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# HOME CARE NEEDS OF CHILDREN WITH NEUROMUSCULAR DISEASES AND THE DIFFICULTIES THEIR FAMILIES FACE

*Necessidades de cuidados domiciliares de crianças com doenças neuromusculares e as dificuldades que suas famílias enfrentam*

Original article

## ABSTRACT

**Objective:** To identify home care needs of children with neuromuscular diseases and the difficulties their families face, in Turkey. **Method:** A descriptive study with a research sample composed of 103 families of children with neuromuscular diseases. The questionnaire form was developed by the researcher and used to collect data, including questions about physical and psycho-social problems; home care needs of children and the family burden at home care. Data was collected within 8 months. For analyzing the data, percentage distributions and Chi-square (Pearson, Fisher) tests were used. **Results:** Among the children, 17.5% were unable to use lower extremities and 68.9% were unable to use lower and upper limbs; 48 (46.6%) used wheelchairs and/or orthosis; 68% did not practice physical exercise; 18.4% of them were receiving respiration therapy. Almost all of the children had some depressive symptoms. Among the relatives, 87.6% had depressive symptoms, 85.4% presented physical problems and 70.8% referred social isolation. Half of them had problems with their spouses and other children; 51.5% of the participants did not have any emotional support source. **Conclusion:** In Turkey, there is not an effective home care system, rehabilitation and polyclinic services which include emotional and social support. However, findings of this study demonstrate the needs of families and children for such services and how they are important for increasing their quality of life.

**Descriptors:** Home Care Services; Family Caregivers; Neuromuscular Diseases; Muscular Dystrophies; Chronic Disease

## RESUMO

**Objetivo:** Identificar as necessidades de cuidados domiciliares de crianças com doença neuromuscular e as dificuldades que enfrentam suas famílias, na Turquia. **Método:** Estudo descritivo com amostra composta por 103 familiares de crianças portadoras de doenças neuromusculares. O questionário foi desenvolvido pelo pesquisador e usado na coleta dos dados, incluindo questões sobre problemas físicos e psicossociais, as necessidades de cuidados domiciliares das crianças e o fardo familiar no cuidado domiciliar. Os dados foram coletados no período de oito meses. Para a análise de dados foi utilizada a distribuição percentual e o Chi-quadrado (Person, Fisher). **Resultados:** Dentre as crianças, 17,5% eram incapazes de utilizar suas extremidades inferiores e 68,9% eram incapazes de utilizar os membros superiores e inferiores; 48(46,6%) utilizavam cadeiras de rodas ou órteses; 68% não praticavam exercícios físicos; 18,4% estavam recebendo terapia respiratória. Quase todas as crianças possuíam sintomas depressivos. Dentre os familiares, 87,6% possuíam sintomas depressivos, 85,4% apresentavam problemas físicos e 70,8% relataram isolamento social. Metade deles referiu problemas com os cônjuges e outras crianças; 51,5% dos participantes não possuíam qualquer meio de suporte emocional. **Conclusão:** Na Turquia, não há um sistema efetivo de cuidados domiciliares, reabilitação e serviços multiprofissionais que contenham suporte social e emocional. No entanto, achados deste estudo demonstram a necessidade por estes serviços e como os mesmos são importantes para a melhoria da qualidade de vida das crianças e de suas famílias.

**Descritores:** Serviços de Cuidados Domiciliares; Cuidadores; Doença Crônica; Doenças Neuromusculares; Distrofias Musculares.

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## INTRODUCTION

Neuromuscular disorders are characterized by progressive muscular weakness and chronic atrophies. Most of them are X-linked recessive. In neuromuscular diseases, especially Duchene-type progressive muscular dystrophy, the atrophy and pseudo hypertrophy formed in the muscles cause a physical dependence for the children, which grows in time. The child's insufficient position for performing daily activities has a negative effect on both the child and the family. Neuromuscular diseases can affect not only the whole skeletal muscles of the body, but the respiratory and circulatory muscles as well. Thus the respiratory and circulatory dysfunctions reach a life-threatening level<sup>(1-4)</sup>.

