



RESEARCH ARTICLE

## The Investigation of Relationship between Functional Mobility Levels of Children with Chronic Disability and Caregivers' Quality of Life

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### Abstract

**Purpose:** This study aims to look at the relationship between carers' quality of life and the functional mobility levels of children with chronic disabilities. **Methods:** The study included 30 children (22 boys, 8 girls) with chronic disabilities and their caregivers. The socio-demographic characteristics of the children and caregivers were collected. Caregivers' quality of life was evaluated with the Adult Carer Quality of Life Questionnaire (AC-QoL), and children's functional mobility was evaluated with the mobility subscale of the Pediatric Evaluation Of Disability Inventory (PEDI-Mobility). **Results:** The age of the children included in the study was 7.0 (5.0-12.0) years and the age of their caregivers was 38.00 (32.75-41.25) years. The AC-QoL score of caregivers was 85.00 (72.00-93.50) out of a total of 120 points, and the PEDI-Mobility score was 33.00 (3.75-53.00) out of a total of 58 points. In the correlation analysis, no significant correlation was found between the PEDI-Mobility total score and the AC-QoL total score ( $p > 0.05$ ). However, there was a negative correlation between the PEDI-Mobility total score and the AC-QoL "ability to care" subscale score ( $r = -0.403$ ;  $p = 0.027$ ). **Conclusion:** According to the results of the study, no relationship was found between the functional levels of children and the quality of life of their caregivers. Studies with a larger sample size and consideration of aspects including sociocultural level, economic considerations, and health services that may affect the quality of life of families are regarded to be necessary in order to achieve more conclusive findings on this subject.

### Keywords

Children with Disabilities, Caregiver, Quality of Life

## INTRODUCTION

Children with disabilities are ones whose neurological, physical, mental, sensory, social, and communicative abilities differ from those of an average or typical child. Therefore, they need professional help. (Sen and Yurtsever, 2007). These children with special care needs require constant attention from family members and healthcare professionals as they exhibit temporary or permanent physical, developmental, behavioral or emotional problems (Coller et al., 2020). Disability

affects not only the child but also the family and caregivers physically, emotionally and socially, paving the way for them to experience multifaceted problems (Sen and Yurtsever, 2007).

Regardless of the degree of disability, this is a traumatic situation for the child and her/his family. Inappropriate reactions to this traumatic situation and the feeling of guilt in the family drag the parents into depression. At the same time, the need for extra time, money and energy for the care of the child causes the parents to experience

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stress and negatively affects the quality of life (Cangür et al., 2013).

Caregivers take on a crucial responsibility to help chronically disadvantaged kids who struggle with daily challenges (Yilmaz et al., 2013). Bringing up a child with disability, raising her/him and meeting her/his needs throughout her/his development affect all members of the family (Stevenson et al., 2006). However, in this process, mothers are more affected by this situation as they are generally the primary caregivers of the child (Ones et al., 2005). It is stated that the experimentation and expectations of children's family with disability vary according to the mother and father. Mothers, who are primarily responsible for the care of the child, take a more active role in solving the difficulties they face and show more effort (Hastings, 2003; Byrne et al., 2010). Various health problems may occur and emotional changes may occur in mothers with disabled children who cannot spare enough time for themselves due to the care of their disabled child (Sertel et al., 2016). Caring for a child with long-term functional limitations can affect mothers' quality of life, and thus poor maternal health may result in decreased work productivity and increased health care costs. This may affect the child, family and society negatively (Tekinarslan, 2013).

It is seen in the literature that caregivers of disabled children face more mental and physical difficulties than those who care for healthy children (Bourke-Taylor et al., 2012). One of the factors that can affect the quality of life of caregivers is the functional competencies of the child with disability. However, there is no consensus in the literature on this issue. Based on this subject, our study aimed to examine the relationship between the functional mobility levels of children with chronic disabilities and the quality of life of their caregivers.

