.

This multidimensional condition is characterized by such inconveniences as limitation in activities, restrictions in social participation, and deterioration in the quality of communication with healthy individuals^[8,9]. Since every disability involves different social and physical barriers with varying levels of limitation in terms of activity and restriction in social participation, disabled individuals, their families, and care providers are affected in significantly different ways in each case^[10-12]. Hence, the daily care needs of children with one type of disability are different from the needs of children with another type^[13].

Parents with a disabled child depend on others due to their child's physical limitations and disability and their QoL parameters are more affected than those of parents with children without disability^[10-12,14].

Both function and QoL are important health outcomes^[15,16]. Historically, only functional outcomes were used since they measure objective dimensions, such as mobility and daily life activities^[17]. More recently, health-related quality of life (HRQL) outcomes have gained popularity for their inclusion of both objective and subjective dimensions which was not mentioned in details in the previous studies.

Recently, there is much research about children with various developmental disabilities evaluating their wellbeing and functional performance in indoor and outdoor activities^[18-20]. It is shown that these children have some difficulties in indoor and

outdoor activities and this situation causes a decrease in the HRQL and satisfaction. However, the children with different disabilities were not evaluated together in these studies^[3,4,21,22]. Also developments in the rehabilitation clinics for the disabled people in Turkey engaged the need of these studies for a better understanding of their needs.

This study intended to examine the differences in HRQL in children with different disabilities, in terms of their self care and social function in their daily life activities. The groups studied are the most common disability groups seen in Turkey, therefore the results of the study should encourage the establishment of educational and rehabilitative approaches, according to the needs of disability groups, which should be undertaken within a holistic approach in children with different disabilities.

Subjects and Methods

Three groups with different disabilities were composed of 41 mild to moderate children with MR, 34 with CP, 27 with HL, who have been receiving special education and rehabilitation in Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation and the Special Education Rehabilitation Clinic between the years 2011 and 2012. Twenty-eight age-matched children were included in this study as a control group.

Disabled children whose diagnosis was approved by health committee reports by a state or university hospital and who were being taken to a rehabilitation clinic twice a week by their mothers, were included in this study. The exclusion criteria were: children with an unknown diagnosis, those having more than one disability, and those with mothers who did not want to participate in this study. There were no accompanying problems like mental, perceptual or communication problems in the CP group. The socioeconomic status of the families was the same according to their income, educational status and the region they live. As the children in control group were mostly going to the state schools, the data collection of the control group was done at

Table 1: Differences of the age between the groups

	MR Mean (SD) (min -max)	CP Mean (SD) (min -max)	HL Mean (SD) (min -max)	Control Mean (SD) (min -max)	Between groups P. value	F	Post Hoc Test P. value<0.05
Age (years)	6.6 (0.7) (5 - 7)	6.0 (0.8) (5 - 7)	6.3 (0.7) (5-7)	5.9 (0.8) (5-7)	0.005	4.436	1-2; 1-4

1. MR: Mental retardation; 2. CP: Cerebral palsy; 3. HL: Hearing loss; 4. control / SD: standard deviation

state schools from similar region. The children and teacher were informed about the study and families were called to come to the school on the day of data collection. The children and the mothers of the disabled were informed about the evaluation procedure and the results and gave written informed consent on a university approved consent form issued by the Ethics Committee of Gazi University. Ethical approval was obtained from the ethics committee in University. All the mothers had the right to quit the study any time they wanted to. The examiners were physical therapists specialized in pediatrics for 12 years.

The Turkish version of the Child Health Questionnaire-Parent Form (CHQ-PF50) was used to evaluate the health related quality of life (HRQL) of children both with disability and healthy^[23]. This form was developed to evaluate the QoL in children between ages 5-8 years. It consists of 14 subsections and includes 50 parameters. This questionnaire provides 15 specific categories related to physical and emotional wellbeing. Global general health (GGH), physical functioning (PF), role of emotional behavior (REB), role of the physical (RP), bodily pain (BP), emotional behavior (BE), global emotional behavior (GBE), mental health (MH), change health (CH), self-esteem (SE), general health (GH), the emotional impact on the parent (PE), the impact on the time of the parent (PT), family activity (FA) and family cohesion (FC) are evaluated. The maximum score possible from all sections is "100" and the worst score is "0". This questionnaire measures the general health condition, and was developed for researchers and clinicians who study children's functional activities. The mothers were informed in detail about the protocol before filling it out and then informed of the final score.

