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Longo Araújo de Melo, Egmar; Moreno Valdés, Maria Teresa; Pinto da Silva, Cruiff Emerson; Badia Corbella, Marta; Arias Martínez, Benito

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# QUALITY OF LIFE AND WISHES IN DUCHENNE MUSCULAR DYSTROPHY: THE PERCEPTION OF CHILDREN AND THEIR PARENTS

## *Qualidade de vida e desejos em Distrofia Muscular de Duchenne: percepções de crianças e de seus pais*

Artigo Original

### ABSTRACT

**Objective:** To assess the agreement between children with Duchenne Muscular Dystrophy (DMD) and their parents regarding the perception of quality of life (QOL) and the wishes expressed by children. **Methods:** The study involved 14 patients (median age = 9.9 years-old) followed up in Sarah Rehabilitation Center – Fortaleza, Brazil and their parents. The following instruments were used: AUQEI questionnaire (Autoquestionnaire Qualité de Vie Enfant Imagé) and Three Wishes Projective Technique, this being analyzed by Nereo & Hinton's system of categories (2003). **Results:** The analysis of AUQEI showed a good agreement with ICC (intraclass correlation coefficient) = 0,699 and a positive and significant correlation between scores of both children and their parents ( $\rho = 0.54$ ,  $p < 0.05$ ). The Three Wishes also showed a good agreement, mainly in the categories of Material Goods and Activities. **Conclusions:** Despite children with DMD and their parents exhibited similar perceptions of the QOL and wishes, we suggest that both be heard in respect to aspects of the rehabilitation program. This study provides additional data concerning the need for child QOL assessment instruments that include parallel versions directed to the children and their parents.

**Descriptors:** Muscular Dystrophy, Duchenne; Quality of life; wishes; agreement

### RESUMO

**Objetivo:** Avaliar a concordância entre crianças com Distrofia Muscular Progressiva do tipo Duchenne (DMD) e seus pais no que diz respeito à percepção de qualidade de vida (QV) e desejos expressados pelas crianças. **Métodos:** O estudo envolveu 14 pacientes (média de idade de 9,9 anos) em acompanhamento no Centro de Reabilitação Sarah Fortaleza – Brasil e seus pais. Os seguintes instrumentos foram utilizados: questionário AUQEI (Autoquestionnaire Qualité de Vie Enfant Imagé) e a Técnica Projetiva dos Três Desejos, esta analisada através do sistema de categorias de Nereo e Hinton (2003). **Resultados:** A análise do AUQEI mostrou boa concordância com coeficiente de correlação intra-classe (ICC) de 0,699 e correlação positiva e significativa entre os escores de ambos crianças e pais ( $\rho = 0.54$ ,  $p < 0.05$ ). Quanto aos Três Desejos, também houve concordância com predomínio das categorias Bens Materiais e Atividades. Apesar de que crianças com DMD e seus pais exibiram percepções similares de QV e desejos, sugerimos que ambos sejam ouvidos com relação a aspectos do programa de reabilitação. **Conclusão:** Este estudo proporciona dados adicionais com respeito à necessidade de utilizar instrumentos para avaliação da QV infantil que incluam versões paralelas para as crianças e seus pais.

**Descritores:** Distrofia Muscular de Duchenne; Qualidade de Vida; desejos; concordância

Egmar Longo Araújo de Melo<sup>(1)</sup>  
Maria Teresa Moreno Valdés<sup>(2)</sup>  
Cruiff Emerson Pinto da Silva<sup>(3)</sup>  
Marta Badia Corbella<sup>(1)</sup>  
Benito Arias Martínez<sup>(1,4)</sup>

1) University of Salamanca  
– Salamanca - Espanha

2) University of Fortaleza (UNIFOR)  
– Fortaleza - CE – Brazil.

3) Sarah Rehabilitation Center  
– Fortaleza - CE – Brazil.

4) University of Valladolid  
– Valladolid - Espanha

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## INTRODUCTION

“Leo, 10 years old, presenting of Duchenne Progressive Muscular Dystrophy (DMD) and had been unable to walk for 6 months. Since then he had used a child wheelchair for locomotion. When asked how he felt about his condition, he said that he was fine because he could still play with his friends in the street, go to school and move around the house. His mother told a different story: Leo has been sad since he lost the ability to walk. Although the wheelchair allows him to go to school, he has been unable to play with his friends as before and generally refuses to leave the house to attend social events.”

This divergence of opinion is the central point of this paper: do parents know their children well enough to assess subjective aspects such as quality of life (QOL) and wishes?

