



Comparison of depression, anxiety, and health related quality of life levels of parents of children with neuromuscular diseases

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Research Article

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Purpose: In this study, the differences in psychological status of the parents of children with moderate disability, associated with neuromuscular diseases (ND), were determined. **Methods:** The parents of 35 children, who had ND, were included in the study. The mother was the primary caregiver in all cases. The Wee-Functional Independence Measurement (Wee-FIM) was used to evaluate the dependence of children. Parents' anxiety, depression and Health Related Quality of Life (HRQOL) levels were assessed using the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory (STAI) and the Nottingham Health Profile (NHP). **Results:** Mothers' trait anxiety levels were higher than fathers. State anxiety levels were similar between two groups ($p>0.05$). Mothers' had worse HRQOL, and they were more depressive ($p<0.05$). Mothers' HRQOL was correlated with the time spent with the child, BDI and trait anxiety scores of mothers, age and education status of mothers and the FIM score of the children ($p<0.05$). Fathers' HRQOL was correlated with time spent with the child, BDI and state anxiety scores of fathers ($p<0.05$). Fathers of sons had worse HRQOL, than fathers of daughters ($p<0.05$). **Conclusion:** Mothers and fathers of children with ND presented several differences with respect to the impact of their caregiving role on psychological status. The vulnerable fathers as well as mothers should be identified, and psychological support should be provided in time. Fathers' active participation in the care may favorably affect the mothers' HRQOL.

Keywords: Disabled children, Parents, Neuromuscular disease, Quality of life.

Nöromusküler hastalığı olan çocukların ebeveynlerinin depresyon, anksiyete ve sağlıkla ilgili yaşam kalite düzeylerinin karşılaştırılması

Amaç: Bu çalışma nöromusküler hastalığa (NH) bağlı orta düzeyde yetiyitimi olan çocukların, ebeveynlerinin psikolojik durumlarını karşılaştırmak amacıyla yapıldı. **Yöntem:** Bu çalışmaya, NH'ı olan 35 çocuğun ebeveyni alındı. Anne tüm olgularda birincil bakımverendi. Çocukların bağımlılık düzeylerini değerlendirmek amacıyla Wee-Fonksiyonel Bağımsızlık Ölçeği (Wee-FIM) kullanıldı. Ebeveynlerin depresyon, anksiyete ve sağlıkla ilgili yaşam kalitesi (SİYK) düzeyleri, Beck Depresyon Ölçeği (BDÖ), Durumluk/Sürekli Kaygı Envanteri (DSKE) ve Nottingham Sağlık Profili (NSP) kullanılarak değerlendirildi. **Sonuçlar:** Annelerin sürekli kaygı düzeyleri babalardan yüksekti. İki grubun durumluk kaygı düzeyleri ise benzer bulundu ($p>0.05$). SİYK annelerde daha kötüydü ve annelerin depresyon düzeyleri babalardan daha yüksekti ($p<0.05$). Annelerin SİYK'si, Wee-FIM puanı, çocuk ile harcanan zaman, anne yaşı ve eğitim durumu, BDÖ ve sürekli kaygı puanı ile ilişki gösterdi ($p<0.05$). Babaların SİYK'si ile çocukla beraber olunan süre, BDÖ ve durumluk kaygı puanı arasında ilişki saptandı ($p<0.05$). Oğulları olan babalarda SİYK, kızları olan babalara göre daha kötüydü ($p<0.05$). **Tartışma:** Anne ve babalar, NH olan çocuklarına bakım vermenin psikolojik durumlarına etkisi açısından çeşitli farklılıklar göstermektedir. Çeşitli duyarlılıkları olan anneler ve özellikle de babalar belirlenmeli ve gecikmeden gerekli psikolojik destek almaları sağlanmalıdır. Babaların çocukların bakımına aktif olarak katılması, annenin SİYK'sini olumlu etkileyebilir.

Anahtar kelimeler: Yeti yitimi olan çocuklar, Ebeveyn, Nöromusküler hastalık, Yaşam kalitesi.

