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# An investigation of factors affecting quality of life in parents of chronically disabled children

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## Abstract

**Aim:** The study's first objective is to compare differences between fathers and mothers with and without chronically disabled children. The study's second objective is to analyze factors influencing the quality of life of mothers and fathers with chronically disabled children comprehensively.

**Materials and Methods:** One hundred sixty parents, 48 mothers and 22 fathers with chronically disabled children, 45 mothers and 45 fathers without chronically disabled children, participated in the research. Data collection was performed by employing the Nottingham Health Profile (NHP), Beck Depression Inventory (BDI), Parenting Stress Index (PSI), Fatigue Severity Scale, Headache Impact Test (HIT), and Pittsburgh Sleep Quality Index (PSQI).

**Results:** The childcare-related workload, HIT, NHP, BDI, and PSQI values of the mothers in the study group and BDI and PSQI values of the mothers in the control group were significantly higher than the values obtained by the fathers ($p<0.05$). Moreover, depression, parenting stress, headache, fatigue, and the percentage of childcare-related workload undertaken by the spouse were observed to affect the quality of life of parents having chronically disabled children ($p<0.05$).

**Conclusion:** As a consequence, we see that parents are affected by their children's disabilities, whereas mothers are affected more. We think that planning multifaceted approaches on the issue will be useful.

## Introduction

The World Health Organization (WHO) has described disability as an inability that interferes with a person's ability to have a lifestyle considered normal according to the person's age, sex, and social status. The first reaction of families with disabled children is shock. This is then followed by the stages of denial, sadness, depression, adjustment, and acceptance [1,2]. In the literature, taking care of a disabled child influences many aspects of parents' lives, involving individuals' physical, social, and emotional health, marital relationships, and financial status [3]. Quality of life is essential for families with disabled family members who spend the entire day with disabled people. It is expressed that families of disabled children have higher vulnerability in psychological and physical terms, and their quality of life is lower [4]. The level of deterioration in quality of life in families of children with chronic disorders is associated with environmental variables as well as socioeconomic status, social support, and genetically based variables such as parent and child characteristics [5]. Parents have stated that the physical demands of taking care of a physically disabled child have a severe effect on their own physical health, especially as their children grow older and their body weight increases. When the literature is reviewed, it is striking that studies on health-related quality of life generally focus on evaluating the quality of life of disabled individuals and their mothers. It is extremely important to determine the roles of fathers in this long-term process. Therefore, the current research was planned in line with two purposes. The study's first objective is to compare differences between fathers and mothers with and without chronically disabled children. The study's second objective is to analyze factors influencing the quality of life of fathers and mothers having chronically disabled children comprehensively.

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## Material and Methods

Forty-eight mothers and 22 fathers among parents of children with chronic disabilities (n=40 Cerebral Palsy, 4 Down Syndrome, 4 Spina Bifida, 2 Brachial Plexus) who presented to the Special Education and Rehabilitation Center and 45 mothers and 45 fathers among parents of children without chronic disabilities (n=45), 160 individuals in total, were enrolled in the research. For the research, the necessary permission was acquired from the Clinical Research Ethics Committee of abant Izzet Baysal University (Protocol NO. 2018/59). Prior to the evaluation, children and parents received information about the objective and method of the research, and an informed consent form was signed.

### *Inclusion criteria*

*For the study group*

- Volunteering to participate in the research
- Having a chronically disabled child
- Continuing a physiotherapy and rehabilitation program in a rehabilitation facility

*For the control group*

- Volunteering to participate in the study
- Having a child without any chronic disability

### *Exclusion criteria*

- Any orthopedic and neurological problems that might prevent participation in the study in parents

### *Assessments*

*Nottingham health profile (NHP)*

Küçükdeveci et al. [6] performed its Turkish validity study. The questionnaire assesses six dimensions concerning health status: pain (8 items), emotional reactions (9 items), energy (3 items), social isolation (5 items), sleep (5 items), and physical activity (8 items). A score of 0-100 can be received from each sub-category. '0' indicates no limitations, and '100' indicates the presence of all listed limitations [7].

*Parenting stress index/short form (PSI/SF)*

It was prepared by Abidin [8] in 1983 to assess stress in parent-child relationships. The lowest score of 36 and the highest score of 180 are obtained from the questionnaire, and high scores indicate high levels of stress in parents.