The Pediatric Evaluation Disability Inventory (PEDI) was used to evaluate the self care, mobility and social function of children in daily life. The

PEDI measures both the capability and performance of functional activities in 3 content domains: (1) Self-care, (2) Mobility, and (3) Social function^[24]. The PEDI consists of 197 functional skill items, and 20 items that assess caregiver assistance and modifications. There are some studies, also for the Turkish population, which confirm the PEDI as a valid assessment tool for functional activities of children with disabilities^[24-26]. The scaled scores (0 to 100) reflect an increasing level of functionality and provide an estimate of the child's ability to perform tasks and the amount of assistance needed, regardless of age.

This is a cross-sectional study. The SPSS for Windows statistic program was used for statistical analysis. All of the parameters were determined using arithmetic averages and standard deviation. The one way Anova test was used for comparison of groups for statistical analysis and the Tukey Test was used for group comparison. The statistical significance level was determined as ($P<0.05$).

Findings

The average age in the study group is shown in Table 1. Forty eight of the subjects in this group were girls and the rest were boys. The age of the mothers was between 28-42 years in both groups.

Quality of Life

According to the CHQ-PF50 results, a difference was found in almost all of the subsections between the children with disabilities and the control group ($P<0.05$). But there were no significant differences in the PF, SE, BP and PE subsections when the children with HL were compared with the control group and in the BP, PE subsections when compared with the MR group ($P>0.05$). No

difference was found in the REB, GBE, GH, FA, FC subsections in the comparison of each disability group ($P>0.05$). The difference was found only in the GGH, PF, and PE subsections between the CP and the HL groups; the RP and BE subsections between the MR and the CP groups and in the BE and MH subsections between the MR and the HL groups ($P<0.05$) (Table 2).

Self Care, Mobility and Social Function

According to the PEDI results in the area of Self-care, each of the 3 groups was different from the control group ($P<0.05$). No difference between the CP and the MR groups was found ($P>0.05$) and the children with CP had the lowest score and differed from children with MR and HL ($P<0.05$), but there was no difference between the MR and the HL group ($P>0.05$). In the Mobility category, it was determined that the children with CP differed from the children with MR and HL ($P<0.05$), but there was no difference between children with MR and HL ($P>0.05$). When their social function was assessed, it was found that the control group differed from the other 3 groups ($P<0.05$), while there was no difference between 3 disability groups ($P>0.05$) (Table 3).

Discussion

The children with different disabilities have disadvantages in contrast to the age-matched healthy peers in their HRQL, self care and social functions in the daily living activities, which are related to their health status. The status of the children with MR and HL were parallel between each other in their HRQL, self care and social function. Moreover, the children with CP are particularly more dependent than the other disability groups with regard to their self care and social function in daily life and have a lower HRQL. The results will provide guidelines for healthcare professionals in implementing effective rehabilitation programs to reduce the level of strain and increase the HRQL, self care and social function of children with different disabilities. It was clearly seen that there are differences in the levels of self care and social function in daily life of children with different disabilities and that their QoL is related to their health status.

In the previous studies on different disability groups, there was a relationship between their functional level and the HRQL, which was not found in others^[18,27]. Some children struggle with