Neuromuscular disorders have chronic, progressive, life-threatening features that are causing the patient and the family to experience the grief process. Anger, feelings of accusation / guilt, depression and change in roles due to the child's illness may cause problems in family relations. Likewise, with the progress of the disease; families may experience a fear of losing their child. Lack of hope for the child's recovery, inability to slow down the progress of the disease and the related lack of self esteem, depression, isolation and burnout are other emotional problems that families may experience<sup>(4,5)</sup>. As well as other countries<sup>(6-9)</sup>, stress, anxiety and depression are common in parents of children with chronic diseases in Turkey, too<sup>(10-12)</sup>. Whereas the level of stress experienced by the family predicts the degree of psychosocial adjustment of the adolescent with DMD<sup>(13)</sup>.

Since neuromuscular disorders have no definite cure, the main purpose of care is to overcome the various problems accompanying the disease and raise the quality of life of the patients and the families. The treatment and care cannot continue in the hospital for a long time, and therefore they have to be effectively given at home. However, there is no public home care system in Turkey. Many private home care agencies give only nursing care and their services are too expensive to be afforded by every family. Also, some physical therapists provide services at home for patients. These private services are not covered by social security systems. Many polyclinic services contain only diagnosis and treatment of diseases and they do not provide psychosocial support services for patients and their families. Understanding of multi-dimensional support for clients is newly developing. While monitoring of the chronically ill patients at home legally falls under the responsibility of community health nurses, this service cannot be effectively performed, either. Because, new political approach for health care system is to leave all health services (from public) to private sector.

Although, to provide support to people who need help is the most important value in our culture, this supports are given in the first days of the problems experienced by close relatives, but it is reduced day by day. In our culture, to be helped by a psychiatrist or psychology counselor is not common when experiencing stress, depression or anxiety, because of the fear to get marked as mad by the society. Consequently, the families who have children with chronic disease are left alone to face their multi-faced problems, especially when much more help is needed.

In Turkey, after the determination of the diagnosis, sending the children to their home environment and leaving them alone with their families and problems is very common. Thus, the lack of psychological and clinical support is evidenced. Despite, the major impact of this fact there were no research about this matter. This study, which has evolved from the above mentioned issues, aimed at determining the home-care needs of children with neuromuscular diseases and the problems and/or the difficulties their families face in home-care.

## METHOD

This descriptive study was conducted in a Neuromuscular Diseases Polyclinic of a university hospital in Istanbul and the Istanbul Office of Turkey Muscular Diseases Association. (Istanbul is the biggest city of Turkey and it has been receiving migration from all other cities of Turkey since the sixties. Therefore, it can be said that the population of this city reflects the wider population of Turkey). Since definite diagnosis of neuromuscular diseases are made only in this polyclinic, almost all patients are monitored there too. Therefore, this study was conducted only in this hospital. In the above mentioned polyclinic, four doctors work two days, every week. The daily applicant number to the polyclinic is 20 to 30, and 1-3 of them are children.

Turkey Muscular Diseases Association has been organizing educational programs to inform patients and families about diseases, rehabilitation programs and various social activities and publishing the 'Life and Hope' bulletin since 1978. The Association has also been supplying wheelchairs, medicine and respiration devices for some patients in need, but their resources are limited, and hence their services are not sufficient.

The population of the study consisted of ill children between the ages of 1-18 years old registered in the neuromuscular diseases polyclinic (536) and the Turkey Muscular Diseases Association (53). The sample of the study calculated to represent the population was 163 children.

However, some exclusion criteria were established: the 53 children registered in the Turkey Muscular Diseases Association were also registered in the polyclinic; some of the patients registered in the polyclinic have passed away; the families residing outside Istanbul did not have their controls made regularly, while some did not agree to participate in the study. Therefore, the total sample was 103 children and these were contacted after an 8-month period. The data collection process lasted for 8 months. The patients came to the polyclinic for control at the end of the 9th month also.

Written permission for the study was provided by the ethics committee of the Hospital and the Association management. Families were informed about the study in the polyclinic or their home/office and their agreement to participate have been included.