*Beck depression inventory (BDI)*

It was prepared by Beck in 1978 with the aim of measuring the level of depression [9]. Its validity and reliability studies were conducted by Teğin in 1980 and Hisli in 1988 [10]. Scoring ranges between 0 and 63. A score of 10-16 refers to mild depression, 17-29 to moderate depression, and 30-63 refers to severe depression.

*Fatigue severity scale (FSS)*

The Turkish validity and reliability studies of the questionnaire, which was developed by Krupp [11] in 1989, were carried out by Armutlu et al. [12]. The scoring of the scale, comprising 9 questions, changes between 9 and 63, and a total score of 36 and higher refers to fatigue.

*Pittsburg sleep quality index (PSQI)*

The PSQI was introduced by Buysse et al. in 1989 to assess sleep quality [13]. Ağargün et al. [14] carried out the scale's Turkish validity and reliability study. The PSQI represents a 19-item self-report scale assessing sleep quality and sleep disorders in the last month. A total score changing between 0 and 21 is obtained. Individuals scoring 5≥ are regarded to have "good sleep quality," and individuals scoring 5< to have "poor sleep quality."

*Headache impact test (HIT)*

With this test, the severity of pain, whether the pain causes limitations in work and leisure activities, and its impacts on fatigue and cognitive characteristics are assessed. It is a test consisting of 6 questions. Every item is answered on a 5-point Likert-type scale, and the total score is obtained. The total score changes in the range of 36-78. If the total score is ≥60, the person's life is significantly affected by headaches, and daily activities are severely limited. Between the scores of 56 and 59, it is stated that headaches affect daily activities significantly. When the score is between 50 and 55, headaches are stated to affect daily activities slightly, and a score of ≤49 means that daily activities have not been affected by headaches yet [15].

### *Data analysis*

As a result of the power analysis, when at least 100 individuals were included in the study, it was calculated that 90% power could be obtained at a 95% confidence level. Statistical analyses were performed using SPSS version 24.0. The individuals' descriptive statistics (mean, standard deviation, etc.) were expressed as number and percentage. In parametric data, the significance test of the difference between the two means was used in the comparison of independent group differences, while the Mann-Whitney U test was used in nonparametric data. In dependent group examinations, the significance test of the difference between two peers was used in parametric data, while the Wilcoxon paired-sample test was used in nonparametric data. Chi-square analysis and McNemar's test were employed for the differences between categorical variables. Linear regression analysis was conducted to reveal the variables with an effect on the dependent variable. In all analyses, $p<0.05$ was regarded statistically significant.

## Results

No difference was observed between the age and occupational status of the groups ($p>0.05$, Table 1). When the time spent by parents to play with children was analyzed, no difference was revealed between the groups and between mothers and fathers ($p>0.05$, Table 2). The childcare-related workload of the mothers in the study group was

**Table 1.** Comparison of the descriptive information of mothers and fathers.

| | | Study Group | Control Group | Total | P |
|---|---|---|---|---|---|
| Mother's characteristics | | | | | |
| Age | Under 30 years | 8 (16.67%) | 11 (24.44%) | 19 (20.43%) | 0.209 ( $\chi^2$=4.539) |
| | Between 31-40 years | 23 (47.92%) | 12 (26.66%) | 35 (37.63%) | |
| | Between 41-50 years | 10 (20.83%) | 16 (35.55%) | 26 (27.95%) | |
| | 51 years and above | 7 (14.58%) | 6 (13.33%) | 13 (13.68%) | |
| Occupation | Housewife | 48 (100%) | 38 (84.44%) | 86 (92.47%) | 0.097 ( $\chi^2$=6.31) |
| | Civil servant | 0 (0%) | 2 (4.44%) | 2 (2.15%) | |
| | Self-employed | 0 (0%) | 4 (8.88%) | 4 (4.30%) | |
| | Other | 0 (0%) | 1 (4.44%) | 1 (1.07%) | |
| Father's characteristics | | | | | |
| Age | Under 30 years | 3 (13.64%) | 7 (15.55%) | 10 (14.92%) | 0.902 ( $\chi^2$=0.575) |
| | Between 31-40 years | 4 (18.18%) | 11 (24.44%) | 15 (22.38%) | |
| | Between 41-50 years | 8 (36.36%) | 13 (28.88%) | 21 (31.34%) | |
| | Age | 7 (31.82%) | 14 (31.11%) | 21 (31.34%) | |
| Occupation | Unemployed | 0 (0%) | 2 (4.44%) | 2 (2.98%) | 0.726 ( $\chi^2$=2.052) |
| | Civil servant | 3 (13.64%) | 5 (11.11%) | 8 (11.94%) | |
| | Worker | 7 (31.82%) | 14 (31.11%) | 21 (31.34%) | |
| | Self-employed | 9 (40.91%) | 20 (44.44%) | 29 (43.28%) | |
| | Other | 3 (13.64%) | 4 (8.08%) | 7 (10.44%) | |