Main goals of rehabilitation in progressive neuromuscular diseases (ND) are to reduce the complications of the disease, maintain the functional independence level and improve quality of life.¹ Rehabilitation requires a multidisciplinary approach, including various health professionals.² Various needs regarding medical, physical, and emotional care of the children with ND place the parents in the multidisciplinary team, whether they are equipped for this role or not.³ Given the fact that the necessary support, training and information regarding care needs are not adequate in many instances, dealing with extensive coordination of care may cause exhaustion and overwhelming feelings due to the management of whole process. The parents may experience profound physical, psychological, social, and financial strain. Their adaptive skills, anxious or depressive personality traits and psychopathological distress in various dimensions may influence their coping with and attitude towards this inevitable major life change.⁴ Therefore, careful assessment of psychological status is one of the most important factors, contributing to treatment and rehabilitation in neuromuscular diseases.

Former studies regarding children with ND mainly focused on the disease-specific problems such as intensity of the disease, being congenital or acquired genetic factors, bladder and bowel problems, sensational and cognitive deficits. In subsequent studies, the meaning of the child's functional status for the family was explored. This approach brought the activities of daily living capacity of the child and his/her dependency upon parents during care, to the fore.⁵ In ND, care needs increase, as the disability of the child increases. Therefore, roles of the family in childhood care change inevitably through the successive stages of the disease.⁶ It was reported that the anxiety, nervousness, tiredness, and hopelessness of parents were associated with the increasing physical dependency and the progression of the Duchenne muscular dystrophy (DMD) with children over 13 years old.⁷

Examining the health related quality of life (HRQOL) can provide information about the

broad impact of the disease on parents' physical, psychological and social well-being or functioning. Psychological status and HRQOL of parents, beginning from the early stages of the ND, when child needs only moderate assistance, deserves evaluation. A greater understanding of strategies that can be implemented to maximize positive outcome, would be possible promptly.^{6,7} Therefore, Cohen suggested that "managing the illness in the context of total family life was associated with the best medical outcome."⁸

Although studies about family perspectives of chronic pediatric conditions are getting more prevalent, adequate information is lacking about the the gender differences within the process of illness adaptation. As a matter of fact, role of fathers is neglected in psychosocial studies involving families with a chronically ill child.^{9,10}

This may be associated with the predominance of mothers in the role of primary caregiver and the presence of mothers within the clinical settings. Fathers, who are considered to have an important role as a support person both for their spouse and children in the family systems perspective, usually do not appear as often as mothers in clinical settings. They usually play a less active role in the care of their disabled children, and a great effort is required to integrate them into clinical studies.⁸ Mothers universally have more parental responsibilities than fathers and centre their lives on the child's illness.

Few studies have explored gender-differences in the experience of parenting of a child suffering from hearing impairment, intellectual disability, diabetes, cancer, or a variety of chronic diseases. There is a lack of study for progressive ND.¹¹ Moreover, very few studies have compared parents within the same family. Although there is contradictory and inconclusive findings, studies have shown that significant differences exist between mothers and fathers in several domains, including adaptation, perception of severity of illness, social support needs, self-esteem, coping behaviours, and involvement in the care of the child.¹²

This exploratory study aims to assess the differences in anxiety, depression and HRQOL

between mothers and fathers of children with moderate disability associated with ND. We also aimed to identify the correlates of HRQOL in both groups.

METHODS

Parents of the children diagnosed with ND at least two years ago and with a need of mild to moderate assistance while performing activities of daily living, were included in this study. Children, who were medically unstable, or with cognitive impairment, were excluded. Among the parents of children who fulfilled the inclusion criteria (n=59 parents), twenty four fathers refused to participate in the study. Therefore, parents of 35 children (15 females, 20 males), who gave informed consent, were included in the study. No significant differences were found between participating and non-participating parents regarding illness factors or sociodemographic variables.

Questionnaires, which took approximately 30 minutes to complete, were applied to the participants by the same researcher, in a private room in the clinic, by using a face-to-face interview technique. This study was performed according to the Helsinki Declaration (2008) principles.

Measures

Information regarding the age and gender of the child, duration of the disease, social insurance, number of siblings, attendance to school, person who took over the care of the child were obtained. Marital status (married/divorced/living separate), age (years), education (years), and working (working/not working) status of the mother and father, time spent with the child, and psychiatric disease history (present/absent) of the parents were recorded. Additionally, parents were asked if they received help for caring for the child, or not. The person who helped to the parents for care activities was also recorded.

