Quality of Life and Duchenne Muscular Dystrophy: Greek Translation of the Pediatric Quality of Life Inventory (PEDSQL)3.0 Duchenne Muscular Dystrophy Module.

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Background

- Duchenne Muscular Dystrophy (DMD) is a rare condition that belongs to a wider group of diseases related to dystrophin, a protein found in muscle fibers, responsible for muscle function[1].
- In DMD, dystrophin is not expressed partially or completely, due to many and different mutations in the relevant gene, resulting in the gradual deterioration of vital functions[1].
- Measuring health-related quality of life (HRQL) in a disease of this nature, with multifactorial management, which includes complex care by doctors of different specialties (neurologists, developmentalists, cardiologists, orthopedics, pulmonologists) and other therapists (occupational therapists, physical therapists, psychologists, nutritionists, nurses), is considered very crucial, in order for decision makers to improve the provision of services for these patients[2].
- PedsQL 4.0 Generic Core is widely accepted and used in HRQL studies including those in DMD patients. PedsQL 4.0 Generic Core and PedsQL 3.0 DMD Module have been used together in order to get more consolidated results in HRQL studies in Duchenne people[3].
- As PedsQL 4.0 Generic Core Greek version has been translated in Greek language and assessed for its reliability and validity, in order to proceed with HRQL studies in Greek-speaking patients with DMD, the PedsQL 3.0 DMD Module has to be translated and validated too.

Objective

The current study aimed to translate the disease specific Pediatric Quality of Life Inventory™ (PedsQL™) 3.0 DMD Module into Greek in order to assess HRQL patients with DMD for national and cross-national studies.

Methods

Study design and Sample

- The study has been carried out between November 2021 and March 2022. The number of participants that signed the form of consent and completed the questionnaire were 28, 17 parents and 11 children with DMD.
- According to MAPI Research guideline for performing the linguistic validation 5 representatives for the questionnaire of each age group are needed.
- The communication with the participants curried out through the intervention of a patients' organization for neuromuscular diseases, MDA-Hellas - a non-profit association. Since there is no national registry for patients with neuromuscular disorders in Greece.
- All participants at the appointment of the interview had been asked to sign the consent form and complete the corresponded questionnaires (child questionnaire and parent proxy).
- After completing the questionnaires and sighing the consent form, both questionnaires and consent form were sent back to the investigator either scanned via-e-mail or as photographs via the mobile phone application "viber", in case printing was not available at home.

Measures, procedures and data analysis

- The 18-item PedsQL 3.0 DMD Module 4 Scales were designed to measure some core dimensions of the life of Duchenne people and their care givers, such as everyday life, therapy, worries and communication.
- The separated age-group of 5-7, 8-12, 13-18 (years old) questionnaires have additional value as these age-groups almost coincide to the different stages of the disease.
- Greek translation of the PedsQL™ 3.0 DMD Module was performed according to established linguistic translation guidelines. All steps were completed, and the final version was accepted by the MAPI Research Trust.
- Data were analyzed with Statistical Package for the Social Sciences (SPSS)20. Descriptive statistics were generated for demographic of children with DMD and clinical variables and are reported as mean and SD values for continuous variables and frequencies/proportions for categorical variables.

Acknowledgement

The study has been approved by the Ethics Committee of the University of Peloponnese, Greece.

Results

- A sample of 28 participants was drawn from different educational, socioeconomic background and disease stage. The aim was to reach the least necessary number set by the procedural guidelines taking into account that DMD is a rare disease. The number of participants in the present study covers the minimum needed one according to MAPI Research Trust.

Participants' Characteristics

- The age range of the Duchenne boys (both the ones been interviewed and the ones not) was from 6-17 with an average age of 10 years old while the age range for the boys been interviewed was from 9-17 with an average age of 12 years old (Table1).

Table 1. Age structure for each dimension of the PedsQL

Children's age group	Parent's age
5-7	41
8-12	47
13-18	45

Cultural adaptation and translation process

- According to the participants, the completion of the questionnaire was admittedly easy and quick. The time required for the completion was approximately 10 minutes for adults and 15 minutes for children. Some parents said, it took them 5 minutes to complete it.
- The majority of the participants found the questions rather simple and relevant to the disease characteristics. Some sections of the translation of the instrument into Greek required cultural adaptation to appropriately reflect the meaning for the Greek-speaking target group.
- Table 2 is presenting the scores of the 4 dimensions of PedsQL 3.0 DMD Module-GR of both the self-reporting questionnaires and the parent-proxy reports in the age groups of 5-7, 8-12 and 13-18 years old according to the calculation guidelines for the certain scores, which sets that the higher the score the better is patients' life.

Table 2. Score results of the four multidimensional scales of the Peds 3.0 DMD Module

	Children age group											
	5-7			8-12			13-18			5-18		
Scale	n	Mean	SD	n	Mean	SD	n	Mean	SD	n	Mean	SD
Parent proxy-report												
DailyActivities	6	65.83	14.29	6	51.67	14.72	5	55.00	30.41	17	57.65	20.09
Treatment	6	85.42	10.94	6	66.67	15.14	5	56.25	17.68	17	70.22	18.43
Worry	6	82.22	14.40	6	59.72	28.95	5	48.33	30.42	17	64.31	27.68
Communication	6	86.11	12.55	6	65.28	29.07	5	58.33	25.00	17	70.59	24.85
Child self-report												
DailyActivities				6	68.33	20.41	5	70.00	27.16	11	69.09	22.45
Treatment				6	72.92	17.97	5	70.00	20.92	11	71.59	18.41
Worry				6	74.31	16.33	5	70.83	27.80	11	72.73	21.11
Communication				6	65.00	27.26	5	78.33	17.28	11	71.67	22.64

Conclusions

The results of the above test confirmed the feasibility of administering the Greek version of PedsQL 3.0 DMD Module. It has a clear focus and is concise. The translation of the questionnaire into Greek was reported from the majority of members of the pilot sample to be easy to understand and was adequately adapted to the Greek culture.

Nevertheless, because further testing is required before the instrument is widely made available, the next step is a field study in Duchenne patients in Greece, in order to create a fully harmonized Greek version of PedsQL 3.0 DMD module, which could be valuable for measuring health-related quality of life of Duchenne patients, in regards to the contribution of the assessment of several interventions that aim to improve Duchenne Patients' quality of life in Greece, for instance reimbursement of future innovative therapies or claiming of better healthcare services.

References

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