



Factors affecting psychological symptoms and life quality of caregiver parents of cerebral palsy patients, a cross-sectional study

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Abstract

Aim: In this study, we examined the factors affecting the psychological symptoms and quality of life of the caregiver parents of the cerebral palsy patients.

Materials and Methods: This cross-sectional study was conducted between May-September 2013 in fifty CP patients and their caregivers. Demographic information, parents' education, family type, households, patients' siblings, drug usage, rehabilitation hospitalizations (NoRH), and gross motor function levels were recorded. The caregivers completed the psychometric symptom checklist (SCL-90-R) and the QoL questionnaire (SF-36). Factors affecting SCL-90-R and SF-36 were evaluated by correlation and regression analysis.

Results: The proportion of symptomatic parents in the psychiatric evaluation ranged from 26% to 58% in subheadings. Psychological symptoms were mostly correlated with low QoL. Quality of life was lower than the population average in all subheadings. GHI and paranoid thoughts were positively correlated with NoRH. Households' number was negatively correlated with NoRH ($p=0.045$, $p=0.032$, $p=0.025$). Interpersonal sensitivity and the siblings' number were positively correlated ($p=0.005$). Father's primary school graduation was a risk factor for increased anxiety ($OR=0.446$, $p=0.030$). The female CP was a risk for paranoid thoughts ($OR=0.410$, $p=0.025$). For SF-36, median scores were low in all components. The nuclear family was a risk factor for low physical components score ($OR=-8.123$, $p=0.009$). Not using any medications was a risk factor for a lower mental component score ($OR=7.953$, $p=0.008$).

Conclusion: The caregiver parents had low QoL and more psychological symptoms. Public healthcare policymakers should plan projects to improve the psychological health and QoL of caregivers.

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Introduction

Cerebral palsy (CP) is a group of permanent disorders in the development of posture and movement due to non-progressive disturbances in the developing fetal or infant brain, causing activity limitation [1]. Cognitive, perceptual, sensory disorders, communication, behavioral disorders, epilepsy, and secondary musculoskeletal system problems may accompany motor disorders [1]. CP patients

need different quality and intensive support than healthy individuals to be self-sufficient, fulfill their daily activities, and be involved in social life. The parents provide the most significant support in the development and treatment processes of the individual with CP. Caring for a child with cerebral palsy can bring financial and psychological difficulties to the family, and families may need support. Although governments or non-governmental organizations make profound contributions to support patients' health and quality of life, the parent's health is also affected and should be evaluated. Cerebral palsy families often must cope with socioeconomic difficulties as well as psychologi-

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cal problems. Parents may experience psychological issues such as anxiety, shock, denial, sadness, anger, avoidance of confrontation with the outside world's attitude, and decreased self-confidence and self-esteem [2-8]. This study was designed to evaluate the quality of life and psychological symptoms of caregiver parents of cerebral palsy patients and determine the factors affecting their psychological health and quality of life.

Materials and Methods

Participants

Written informed consent was obtained from each patient. Ethical approval for this study was obtained from the Ethics Committee of Ankara Physical Therapy and Rehabilitation Training and Research Hospital (Date: 10.04.2013, no: 2024). The study was conducted under the principles of the Declaration of Helsinki. The 50 caregivers of the CP patients were included from inpatient clinic between May and September 2013 using the convenience sampling method. The inclusion criteria for the caregiver were to be the primary caregiver of the child with CP and to be between the ages of 18-90. The exclusion criterion was being over 18 years of age for CP patients. The questionnaires were filled in face-to-face by the same doctor who was trained in the questionnaires. Cerebral palsy patients were evaluated by the same physiatrist trained in GMFCS and their medical information was recorded.

Cerebral palsy patients' assessment

The demographic characteristics (age, sex), medications, number of hospitalizations (NoH), number of rehabilitation hospitalizations (NoRH) were obtained. The functionality level of the patients was evaluated with Gross Motor Function Classification System (GMCSF), which has a Turkish validation and reliability [9]. GMFCS classifies the gross motor skills of individuals aged 0-18 as five levels. Level 5 represents fully dependent gross motor functionality without head and trunk control, while level 1 represents minimal motor retardation, varying according to age.

Caregivers and family structure assessment

The educational status of the parents, family type (nuclear, expended, or single parents), number of siblings, number of households were assessed. The Symptom Checklist-90-R (SCL-90-R) for psychometric evaluation and short form-36 (SF-36) questionnaires for quality-of-life assessment were completed.