## MATERIALS AND METHODS

### *Participants*

In this cross-sectional study, 30 children with chronic disabilities between the ages of 0-18 who participated in physical therapy and rehabilitation programs in special education and rehabilitation centers and their caregivers were included. Inclusion criteria of chronically disabled children; physical, mental, or both were considered chronic disabilities, being between 0-18 age, and voluntary to join to the study. Exclusion criteria; not wanting

to participate in the research and not having the ability to follow the verbal instructions given to her/him. Inclusion criteria of caregivers; having a child with physical, mental, or both, who is considered a chronic disability, being able to read and write in Turkish, and agreeing to participate in the research voluntarily. The exclusion criteria are; not accepting to participate in the study, having communication problems, having any psychiatric disorder and having recently experienced an event that may significantly affect the quality of life. In order to carry out the study, ethics committee permission was obtained from the Non-Interventional Research Ethics Committee of Dokuz Eylül University with the decision number 2023/01-09 dated 04.01.2023. Before the study, the children to be included in the study and their caregivers were informed about the purpose of the study and the evaluation method. Written informed agreement was acquired from the families for this study in following with the guidelines set out in the Declaration of Helsinki.

### *Data collection tools*

Within the scope of the study, the socio-demographic characteristics of the children and their caregivers were questioned using the form created by the researchers. The quality of life of the caregivers was evaluated with the Adult Carer Quality of Life Questionnaire (AC-QoL), and the functional mobility level of children was evaluated with the Mobility sub-title of the Pediatric Evaluation of Disability Inventory (PEDI-Mobility).

### *Adult Carer Quality of Life Questionnaire*

It was developed by Stephen Joseph et al. (Joseph et al., 2012). The questionnaire examines the quality of life under 8 sub-titles and consists of 40 questions. Each question can be answered as "never", "sometimes", "often" and "always". The highest score that can be obtained from the questionnaire is 120. The scores obtained after scoring are classified as 0-40 points denoting low quality of life, 41-80 points expressing average quality of life, and 81-120 points expressing high quality of life. The Turkish reliability and validity of the questionnaire was carried out by Gençer (Gençer, 2020).

### *Pediatric Evaluation of Disability Inventory*

The Pediatric Evaluation of Disability Inventory is a clinical assessment tool used to evaluate functional abilities, performance and

changes in functional skills in children with disabilities between the ages of 6 months and 7.5 years, and it is also a frequently used tool in the assessment of older children in case of functional delay (Haley et al. , 2010). The Turkish validity and reliability study of the scale was performed by Erkin et al. (Erkin et al., 2007). The scale is divided into 3 main titles: functional skills, help of caregivers and modifications. Functional skills subheading consists of 197 questions. This subsection is organized as Self-Care subsection 73, Mobility subsection 59 and Social Functions subsection 65 items. The Caregivers' Help section consists of 20 questions and scores are made according to the amount of help the child needs during functional abilities. The modification section includes 20 questions on the environmental regulations that the child uses while performing his/her daily life skills. Each question is scored as 0 = cannot, 1 = can. Scoring can be done during the interview with the family, as well as following the observation of the behaviors by the physiotherapists. The subscales of the PEDI can also be applied separately from each other. In this study, the "Mobility" subscale within Functional Skills was used to determine the functional mobility levels of individuals with chronic disabilities.

**Statistical analysis**

The data obtained from the research were analyzed with the Statistical Package for Social Sciences (SPSS®) Windows 24.0 package program. The conformity of the data to the normal distribution was evaluated with the Shapiro-Wilk test. Descriptive statistics were given as the median (IQR25/75). Spearman Correlation test was used to determine the relationship between functional mobility level of children and quality of life of caregivers. The sample size of the study was calculated as a minimum of 29 participants using the G\* Power 3.1 software by taking 85% power,  $\alpha=0.05$ , correlation  $pH1=0.48$  and correlation  $pH0=0.00$ .

**RESULTS**

Thirty children (22 boys and 8 girls) with chronic disabilities and their mothers were included in this study. All caregivers included in the study were mothers. The mean age of the children included in the study was 7.0 (5.0-12.0) and the mean age of their mothers was 38.00 (32.75-41.25). 93.3% of the mothers were married. The participants' general characteristics are given in Table 1 and Table 2.