Data was collected with a questionnaire based on literature information<sup>(1-5,14-16)</sup>. The questionnaire included 44 questions, from which 12 were about the reflection of the experienced/felt statements. The other questions were about the demographic data of the child and the parents, information about the child's disease process, care activities and treatment, the level of physical function, verbal communication skills of the child, relations of the child with his/her surrounding and home care needs for the maintainance and/or restoration of health, information about the family characteristics and other family members' health status, caregiver function's of the families, the experience and support needs of families and child during home care. In order to inquire about the feelings and/or psychosocial reactions of the child and the parents, expressions which determine the emotions, such as anger, anxiety, grief, depression, accusation and helplessness, were listed. The expression samples which were in the list were: "I feel that something wrong will happen", "I am so bored", "I am in depression", "I get angry very quickly", "I shout to everybody", "I want to break everything", "I blame the child because of the illness and being so dependent", "I find myself or/and my spouse responsible/guilty because of the child's illness", "I do not want to do anything", "I do not get pleasure from the life", "I do not want to speak and see anybody", "I want to die", "I feel tired, exhausted and unfortunate", "I feel pain inside me", "I am too sorry", "All bad things happen to me". Similar expressions were listed for that the child and the child's psycho-social reactions could be evaluated from the parents' point of view. The emotional reactions of the child and the parents which were described as "restless, angry, aggressive, nervous" have been collected under the name of "anger"; other emotions such as "insecure, unhappy, displeased with everything and/or himself/herself, withdrawn and sorrowful" were

grouped as "depressive symptoms". A group was created from expressions related to guilt and blame emotions. This data collecting form was evaluated by the faculty members from pediatric nursing and community health nursing departments for determining of the questionnaire's ability to explore the targeted subject. Also, 10 parents were included in the pilot study to determine the comprehensibility of the questions.

Because a questionnaire was used for exploring participants' psycho-social reactions rather than using any scales, the findings were named as "depressive symptoms" rather than "depression".

During the 8 months period, a maximum of 3 patients at a week were contacted. Some days, no child came to the polyclinic for control. The questionnaire was filled by only one parent from each family and it was applied by a researcher. Families of the children registered in the Muscular Diseases Association have been invited to the Association and questionnaire was given to those who have agreed. For the families residing in Istanbul but not coming to the association or the polyclinic, data collection was performed by the researches at home or office visits. The length of time for filling out the questionnaire varied between 25-45 minutes.

For data evaluation, SPSS for Windows software has been used, and percentage dispersion and chi-square (Pearson, Fisher) tests have been applied.

## RESULTS

Most of the interviewed parents were mothers (70.9%) and the others were fathers. In 64.1% of the families, child care was provided only by the mother and 65% of the families did not have any relatives that could handle the child care. The percentage of families that had another dependent member other than the patient was 22.3% and 17.5% of them had more than one child with a neuromuscular disease. 27.2% of the families had no social insurance. The budget of the families (57.3%) had been affected by the treatments and care expenditures of the ill children and 39% of them had been supported by their relatives and the Muscular Diseases Association. Suitable home arrangements for diseased children had been made only by 30.1% of the families. Other families who have dependent children had not had enough money for making these arrangements.

Among the ill children, 39.8% were aged between 10-14 years and 37.9% were aged over 14. The great majority of the children (89.3%) were boys and 53.4% of them (n: 55) had never attended school. From these, only 6 had not done so due to being too young, and the rest had not attended school because of the restrictions imposed

by the disease. Health problems other than neuromuscular diseases were present in 22 children and in 13 of them these problems had occurred as complications of the diseases. The age of diagnosis was between 5-9 years in 57.3% of the children, and between 1-4 years in 34% of them. Only 9.7% of children had motor neuron disease and myopathies, the rest had muscular dystrophy.

An examination of the difficulties that the child's emotional reactions cause in the family showed that 86.2% of the families whose children experienced anger had difficulties in this matter. Depressive symptoms of the child caused difficulties in 80.9% of the families.