Table 2: Child health questionnaire-parent form (CHQ-PF50) scores of the groups

Parameter	MR Mean (SD)	CP Mean (SD)	HL Mean (SD)	Control Mean (SD)	Between groups P. value	F	Post hoc test P. value<0.05
Global general Health	45.3 (22.5)	35.8 (20.4)	52.6 (21.3)	72.3 (17.1)	<0.001	18.26	1-4; 2-4; 3-4; 2-3
Physical Functioning	57.8 (34.5)	44.8 (40.3)	69.5 (29.8)	91.4 (17.9)	<0.001	11.27	1-4; 2-4; 2-3
Role emotional Behavior	56.5 (34.5)	45.8 (38.7)	53.9 (38.3)	98.4 (4.9)	<0.001	15.41	1-4; 2-4; 3-4
Role physical	62.3 (39.6)	41.1 (37.1)	62.9 (39.8)	100 (0.0)	<0.001	16.44	1-4; 2-4; 3-4; 1-2
Bodily pain	69.2 (28)	62.4 (26.9)	77.0 (23.8)	81.1 (21.1)	0.02	3.56	2 - 4
Behavior emotional	57.7 (18.6)	68.8 (15.5)	70.5 (16.0)	86.9 (11.5)	<0.001	17.69	1-4; 2-4; 3-4; 1-2; 1-3
Global behavior emotional	36.9 (25.3)	41.3 (36.7)	41.7 (20.1)	85.7 (15.8)	<0.001	21.14	1-4; 2-4; 3-4
Mental health	57.2 (19.6)	60.0 (17.1)	69.1 (18.7)	81.2 (12.6)	<0.001	12.10	1-4; 2-4; 3-4; 1-3
Self-emotional	59.7 (16.3)	53.6 (22.8)	62.9 (18.9)	73.8 (16.3)	<0.001	6.37	1 - 4; 2 - 4
General health	41.9 (12.9)	38.5 (14.8)	46.6 (13.2)	69.3 (18.3)	<0.001	26.92	1-4; 2-4; 3-4
Parental Emotional	71.3 (38.6)	62.8 (44.1)	88.4 (40.1)	87.5 (12.7)	0.01	3.81	2-3; 2-4
Parental time	52.3 (32.4)	46.3 (28.4)	61.7 (31.9)	85.7 (16.8)	<0.001	11.73	1-4; 2-4; 3-4
Family activity	52.2 (26.2)	52.8 (24.7)	61.4 (22.9)	86.2 (13.6)	<0.001	14.72	1-4; 2-4; 3-4
Family cohesion	64.4 (24.5)	66.7 (24.3)	65.2 (21.1)	85.3 (13.8)	0.001	6.08	1-4; 2-4; 3-4

1. MR: Mental Retardation; 2. CP: Cerebral Palsy; 3. HL: Hearing Loss; 4. Control / SD: Standard Deviation

Table 3: Pediatric evaluation of disability inventory (PEDI) scores of the groups

	MR Mean (SD)	CP Mean (SD)	HL Mean (SD)	Control Mean (SD)	Between groups P. value	F	Post hoc test P. value<0.05
Self care	45.7 (16.0)	36.5 (20.4)	51.7 (19.6)	72.2 (1.5)	<0.001	26.11	1-4; 2-4; 3-4; 2-3
Mobility	39.3 (16.9)	26.6 (18.7)	42.4 (15.3)	58.9 (0.2)	<0.001	24.93	1-2; 1-4; 2-3; 2-4; 3-4
Social function	30.8 (15.8)	33.1 (19.3)	36.9 (17.3)	63.9 (1.5)	<0.001	28.73	1-4; 2-4; 3-4

1. MR: Mental retardation; 2. CP: Cerebral palsy; 3. HL: Hearing loss. 4: Control SD: standard deviation,

their conditions from an early age and this struggle lasts their whole life^[28,29]. One of these diseases is CP. Physical function impairment that can require lifelong care is the main actor in CP. Although care is one of the obligations of being a parent, as the physical function limitations increase and long term dependence takes place, the anxiety of family increases, too.

The most physically dependent in our study was CP group and they suffer from physical limitations in their daily life^[28-30]. The higher the child's level of disability and the more severe the motor deficit, the higher the reduction in the physical aspects of quality QoL. The studies done by Schneider et al and Majnemer et al also reflects the result of ours, and shows that due to physical limitations, children with CP have physical role limitations in indoor and outdoor activities^[31,32]. We also think that physical limitations and physical role inadequacies affect the family's point of view regarding their child's general state of health. Therefore, when we examined the results of GGH, the children with CP differed from the HL group which had the least physical function, and the control group.

Pain, which is impairment according to model of ICF (International Classification of Function), in children with cognitive impairment and CP is a particularly relevant issue due to its high prevalence and impact on the QoL^[32]. The literature reveals that spasticity causes painful contractures, windswept deformity, scoliosis, and hip dislocation, resulting in pain and difficulty in positioning, sitting, standing, and walking^[33]. Similarly, in our study it was seen that children with CP have more pain and discomfort. Therefore it is thought that especially in children with CP early physiotherapy and rehabilitation interventions can help keep pain under control

and their QoL can be positively affected.