SCL-90-R is a relatively brief questionnaire designed to evaluate an extended range of symptoms of psychopathology with Turkish validity and reliability [10,11]. The symptom dimensions are somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid thoughts, psychoticism, and a category of "additional items," which helps clinicians assess other aspects of the symptoms (e.g., lack of appetite). In addition, a general index score is obtained from the scale, and the level of discomfort felt can be determined with this score. Each item is a five-point Likert scale, 0 (never) – 4 (advanced). The higher the score, the more severe the psychopathology is considered. Cut-off

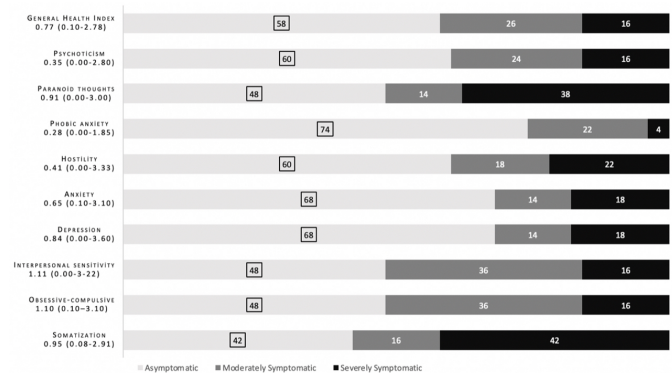


Figure 1. Percentage distribution and median (min-max) values of the scores of the parents in SCL-90-R dimensions.

values defined in the literature were used to evaluate the ratio of moderate and severe symptomatic patients [12]. The percentage of patients who scored above the determined cut-off value was calculated.

The Short Form-36 (SF-36) Health Questionnaire is a 36-item patient-reported questionnaire evaluating patient health status and quality of life in eight sections consisting of physical functioning, bodily pain, general health perception, vitality, physical role functioning, emotional role functioning, social role functioning, and mental health [13]. The scores are calculated separately for each category, and a score between 0-100 is obtained. The lower the score is associated with more disability. The scores of the SF-36 parameters were compared with the mean values in the study in which the norm values of the SF-36 parameters were calculated for the Turkish population [14]. Also, the SF-36 physical component summary and SF-36 mental component summary were calculated. To compare the reduction of the QoL parameters, the median scores of the patients in our study were divided into the normal values of SF36 parameters in the Turkish population [14].

Statistical analysis

The statistical analysis of the data was done with Windows SPSS 18.0 program. The conformity of the data to the normal distribution was analyzed with the Kolmogorov-Smirnov test. Frequency distributions of the data were given as mean, \pm standard deviation, and percentage. In the comparison of the two groups; chi-square test for categorical data, group comparisons; For data including continuous variables, the independent sample t-test was used for those with normal distribution, and Mann Whitney-U test for those with non-normal distribution. The correlations were assessed between continuous variables of patients' medical and family characteristics and psychiatric symptom dimensions and quality of life evaluations by the Spearman correlation test. Patients' medical and family characteristics are tested with linear regression analyses using 95% confidence intervals for calculating risks for psychiatric symptom dimensions and quality of life evaluations. The statistical significance was accepted as $p < 0.05$.

Results

All participants completed the study, and no data were missing. The mean age of CP patients included in this

Table 1. Sociodemographic and clinical features of participants.

Variables of the CP	Number (percentile)/ Mean (\pm SD)	Variables of the Family Structure	Number (percentile)/ Mean (\pm SD)
Age	7.4 (\pm 3.3)	Mother's age	33.9 (\pm 7.9)
Sex		Family type	
Male	24 (48%)	Nuclear	29 (58%)
Female	26 (52%)	Extended	16 (32%)
		Separated	5 (10%)
NoH	6.5 (\pm 5.3)	Mothers' occupation	
Non-rehabilitation	%24	Housewife	48 (96%)
Rehabilitation	%76	Retired	1 (2%)
		Worker	1 (2%)
NoRH		Fathers' occupation	
1	16 (32%)	Worker	49 (98%)
2	15 (30%)	Unemployed	1 (2%)
3	10 (20%)		
4	3 (6%)		
5-7	0 (0%)		
8-11	6 (12%)		
		Siblings number	1.4 (\pm 1.2)
		Household number	5.6 (\pm 3.3)
GMFCS		Mothers' education	
Level 1	1 (%2)	Illiterate	5 (10%)
Level 2	9 (18%)	Primary education	34 (68%)
Level 3	10 (20%)	High school	9 (18%)
Level 4	15 (30%)	University or higher	2 (4%)
Level 5	15 (30%)		
Medication		Fathers' education	
None	29 (58%)	illiterate	1 (2%)
Anti-epileptic	10 (20%)	Primary education	34 (68%)
Muscle relaxant	9 (18%)	High school	12 (24%)
		University or higher	3 (6%)

NoH: number of hospitalizations.