As seen on table III, a total of 85.4% of the parents experienced physical problems and most of these were

Table I - Physical dependence of children affects on emotional reactions

| Emotional Reactions Of children | Level of physical dependence |             |                           |             |                           |             |            |              |
|---------------------------------|------------------------------|-------------|---------------------------|-------------|---------------------------|-------------|------------|--------------|
|                                 | independence                 |             | not use lower extremities |             | not use upper extremities |             | Total      |              |
|                                 | n                            | %           | n                         | %           | n                         | %           | n          | %            |
| <b>Anger</b>                    |                              |             |                           |             |                           |             |            |              |
| Yes, there is                   | 9                            | 10.3        | 16                        | 18.4        | 62                        | 71.3        | 87         | 100.0        |
| No, there is not                | 5                            | 31.3        | 2                         | 12.5        | 9                         | 56.3        | 16         | 100.0        |
| <b>Total</b>                    | <b>14</b>                    | <b>13.6</b> | <b>18</b>                 | <b>17.5</b> | <b>71</b>                 | <b>68.9</b> | <b>103</b> | <b>100.0</b> |
| <b>Fisher p&gt;0.05</b>         |                              |             |                           |             |                           |             |            |              |
| <b>Depressive symptoms</b>      |                              |             |                           |             |                           |             |            |              |
| Yes, there is                   | 10                           | 10.6        | 17                        | 18.1        | 67                        | 71.3        | 103        | 100.0        |
| No, there is not                | 4                            | 44.4        | 1                         | 11.2        | 4                         | 44.4        | 9          | 100.0        |
| <b>Total</b>                    | <b>14</b>                    | <b>13.6</b> | <b>18</b>                 | <b>17.5</b> | <b>71</b>                 | <b>68.9</b> | <b>103</b> | <b>100.0</b> |
| <b>Fisher p&gt;0.05</b>         |                              |             |                           |             |                           |             |            |              |

Table II - Social and communicative problems of the children and the difficulties of the parents (N: 103)

| Communication                   | Level of problems of child |      |      |      |    |      |       |       | Difficulties of parents |      |      |      |    |      |       |       |
|---------------------------------|----------------------------|------|------|------|----|------|-------|-------|-------------------------|------|------|------|----|------|-------|-------|
|                                 | Much                       |      | Some |      | No |      | Total |       | Much                    |      | Some |      | No |      | Total |       |
| Problems of children            | n                          | %    | n    | %    | n  | %    | n     | %     | n                       | %    | n    | %    | n  | %    | n     | %     |
| Obscure of verbal communication | 10                         | 9.7  | 9    | 8.7  | 84 | 81.6 | 103   | 100.0 | 6                       | 31.6 | 13   | 68.4 | 0  | 0.0  | 19    | 100.0 |
| Communication with friends      | 25                         | 24.3 | 34   | 33.0 | 44 | 42.7 | 103   | 100.0 | 14                      | 23.7 | 34   | 57.6 | 11 | 18.6 | 59    | 100.0 |
| Continuing friendship           | 28                         | 27.2 | 37   | 35.9 | 38 | 36.9 | 103   | 100.0 | 16                      | 24.6 | 41   | 63.1 | 8  | 12.3 | 65    | 100.0 |
| Joining friendly meetings       | 50                         | 48.5 | 28   | 27.2 | 25 | 24.3 | 103   | 100.0 | 23                      | 29.5 | 35   | 44.9 | 20 | 25.6 | 78    | 100.0 |



of a psycho-physiologic nature (headache, stomachache, early menopause, hypertension due to unknown causes). Although 89 of parents experienced one or more problems, only 22 of them received help from professionals, such as nurses, psychologists, from social agents, and this was only for a short period of time.

The parents' experience of depressive symptoms, anger, isolation, fatigue and physical complaints was compared to some independent variables, such as the child's period of illness, physical dependence, presence of another dependent family member, presence of relatives that might handle the child's care if necessary. It was found that all of these did not cause statistically significant differences ( $P>0.05$ ). However, parents experiencing fatigue in the group of children with health problems other than the neuromuscular disease was statistically significant high ( $X^2: 5.92, P<0.05$ ). This was also seen from parents who stated that their children had depressive symptoms, experienced depressive symptoms ( $X^2: 5.25, P<0.05$ ) and physical complaints, (Fisher,  $P<0.05$ ) which were significantly high.

