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# Quality of life assessment in patients with duchenne muscular dystrophy

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***Abstract*---**Background: Duchenne muscular dystrophy is associated with variable physical and psychosocial sequalae, to patients and their caregivers. Aim: This study aimed to assess quality of life in various dimensions in children with Duchenne Muscular Dystrophy (DMD) and in their caregivers. Patients and methods: This study included all children diagnosed with Duchene Muscular Dystrophy (DMD) registered in the Pediatric Neurology Clinic of Alexandria University Specialized Children's Hospital. Pediatric Quality of Life (PedsQL ™ 3.0) Duchenne Muscular Dystrophy Module was applied to the children and their caregivers. Results: In toddler group, the mean score was 34.41 ± 26.84 SD for daily activity, 48.64 ± 21.41 SD for medications, 28.71 ± 20.70 SD for anxiety, 60.15 ± 21.01 SD for communication and 42.98 ± 15.41 SD and for total quality of life. In parents' group, the mean scores were as following: 45.35 ± 30.66 SD for daily activity, 50.32 ± 18.79 SD for medications, 20.40 ± 19.32 SD for anxiety, 54.59 ± 20.92 SD communication and 42.55 ± 14.86 SD for total quality of life. Conclusion: Duchenne muscular dystrophy causes significant impairment in all aspects of quality of life in patients and their caregivers.

***Keywords*---**quality of life, duchenne muscular dystrophy, caregivers.

## Introduction

Duchenne Muscular Dystrophy (DMD) is a neuromuscular disorder characterized by increasing degeneration and weakness of muscles. DMD can cause motor disability, respiratory and cardiac dysfunction, and may eventually lead to mortality [1]. Duchene Muscular Dystrophy symptoms occurs when there is absence of Dystrophin. The function of dystrophin is to keep muscle cells intact. DMD symptom usually starts in early childhood period between 3 to 5 years of age. DMD usually affects boys but in rare situations it can affect also girls [2]. Duchene Muscular Dystrophy is an X-linked condition in which the mutation on X (locus Xp 21) chromosome leads to impaired synthesis of dystrophin protein with subsequent progressive muscle degeneration [3].

In 1987, it was the first time to identify the dystrophin gene [4] and it was found to account for approximately 0.1% of the total human genome and hence it is considered to be the largest gene ever identified in human genome [5]. Since first description of the disease, many therapeutic trials including medications, genetic based therapies, stem cell therapies have been tried and studied. The aim of these trials was to slow down the disease progression, improve the clinical condition and hence to increase life expectancy [6]. The global DMD prevalence was estimated to be 7.1 cases/100000 males and 2.8 cases/100000 in the general population [7].

Duchene Muscular Dystrophy generally manifests itself early in childhood. Affected children experience proximal muscular weakness and loss of muscle bulk, particularly in the upper legs and pelvic area (hip girdle), as well as the upper arms and shoulder area (shoulder girdle) [8]. The potential life-threatening problems of DMD usually appears by late teens. These complications include progressive cardiomyopathy and myocardial dysfunction [9]. This can lead to disturbance of cardiac rhythm and heart failure which can be fatal. Also, the intercostal muscles become progressively weaker leading to increasing breathing difficulty, recurrent chest infections, ineffective cough. With time, respiratory failure evolves and needs ventilatory support [10,11]. Being a chronic health problem with progressive motor disability, DMD has a significant effect on the quality of life of children and their caregivers. Many studies discussed the effect of DMD on various aspects of quality of life.

## Patients and methods

The study included all children diagnosed with DMD registered in the Pediatric Neurology Clinic of Alexandria University Specialized Children's Hospital (Smouha) in which the study was done. The study included children diagnosed with DMD and registered in the clinic during the period from January 2000 to December 2019. All records of the study group of children were revised regarding the process of diagnosis. In most of children, diagnosis was made based on genetic testing while few numbers of children were diagnosed either by muscle biopsy or only based on clinical and electrophysiological criteria.

## Methods

Following approval of Alexandria University Ethical Committee, an informed consent from parents, or legal guardians of all patients included in the study was obtained. All patients who were fulfilling the inclusion criteria and have been attending the Pediatric Neurology Clinic of Alexandria University Specialized Children's Hospital (Smouha) during the study period were subjected to the following:

Basic Demographic and clinical data: including chronological age, gender, family pedigree, consanguinity, family history of DMD. Age of onset of muscle weakness (age of diagnosis): the age that was concerned is the age at which parents became concerned about the motor abilities of the child, not the age at which the final diagnosis was made. Level of ambulation and degree of limitations of daily life activities, age of loss of ambulation (in non-ambulant children).

