Pediatric Quality of Life Inventory (PedsQL) 3.0 Duchenne Muscular Dystrophy module-Greek Translation: A Quality of Life tool in Duchenne Muscular Dystrophy

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Abstract: - **Purpose:** Duchenne Muscular Dystrophy (DMD) is a genetic disorder in boys' early childhood that adversely affects the cardiac, respiratory, and skeletal muscle's function and emotional and social functioning as aspects of health-related quality of life (HRQoL). The current study aimed to translate the disease-specific Pediatric Quality of Life Inventory™ (PedsQL™) 3.0 DMD Module into Greek to make it feasible to administer in patients with DMD for national and cross-national studies.
Methods: Established guidelines, using forward-back translation were followed for the performance of the Greek translation of the PedsQL™ 3.0 DMD Module and approval was given by the creator of the instrument. The administration of the Greek version of the module took place at the patients' organization MDA-Hellas, a non-profit association for neuromuscular disorders, to 28 participants, children with DMD (aged 8-18 years), and their caregivers. The inventory consists of a child self-report format for children aged 8 to 18 years and a caregiver proxy-report format for children ages 5 to 18 years.
Results: The module encompasses four scales: 1) Daily activities (5 items), 2) Treatment (4 items), 3) Worry (6 items) and Communication (3 items). All the questions of the PedsQL™ 3.0 DMD module were translated without any major discrepancy. The results confirmed the feasibility of administering the Greek version of the PedsQL 3.0 DMD Module. It has a clear focus and is concise. The results showed that the quality of life of DMD patients from age 5 to 18 years is affected as reported by parents.
Conclusion: The results showed that the translation of the Greek version of the PedsQL 3.0 Duchenne Muscular Dystrophy Module questionnaire was well perceived and accepted. It has a clear focus is comprehensive and can be used for health-related quality-of-life studies in Greek-speaking patients with Duchenne Muscular Dystrophy-DMD aged 5-18 years old.

Key-Words: Duchenne Muscular Dystrophy, DMD, PedsQL3.0 DMD Module, Greek translation

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1 Introduction

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], [2]. In Duchenne muscular dystrophy, dystrophin is not expressed partially or completely, due to many different mutations in the relevant gene, resulting in the gradual deterioration of vital functions. The first crucial function to be affected is movement. Ambulation is definitively lost around the ages of 10-14, while afterward comes the loss of upper trunk movement. Consequently, smooth muscle weakness affects respiratory and cardiac function irreversibly. Cardiac or respiratory arrest is the leading cause of death among patients with DMD, [2], [3]. Life expectancy for patients with DMD is late in their third decade of life, [3].

Measuring health-related quality of life in a disease of this nature, with multifactorial management, which includes complex care, [4], [5], [6], 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.

PedsQL 4.0 Generic Core is widely accepted and used in health-related quality-of-life studies, [7], including those in DMD patients, [8], [9], [10], [11], [12], [13], [14], [15]. PedsQL 4.0 Generic Core and PedsQL 3.0 DMD Module have been used together to get more consolidated results in health-related quality of life studies in Duchenne people, [14], [15]. As the PedsQL 4.0 Generic Core Greek version has been translated into Greek language and assessed for its reliability and validity, [16], [17], to proceed with health-related quality of life studies in Greek-speaking patients with DMD, the PedsQL 3.0 DMD Module has to be translated and validated too.

In this light, the present study aims to present the procedure of the translation of the PedsQL (Pediatric Quality of Life Inventory™) Duchenne Muscular Dystrophy Module (DMD) 3.0 version into the Greek language. The PedsQL Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system. The PedsQL Condition-Specific Modules complement the Generic Core Scales for use in designated clinical populations and are designed to provide greater measurement sensitivity for circumscribed populations. The PedsQL 3.0 DMD Measurement Model is a disease-specific module for measuring health-related quality of life (HRQoL) in children and adolescents with Duchenne Muscular Dystrophy

2 Problem Formulation

2.1 Methods

2.1.1 Study Design and Sample

The study has been approved by the Ethics Committee of the University of Peloponnese, Greece. It was 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 guidelines for performing the linguistic validation 5 representatives for the questionnaire of each age group are needed. Although it was made an effort to reach 6 participants per questionnaire (20% more than requested) this was not achievable in all cases such as in the age group of 13-18. Taking into consideration that we are dealing with a rare disease; the study sample can be considered as a presentative for Greece. Finally, in the group aged 5-7 years, 6 parents were interviewed for the proxy report, in the group aged 8-12 years, 6 children for the self-report and 6 parents for the proxy report were interviewed and in the group age 13-18 years, 5 adolescents for the self-report and 5 parents for the proxy-report were interviewed.

The communication with the participants was carried 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, MDA-Hellas had the most comprehensive registry of Duchenne patients.