The effect of the child's neuromuscular disease on the social interaction of the parents was explored and it was found that 74.8% of parents could not get involved in their hobbies, 67% had limited social activities, 61.2% had poorer relations with their friends and neighbors, 51.5 % had poorer and problematic relations with their spouses and 40.8% with their other children.

More than half of the parents explained that the duration of the child's illness, the level of dependence, the number of family members taking responsibility for the child care and the presence of another family member in need of care had negative effects on their social lives and relations, but these effects were not statistically significant ( $p>0.05$ ). However, whether the child had health problems in addition to the neuromuscular disease had significant statistical effect on relationship between spouses ( $X^2: 4.31, p<0.05$ ) and had significantly negative effect on their social group activities ( $X^2: 5.86, p<0.05$ ).

Table III - Health problems of parents were caused from diseases of their children (N: 89)

| Health problems                     | n* | %    |
|-------------------------------------|----|------|
| Depressive symptoms                 | 78 | 87.6 |
| Physical problems except to fatigue | 76 | 85.4 |
| Fatigue                             | 65 | 73.0 |
| Social isolation                    | 63 | 70.8 |
| Anger and aggression                | 56 | 62.9 |

\*Parents have more than one problem

The lack of any source of emotional support was referred by 51.55 of the parents, others explained to share their feelings with spouses, family members, relatives and friends; 39% of these groups were supported economically by the relatives or association. Other strategies used by the parents for coping with stress were crying (58.3%); praying (48.5%); smoking cigarette with alcohol consumption (25.2%); eating always something (9.7%) or hurling something and/or hitting with the fist somewhere (10.7%).

## DISCUSSION

More than half of the children could not use all their limbs. Atrophy and pseudo-hypertrophy formations first start in the lower extremity muscles and spread towards the upper extremities. Weakness of the muscles, loss of endurance, atrophy, and joint contracture are the reasons of handicaps in neuromuscular diseases<sup>(1,3,17)</sup>.

Although 27.3% of families had not any social insurance, all dependent children had got the wheelchair. According to Turkey's laws, when patients have a health report which is given by doctors committee of a big hospital, social insurance organizations pay for complex wheelchairs without a motor. Even if the children have got the wheelchair; they need help for getting on it and mobilization with it. Also, to get on and to get off wheelchair for older, heavy and dependent children is very difficult for parents. Additionally, big part of families could not make suitable home arrangements for children ambulation and/or mobilization by wheelchair. Whereas Duger et al explored a negative correlation between back disability of mothers and environmental barriers, dependency of children with muscular dystrophy<sup>(18)</sup>. Also, physical obstacles out of home environment have caused many mobilization problems to be experienced by disabled people for many years in Turkey. All these factors can cause children to stay in bed and can negatively affect their physical, psychosocial and mental health.

To more than half of the children (68.0%) physical exercises were being applied at home. Physical exercise is vital for children with neuromuscular diseases; however, rough exercising can damage muscles instead of making them stronger and can trigger heart problems. Balanced and active exercises keep the muscle functions at optimum level<sup>(1,3)</sup>. Our study showed that the percentage of families getting the physiotherapist help was limited and the families to whom were given this responsibility had difficulties. Not being able to call a physiotherapist home brings about the risks of not being able to apply or misapplying the exercises to the child. However, the main purpose in the treatment of neuromuscular diseases is to preserve the patient's functions

and independence and raise the quality of life as much as possible. The care applied only by family members might be insufficient to slow down the complications. Karaduman, Tunca, Aras, found that the diseased children did not want to take part in the exercise programs carried out by their families at home and families might prefer forcing the child to do exercising<sup>(19)</sup>.