Quality of life: Pediatric Quality of Life (PedsQL ™ 3.0) Duchenne Muscular Dystrophy Module: Pediatric Quality of Life (PedsQL ™ 3.0) Duchenne Muscular Dystrophy Module. The questionnaire has parent form for all children and patient form for children older than 8 years old. The questionnaire was administered to children with DMD and their parents during follow up visits to the clinic.

Instructions of use of the questionnaire were applied as following: 1. The questionnaire was completed before the participant completed any other healthcare related forms 2. If the child was unable to self-administer the questionnaire, the items were read aloud to the child. 3. Parents and children completed the questionnaire independently of each other as possible. 4. If there was difficulty for the child or parent to understand the question, no explanation was offered to them, but they were asked to answer the item as they feel its meaning, or they couldn't answer the question if they wanted so. 5. Any refusal or non-completion of the questionnaire was documented.

### Items and scoring of the questionnaire

the questionnaire has 4 dimensions and a number of items in each dimension: daily activities (5items), treatment (4 items), worry (6 items) and communication (3 items). For each item there is reversed scoring, so higher scores mean low problems.

### Scoring of dimensions

Items of the questionnaire were scaled in the form of 5-point Likert scale. Scales ranged from 0 (Never) to 4 (Almost always). Next step is reversal of the score and linear transformation to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). The score of any scale were not computed if more than 50% of the scale items are missing. Final step is calculation of the mean score in each scale by dividing the sum of the items over the number of answered items.

**Statistical analysis of the data**

Data were fed to the computer and analysed using IBM SPSS software package version 20.0. (Armonk, NY: IBM Corp) Qualitative data were described using number and percent. Quantitative data were described using range (minimum and maximum), mean, standard deviation, median and interquartile range (IQR).

**Results**

Total number of seventy-eight children diagnosed with DMD and following in pediatric neurology clinic in AUCH were enrolled in the present study and found to match the inclusion criteria of the study. No one from parents and/or caregivers refused to participate in the study or to complete the questionnaire.

Demographic data (table 1): In the study group the mean age was 9.82 years ± 3.38 SD with interquarter range (IQR) 9.0 (7.0 – 12.0), 59% were with age between 5-10 years and 41% more than 10 years of age. Regarding age of disease onset (in years), 1.3% with age of onset less than 3 years, 71.8% with age of onset between 3-5 years and 26.9% with age of onset more than 5 years. The mean age of onset (years) was 4.63 ± 1.29 SD with interquarter range 4.25 (4.0 – 5.50). Consanguinity was found in 17.9% of cases with 42.3% with positive family history of Duchenne Muscular Dystrophy.

Stage of illness (Table 2): Ambulant children represented 66.7% while 33.3% were non ambulant. In the ambulant group 42.3% were in the early ambulant stage, 24.4.1% were late ambulant. In the non-ambulant group 29.5.3% were early non ambulant, 3.8% were late non ambulant.

Scores quality of life questionnaire (QOL) (table 3): In Toddler questionnaire, total number of 55 children with age more than 8 years completed the questionnaire. For daily activity, mean score was 34.41 ± 26.84 SD and Median (IQR) was 25.0 (15.0 – 52.50). for Medications, mean score was 48.64 ± 21.41 SD and median (IQR) was 43.75 (31.25 – 65.63). for Anxiety, mean score was 28.71 ± 20.70 SD and median (IQR) was 25.0 (16.66 – 39.58). for Communication, mean score was 60.15 ± 21.01 SD and median (IQR) was 66.66 (50.0 – 66.66). The mean score for total quality of life was 42.98 ± 15.41 SD and median (IQR) was 43.23 (31.77 – 54.27).