Although studies of child QOL have often used parents as respondents, in recent years the opinion of the children themselves has been more valued<sup>(1-6)</sup>. This is the result of studies that showed divergence of opinion between parents and children in relation to child QOL<sup>(7-10)</sup>.

Child QOL is characterized by the subjective perception of the child in conjunction with objective aspects related to five domains: emotional well-being, physical well-being, interpersonal relations, personal development and activities and material well-being<sup>(11)</sup>.

The main difficulties in studying QOL in childhood are the lack of well-structured conceptual models and of valid and reliable assessment instruments that can be used in different groups and contexts<sup>(12,13)</sup>.

Eiser and Morse<sup>(14)</sup> call attention to the difference between how children and adults view QOL. Duffy et al.<sup>(15)</sup> showed clearly that there is a good degree of agreement between children with chronic arthritis and their parents in respect to the assessment of aspects that directly affect QOL, such as physical and psychological function, as well as general symptoms.

The use of representatives to assess QOL in childhood arises from the hypothesis that children are not reliable respondents, owing to their lack of linguistic and cognitive ability to understand and respond to questionnaires<sup>(13,16,17)</sup>.

Eiser and Morse<sup>(14)</sup> report that children are capable of expressing emotions, depending on how they are questioned and reinforce the importance of using figures to help in understanding the response options. The advantages of using figures include increasing the children's interest, improving their understanding, and holding their attention, which contributes to obtaining more reliable responses<sup>(4,14,18)</sup>. Studies show that from the age of 5 years children can be considered reliable respondents and can assess their disability<sup>(5,10,19,20)</sup>.

Despite innumerable advances in the health field and the emergence of new drugs, some diseases remain incurable, such as DMD, a genetic condition that affects 1:3500 male births<sup>(21,22)</sup>. Its progressive and fatal evolution may have a significant impact on the life of a child and compromise QOL<sup>(23-26)</sup>.

Although it is considered rare, many patients with DMD undergo systematic treatment at rehabilitation centers in Brazil. A review article on QOL in DMD reported the lack of research in Brazil and no study was found in the international literature that assessed the agreement between parents and children with DMD<sup>(27,28)</sup>.

The purpose of this article was to assess the agreement between children with DMD and their parents in respect to QOL and the wishes expressed by the children.

## METHODS

A total of 14 patients with DMD, treated at the Sarah Rehabilitation Center in Fortaleza, Brazil, and their main caregiver (father, mother or grandfather) took part in the study.

This study was approved by the Research Ethics Committee of the Sarah Network of Rehabilitation Hospitals. The data were collected at the Sarah Rehabilitation Center Fortaleza between August and October, 2005. Number of Ethical Approval: 14.200353/03 (11/08/2005)

The children were interviewed individually by the first author who, immediately afterwards, interviewed one of the parents, who was instructed to answer the questions, taking into account the child's perception. The data collection instruments used were: the AUQEI (Autoquestionnaire Qualité de Vie Enfant Imagé) questionnaire and the Three Wishes Projective Technique.

The qualitative assessment responses (Three Wishes Projective Technique) were recorded and subsequently fully transcribed.

The AUQEI, validated in Brazil by Assunção Jr. et al.<sup>(29)</sup>, is a generic questionnaire to assess quality of life, directed to children from 4 to 12 years of age, and is considered a valid and reliable second review of child QOL instruments<sup>(2)</sup>. It consists of 26 questions that explore family and social dimensions, activities, health, body functions and separation, comprising the 4 domains: Function, Autonomy, Family and Leisure.

The instrument was read by the first author, who used the AUQEI faces to facilitate the understanding of the test. Scores of 0, 1, 2 and 3 correspond, respectively to very unhappy, unhappy, happy and very happy, which enables the obtaining of a single score resulting from the sum of the scores attributed to the items.

The Three Wishes Projective Technique was used to provide a “window” within the child’s emotional experience, particularly for wishes that touch on difficulties experienced by the child<sup>(30)</sup>.

For the application of the Three Wishes Projective Technique, the caregivers were instructed to answer, according to their own perception, which three wishes the child would like to have fulfilled. They were questioned as follows: If your child could make three wishes, any three wishes in the entire world, what would they be? The same question was asked to the children: If you could make three wishes, any three wishes in the entire world, what would they be?

All children were subjected to a psychometric evaluation using the Raven’s Progressive Matrices - Special Scale.