Wee-Functional Independence Measure (Wee-FIM), which consists of 18 items on self-care, sphincter control, mobility, locomotion, communication, and social integration parameters, was used to evaluate independence level of

children in activities of daily living. Each item of Wee-FIM has a scoring of 1-7 points, so total score range of the Wee-FIM is 18-126 points (18-36 points: completely dependent, 37-90 points: needed to supervision and assistance while performing activities, 90-126 points completely independent).¹³

Beck Depression Inventory (BDI), which is a self-rating instrument developed by Beck and his colleagues, in order to identify potential cases of depressive illness and to measure the severity of twenty one depressive symptoms on a 4-point scale ranging from 0-3 points, was used in this study. The total maximum score of this inventory is 63 points, and the optimum cut-off point was found to be 16/17 points, in the reliability and validity study of Turkish version, in accordance with the original study.¹⁴

State-Trait Anxiety Inventory (STAI), which has been shown to be valid in Turkish language, was used for assessment of the anxiety levels of the parents in this study. State anxiety refers to the subjective and transitory feeling of tension, nervousness, and worries at a given moment, and consists of 20 statements that evaluate how the respondent feels "right now, at this moment". Trait anxiety consists of 20 statements that evaluate how the respondent feels "generally", and refers to relatively stable individual differences in anxiety proneness as a personality trait in the tendency to perceive and respond to stressful situations with elevations in the intensity of state anxiety reactions. Each STAI item is given a weighted score of 1 to 4. A rating of four indicates the presence of high levels of anxiety for ten state anxiety items (Number 3, 4, 6, 7, 9, 12, 13, 14, 17 and 18) and eleven trait anxiety items (Number 22, 24, 25, 28, 29, 31, 32, 35, 37, 38, 40). A high rating indicates the absence of anxiety for the remaining 10 state anxiety items and nine trait anxiety items. Scores for both the state anxiety and trait anxiety scales can vary from a minimum of 20 to a maximum of 80. Usually a cut-off score >40 points is used in prior studies.¹⁵

The HRQOL of the parents were assessed by Turkish version of the Nottingham Health Profile (NHP), which is a self administered questionnaire,

assessing the subjective perception of physical, emotional, and social aspects of health. Energy, pain, physical mobility, emotional reactions, sleep, and social isolation are the evaluated health dimensions in NHP. The subjects were asked to answer the questions in the profile as yes or no. Higher scores on the NHP indicate worse quality of life.¹⁶

Statistical analysis:

SPSS version 15.0 was used for the statistical analyses. Descriptive characteristics of the children and parents were presented as mean \pm standart deviations, frequency and percentages. Most of the variables were not normally distributed except STAI state anxiety scores. We used either a Wilcoxon's signed rank test for dependent samples or paired sample t test, as appropriate, to compare the fathers over mothers. Correlations were calculated using Spearman correlation coefficients. Level of significance was set at $p < 0.05$. Mann Whitney U test was used for the comparison of NHP scores between the parents who had male or female children.

RESULTS

Mean age of the children in this study was 8.37 ± 3.80 years. Among 35 children, 22 (62.86%) had DMD, 8 (22.86%) had spinal muscular atrophy, and 5 (14.29%) had other ND. The mean duration of the ND was 6.07 ± 3.25 years. According to the mean Wee-FIM scores (74.74 ± 33.22 points), children needed only observation and moderate help during mobility, locomotion, and activities of daily living. Demographic data (gender, social insurance, number of siblings, and attendance to school) of the children are presented in Table 1.