Parents questionnaire. All parents/caregivers completed the questionnaire. The mean score for daily activity was 45.35 ± 30.66 SD and median (IQR) was 40.0 (25.0 – 75.0), the mean score for medications was 50.32 ± 18.79 SD and median (IQR) was 50.0 (37.50 – 62.50), the mean for Anxiety was 20.40 ± 19.32 SD and median (IQR) was 16.66 (4.17 – 29.17), for communication, mean score was 54.59 ± 20.92 SD and median (IQR) was 58.33 (41.66 – 66.7). The mean total quality of life score was 42.55 ± 14.86 SD and median (IQR) was 42.86 (31.98 – 53.33).

Table (1): Distribution of the studied cases according to demographic data (n = 78)

| Demographic data | No. | % |
|---|---|---|
| Age (years) | | |
| <5 | 0 | 0.0 |
| 5 – 10 | 46 | 59.0 |
| ≥10 | 32 | 41.0 |
| Min. – Max. | 5.0 – 19.0 | |
| Mean ± SD. | 9.82 ± 3.38 | |
| Median (IQR) | 9.0 (7.0 – 12.0) | |
| Age of onset (years) | | |
| <3 | 1 | 1.3 |
| 3 – 5 | 56 | 71.8 |
| >5 | 21 | 26.9 |
| Min. – Max. | 2.50 – 8.0 | |
| Mean ± SD. | 4.63 ± 1.29 | |
| Median (IQR) | 4.25 (4.0 – 5.50) | |
| Consanguinity | | |
| Non consanguineous | 64 | 82.1 |
| Consanguineous | 14 | 17.9 |
| Family history | | |
| Negative | 45 | 57.7 |
| Positive | 33 | 42.3 |
| If +ve family history (n = 33) | | |
| Brother | 12 | 36.4 |
| Maternal cousin/maternal uncle | 16 | 48.5 |
| Both | 5 | 15.2 |

IQR: Inter quartile range SD: Standard deviation

Table (2): Descriptive analysis of the studied cases according to level of ambulation

| Stage of the disease | Initial (n = 78) | |
|---|---|---|
| | No. | % |
| Ambulant | 52 | 66.7 |
| Early ambulant | 33 | 42.3 |
| Late ambulant | 19 | 24.4 |
| Non Ambulant | 26 | 33.3 |
| Early non ambulant | 23 | 29.5 |
| Late non ambulant | 3 | 3.8 |

Table (3): Descriptive analysis of the studied cases according to quality of life

| Quality of life (QOL) | Toddler (n = 55) | Parents (n = 78) |
|---|---|---|
| Daily activity | | |
| Min. – Max. | 0.0 – 90.0 | 0.0 – 100.0 |
| Mean ± SD. | 34.41 ± 26.84 | 45.35 ± 30.66 |

| | | |
|---|---|---|
| Median (IQR) | 25.0 (15.0 – 52.50) | 40.0 (25.0 – 75.0) |
| Medications | | |
| Min. – Max. | 0.0 – 87.5 | 0.0 – 100.0 |
| Mean ± SD. | 48.64 ± 21.41 | 50.32 ± 18.79 |
| Median (IQR) | 43.75 (31.25 – 65.63) | 50.0 (37.50 – 62.50) |
| Anxiety | | |
| Min. – Max. | 0.0 – 87.50 | 0.0 – 75.0 |
| Mean ± SD. | 28.71 ± 20.70 | 20.40 ± 19.32 |
| Median (IQR) | 25.0 (16.66 – 39.58) | 16.66 (4.17 – 29.17) |
| Communication | | |
| Min. – Max. | 8.33 – 100.0 | 0.0 – 100.0 |
| Mean ± SD. | 60.15 ± 21.01 | 54.59 ± 20.92 |
| Median (IQR) | 66.66 (50.0 – 66.66) | 58.33 (41.66 – 66.7) |
| Total quality of life | | |
| Min. – Max. | 10.42 – 82.92 | 10.83 – 68.02 |
| Mean ± SD. | 42.98 ± 15.41 | 42.55 ± 14.86 |
| Median (IQR) | 43.23 (31.77 – 54.27) | 42.86 (31.98 – 53.33) |