### Data analysis

#### AUQEI questionnaire

The level of agreement between the children and their parents was analyzed using the intraclass correlation coefficient (ICC) for the two-way model (ICC 1 and ICC 2), with absolute agreement and confidence interval of 95%. The agreement values were interpreted, taking into account the criteria of April et al.<sup>(31)</sup>: slight agreement (< 0.20); fair agreement (0.21-0.40); moderate agreement (0.41-0.60); good agreement (0.61-0.80) and very high agreement (> 0.81).

Paired t-test was used to analyze the agreement of each domain and the results are shown in a box-plot graph. The total test scores of the children and of the parents were correlated using Spearman’s correlation coefficient (with correction for tie scores) and its respective significance level of 5%. Wilcoxon’s test was performed to determine if there was a difference between the child’s and the parent’s perception of QOL (significance level of 5%).

SPSS (Statistical Package for the Social Sciences) software, version 13, was used to tabulate and analyze the data.

#### Three Wishes Projective Technique

The responses were transcribed and classified according to the categorical system established by Nereo and Hinton<sup>(27)</sup>, considered valid and reliable.

The system includes: 1) Material goods; 2) Pets; 3) Activities; 4) Family/interpersonal; 5) Future/goal; 6) Personal attribute; 7) Situational; 8) Situational/Health-Related; 9) Altruism; 10) Fantasy; 11) Negative wishes; 12) No wishes; 13) Miscellaneous.

The distribution of the children’s responses was performed by consensus.

## RESULTS

The sample comprised children in the 8 to 11 age group (mean of 9.9 years), with a predominance of 11 year-olds (42.9%). Only four patients (28.6%) did not attend school and of these, none were able to walk. Eleven patients (78.6%) could not walk, 2 (14.3%) were able to walk and 1 (7.1%) was in transition to a wheelchair. From the 11 patients who could no longer walk, 3 (27.3%) had no wheelchair. The results of psychometric assessment suggest that 8 children had cognitive repertoire consistent with the age, and 6 children had mild to moderate intellectual disability (Table I). Depressive symptoms were not identified in any of the studied patients, after screening conducted by the Department of Psychology of Children’s Rehabilitation Program.

In respect to the socioeconomic characteristics of the family, 92.9% owned their own house, 50% had elementary level schooling, and only 28.6% had finished high school. Eighty-five percent of the caregivers were mothers, in addition to 1 father (7.5%) and 1 grandfather (7.5%) who filled the role of father (Table I). As to family income, 14.3% reported earning 1 minimum monthly wage\* while 50% reported earning 2 minimum wages (\*at the time it was equivalent to 350 reais or 190 US dollars).

Table I - Child characteristics

| Child Characteristics (n=14)    |                  |
|---------------------------------|------------------|
| <b>Mean age, y (SD)</b>         | <b>9,9 (1,1)</b> |
| <b>Intellectual Disability*</b> |                  |
| Yes                             | 6                |
| No                              | 8                |
| <b>School</b>                   |                  |
| Yes                             | 10               |
| No                              | 4                |
| <b>Locomotion</b>               |                  |
| Gait                            | 3                |
| Wheelchair                      | 11               |
| <b>Parent participant</b>       |                  |
| Father                          | 1                |
| Mother                          | 12               |
| Grandfather                     | 1                |

\*Evaluated by the Raven’s Progressive Matrices - Special Scale.

Playing was the most widely reported activity (38.1% of the patients), followed by going on outings (27.3%) and playing videogames (13.6%). Riding a bicycle, watching television, going to church, going to the beach or traveling with their family were also cited as leisure activities.

### Three Wishes Projective Technique

The categories resulting from the responses of the children and of their parents are shown in Figure 1. The highest agreement between the children and their parents was in the Material Goods category. The second most prevalent category was Activities, followed by Situational/Health-Related. The category Situational/Health-Related was reported by the parents through 11 wishes and by the children through 7 wishes, showing that, in the parents' perception, the children are more concerned with the disease than was in fact shown.

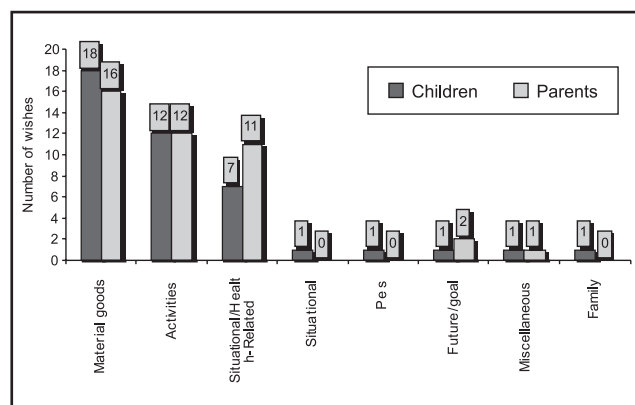


Figure 1 - Wishes of the children and of their parents by category

One finding that should be pointed out is the number of wishes mainly expressed by the children related to toys and other leisure activities. This shows that, despite the children had being able to express themselves on any aspect of their disease, playing was more referred than the many limitations imposed by DMD.