Table 2. Distribution characteristics of SF-36 parameters.

SF-36 parameters	Median (min-max)	Normative values*	Median/norm
GH	47.3 (17.2-62.6)	69.1	68%
BP	51.6(19.9-62.6)	81	64%
PF	49.9 (21.5-57.1)	82.9	60%
VT	46.7 (25.4-68)	63.4	74%
PRF	49.2 (28-56.2)	82.9	59%
ERF	44.8 (23.7-55.3)	89.0	50%
SRF	40.9 (13.7-57.1)	90.1	45%
MH	52.7 (20-100)	70.1	75%

GH: general health, BP: bodily pain, PF: physical functioning, VT: vitality, SRF: social role functioning, PRF: physical role functioning, ERF: emotional role functioning, MH: mental health, component summary, min: minimum, max: maximum. * Normative values were taken from the study of Demiral (2006) [14].

study was 7.4 (\pm 3.3) years, and 24 (48%) of these patients were male. While the 60% of the patients had GMFCS levels 4 and 5, the percentage of patients with level 1 limited to 2%. The mean number of hospitalizations was 6.5 \pm 5.3 times. Although 76% of hospitalizations were for rehabilitation purposes, there were also hospitalizations in the intensive care unit, eye, neurosurgery, and orthopedics and infection clinics. The caregivers of the patients were all mothers. Both parents of all patients were alive. All of the mothers were unemployed, and fathers were employed except one for each. The illiterate ratio of mothers and fathers were 10% and 2%, respectively. The mean number of siblings and households were 1.4 \pm 1.2 and 5.6 \pm 3.3, respectively (Table 1).

The evaluation of the SCL-90-R of the caregivers revealed the 42% of the parents was moderately or severely impaired in terms of general health index (Figure 1).

The median SF-36 scores of the caregivers divided by the normal values of SF-36 parameters in the Turkish population were calculated to evaluate the normalized ratio of the Turkish population, was between 45-75% (Table 2).

No correlation was found between the SF-36 parameters with patients' medical characteristics and family structure. The interpersonal sensitivity scores and the number of siblings ($p=0.005$, $r=0.387$) were found to be positively correlated. Paranoid thoughts score was positively correlated with the number of hospitalizations for rehabilitation ($p=0.032$, $r=0.304$). The general health index and the number of hospitalizations for rehabilitation were positively correlated ($p=0.045$, $r=0.280$). The parameters of the SCL-90-R and SF-36 were analyzed for the risk factors such as patients' gender, family type, maternal and paternal education status. Being a primary school graduate of the father was a risk factor for anxiety (OR=0.446, CI=0.046 - 0.845, $p=0.030$). The female gender CP was a risk of paranoid thoughts in the parent (OR=0.410, CI=0.053 - 0.767, $p=0.025$). The nuclear family type was a negative risk factor for the SF-36 PCS score of the parent (OR=-8.123, CI=-14.097 - -2.149, $p=0.009$). The medicine utilization of CP was a positive risk factor for the SF36-MCS score of the parent (OR=7.953, CI= 2.145 -13.762, $p=0.008$).

Discussion

This current study showed the caregiver parents of CP had increased psychopathological symptoms as well as they have a low quality of life compared to Turkish population. Also, the psychological symptoms and life quality were found to be affected by the factors such as the literacy of the parents, number of children, gender of the CP, number of households, the family structure, the number of hospitalizations, and the use of drugs. In addition, there were associations between QoL and psychiatric symptoms. In this current study, nearly the half of the parents had moderately or severely impaired psychological status according to SCL-90-R. The most affected dimensions were somatization, paranoid thought, obsessive-compulsive behavior, and interpersonal sensitivity, while the least affected dimensions were phobic anxiety, depression, and anxiety.