**Table 1.** Socio-demographic and clinical characteristics of children with disabilities

|                          | n=30                     | n                   | %    |
|--------------------------|--------------------------|---------------------|------|
| Age (median – IQR 25/75) |                          | 7.00 (5.00 – 12.00) |      |
| Gender                   | Female                   | 8                   | 26.7 |
|                          | Male                     | 22                  | 73.3 |
| Diagnosis                | Cerebral Palsy           | 15                  | 50.0 |
|                          | Autism Spectrum Disorder | 5                   | 16.7 |
|                          | Delayed Development      | 4                   | 13.3 |
|                          | Other                    | 6                   | 20.0 |

IQR25/75: Interquartile Range 25th 75th Percentile

**Table 2.** Socio-demographic characteristics of caregivers of children with disabilities

|                          | n=30              | n                     | %    |
|--------------------------|-------------------|-----------------------|------|
| Age (median – IQR 25/75) |                   | 38.00 (32.75 – 41.25) |      |
| Marital Status           | Married           | 28                    | 93.3 |
|                          | Single            | 2                     | 6.7  |
| Education Status         | Uneducated        | 2                     | 6.7  |
|                          | Primary School    | 9                     | 30.0 |
|                          | Secondary School  | 4                     | 13.3 |
|                          | High School       | 10                    | 33.3 |
|                          | Associate Degree  | 1                     | 3.3  |
|                          | Bachelor's Degree | 3                     | 10.0 |
| Number of Children       | Master's Degree   | 1                     | 3.3  |
|                          | One               | 9                     | 30.0 |
|                          | Two               | 11                    | 36.7 |
|                          | Three             | 8                     | 26.7 |
|                          | Four              | 2                     | 6.7  |

IQR25/75: Interquartile Range 25th 75th Percentile

AC-QoL total score median score was 85.00 out of 120.00. PEDI Mobility's total score median score was 33 out of 58. The median and interquartile range values of the subscales are given in Table 3.

**Table 3.** Scores of PEDI and AC- QoL

|                    | Median | (IQR25/75)      |
|--------------------|--------|-----------------|
| PEDI - Mobility    | 33.00  | (3.75-53.00)    |
| AC-QoL Total Score | 85.00  | (72.00 - 93.50) |
| Support for caring | 10.50  | (4.75 – 12.00)  |
| Caring choice      | 9.00   | (4.75 – 12.00)  |
| Caring stress      | 10.00  | (6.50 – 12.50)  |
| Money matters      | 5.30   | (3.75 – 8.00)   |
| Personal growth    | 12.00  | (10.00 – 15.00) |
| Sense of value     | 14.00  | (10.75 – 15.00) |
| Ability to care    | 12.00  | (9.75 – 13.25)  |
| Carer satisfaction | 14.00  | (12.75 – 15.00) |

IQR25/75: Interquartile Range 25th 75th Percentile, PEDI – Mobility: Mobility Subscale of Pediatric Evaluation of Disability Inventory, AC-QoL: Adult Carer Quality of Life Questionnaire

No relationship was found between mothers' quality of life and the functional mobility levels of their children. There was a moderate negative correlation between the PEDI-Mobility total score and the AC-QoL "ability to care" subscale score ( $p < 0.05$ ) (Table 4.)

**Table 4.** Correlation between caregivers' quality of life and chronic disabled children's PEDI mobility scores

|                    | PEDI - MOBILITY |         |
|--------------------|-----------------|---------|
| AC-QoL Total Score | r               | -0.287  |
|                    | p               | 0.124   |
| Support for caring | r               | -0.048  |
|                    | p               | 0.801   |
| Caring choice      | r               | 0.185   |
|                    | p               | 0.326   |
| Caring stress      | r               | -0.140  |
|                    | p               | 0.461   |
| Money matters      | r               | -0.251  |
|                    | p               | 0.180   |
| Personal growth    | r               | -0.188  |
|                    | p               | 0.320   |
| Sense of value     | r               | -0.250  |
|                    | p               | 0.183   |
| Ability to care    | r               | -0.403* |
|                    | p               | 0.027*  |
| Carer satisfaction | r               | -0.281  |
|                    | p               | 0.133   |

## DISCUSSION

This study aims to investigate the relationship between the functional mobility levels of children with chronic disabilities and caregivers' quality of life. We found a moderate negative correlation between the PEDI-Mobility total score and the AC-QoL "ability to care" subscale score ( $p < 0.05$ ). Caring for a child with a chronic disability is a rather time-consuming activity, mothers quit their jobs (Caicedo, 2014),

and restrict their social life to maintain it. Chronic conditions can be seen with many complications. This may increase health expenditures for children with chronic disabilities (Lindley and Mark, 2010). As a result of this situation, caregivers may experience financial stress (Barutcu et al., 2021). Studies showed severe disability makes this cost bigger, but we didn't find any relationship between Money matters subscale of AC-QoL and PEDI Mobility. The reason for this situation may be the

financial situation of the participants. Future studies should examine the effect of "income status" on quality of life.