Primary caregiver in each case was the mother. Twelve (34.28%) mothers reported that they were receiving help for caring their children. This help was obtained from fathers in seven cases (20%), grandmothers in three cases (8.57%), and a professional caregiver in two (5.71%) cases. The mean age of parents did not differ significantly (mothers: 34.88 ± 7.08 years and fathers: 39.23 ± 7.88 years) ($p > 0.05$). Education level and

working status of the parents are presented in Table 2. Education status of the mothers was lower than that of fathers (9.79 ± 3.55 and 11.6 ± 3.33 years, respectively) ($p < 0.05$). All parents were married but only 16 (45.71%) were living together, and the remaining 19 parents (54.29%) were living separately. There was no self-report history of ever having been diagnosed with a psychiatric disorder. Mothers were spending more time with their children than the fathers (16.85 ± 8.63 hours and 4.52 ± 3.15 hours in a day, respectively) ($p < 0.05$).

Comparison of anxiety, depression and health related quality of life

Mothers' trait anxiety levels were higher than those of fathers; however, state anxiety levels did not differ significantly between mothers and fathers (Table 3). Sixty percent of mothers scored above the cut-off point in state anxiety and 90% of them were above in trait anxiety scores. Forty-three percent of fathers scored above the cut-off point in state anxiety and 76 percent of them were above the trait anxiety cut-off point. Mothers' NHP scores were higher (worse HRQOL) than fathers, and they were more depressive (Table 3). Thirty percent of mothers scored above the cut-off point in BDI, 10% of fathers scored above the cut-off point. Normative data was not available for NHP scores for Turkish version.

Correlates of health related quality of life

Correlation analyses were performed in order to investigate the factors related with HRQOL of the mothers and fathers. The mean total NHP score of the mothers was positively correlated with the time spent with the child ($\rho = 0.60$, $p < 0.001$), their BDI score ($\rho = 0.71$, $p = 0.01$), their trait anxiety scores ($\rho = 0.38$, $p = 0.04$) and negatively correlated with the FIM score of the children ($\rho = -0.50$, $p = 0.005$), their age ($\rho = -0.34$, $p = 0.048$) and education status ($\rho = -0.341$, $p = 0.047$). The mean NHP total score of fathers was correlated with time spent with the child ($\rho = 0.40$, $p = 0.001$), and their BDI scores ($\rho = 0.82$, $p < 0.001$) and their state anxiety scores ($\rho = 0.47$, $p = 0.04$). Education status, age and income were not correlated with NHP scores of fathers. Fathers' HRQOL was not related with

NHP scores or anxiety and depression levels of their spouses. Fathers who had a son had higher NHP scores, (worse HRQOL) than fathers who had a daughter (64 ± 58 versus 29 ± 52 , respectively, $p < 0.05$). Mothers NHP did not differ with respect to gender of their children ($p > 0.05$).

Table 1. Demographic characteristics of the children.

	n (%)
Gender	
Female	15 (42.9)
Male	20 (57.1)
Number of siblings	1.37 \pm 0.94
Social insurance	
Present	31 (88.6)
Absent	4 (11.4)
Attendance to school	
Yes	16 (45.7)
No	19 (54.3)

Table 2. Education levels and working status of parents.

	Mothers n (%)	Fathers n (%)
Education level		
Primary school	19 (54.3)	11 (31.4)
High school	7 (20.0)	10 (28.6)
University	9 (25.7)	14 (40.0)
Working status		
Working	8 (22.9)	34 (97.1)
Not working	27 (77.1)	1 (2.9)

DISCUSSION

Multidisciplinary team approach is essential in management of children with ND. Although this team may vary depending on the age of the child, the level of development, the severity of the

condition, and the availability of the services, parents are always the inevitable members, having an active participation in every phase.¹⁻³ To the best of our knowledge no studies have investigated the parents of the children in early stage of ND, with respect to the impact of caregiving role, on their psychological status and HRQOL. The major differences between fathers and mothers of these children have not ever been explored.

Our study highlights that parents had substantial anxiety although their children were moderately dependent. Trait anxiety level was found to be higher in mothers in this study, although state anxiety level did not differ between two groups. Actually the anxiety levels of both mothers and fathers were above the frequently used threshold (STAI score > 40 points).¹⁵ We found that mothers were more depressed and had worse HRQOL as compared to fathers.