Table (4): Comparison between ambulant and non-ambulant children according to quality of life

| Quality of life (Qol) | Toddler (n = 55) | | Parents (n = 78) | |
|---|---|---|---|---|
| | Ambulant (n = 31) | Non-Ambulant (n = 24) | Ambulant (n = 52) | Non-Ambulant (n = 26) |
| Daily activity | | | | |
| Min. – Max. | 0.0 – 90.0 | 0.0 – 50.0 | 0.0 – 100.0 | 0.0 – 62.50 |
| Mean ± SD. | 48.23 ± 26.44 | 16.56 ± 13.75 | 57.98 ± 28.08 | 20.10 ± 17.10 |
| Median (IQR) | 45.0 (25 – 67.5) | 15.0 (5 - 25) | 62.50 (27.5 - 70) | 17.50 (2.5 - 30) |
| U(p) | 109.50*(<0.001*) | | 199.0*(<0.001*) | |
| Medications | | | | |
| Min. – Max. | 12.50 – 87.50 | 0.00 – 87.50 | 12.50 – 81.25 | 0.00 – 100.00 |
| Mean ± SD. | 55.04 ± 18.29 | 40.36 ± 22.65 | 54.09 ± 14.48 | 42.79 ± 23.89 |
| Median (IQR) | 56.25 (43.8 – 68.8) | 37.50 (25 – 56.3) | 56.25 (40.6 – 62.5) | 46.88 (18.8 – 56.3) |
| U(p) | 221.50*(0.010*) | | 459.0*(0.020*) | |
| Anxiety | | | | |
| Min. – Max. | 0.00 – 87.50 | 0.00 – 41.66 | 0.00 – 66.66 | 0.00 – 75.00 |
| Mean ± SD. | 37.77 ± 21.00 | 17.01 ± 13.34 | 25.64 ± 18.73 | 9.94 ± 16.20 |
| Median (IQR) | 37.50 (22.92 -50) | 16.66 (4.17 - 25) | 20.83 (8.3 - 25) | 2.08 (0 – 12.5) |
| U(p) | 154.0*(<0.001*) | | 301.50*(<0.001*) | |
| Communication | | | | |
| Min. – Max. | 8.33 – 91.66 | 25.00 – 100.00 | 8.33 – 91.66 | 0.00 – 100.00 |
| Mean ± SD. | 54.30 ± 20.85 | 67.70 ± 19.08 | 54.16 ± 17.89 | 55.45 ± 26.35 |
| Median (IQR) | 58.33 (37.5 – 66.7) | 66.66 (58.3 – 79.2) | 58.33 (50 – 66.7) | 62.50 (41.7 - 75) |
| U(p) | 247.0*(0.031*) | | 623.0 (0.570) | |
| Total quality of life | | | | |
| Min. – Max. | 10.42 – 82.92 | 17.19 – 60.21 | 13.54 – 68.02 | 10.83 – 62.50 |

| | | | | |
|---|---|---|---|---|
| Mean ± SD. | 48.83 ± 15.04 | 35.41 ± 12.51 | 47.80 ± 12.52 | 32.07 ± 13.75 |
| Median (IQR) | 47.29 (43.2 – 57.1) | 32.76 (27.9 – 44.3) | 47.50 (38.5 – 49.3) | 31.51 (18.75 – 40) |
| U(p) | 175.0*(0.001*) | | 275.50*(<0.001*) | |

U: Mann Whitney test
p: p value for comparing between Ambulant and non-Ambulant
*: Statistically significant at p ≤ 0.05

**Discussion**

This study comprised 78 children diagnosed with Duchenne muscular dystrophy attending the Pediatric Neurology Clinic at Alexandria University Children's Hospital during the period from January 2000 to December 2019. All the parents complete the questionnaire. And the toddler form was completed by all children more than 8 years (55 children). In the present study, the mean age of onset (years) was 4.63 ± 1.29 SD with age of onset between 3-5 years in 71.8% of children, and 26.9% of children had onset of symptoms more than 5 years of age and in only 1.3% of cases, the age of onset was less than 3 years. The questionnaire results were analyzed and compared between ambulant and non-ambulant children and also between parents and children's results.