### AUQEI instrument

The result of ICC analysis showed a value of 0.699 ( $p < 0.05$ ), which represents good agreement between the children and their parents in relation to QOL.

The average QOL scores was respectively, 51 and 49 points, on the perception of children and of parents, which indicates good quality of life in the view of both, considering the cutoff score of 48, established by Assumpção Jr et al<sup>(29)</sup>. The distribution of the AUQEI scores of the children and of their parents is shown in Figure 2. A positive and

significant correlation was observed between the total test scores of the children and of their parents ( $\rho = 0.54$ ,  $p < 0.05$ ). Wilcoxon's test showed no significant differences, indicating that the children's perception of QOL did not differ from that of their parents. The t-test also showed no differences between the means of the children and of the parents.

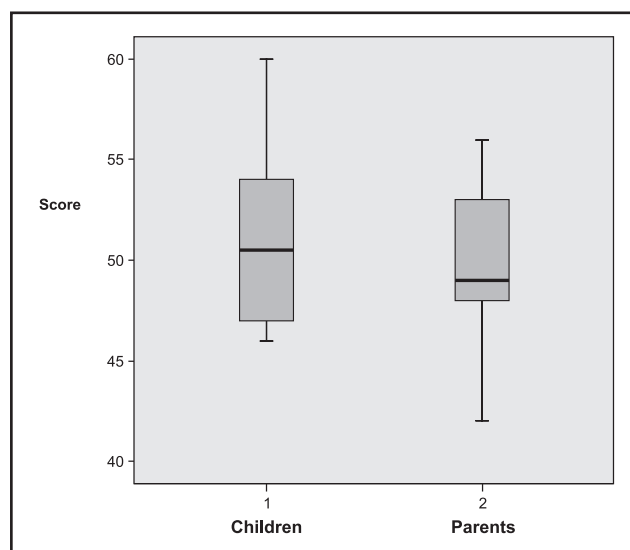


Figure 2 - Boxplots illustrating the distributions of AUQEI scores of children and their parents. NOTE: The box in each box plot spans the interquartile range, and lines indicate location of first quartile, median, and third quartile. Whiskers extend to the last data point within 1.5 times the interquartile range in either direction.

In Figure 3, the AUQEI scores of the children and of their parents are compared for each domain. The calculation for each domain of AUQEI was performed to investigate where the greatest agreement occurred. The results of this analysis yielded an ICC of 0.59 (moderate agreement) for the function domain; ICC of 0.58 (moderate agreement) for the leisure domain; ICC of 0.47 (moderate agreement) for the family domain; and ICC of 0.12 (slight agreement) for the autonomy domain. According to this analysis, the highest agreement was for the function and leisure domains, followed by the family domain.

## DISCUSSION

The main purpose of this investigation was to answer one of the most unsettling questions surrounding the methodology of child QOL research: Do parents know their children? Should child QOL be assessed through the perception of the children, their parents, or both?



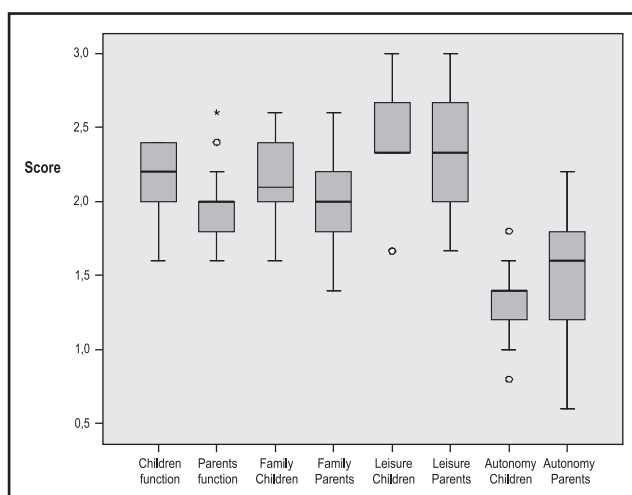


Figure 3 - Boxplot illustrating the distributions of AUQEI scores of children and their parents by domain. NOTE: The box in each box plot spans the interquartile range, and lines indicate location of first quartile, median, and third quartile. Whiskers extend to the last data point within 1.5 times the interquartile range in either direction and additional points present outlier observations.