It has to be noted that caregiving tasks were not equally shared between partners. They were primarily on the basis of caregiving role. Primary caregiver in each case was the mother in this study. Accordingly, mothers were spending almost all of their times in caring for their children (mean=16.85 hours per day); however, fathers were spending significantly less time with their children. As in many other countries, fathers are generally the ones who earn a living for the family in Turkish culture. Thus, mothers usually meet almost all of the demands of care giving and spend much more time with the child.¹⁷ In accordance with the literature, the findings of this study pointed out that having a child with a disabling progressive disease has not modified this traditional role-sharing.¹¹ Previous studies also suggest that mothers feel more responsible for the care and upbringing of the child with a disability,¹⁸ and fathers take on fewer parental responsibilities.¹⁹

Additionally overmentioned studies show that mothers are at higher risk for problems adjusting to the demands of their parental role and endure greater stress from physical care of the child and the emotional effects of the child's disabilities.^{8,12,20} In accordance with the literature, the mothers in this study who were spending almost all of their

Table 3. State-Trait Anxiety Inventory, Beck Depression Inventory and Nottingham Health Profile (NHP) scores of the parents.

	Mothers Mean±SD	Fathers Mean±SD	p
State-Trait Anxiety Inventory			
State anxiety	43.65±5.8	41.05±6.68	0.12
Trait anxiety	48.34±6.69	43.64±4.53	<0.001
Beck Depression Inventory	16.42±23.65	11.02±24.61	0.02*
Nottingham Health Profile			
Energy level	42.31±39.01	11.12±24.34	<0.001
Pain	17.06±24.37	3.78±7.1	<0.001
Emotional reaction	38.91±38.47	17.8±21.1	0.01*
Social isolation	28.23±35	6.29±15	<0.001
Sleep	23.22±26.5	7.34±12.19	0.01*
Physical activity	10.66±15.14	3.24±6.49	<0.001
Total	157.14±145.68	49.6±57.44	<0.001

*p<0.05.

times with their children, might be more prone to psychosocial problems than fathers, beginning from the early stages of the ND. Mothers' HRQOL was found to be worse than fathers', in all parameters (energy level, pain, social isolation, emotional reactions, physical activity, and sleep dimensions). As mothers were the primary caregiver of the child, with only 34% of them receiving help for this task, they might experience persistent parenting stress with the ill child. On the contrary, almost all fathers were working, and consequently they might experience a greater distance to medical field and exposed possibly less disease-specific parenting stress compared to mothers.

Mothers might have high involvement with regards to caring for the child. Mothers probably organized their life around the child and were dissatisfied with the distribution of tasks. Spending almost all of the day for caring; a full-time occupation often requires a lifestyle change for the mothers, which means that they have no time or energy to meet their other needs for well-being. They might feel limited by the boundaries,

imposed by the illness, lacking any personal space in which to develop as a person. In brief, this traditional unequal distribution of responsibilities might result in a sense of injustice and might increase mothers' stress as suggested in previous studies.²¹

Besides it should be noted that 54.29% of the couples included in this study were living apart from each other although they were married legally. Hornby states that fathers of a child with a disability experience more couple-related distress and leave the family more often than other spouses.²⁷ The presence of the child with a health problem may destabilize the marital dynamic. The demands of the child's condition may jeopardize the couple's relationship. However, given that mothers needed support for the demands of caregiving for their children with ND, being a single mother would increase their psychological distress obviously. Impairment of the family integrity, in addition to the increasing parental responsibilities of mothers might have contributed to the worse HRQOL in mothers beginning from the early stage of the disease. Actually, studies

showed that marital conflicts about homemaking tasks and emotional support have the most negative influence on the perception of mothers.^{22,23}

We found that HRQOL of mothers was getting worse, with increasing dependency level and time spent with the child. Depression and trait anxiety levels were also related with HRQOL of mothers. These anticipated findings were repeatedly reported in the previous caregiver research though some contradictory findings exist with respect to the association of dependency level to HRQOL.^{3,24}

In our study, it was found that, age and education status of mothers were weakly correlated with HRQOL of mothers. The HRQOL of mothers increased, as their age and level of education increased. Previous studies suggested that coping mechanisms may mediate the impact of caregiver age on quality of life.²³ Studies indicated that as the level of education rises, anxiety levels decrease and HRQOL increase in both males and females.^{2,3}