When we looked at the BE and GBE subsections, it was clear that questions are not directly related to children's disabilities, but considerably reflect the psychosocial and emotional state of children in daily life. It gives an idea about the social function restrictions. Since children with CP and HL have similar features, especially in the behavioral area, it shows that they also have similar problems in the psychosocial and emotional domains in daily life. In spite of the fact that children with MR benefit from special education and psychosocial support services, their lower scores compared to the other two groups show that their emotional level is more affected. Social support alleviates depression, increases self-confidence, reinforces coping mechanisms, and improves the psychological health and life satisfaction of individuals, which has to be taken into account for these families and children^[10,13,34].

Physical and mental health of children require special health care, which is associated with healthy mental development^[35-37]. These children have health issues, including emotional and behavioral problems and functional inadequacies. The effect of this type of chronic disease on a child's mental state depends on the type of the disease, the participation of the child in intervention programs and the range of protective factors^[35-37]. In our study, it was seen that these children are generally different from their typical developing peers in terms of emotional, behavioral and mental health subsections.

The common parameters which were affected in the 3 groups included in the study were GH, FA and FC. In most of the studies conducted with chronically disabled children, it is reported that the QoL of these families decreases^[3,4,38]. It has been observed that mothers with a disabled child

experience more problems when compared with the families of healthy children. It is thought that this situation has detrimental effects on family life, parental behaviors and mutual support among family members^[28,29]. As different disability groups were compared in our study, it was evident that the behavior and activities of the families in children with CP were more affected. We believe this is due to the fact that social acceptance is harder in children with CP because of the physical appearance and the severity of the functional inadequacy, as well as the care that is needed during the entire lifetime which greatly affects the life style of the family and the relationship between the members.

The PEDI is a valuable test which reflects the daily life activities, self care and social function, which states the participation according to ICF and the degree of the disability^[39]. Activity limitations and social function restriction form negative aspect of ICF functioning and disability are very closely related with functional independence in daily living activities. Although 3 groups were considered to be disabled, difference in these groups from the control group and differences among themselves are significant in terms of the literature. As there is no difference between the CP and MR groups in the area of self-care, it appears that these children are more dependent in terms of self care activities in daily life while the children with HL are more independent. As can also be seen in the literature, the lowest scores are seen particularly in the CP group and this fact makes it clear that with an increased capacity for physical performance, there is a corresponding increase in capacity for self care and thus independence^[40]. Our results also demonstrate that the severe limitations in cognition and communication of disabled children are a burden on family life.

Three groups differ from the control group in the area of self-care according to PEDI. While there was no difference between children with CP and HL, the lowest scores were recorded by children with CP. In terms of mobility, children with CP are different from children with MR and HL; however, there is no distinction between children with MR and HL. It has been found that over time, especially children with HL, fall behind their peers in terms of self-care and social functions^[41]. Having no physical disability enables children with MR and HL to be more independent

in their daily life. The control group is different from the other 3 groups in terms of social functions but there was no difference among the other 3 groups. This suggests that no matter what kind of disability is experienced, it creates problems for both the children and the parents in terms of participation and/or integration in social life. Also, social support plays an important role in reducing the strain that is experienced by mothers of the disabled children^[42]. Family function played a central role in both the physical and the psychological health of caregivers. These findings suggest that health care providers who work with families of children with long-term disabilities should develop interventions that support and nurture the family as a whole.

In the present study we had some limitations to be taken into account. The sample size for children is small in numbers and may not reflect the status of all the disabled children living in Turkey. The future research must be carried out in a broader extent. This will give an opportunity to discuss in details.

Conclusion

It is concluded that the most affected group was children with CP. The results will provide guidelines for healthcare professionals in implementing effective rehabilitation programs, especially to those with CP, to reduce the level of strain and increase the HRQL, self care and social function of children with different disabilities. Rehabilitation goals related to increasing social function and QoL should promote and enhance health and wellbeing, rather than perpetuating the traditional emphasis on preventing and minimizing long term disabilities and impairments in accord with the World Health Organization ICF model. Therefore, this study was necessary to identify HRQL, self care and social function of the children with different disabilities in order to enable successful interventions.

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Conflict of Interest: None

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