Chronic respiratory failure is one of the life-threatening factors in muscular dystrophy and that breathing exercises, endurance and muscle strengthening training increase maximal aspiratory and expiratory pressures and the vital capacity<sup>(2,3)</sup>. In our study, the percentage of children to whom respiratory exercises were applied was only 18.4% (n:19). Considering that 68.9% of the children were completely dependent, it can be said that respiratory exercises were neglected. The families of the 14 children to whom respiratory exercises were applied have stated that they had had difficulties in this matter, which brings to mind the possibility of other children and families having neglected respiratory exercises due to such difficulties. These findings clearly show the necessity of professional help for families to apply physical and respiratory exercises at home.

An evaluation of the child's emotional reactions causing problems in the family has shown that a high percentage of families experience problems in this matter. Anger may be explained as a way of expressing the child's feelings of frustration, helplessness and incompetence. However, these feelings that the child expresses may cause communicative problems with their family members, their friends and other individuals around them. This may lead to the isolation of the children and families since people can not understand these reactions of children as a stage of grief process. Besides, as the children develop psychosocially with age, their expectancies alter as well. Among the children, 37.8% were in the 15-18-age span. This is a period during which even healthy children experience common developmental crisis. Adding the physical dependence of the child and visible deformations on the body, it is inevitable that the child will reflect anger and cause related problems for the family. Nereo, Fee, Hinton concluded from their study results that stress in mothers of boys with DMD is elevated, possibly due to increased problem behaviors, particularly in social interactions rather than due to the physical demands of the disease alone<sup>(8)</sup>. Since, muscular dystrophy affect face and tongue muscles, it is expected from children to have communication problems. Also, verbal IQ level, and memory abilities of especially younger boys with DMD were significantly low<sup>(20-22)</sup>. The child's intellectual, verbal and emotional problems following physical ones also lay the groundwork for social problems. That is why it is not

surprise to found that more than half of children in our study had communication and social problems. Durkaya found that 37.8% of verbal and hearing-impaired children have poor relations with their peers and caregivers of them have problems in this matter<sup>(23)</sup>. In an other study, parents whom their children treated by hemodialysis, were complained that the children's relations with their peers are extremely limited due to shame from their physical appearances and functional insufficiencies<sup>(24)</sup>.

Depressive symptoms of the child caused problems in 80.9% of the families. Due to increasing physical dependence, children cannot take part in several of their coevals' activities and they start to feel more incompetent. The change of physical image, strong feelings of incompetence, worthlessness, and solitude may lead to lack of self esteem<sup>(4,5)</sup>. All these feelings lay the groundwork for the child's depressive symptoms. Studies showed that, major<sup>(25)</sup> or minor depressive symptoms, anxiety, isolation, self-depreciated and insecurity<sup>(9,26)</sup> were common among children with DMD.

Having a child with a neuromuscular disease necessitates the constant ability to deal with stress and many losses. Strong stressors and threats, such as the constant progress of the disease, having no cure, loss of earned abilities in time, death being in adolescence period, not having enough knowledge and accessories for managing the disease may exhaust the parent's strength to cope with difficulties. Depression is the most common problem of caretakers of chronic patients which include the neuromuscular diseases<sup>(6-9,11,12)</sup>. Also, it may trigger the depressive symptoms in case the care givers see themselves in a less fortunate and worse position than their peers<sup>(14)</sup>. Having an unhealthy child may be considered as a shameful situation by the society, thus these families may be excluded from social relations or may be approached with feelings of pity<sup>(24)</sup>. This may lead to even more depression and isolation for the family. Amosun, Ikuesan, Oloyede studied with the caregiver of disabled children and suggested that, their mental health should be assess periodically, even psychological aspects of caregivers should be a part of the treatment of handicapped child<sup>(27)</sup>.

The most affected social aspects of parents in our study were their hobbies (74.8%) and group activities (67%). Parents may feel bad when they spend time for activities other than the child's care and consider this as time stolen from the child. Our society encourages such feelings and thoughts, too. Griffin stated that caretakers can spend time for their social activities during the early stages of the disease, but they experience social isolation as their responsibilities and duties become graver with the increase of the child's

dependence<sup>(15)</sup>. Bach et al found that much more half of care givers felt that their life were hard rather than easy, and tied down rather than free<sup>(28)</sup>. In addition, 65% of the families in our study did not have any relatives that could handle the child care and also much more than half of the participants had fatigue and/or depressive symptoms that may had been caused due to restricted social activities.