A research group examined the effect of education on anxiety level of parents who have children with intellectual disability, and found that after a structured education with respect to the health problem of the child, anxiety level of mothers significantly decreased.²⁵

With increasing time spent with the child, HRQOL is getting worse in fathers as well; however, the relation was weaker as compared to mothers. Moderate relation between dependency level and HRQOL, found in mothers, did not exist fathers. This was an expected finding since they were not primary caregivers, and they were spending less time with the child. In other words, they were less exposed to the disability of their children and relevant demands. Actually, more than half of fathers were apart from their spouse and children. Many studies show that marital satisfaction is important for fathers as well as mothers.²⁶ Heaman states that fathers present more stress relating to time needed to be spent with their wife without the child being present.²⁶ Nevertheless in our study, fathers' HRQOL was not found to be related with psychological status

and HRQOL of their spouses, a finding consistent with most of the fathers being apart from the family. Their being apart from the family might have implications about their comparable state anxiety to their wives, as well. Fathers HRQOL was related with their depression level strongly and state anxiety level moderately, which was a frequently reported finding in care giver literature.^{24,26} It has been reported that child's chronic illness has an impact on the sense of competence and self-esteem of fathers. They appear to derive low satisfaction from their ill child and feel inadequate in caring for him or her. Consequently, they become less involved and detached from the child. They were found to be more concerned about social acceptance of the child.²⁴

Fathers' HRQOL was not found to be related with their educational level, age or income. Hornby suggests that social class, educational level and income are inversely related to the stress felt by fathers.²⁷ In previous studies, it has been reported that fathers present more stress in connection with their financial ability to meet the child's needs as compared with mothers.^{8,26} The fathers in this study seemed to keep their distance from the problems, which was reported to have an impact on quality of life in the literature. However, we found that fathers of sons had worse HRQOL than those of the fathers of daughters. Mothers HRQOL did not differ with respect to gender of their children. This finding worth to discuss as there are similar findings in the relevant literature. Compared with the mothers, the fathers' experience and stress levels are more affected by the gender of their children.²⁸ This finding may be related to the fathers' high expectations of their sons. The father may have more trouble adjusting to a son's health problem, than a daughter's and adapting his expectations of the son, accordingly. Traditional role of fathers, particularly with boys, chiefly involves playing with the child,²⁶ and opportunities for play may be restricted when the child is severely disabled.²²

In this study, trait anxiety and depression levels were found to be higher in mothers. Although some studies indicate no significant difference in

terms of overall anxiety, depression or self-esteem between fathers and mothers,²⁹ other studies show that the experiences of fathers and mothers differ.^{19,30} Latter studies indicate that the mothers of a child with a health problem are more likely to feel depressed and experience greater emotional distress than fathers. Above all, these are expected findings based on the literature on gender differences, leading to the hypothesis that mothers would report more anxiety, distress, and complaints than fathers. However, both depression and anxiety levels were evaluated by self-report scales in our study. These differences often result from the fact that fathers and mothers of a child with a health problem experience this situation in different ways.¹⁹ Mothers tend to deal with their stress by expressing their emotions. Women are generally recognized as ascribing more importance to their feelings and emotions. However, this type of strategy is rarely employed by fathers.^{22,31}

Being apart from their spouses may affect psychological status. Compas and Williams stated that mothers living alone, had higher levels of daily stress, and depression due to personal and familial health problems.³² Kronenberger and Thompson indicated that mothers having children with physical disability needed more support than the others, and marital quality had an important impact on their psychological health.³³

The results of many studies reflect major stoicism in fathers of children with a health problem. Social standards often make it difficult for fathers to cry in the presence of others. In addition, fathers mostly use the avoidance strategy which involves evading, escaping from or denying the problem. This strategy, is suggested to be reinforced by traditional gender roles, where men need to hide their vulnerability.^{20,22,31} On the other hand these fathers reported similar state anxiety to their spouses. We may tentatively speculate that it is because these fathers were requested to fill out the state anxiety questionnaires (given that state anxiety refers to the subjective and transitory feelings of tension, nervousness, and worries at a given moment) in the rehabilitation setting of their children, where they did not have the chance of

escaping from or denying the health problem and would feel inevitably anxious.