Chronic disabled child's care getting harder year by year. Our sample's mean age was 7.00. Literature suggest that mother's quality of life decreases with children's age (Bumin et al., 2008). Maybe this is one of the reasons we don't have any correlation between other parameters.

Studies showed that the physical abilities of a child are important factors that affect mother's quality of life (Dehghan et al., 2016). In our study %50 of the participants were diagnosed with Cerebral Palsy. Cerebral Palsy is a developmental disability that has difficulties with motor skills and also they may have cognitive, and sensory impairments (Gulati and Sondhi, 2018). The complexity of disability affects parents' well-being in more than one problem (Isa et al., 2013). These consequences result in dependence on the caregiver. Therefore, we expected to find the statistically important difference between functional mobility and mother's quality of life. . Studies in the literature found that functional level association between lower quality of life (Sonune et al., 2021; Yilmaz et al., 2010). In a study conducted by Sonune et al., in which the relationship of depression and quality of life of mothers of children with cerebral palsy were examined with the functional level, it was found that the quality of life was significantly affected by the functional level (Sonune et al., 2021).

But, our findings weren't consistent with the literature. In another study, the quality of life of the families of children with learning disabilities, mental retardation, autism spectrum disorder, and physical disability was compared. It was found that the worst quality of life is in families whose child has autism spectrum disorder, and families of children with physical disabilities have the best quality of life after families who had child with learning disability (Haimour and Radi, 2012).

In current study we didn't find any relationship between functional level and mother's quality of life. This may be due to the fact that our group of participants was heterogeneous. We have physically and mentally disabled children in this study. Children with Autism Spectrum Disorder have better functional levels than physically disabled children. Disease characteristics, complications, and treatment regimes have important effects on quality of life and show

differences with disability type. For instance, in a study conducted by 203 children with cerebral palsy in Iran, it was found that the quality of life of mothers decreases as the child's level of impairments increases (Farajzadeh et al., 2020).

Most of the studies in the literature focus on the negative aspects of caregiving. Although caregiver's demands are challenging, studies cited that positive aspect of caregiving (Schulz and Sherwood, 2008; Shirai et al., 2009). Helping a person who had a disability makes them feel good and useful. Caregivers experience satisfaction because of this situation. Some of them use it as a coping strategy (Li-Tsang et al., 2001). The results of this study also support this situation in the literature. We found a moderate negative correlation between the PEDI-Mobility total score and the AC-QoL "ability to care" subscale score ( $p < 0.05$ ).

Our study have some limitations. First, this study only contains chronically disabled children and their mothers who live in İzmir. To generalize the results we need another study from other cities in Turkey. In order to reach more solid evidence on this subject, it is thought that studies that will take into account factors such as larger sample size and sociocultural levels of families are needed.

Second, mothers are primary caregivers in Turkey, and because of this reason, we included only mothers (Ones ve ark., 2005). Future studies should add caregiver fathers will enable the investigation of the effect of the gender factor on the quality of life.

In conclusion our study supported that caregiving may have positive effects on mothers' ability to care, depending on the child's functional level. In this direction, informing and training families about caregiving will be an important step as it can increase the quality of life of mothers by supporting the results of our study.

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#### **Conflict of interest**

No disagreement of interest is said by the writers. In addition, no financial support was received.

**Ethics Committee**

(Date: 04.01.2023; Decision number: 2023/01-09). Participants who volunteered for the study were informed with a written informed consent form.

**Author Contributions**

Study Design, RA, ND, TT; Data Collection, RA, ND; Statistical Analysis, MK; Data Interpretation, RA, ND, MK, TT; Manuscript Preparation, RA, ND, MK, TT; Literature Search, RA, ND, MK, TT. All authors have read and agreed to the published version of the manuscript.

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