The ambulant group of children were 52 children with the age ranging from 5 to 13 years, mean age of 8.29 years and median age of 8 years. This group is subdivided into: early ambulant group of 33 children (42.3% of total children) and late ambulant group of 19 children (24.4%). The non-ambulant group included 26 children with minimum age of 6 years, maximum age of 18 years, mean age of 12.85 years and median age of 13 years. This group was subdivided into: early non ambulant group of 23 children (29.5%) and late non ambulant group of only 3 children representing 3.8% of total study cases. Taking into consideration the mean scores of each dimension of the questionnaire, results are consistent with significant impairment in all dimensions. The mean of each dimension varied between parents and toddler questionnaires and according to the stage of disease (ambulant and non-ambulant)

The mean for dimension of the questionnaire for parents and toddlers were as following: daily activities (34.41 ± 26.84 for toddlers and 45.35 ± 30.66 for parents), medications (48.64 ± 21.41 for toddlers and 50.32 ± 18.79 for parents), anxiety (28.71 ± 20.70 for toddlers and 20.40 ± 19.32 for parents) and communication (. From these data, the mean score for each domain and for the total quality of life score are below the 50% level except for the dimension of communication in which the score is more than 50% (60.15 ± 21.01 for toddlers and 54.59 ± 20.92 for parents)

Comparing QOL scores for the ambulant and non-ambulant children (table 4), all the scores in the non-ambulant groups were less than the ambulant group of children (higher problems) except for the communication problems which were less in the non-ambulant group. The significance level varies between different dimensions (P=<0.001 for daily activities and anxiety- P=0.001 for medications in parents form and P=0.002 in toddler form). Regarding communication domain,

problems were more in the ambulant group but the difference was significant only in toddler form (p=0.03) not in parents form (P=0.5)

Compared with the present results regarding quality of life of the DMD patient, Lue et al., study concluded that adolescent having DMD had poor quality of life either in health-related or global aspects. Social health and physical condition of the child when more affected, were associated with poor QOL. The study suggested that participation in social activities is recommended to achieve better quality of life for patients having DMD and also to improve rehabilitation programs using assistive devices for more easy arm function and encourage more participation[12]. In Zamani et al. study, boys with DMD had a quality of life which is quite satisfactory. The study results also showed that boys with DMD had a positive attitude toward life despite the nature of their disease which is progressive and the barriers against physical activities and social relationships [13].

Quality of life scores were found lower in children suffering from more pain and a significant correlation was detected between scores of pain scales and those of youth quality of life questionnaire studies (Hunt et al., 2016). Similarly, in Pangalila et al., (2015) study, children with DMD showed frequent symptoms of pain (73.4%), fatigue (40.5%), depression (19%) and anxiety in (24%) of cases. A significant relation was found between fatigue and overall quality of life score. [14,15,].Regarding anxiety in parents, Landfeldt et al. study [16] showed that about 70% of parents suffered from anxiety and depression. Level of anxiety varied according to patients' health and mental status and also correlated with cost burden every year and hours per week of leisure time dedicated to informal care. In Magliano et al. [17] study, high number of relatives report being worried about future of other family members. However, no difference was detected between levels of anxiety in patient mothers versus controls in Ozyurt et al.,[18] study.

Landfeldt et al.[19] conducted a cross-sectional study to measure health-related quality of life (HRQOL) in patients with DMD. A total of 770 patient–caregiver pairs participated in the study. More than 84% of parents perceived their patients, irrespective of their ambulatory level, as happy/somewhat happy and in excellent/very good/good health. In contrast, mean patient declined with progression of the disease, from 0.75 in early ambulatory patients to 0.15 in the most non-ambulant patients who are severely affected. Also, there was a decline in the mean patient PedsQL scores across ambulatory classes from 80 to 57.

Baiardini1 et al., [20] studied quality of life (health-related) and its determinants in children with DMD and in their caregivers. Caregivers of 27 DMD patients completed the validated Children Health Questionnaire and the Family Strain Questionnaire. Compared to normative group, children had much lower scores in 10 of 15 of the dimensions of the questionnaire. Only the use of ventilators and wheelchairs was associated significantly with lower health related quality of life in Physical Functioning. Regarding Family Strain Questionnaire, children's characteristics didn't affect scores. And according to the study, Despite the fact that DMD impairs health-related quality of life, still both children and their caregivers have some areas of well-being.

## Conclusion

In view of the progressive nature of the disease, DMD has a major effect on quality of life in children and their caregivers. All aspects of quality of life are significantly affected in both parents and children's questionnaires with more affection in the non-ambulant group of children. Our study should be viewed in the light of its limitations. The main limitation of the study is the small number sample size. But it can be considered an attempt to clarify the impact of Duchenne muscular dystrophy in real life. Therefore, this could be a preliminary data that must be followed by further research with larger and, longitudinal samples, before conclusions can be made regarding effect of DMD on quality of life.

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