Based on the AUQEI and Three Wishes Projective Technique results, we observed that the parents of the children under study knew them well.

As to the Three Wishes Projective Technique, the Material Goods Category prevailed in the perception of both, followed by the Activities category. This may be explained by the large number of wishes included in the Material Wishes and Activities categories and that these wishes are not directly limited by the disease, but rather represent real wishes that can be fulfilled despite the restriction in mobility.

Although it is supposed that the impact of the disease could be expressed through the predominance of the Situational/Health-Related category, it occupied the third place in the perception of both. However, it is important to point out that it was more prevalent in the parents' perception. This evidences that agreement is affected by parental stress and that mothers who consider their well-being poor, judge their children in the same way<sup>(10,32,33)</sup>.

Nereo and Hinton assessed the Three Wishes of children with DMD and compared them to the wishes of their healthy siblings and to those of a group of non-related healthy children. The results showed that only 16.25% of the patients with DMD expressed health-related wishes. The authors emphasize that these results may be owing to the age group of the study subjects (6-12 years), since it is from the beginning of adolescence and the onset of adulthood that the greatest limitations of the disease are observed<sup>(30)</sup>.

Different from the research performed by Nereo and Hinton<sup>(30)</sup>, this study assessed the Three Wishes of the

children according to their own perception, as well as that of their parents. It is worth mentioning that, despite the parents' being instructed to respond according to what they judged to be the child's wish, the projection of their own wishes was observed. This can be seen by the greater number of wishes expressed by the parents in relation to walking, not as prevalent in the children, reflecting the fact that the families have greater concern for the disease than the children themselves<sup>(7,17)</sup>. The findings of this study in relation to the Three Wishes corroborate those of Nereo and Hinton and support the idea that children with DMD behave similarly to their healthy peers<sup>(30)</sup>.

The analysis of the AUQEI data showed good agreement between the children and their parents, with respect to the perception of QOL. In studies carried out in children with stomas, juvenile arthritis, cancer, cerebral palsy and asthma, there was also good agreement in the perception of QOL between children and their parents in most of the domains assessed<sup>(15,31-36)</sup>.

This may occur because children with greater motor damage are more dependent on their parents, which may reflect on a greater knowledge about the aspects related to the child's QOL. In accordance to this idea, Eiser and Morse observed less agreement between healthy children and their parents than in children with some type of disease<sup>(17)</sup>. Furthermore, it is suggested that parents become more aware over time of the difficulties faced by their children<sup>(28)</sup>. In the present study, 11 children had already lost the ability to walk, which confirms the advanced degree of muscle weakness suffered by the majority of the sample.

As to the isolated study of the domains, the ICC was higher for the Function, Family and Leisure domains. There are reports of greater agreement between caregivers and children in relation to the Physical Function and Physical Symptoms domains, compared to less visible domains, such as Social and Emotional Function<sup>(9,31,36)</sup>.

Another aspect to be emphasized is the lack of consensus regarding the statistical methods used to analyze the agreement between children and their parents. According to recent studies, the most suitable method to examine the agreement between examiners is the intraclass correlation coefficient, together with an analysis of mean score differences<sup>(17,37,38)</sup>. The present study was developed according to this tendency, in order to obtain a more reliable analysis of the agreement between children with DMD and their parents.

## CONCLUSIONS

In summary, despite children with DMD and their parents exhibit similar perceptions of the QOL and wishes of their children, we suggest that both be heard in respect to

aspects of the rehabilitation program. When both opinions are considered, the complementarity of information may translate into gains and changes in the rehabilitation program and as a consequence increase treatment compliance. Moreover, the rehabilitation professional will have the opportunity of hearing the child's opinion without the influence or interpretation of the parent.

These aspects reinforce the need for child QOL assessment instruments that include parallel versions directed to children and to their parents or caregivers.

This study used two instruments to assess the agreement between children and their parents, one quantitative and the other qualitative, and both showed similar perceptions. The main limitation of this research is the small and homogeneous sample, which may have influenced the results. However, it is worth noting the rare nature of the disease, which makes the sample representative of the region.

We suggest the development of studies involving children with DMD at different stages of the disease, as well as with distinct socioeconomic profiles, in order to analyze if these aspects influence agreement between children and their parents.

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**Address of correspondence:**

Egmar Longo Araújo de Melo  
 University of Salamanca - INICO  
 Avda. de la Merced, 109-131 37005  
 Salamanca - Espanha  
 Mail: egmarlongo@yahoo.es / egmarlongo@hotmail.com