According to the reports of the World Health Organization, the global prevalence of depression and anxiety were 4.4% and 3.6% [15]. In this study, the ratio of patients with moderate to severe depressive and anxiety symptoms were 32% and 32%, respectively. Our findings is similar to literature, the depression and anxiety levels of mothers with CP, this ratio was found to be between 7% and 31% for depression, between 8% and 31% for anxiety, and it was shown to be more common than the general population [3-6,16]. In our study, the father's primary school graduation was found as a risk factor for high anxiety scores. Anxiety was found to be more common in adults who had less than high school education in the literature (12.9 vs. 5.0 to 4.3 percent) [17]. In our study, however, anxiety rates were found to be much higher. The level of education has an essential role in coping with psychological problems, and uneducated families should be supported more in this regard [18]. The frequency of phobic anxiety was 32% in our study, the prevalence of phobia in adult women is found to be approximately 12% in the literature [19]. Although the least affected dimensions were phobic anxiety, depression, and anxiety; the frequency of these sub-scales are still very

high.

Prevalence rates for somatoform disorders in the general population range from 10 to 20% while in our study, the rate of mothers with moderate and severe symptoms of somatization was 58% [20].

Although the frequency of paranoid ideation without psychosis is around 4%, it has been reported that Paranoid ideation can be found between 15% and 33% of the population [21]. The proportion of mothers who had moderate to severe paranoid thoughts score was %52 in our study. Obsessive-compulsive disorder (OCD) affects 1.2-3% of the population [22,23]. In our study, even the rate of patients describing severe OCD symptoms was 16%. We thought that these might be due to the hypersensitivity to cope with the difficulties in the care of the child, however, with increased severity of OCD symptoms were related to worsened mental health, social and emotional role functioning, and bodily pain. In our study, the IPS symptom scores were moderately and severely high in 52% of the mothers. IPS was found to be associated with having an increased number of children. IPS can be considered as a compensatory mechanism, especially if the mother has a child who has difficulties in expressing emotions, but having this personality trait extreme triggers behaviors such as social anxiety and avoidance in the mother and leads to social and behavioral inhibition of the mother [24]. In our study, it was shown that increased IPS scores were associated with decreased social and emotional role functions and mental component scores. Therefore, mothers with multiple children should be evaluated regarding excessive IPS and supported when necessary.

In our study, 40% of mothers had moderate to severely high hostility scores. While there is no study on hostility rates in Turkey, it is known that the overall prevalence of inappropriate, intense, or poorly controlled anger in the USA is 7.8% [25]. Hostility was related to all parameters of SF-36 except for physical role functioning.

While the rate of psychotic disorder in the community varied between 1.5% and 3.5%, 40% of our patients had psychotic symptoms [26].

This current study showed that the mother's general health index and paranoid thoughts worsened with the increase of the number of rehabilitation hospitalizations. The length of stay in rehabilitation clinics was long and being a patient accompanist can be uncomfortable for the caregivers. This finding showed us the importance of avoiding unnecessary hospitalizations and ensuring that patients receive rehabilitation at home or outpatient clinics.

In addition to these factors, having a CP child of the female gender is found to be a risk factor for paranoid thoughts. We considered that this risk might be due to the sexist roles in society. Gender equality in our community should be researched, studies should be planned, and a roadmap should be drawn to reduce parents' stress who have a female gender child.

No relationship was found between parents' psychological status with patients' gross motor functional level in our study, whereas Al-Gamal et al. found that parents of patients with severe disability were more likely to experience a higher level of perceived stress and depression [27]. In

a study conducted in Australia, the effect of GMFCS levels of patients with CP on the psychological well-being of mothers was investigated, and similar to the results of our study, no correlation was found between psychological well-being and severity of disability [28]. The effect of the disability level on the psychological well-being of the parents is still contradictory in the literature.

The mothers' quality of life was low in all subheadings. The decrease in quality of life was between 45-75% in all sub-headings compared to the population, and the biggest differences were in social role function and emotional role functions. We think that the weakness in the social role functioning is related to the working rates of mothers. In our study, the employment rate of mothers was very low as 2%, while the rate of female employment is 28.7%, and the rate of working mothers with babies under the age of 3 is 26.7% in Turkey [29]. All the primary responsible people for the care of CP patients were the mothers and this is related to the distribution of duties for the mother and father by society.

We anticipate that mothers' not having a business life reduces their participation in social life and decreases their social role functions. In our opinion, parents should be encouraged for an equal distribution of duties, and arrangements should be made to support mothers' participation in social life.