$p<0.05$ statistically significant difference; $\chi^2$: Chi-square test.

significantly higher than the fathers ($p<0.05$, Table 2). When the childcare-related workload percentage of the spouse was examined, the percentage of the fathers in the study group in supporting mothers was revealed to be significantly lower ($p<0.05$, Table 2). When the BDI and PSQI total scores were reviewed, it was determined that the values of the mothers in the study and control groups were higher in comparison with the fathers ($p<0.05$, Table 3). When the parenting stress levels were checked, the stress levels of the parents in the study group were significantly higher compared to the parents in the control group ($p<0.05$, Table 3). When the HIT scores were reviewed, the scores of the mothers in the study group were revealed to be higher in comparison with the fathers ($p<0.05$, Table 3). When the NHP total scores were examined, the scores of the mothers in the study group were higher compared to the fathers and the mothers in the control group ($p<0.05$, Table 3). When the factors that might influence the NHP total scores of the mothers in the study group were considered, spouse's workload percentages, BDI, PSI, HIT and fatigue levels were observed to be statistically significant ($p<0.05$, Table 4). All these factors, except for the spouse's workload percentage, increased the NHP total scores. However, the increase in the spouse's workload percentage had a decreasing impact on the NHP total scores (Table 4). The BDI, PSI, HIT and fatigue levels of the fathers in the study group were revealed to be statistically significant ($p<0.05$, Table 4). All these factors were observed to be effective in increasing the NHP total scores (Table 4).

## Discussion

At the end of the research, it was observed that the parenting stress levels of the mothers in the study group were higher than the mothers in the control group, and the depression, sleep, headache, and quality of life values of the mothers in the study group were worse compared to the fathers. Furthermore, depression, parenting stress, headache, fatigue, and the percentage of childcare-related workload undertaken by the spouse were observed to affect the quality of life of parents having chronically disabled children. Terra et al. [16] indicated that mothers of children with CP had worse quality of life than mothers having healthy children. They also stated that the disability of the child affected not only the child's life but also the family's life. When parents of children with disabilities were compared to parents of children without disabilities in terms of personal stress, marital satisfaction, and social environment, they were observed to experience higher levels of stress [17]. It was mentioned that mothers having disabled children were very sad, and their social lives, work lives, and family relations were influenced after having disabled children [18]. Singhi et al. reported greater financial burden, poor social interaction, and adverse impacts on mental and physical health resulting from having a disabled child, compared to families of healthy

**Table 2.** Comparison of the characteristics of parents in the study and control groups.

| | Study Group A.M±S.D | Control Group A.M±S.D | P |
|---|---|---|---|
| Duration of marriage (years) | 20.36 ± 10.66 | 21.12 ± 11.12 | 0.794 (t=0.262) |
| Play time of the mother (HOURS) | 0.83 ± 1.26 | 1.56 ± 1.33 | 0.058 (z=-1.896) |
| Play time of the father (HOURS) | 1.57 ± 1.78 | 1.83 ± 1.47 | 0.550 (z=-0.631) |
| Intra-group p | 0.475 (t=-0.729) | 1 (t=0) | |
| Mother's workload in childcare % | 83.44 ± 14.66 | 76.67 ± 28.72 | 0.946 (z=-0.067) |
| Father's workload in childcare % | 32.73 ± 23.13 | 33.57±30.10 | 0.938 (t=0.078) |
| Intra-group p | 0.0001* (t=6.793) | 0.154 (t=1.754) | |
| Father's support to the mother % | 13.65 ± 14.09 | 10±10 | 0.570 (z=-0.569) |
| Mother's support to the mother % | 66.36 ± 23.81 | 54.29±30.47 | 0.284 (t=-1.094) |
| Intra-group p | 0.0001* (t=-7.623) | 0.061 (t=-2.585) | |

*p<0.05 statistically significant difference, A.M: Arithmetic mean, S.D: Standard deviation, t=Significance test of the difference between two means; z: Mann-Whitney U test.