The main limitation of the present study is the low number of subjects involved. The reason for the limited number of parents, who accepted to participate in the study, stems from the inclusion criteria that necessitate evaluating both mothers and fathers of each child. Many fathers' refused to participate in the study. Although it was not possible to incorporate into the data of the study, refusal of many fathers was an important observation for this study, which we may tentatively interpret that these fathers were considering this situation as humiliating or denying the health problem of their children. Another limitation was the lack of a control group consisting of the parents of children without a disability. We confined the study to the comparison of mothers' and fathers' psychosocial characteristics.

Psychological well-being of parents of children with ND is important for the success of rehabilitation and treatment of the child. Thus, parents of children with ND should be screened periodically to determine the level of stress they are experiencing and what factors might be contributing to this stress, beginning from the early stages of the ND. Parents with poor psychological status should be referred for further evaluation and counseling. Professionals should take into account the needs and resources of the families, when developing a child's treatment plan. The child's program should not place excessive demands on parents since this could increase their stress levels. Parents should be supplied with information concerning the disease, progress and treatment plan. Education might decrease the parents' distress level. However, if such information is not requested, it should be given when the professionals feel parents can handle it. Particularly fathers may deny health problem of their children, and avoid any contact with health care team. Implementing psychological evaluation and support may enable fathers, to get through this situation. Psychological intervention by professional means may contribute to the active participation of the fathers in the caregiving

process. Besides modification of the distribution of parental responsibilities, which was previously based on the traditional roles, should be considered, by using the necessary social interventions, because involvement of both parents in the care of the child is crucial for the child's successful treatment. Moreover, family cohesiveness, cooperation, and participation of family members in the care of the ill child, appear to enhance father's marital satisfaction and involvement in the care of the ill child. When fathers take fewer responsibilities, mothers lack of other psychosocial support, may feel overloaded, dissatisfied with the distribution of tasks, resulting in increased anxiety and depression, and decreased quality of life. Consequent frustration may interfere with caregiving responsibilities. Today, fathers are expected to play a greater role in parenting, especially in our increasingly mobile society where extended families are not always available for support. Consequently, parenting and care research also must focus on fathers' roles and responses to various experiences. Inclusion of fathers in health care research, can be a challenge, but needs to be performed. The care of a child with ND is a team effort beginning from the early stages of the disease. Family-centred interventions which include both mothers and fathers in the team, would contribute to the successful management of children with ND.