In our study, living as a nuclear family was a risk factor for low physical components summary scores. If we compare the distribution of family structure in our study with the distribution of family statistics in Turkey; The rate of single-parent families in Turkey is 9.7% and this rate is almost the same as in our study. The rates of extended family and nuclear family in Turkey and in our study are 14%, 32%, and 65.2%, 58%; respectively [29,30]. We think this is because families with cerebral palsy need more to live as extended families. As it is pointed in the literature, low social support and low self-efficacy of a caregiver, as well as low-income levels, were shown as a risk factor for a high level of stress and depression; our patients may be evaluating the advantages of living as an extended family in terms of household income and social support [4,16]. CP families living as a nuclear family may need financial and social support more than extended families, and families should be evaluated in this regard.

Interestingly, the mental health score of the parents was better if the children were receiving drug treatment. This situation can be evaluated as reducing the emotional stress of the family with the positive effect of regressing the sick child's symptoms with medication.

No relationship was conducted between patients' gross motor functional levels and caregivers' quality of life in our study. But the literature on this subject was contradictory. Eker et al. found that the role physical, emotional, vitality, and mental health subscale scores of the SF-36 were negatively correlated with GMFCS [31]. Prudente et al. investigated the effect of changes in gross motor functionality after ten months of rehabilitation on the quality of life of mothers. They found improvement in the bodily pain of mothers [2]. In our study and Eker's study, patients' functional levels were heterogeneous. A more homogeneous group and more studies are needed to fully demonstrate

the impact of the functionality on caregivers' quality of life.

In our study, the parents' education levels are below the population average. For example, the rate of illiterate people over the age of 25 in Turkey was 6.9%, 1.2% for females and males; this rate was 10%, 2% for the mothers and the fathers in our study [32]. The national rate of university graduates was 18.5% and 23.1% for women and men, while in our study, it was only 4% and 6% for mothers and fathers, respectively [32]. When the relationship between education status and having a child with cerebral palsy is evaluated, it was shown that parents with low educational levels had an increased risk of having a child with CP [32]. Among the reasons for this increased risk, it is thought that educated parents are more competent in learning and complying with health advice during and before pregnancy, having a higher socioeconomic level and accessing better quality health care, and knowing the risks of consanguineous marriages.

According to our findings, the number of hospitalizations for rehabilitation decreased as the number of households increased. Still, the number of siblings did not affect the number of hospitalizations for rehabilitation. This effect was thought to be due to extra adults who could help care for the child at home. In our hospital, admission decisions are given in these situations if the patient's family has willing to inpatient rehabilitation; i. the patient's functional status is below their motor capacity, ii. the family cannot provide the essential care for the child at home, iii. the family needs an education that should be under supervision, iv. there is no rehabilitation center near the place they live or transferring the patient outside the home is challenging to do every day (for example, living in an apartment with no elevator, there is no person strong enough to transport the patient to the floors). Considering the reasons for hospitalization decisions, we think that providing support to families for childcare or housework can improve the quality of childcare and thus reduce the need for hospitalization and improve mothers' quality of life. When such support is given by identifying the real needy, it is vital to research the advantages and disadvantages of the health system. Data such as household income and the number of healthy adults living in the house can determine the actual, needy people. More studies are needed to decide which families need the support most.

Conclusion

The psychological state of caregivers of CP patients is affected by parameters such as the number of children and the number of households, and these individuals have a low quality of life and psychiatric general health perceptions. The parents should be questioned whether they can find additional support when needed to care for the child. They should be supported as required, and mothers' participation in social life should be supported. Because inpatient rehabilitation negatively affects the health of the mothers, outpatient rehabilitation or home-based rehabilitation should be encouraged. Parents' psychiatric symptoms and quality of life were related to each other. Parents have symptoms such as somatization, paranoid thought, obsessive-compulsive behavior, and hostility

more frequently than anxiety and depression, and they are related to low quality of life. It is thought that parents need psychological support as well as social support.

Limitations

Since the caregivers were mothers in our study, no fathers could be evaluated. It is unknown how much the fathers are affected by their children's illness and the responsibilities of the care process. If fathers were also assessed, needs and goals could be more clearly predicted.

Ethics approval

Ethical approval for this study was obtained from the Ethics Committee of Ankara Physical Therapy and Rehabilitation Training and Research Hospital (Date: 10.04.2013, no: 2024).

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