**Table 3.** Comparison of the depression, pain, sleep, stress, headache, fatigue values of parents in the study and control groups.

| | Study Group A.M±S.D | Control Group A.M±S.D | Inter-group p |
|---|---|---|---|
| BDI mother | 13.90 ± 8.12 | 11.40 ± 6.56 | 0.112 (t=-1.603) |
| BDI father | 8.75 ± 7.16 | 9.23 ± 7.15 | 0.812 (z=-0.238) |
| Intra-group p | 0.001* (t=3.959) | 0.017* (t=2.499) | |
| PSQI total mother | 6.58 ± 4.05 | 4.93 ± 2.55 | 0.093 (z=-1.679) |
| PSQI total father | 4 ± 2.41 | 4.22 ± 3.25 | 0.779 (z=-0.28) |
| Intra-group p | 0.002* (z=-3.075) | 0.025* (z=-2.235) | |
| PSI mother | 91.83 ± 27.49 | 68.91 ± 19.59 | 0.0001* (t=-4.532) |
| PSI father | 78.33 ± 21.32 | 63.58 ± 20.87 | 0.008* (z=-2.672) |
| Intra-group p | 0.417 (z=-0.812) | 0.049* (t=2.026) | |
| HIT mother | 57.52 ± 10.71 | 53.88 ± 8.91 | 0.084 (t=-1.75) |
| HIT father | 53.63 ± 7.28 | 51.4 ± 7.77 | 0.083 (z=-1.736) |
| Intra-group p | 0.044* (t=2.139) | 0.102 (t=1.674) | |
| FSS mother | 44.02 ± 13.61 | 37.14 ± 15.94 | 0.066 (z=-1.837) |
| FSS father | 38 ± 15.15 | 34.96 ± 13.72 | 0.278 (z=-1.084) |
| Intra-group p | 0.208 (t=1.298) | 0.242 (t=1.186) | |
| NHP$_T$ mother | 208.74 ± 156.79 | 108.59 ± 95.31 | 0.002* (z=-3.156) |
| NHP$_T$ father | 117.58±120.06 | 84.46 ± 103.49 | 0.337 (z=-0.959) |
| Intra-group p | 0.01* (t=2.848) | 0.092 (t=1.727) | |

*p<0.05 statistically significant difference; A.M: Arithmetic Mean; S.D: Standard Deviation; In intergroup examinations; t: Independent Samples t-test; z: Mann-Whitney U test; In intra-group examinations; t: Dependent Samples t-test; z: Wilcoxon Paired Two Samples test, BDI: Beck depression inventory, VAS: Visual analog scale, PSQI: Pittsburgh sleep quality index, PSI: Parenting stress index, HIT: Headache impact test, FSS: Fatigue severity scale, NHP: Nottingham health profile (Total).

**Table 4.** Factors affecting quality of life of mothers and fathers in the study group.

| Variables with investigated effects on the NHP Total | Beta | T | P | 95% C.I - Lower Limit | 95% C.I - Upper Limit |
|---|---|---|---|---|---|
| BDI mother | 0.69 | 6.469 | 0.0001* | 9.179 | 17.47 |
| Play time of the mother | -0.356 | -2.586 | 0.013 | -78.811 | -9.818 |
| Workload percentage of the mother | 0.26 | 1.83 | 0.074 | -0.279 | 5.848 |
| Spouse's workload percentage of the mother | -0.312 | -2.227 | 0.031* | -6.608 | -0.334 |
| PSQI total | 0.486 | 3.774 | 0 | 8.779 | 28.85 |
| PSI mother | 0.524 | 4.168 | 0.0001* | 1.544 | 4.428 |
| HIT mother | 0.648 | 5.775 | 0.0001* | 6.184 | 12.8 |
| FSS mother | 0.504 | 3.962 | 0.0001* | 2.858 | 8.762 |
| Play time of the father | -0.459 | -2.252 | 0.036 | -59.749 | -2.184 |
| Workload percentage of the father | 0.158 | 0.714 | 0.484 | -1.546 | 3.154 |
| Spouse's workload percentage of the father | -0.217 | -0.993 | 0.332 | -3.331 | 1.182 |
| PSQI total | 0.154 | 0.729 | 0.474 | -14.09 | 29.375 |
| PSI father | 0.546 | 3.059 | 0.006* | 0.991 | 5.162 |
| HIT father | 0.51 | 2.78 | 0.011* | 2.136 | 14.678 |
| FSS father | 0.525 | 2.895 | 0.008* | 1.18 | 7.145 |
| BDI father | 0.645 | 3.956 | 0.001* | 5.146 | 16.483 |