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Initially, there was an introductory presentation about the purposes of the present study to the registered members of MDA-Hellas on the Duchenne Awareness Day on the 7th of September 2021. During November, e-mails were sent to the members of MDA-Hellas to participate in the cognitive interviews twice. The second one was a reminder mail. Some participants responded and with the aid of the social service of the patients' organization, an effort started to book phone or teleconference appointments. The appointments could not take place face to face due to Covid19 pandemic safety protocol which imposed social distancing and avoidance of contact. The appointments were made only during weekends for the patients' convenience. That was the reason that the total duration of the cognitive interviews was more than expected.

All participants at the appointment of the interview were asked to sign the consent form and complete the corresponding questionnaires (child questionnaire and parent proxy). After completing the questionnaires and signing 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. During the conversation with them, participants were asked the following questions: a) what items were difficult to answer, b) what items were confusing or difficult to understand, and c) suggestions for alternatives to rephrase some items. Mixed cognitive techniques such as "*think-aloud*" and "*verbal probing*", [18], were used by the principal investigator.

2.1.2 Measures and Procedures

The 18-item PedsQL 3.0 DMD Module 4 Scales were designed to measure some core dimensions of the life of DMD patients and their caregivers such as everyday life, therapy, worries, and communication. The separated age groups of 5-7, 8-12, and 13-18 (years old) questionnaires have additional value as these age groups almost coincide with the different stages of the disease. The 18 items of the questionnaire are presented in Table 1 and Table 2.

The translation process was included in the creator's approval of the study. 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.

Mapi Research Trust is a non-profit, full-service provider, promoting the use of Clinical Outcomes Assessments (COAs) in studies, and encouraging exchanges of Patient-Centered Outcomes (PCO) and Clinical Outcome Assessment information among academics, pharmaceutical companies, and health researchers. It is the owner of the copyright of all PedsQL™ questionnaires. The translations of these questionnaires must be conducted in close collaboration with the MAPI Research Institute and its translation guidelines. MAPI Research Guidelines present a widely accepted procedure, [19], which includes three necessary steps for the linguistic validation of the translation: forward and backward translation and patient testing.

Table 1. PedsQL 3.0 DMD module-Self-report

In the past ONE month, how much of a problem has this been for you…					
DAILY ACTIVITIES (problems with…)	Never	Almost Never	Sometimes	Often	Almost Always
1. I have trouble eating with a fork and knife	0	1	2	3	4
2. It is hard to write or draw with a pen or pencil	0	1	2	3	4
3. It is hard to put on my clothes	0	1	2	3	4
4. It is hard to use the toilet without help	0	1	2	3	4
5. I need more time than others to complete tasks	0	1	2	3	4
TREATMENT (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to take medicines	0	1	2	3	4
2. My physical therapy or daily stretching hurts	0	1	2	3	4
3. It is hard to be responsible for my medicines or phys	0	1	2	3	4
4. It is hard to manage my muscle problem	0	1	2	3	4
WORRY (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. I worry about my muscle problem	0	1	2	3	4
2. I worry whether or not my medicines are working	0	1	2	3	4
3. I worry about my family	0	1	2	3	4
4. I worry about needing help from others	0	1	2	3	4
5. I worry about not being accepted by others	0	1	2	3	4
6. I worry about being treated differently from others r	0	1	2	3	4
COMMUNICATION (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses quest	0	1	2	3	4
3. It is hard for me to explain my muscle problem to ot	0	1	2	3	4

Initially, two independent translators, native speakers of the "*target*" language (Greek), translated into Greek. A reconciled version was produced with the collaboration of the translators and the principal investigator, aimed to produce a conceptually equivalent translation of the original questionnaire in a local and easy-to-understand language. The combined version was translated backward to the "source" language (English) by a third independent translator, bilingual in the "source" language. After the MAPI Research agreement, the backward translation could be used in the cognitive interviews to evaluate the semantics and linguistic adaptation into Greek.

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Table 2. PedsQL 3.0 DMD module-Parent-proxy

In the past ONE month, how much of a problem has your child had with…					
DAILY ACTIVITIES (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. Trouble eating with a fork and knife	0	1	2	3	4
2. Difficulty writing or drawing with a pen or pencil	0	1	2	3	4
3. Difficulty putting his/her clothes on	0	1	2	3	4
4. Using the toilet without assistance	0	1	2	3	4
5. Needing more time to complete tasks	0	1	2	3	4
TREATMENT (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. Taking medicines	0	1	2	3	4
2. Physical therapy or daily exercise causing pain	0	1	2	3	4
3. Difficulty being responsible for medicines or physical therapy	0	1	2	3	4
4. Difficulty managing his or her muscle problem	0	1	2	3	4
WORRY (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. Worrying about his or her muscle problem	0	1	2	3	4
2. Worrying about whether or not medicines are working	0	1	2	3	4
3. Worrying about his or her family	0	1	2	3	4
4. Worrying about needing help from others	0	1	2	3	4
5. Worrying about not being accepted by others	0	1	2	3	4
6. Worrying about being treated differently than others his/her age	0	1	2	3	4
COMMUNICATION (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
2. Difficulty asking the doctors and nurses questions	0	1	2	3	4
3. Difficulty explaining his/her muscle problem to other people	0	1	2	3	4