More than half (51.5%) of the parents have stated that the child's disease had had a negative effect on the relation between the spouses. The genetically hereditary nature of neuromuscular diseases and having a second children with the same disease may cause the spouses to blame and feel angry at each other. Besides, the spouses' being at different stages of grief process and lack of understanding between them may lay the groundwork for conflicts in the relation<sup>(5)</sup>. For almost half of the families (40.8%), relations with their other children have become worse. Since the home care of the diseased children takes most of the time of the parents, feelings of being neglected, sulk, anger and jealousy are common among healthy siblings. Also, the parents' experiencing depression, blaming/guilt and physical fatigue may exhaust their tolerance and cause them to neglect or insult their other children<sup>(5,24)</sup>.

Physical problems of our parents were generally of psycho-physiologic nature. These problems are a result of caretakers shouldering more responsibilities than they can handle, getting no support for care and thus wearing out due to ineffective coping<sup>(15)</sup>. Leonard, Johnson, Brust found that caregivers who could not manage to provide home care for children with disabilities had poor physical and mental health and received less emotional support from friends and family than they needed<sup>(29)</sup>. Sherman found that utilization of respite services reduced significantly somatic complaints of primary care givers of children with chronic diseases<sup>(30)</sup>.

In our study, 63.1% of the parents experienced fatigue. Caring round the clock for a highly dependent child may push the physical and emotional limits of the caretakers. Not only does helping with the needs of a neuromuscular diseased, fully dependent child take all the day time of the family members, but also the parents have to turn the children in their beds at night since they cannot do it themselves due to the nature of the disease. Thus, family members who are physically exhausted during the day cannot rest at night either and therefore experience fatigue. Fatigue has a negative effect on the individual's well being, his/her daily performance, daily activities and relations<sup>(14)</sup>. Additionally, care burden, restricted social activities, fear, insecurity, facing death, lack of emotional, practical and information-related support may be risk factors for fatigue and burnout<sup>(31)</sup>.

Economic sufficiency is a good strategy for coping with stress. Unfortunately, more than half of the families had economic problems. Some of the other coping strategies which were used by participants were not only ineffective, but also harmful for health, such as eating more, using substances and aggressive behaviors. Crying and praying are the most common used the coping strategies by family members in our country<sup>(10,23,24)</sup>. So, it can be said that most parents in the study are vulnerable to risk factors due to applying only short effective and emotion oriented coping strategies rather than problem solving oriented ones. However, having a dependent child -or will be dependent near future- and not having effective support systems, such as professional home care services or respite care services, bring to many responsibilities, problems, stressors together that one would not be able to solve them easily only using these kind of coping strategies.

## CONCLUSIONS

This research clearly states the overall nursing care need of children with neuromuscular disease and their families. The data acquired from the research would have a crucial role and could be a guide in determining the problem area of the nurses during the nursing care planning for the diseased children and their families. Consequently, the hospitalization of diseased children because of the complications will decrease and the quality of life of the diseased children and their families will increase. In Turkey, there is not an effective home care system, rehabilitation and polyclinic services which include emotional and social support. However, findings of this study demonstrate the needs of families and children for such services.

According to our findings, it can be said that especially the 23rd, 24th, 27th, 28th and 29th items of children's rights agreement related with health care services and children education rights were ignored or infringed by government. Law for Disabilities became effective last year, but this law needs to be supported with appropriate health care system changing.

Considering that children with neuromuscular diseases need constant care by health professionals and many families lack the financial resources to afford it, besides family members and children have many byo-psycho-social problems, home care and related services should be included in health security system in our country and the facilities within health security should be extended. Since most of the parents have physical diseases and/or have psychological disease risks, if this condition continues, the parents can become patients who will need treatment and care, also, in the future.



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