*$p<0.05$ statistically significant effect; Std.Beta: Standardized Beta coefficient; t: Linear Regression analysis test value; 95% C.I - Lower Limit: 95% Confidence Interval Lower Limit, 95% C.I - Upper Limit: 95% Confidence Interval Upper Limit, BDI: Beck depression inventory, VAS: Visual analog scale, PSI: Parenting stress index, HIT: Headache impact test, FSS: Fatigue severity scale.

children [19]. Studies in the literature have generally investigated the effects on the mother. In this study, fathers with and without chronically disabled children were also included in the study. Thus, the conditions of parents both within themselves and between each other were evaluated. At the end of the research, the quality of life of mothers with disabled children was observed to be worse. However, this difference in quality of life was not detected in fathers. When the literature was reviewed for its reasons, it was shown that fathers spent less time with disabled children than mothers, and they could not help mothers so much with childcare [20]. In their study, Yeung et al. [21] detected that in families with typically developing children aged between 0-12 years, fathers dealt with children less than mothers, and this difference remained the same throughout their children's development. It was reported that mothers experienced their emotions more intensely and experienced more health anxiety than fathers. Hobdell et al. [22] It was reported that mothers with disabled children gave up on daily activities to fulfill the needs of their children and felt emotional and lonely. Likewise, in our study, the quality of life of the mothers in the study group was worse than that of the fathers. Since they were not the main subject of our study, it was not questioned whether mothers were able to deal with their own hobbies and how much time they spent for themselves. We assume that it will be useful to question such social activities in more detail in future studies. In our study, it was observed that the percentage of the childcare-related workload undertaken by the mothers in the study group and the percentage of the childcare-related workload undertaken by the spouse were higher compared to fathers. Similarly, it was observed that the increase in the percentage of the childcare-related workload undertaken by the spouse positively influenced the quality of life. In summary, especially the father's support to the mother in childcare will have impacts on enhancing the mother's quality of life. Social and cultural differences have been assumed to be possibly effective here. In Turkey, studies have shown that it is rather mothers who take care of disabled children [23,24]. As a result of their study conducted in Cyprus, Bağkur et al. [25] stated no difference between the care times of the mother and the father for the disabled child, and the father provided all kinds of childcare-related support to the mother. It was asserted that, since the increase in the chronic disability level of the child would affect the parent's care time, it would adversely affect sleep, socialization, and symptoms [26]. In our study, the PSQI total scores of the mothers in the study and control groups were also revealed to be higher than those of the fathers. Considering that mothers dealt with their children more and mothers' percentages of the childcare-related workload were higher, this was an expected situation. It was thought that social habits might also play a role in this situation. Therefore, we are of the opinion that it will be important to conduct more detailed studies in different societies. It was reported that having a disabled child was closely related to the psychological symptoms of parents [27-29]. In our study, the stress levels of the parents in the study group were higher in comparison with the parents in the control group. It is remarkable that the BDI levels were higher in mothers in the study and control groups compared to fathers. Whether or not they had disabled children, high levels of stress and depression symptoms in mothers indicate that mothers play a key role in childcare. Moreover, it can be assumed that mothers are influenced emotionally by the condition of their children more because they spend more time with their children, and fathers are at home only in the evening due to working during the day. At the end of this research, a conclusion was achieved that the spouse's workload percentage, depression, parenting stress, headache and fatigue levels influenced the quality of life of parents having chronically disabled children. When the care times of children and the percentages of workload undertaken were reviewed, mothers in the study group were found to undertake more workload in childcare compared to the fathers and the mothers in the control group.

## Conclusions

In conclusion, we see that parents are affected by their children's disabilities, whereas mothers are affected more. While the care of a disabled individual is planned, we believe that planning home care services that will ease the mother's workload and planning multifaceted approaches such as social, psychological, and family education for the family will be useful.

### *Limitations*

The inhomogeneity of individuals with chronic disabilities included in the study is the limitation of our study.

### *Ethics approval*

This for the research, the necessary permission was acquired from the Clinical Research Ethics Committee of abant Izzet Baysal University (Protocol NO. 2018/59).

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