2.1.3 Data Analysis

Data were analyzed with Statistical Package for the Social Sciences (SPSS) 20. Descriptive statistics were generated for the 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.

3 Problem Solution

3.1 Results

A sample of 28 participants was drawn from different educational, and socioeconomic backgrounds and disease stages.

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 according to MAPI Research Trust. More specifically, the PedsQL 3.0 DMD Module consists of self-reported questionnaires and parent-proxy reports for the following age groups: 8-12 years old and 13-18 years old. For the age group 5-7 years old, only parent-proxy reports are available. According to the MAPI Research guidelines for the linguistic validation of the translated questionnaire, at least 5 individuals for each questionnaire are necessary for the validation, that is at least 25 in total for this specific questionnaire.

3.1.1 Participants' Characteristics

The age range of the Duchenne boys (both the ones being interviewed and the ones not) was from 6-17 with an average age of 10 years old while the age range for the boys being interviewed was from 9-17 with an average age of 12 years old. The age range of the parents (13 women and 4 men) that participated was from 36-52 years old with an average age of 44 years (the mean age for women was 42 years and for men 49 years old) (Table 3 Age structure for each age group of the PedsQL 3.00 DMD module).

Table 3. Age structure for each age group of the PedsQL 3.0 DMD module

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

With respect to the sociodemographic characteristic of the sample, it was achieved to obtain a variety in terms of geographical distribution, heredity of the disease, and educational level. The sample came from different places in Greece and in particular 12 were from Attica (Athens), 3 were from northern Greece (area of Kavala), 2 were from southern Greece (1 from Patras, 1 from Korinthos), and two from eastern Greece (1 from Arta, 1 from Amphilochia).

As for heredity, this was the case for 13 parents and for the rest four it was de novo mutation. There were differences in the educational level as 7 had graduated from high school, 5 had higher education referred to either a university degree or Master of Science and 6 had scientific training diploma. 15 out of 17 of the participants were receiving an allowance due to the condition of the boy. Additionally, concerning their work status, 13 were working either full-time or with reduced hours due to the child's condition, 4 weren't working due to the child's condition and one had an early retirement for the same reason. All parents were married except for two cases (1 divorced and 1 single mother).

Regarding some of the milestones of the standard of care receiving the boys, 15 out of 17 were on cortisone and 16 out of 17 were on physiotherapy. As it concerns their ambulation status, in the age group of 13-18 years, 3 were non-ambulant and 2 ambulant, in the age group of 8-12 years, 4 were ambulant and 1 non-ambulant while in the age group of 5-7 years old, all boys were ambulant. A wide heterogeneity of the boys' population was also confirmed by the kind of mutation in each case.

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3.1.2 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. In the age group of 5-7 years old, some parents expressed their doubt whether the fact that their kids could not meet some skills was the result of their condition or their overprotectiveness due to their condition regarding the items of "*everyday life*". And by answering the questionnaire they realized this. Item number 1 "*to eat with fork and knife*" raised also questions, in particular for young children because the majority of parents do not let their kids use the knife anyway. They were told that the question had to do with being able to eat on their own without help. Another parent in the 8-12 years age group commented that he was rather skeptical whether his kid understands the meaning of the expression "*his muscle problem*" due to the fact that while the kid's score in the question *"It is hard to manage my muscle problem"* was "0" (not a problem), the parent's score to the respective question "*Difficulty managing his or her muscle problem*" was "4" (very much of a problem). In general, the questionnaire was well accepted although not all of the kids are aware of their situation with details, meaning that some kids do not know the name of their disease, others do not know its progression either due to their parents' reluctance of letting them know or due to their age and their degree of maturity to conceive it. But as no other alternatives were proposed instead of this expression, the investigator kept it as such.

The translation of the introductory page (1st page) of each questionnaire either self-reports or proxy ones was kept the same as in the PedsQL 4.0 generic core GR, for the PedsQL 3.0 DMD module GR to be aligned with the questionnaire of the Greek version of the generic core.