REFERENCES

1. Mc Donald CM. Physical activity, health impairments, and disability in neuromuscular diseases. *Am J Phys Med Rehabil.* 2002;81:108-120.
2. Jung-won L, Zebrack B. Caring for family members with chronic illness. A critical review of caregiver literature. *Health Qual Life Out.* 2004;17:50.
3. Glozman JM. Quality of life of caregivers. *J Neurophysiol.* 2004;14:183-196.
4. Chen JY, Clark MJ. Family function in families of children with duchenne muscular dystrophy. *Fam Community Health.* 2007;30:296-304.
5. Yılmaz Ö, Akı E, Düger T, et al. Susceptibility of mothers of children with muscular dystrophy to chronic back pain. *J Back Musculoskelet.* 2004;17:51-55.
6. Thompson RJ, Zeman LJ, Fanurik D, et al. The role of parent stress and coping and family functioning in parent and child adjustment to Duchenne muscular dystrophy. *J Clin Psychol.* 1992;48:11-19.
7. Svavarsdottir EK, Orlygsdottir B. Comparison of health-related quality of life among 10- to 12-year-old children with chronic illnesses and healthy children: the parents' perspective. *J Sch Nurs.* 2006;22:178-185.
8. Antle BJ, Mills W, Steele C, et al. An exploratory study of parents' approaches to health promotion in families of adolescents with physical disabilities. *Child Care Health Dev.* 2008;34:185-193.
9. Rentinck ICM, Ketelaar M, Jongmans MJ et al. Parents of children with cerebral palsy: a review of factors related to the process of adaptation. *Child Care Health Dev.* 2006;33:161-169.
10. Pharez V, Lopez E, Fields S, et al. Are fathers involved in pediatric psychology research and treatment? *J Pediatr Psychol.* 2005;30:631-643.
11. Pelchat D, Lefebvre H, Levert M J. Gender differences and similarities in the experience of parenting a child with a health problem: Current state of knowledge. *J Child Health Care.* 2007;11:112-131.
12. Katz S. Gender differences in adapting to a child's chronic illness: A causal model. *J Ped Nurs.* 2002;17:257-269.
13. Ottenbacher KJ, Msall ME, Lyon N, et al. The WeeFIM instrument: it's utility in detecting change in children with developmental disabilities. *Arch Phys Med Rehabil.* 2000;81:1317-1326.
14. Beck AT, Ward CH, Mendelson WM, et al. An inventory for measuring depression. *Arch Gen Psychiatry.* 1961;4:561-571.
15. Oner N. The validity study of adapted Turkish version of an anxiety inventory: an abstract of a research. *J Psychol.* 1978;1:12-17.
16. Küçükdeveci A, McKenna SP, Kutlay S et al. The development and psychometric assessment of the Turkish version of the Nottingham Health Profile. *Int J Rehabil Res.* 2000;23:31-38.
17. Abi Daoud MS, Dooley JM, Gordon KE. Depression in parents of children with duchenne muscular dystrophy. *Pediatr Neurol.* 2004;31:16-19.
18. Pelchat D, Lefebvre H, Perreault M. Differences and similarities between mothers'and fathers' experiences of parenting a child with a disability. *J Child Health Care.* 2003;7:231-247.
19. Bristol MM, Galagher JJ, Schopler E. Mothers and fathers of young developmentally disabled and non-disabled boys: adaptation and spousal support. *Dev Psychol.* 1988;24:441-451.
20. Krauss MW. Child-related and parenting stress: similarities and differences between mothers and

- fathers of children with disabilities. *Am. J Ment Retard.* 1993;97:393–404.
21. Pelchat D, Bisson J, Ricard N, et al. The longitudinal effects of an early family intervention program on the adaptation of families of children with a disability. *Int J Nurs Stud.* 1999;36:465–477.
 22. Heath DT, Orthner DK. Stress and adaptation among male and female single parents. *J Fam Issues.* 1999;20:557-587.
 23. Karaduman A, Yılmaz Ö, Tüzün E, et al. A comparison of quality of life in children with cerebral palsy and neuromuscular diseases. *Fizyoter Rehabil.* 2010;21:3-10.
 24. Lim J, Zebrack B. Caring for family members with chronic physical illness: a critical review of caregiver literature. *Health Qual Life Outcomes.* 2004;2:50.
 25. Uyaroglu AK, Bodur S. Anxiety of parents of mentally handicapped children and affects of informing on anxiety level. *TAF Prev Med Bull.* 2009;8:405-412.
 26. Heaman DJ. Perceived stressors and coping strategies of parents who have children with developmental disabilities: a comparison of mothers and fathers. *J Pediatr Nurs.* 1995;10:311-320.
 27. Hornby G. Effects on fathers of children with Down Syndrome. *J Child Fam Stud.* 1995;4:239-255.
 28. Trute B. Gender differences in the psychological adjustment of parents of young, developmentally disabled children. *J Child Psychol Psych.* 1995;36:1225–1242.
 29. King GA, King SM, Rosenbaum PL. How mothers and fathers view professional caregiving for children with disabilities. *Dev Med Child Neurol.* 1996;38:397-407.
 30. Beckman PJ. Comparison of mothers' and fathers' perceptions of the effects of young children with and without disabilities. *Am. J Ment Retard.* 1991;95:585-595.
 31. Pelchat D, Bisson J, Bois C, et al. The effects of early relational antecedents and other factors on parental sensitivity of mothers and fathers. *Infant Child Dev.* 2003;12:27-51.
 32. Compas BE, Williams RA. Stress, coping, and adjustment in mothers and young adolescents in single- and two-parent families. *Am J Community Psychol.* 1990;18:525-545.
 33. Kronenberger WG, Thompson RJ. Medical stress, appraised stress, and the psychological adjustment of mothers of children with myelomeningocele. *J Dev Behav Pediatr.* 1992;13:405-411.