Table 4 presents 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. These results are not sufficient to validate the questionnaire, because more assays are needed for its validation, such as the calculation of internal consistency and reliability (Cronbach's alpha factor), item subscale correlations, test-retest reliability parent-child agreement, and construct validity. And for it, a wider sample of patients and their parents is needed. Since the results of the patients testing the Greek translation of the PedsQL 3.0 DMD Module were well perceived, the PedsQL 3.0 DMD Module-GR questionnaire could be attributed to a larger number of participants. Although the sample is very small, the results in each age group reflect the course of the disease. The total results of the scale score decrease as the age increases, which is expected taking into consideration the worsening of the patient's condition as they grow older. This tendency is described both in self-reports as well as in parent proxy reports. Nevertheless, the degree of agreement between self-reports and parent-proxy reports differs a lot as patients' scores are higher than their parents in the respective sections of the questionnaire. But this has been observed in other studies also, as it seems that parents translate their children's abilities and attitudes more dramatically than they do the children themselves.

3.1.3 Discussion

DMD has profound implications for the long-term functionality of young children, imposing chronic disabilities that severely limit their daily activities. As the symptoms of dystrophy advance, these children progressively lose their ability to participate in and show interest in various tasks. The impact of DMD extends beyond the affected children, significantly affecting the quality of life of their parents. The parents find themselves bound to the child's side, providing constant assistance in household chores and the child's responsibilities. This situation necessitates their unwavering commitment to ensure the smooth functioning of both the household and the child's well-being.

With the expansion of clinical trial initiatives on a global scale and the growing focus on pediatric demographics, there arises a heightened demand for a diverse array of pediatric patient-reported outcome (PRO) assessments, inclusive of translations into various languages. However, there aren't many options for disease-specific questionnaires for Duchenne Muscular Dystrophy to assess the quality of life with health-related quality of life questionnaires, Quality of Life Inventory (PedsQL)3.0 Duchenne Muscular

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Dystrophy module was chosen to be translated in the Greek language as it has already been used in similar studies, it is simple and quick and it can be combined with Quality of Life Inventory (PedsQL) 4.0 Generic Core which has been already translated into Greek and has been validated. Hence, the primary objective of the present study was to undertake the translation of a comprehensive assessment tool designed to gather feedback from parents/caregivers of children diagnosed with DMD. This tool aimed to capture vital insights into the daily lives of both the children and their parents, shedding light on the challenges and difficulties encountered during routine days. By delving into the experiences and perspectives of parents and children alike, the study sought to gain a deeper understanding of the multifaceted issues and obstacles they confront regularly.

Table 4. Score results of the 4 multi-dimensional scales of the PedsQL 3.0 DMD Module

	Children age group							
	5-7			8-12			13-18	
	n	Mean	SD	n	Mean	SD	n	Mean	SD
Parents								
Daily Activities	6	65,83	14,29	6	51,67	14,72	5	55,00	30,41
Treatment	6	85,42	10,94	6	66,67	15,14	5	56,25	17,68
Worry	6	82,22	14,40	6	59,72	28,95	5	48,33	30,42
Communication	6	86,11	12,55	6	65,28	29,07	5	58,33	25,00
Total Score	6	79,90	9,84	6	60,83	12,53	5	54,48	21,55
Children								
Daily Activities				6	68,33	20,41	5	70,00	27,16
Treatment				6	72,92	17,97	5	70,00	20,92
Worry				6	74,31	16,33	5	70,83	27,80
Communication				6	65,00	27,26	5	78,33	17,28
Total Score				6	69,87	6,59	5	72,29	19,72

The translation of Quality of Life Inventory (PedsQL) 4.0 Generic Core used as guidance for the translation of Quality of Life Inventory (PedsQL) 3.0 Duchenne Muscular Dystrophy module. As the cognitive interviews couldn't take place in one day with all the participants gathered together due to COVID-19 rules for social distance, participants and researchers missed the opportunity to interact concerning the comments made on the linguistic adaptation in the Greek language and culture. However, patients and their caregivers took the procedure well enough to encourage the next steps.

4 Conclusion

In general, the questionnaire was well-perceived and well-accepted. The results of the above test confirmed the feasibility of administering the Greek version of the PedsQL 3.0 DMD Module. It has a clear focus and is concise. The translation of the questionnaire into Greek was reported by the majority of members of the pilot sample to be easy to understand and adequately adapted to 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, to create a fully harmonized Greek version of the PedsQL 3.0 DMD module, and to measure the health-related quality of life of Duchenne patients in Greece, in regards to the contribution of several interventions that aim to improve Duchenne Patients' quality of life in Greece.

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Contribution of Individual Authors to the Creation of a Scientific Article
- Eleni Katsomiti, Catherine Kastanioti, and Elisabeth Chroni attributed to the study conception and design
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- George Mavridoglou was responsible for the statistics
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Conflict of Interest
The authors have no conflicts of interest to declare.