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Physical Activity in Boys With Duchenne Muscular Dystrophy Is Lower and Less Demanding Compared to Healthy Boys

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Abstract

This study describes the amount of physical activity and perception of physical activity in boys with Duchenne muscular dystrophy (DMD) compared to healthy boys. A questionnaire described 6 domains of physical activity. Four Duchenne muscular dystrophy subgroups were made: early and late ambulatory, nonambulatory with relative good, or limited arm function. Eighty-four boys with Duchenne muscular dystrophy (15.0 $\pm$ 6.4 years) and 198 healthy boys (14.0 $\pm$ 4.3 years) participated. Daily activities were more passive for boys with Duchenne muscular dystrophy. Physical activity was less and low demanding compared to healthy boys. It decreased with disease severity ($P < .05$), whereas screen time increased ($P < .05$). Benefits of physical activity in boys with Duchenne muscular dystrophy were having fun and making friends. Barriers were lack of sport facilities and insufficient health. This study helps to quantify poor engagement in physical activity by boys with Duchenne muscular dystrophy, and demonstrates factors that contribute to it. Suggestions to stimulate physical activity are made.

Keywords

Duchenne muscular dystrophy, physical activity, neuromuscular disorders, physical activity questionnaire, perception of physical activity

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Duchenne muscular dystrophy is the most common inherited dystrophinopathy in children caused by the absence of the structural protein dystrophin. The estimated incidence is 1 in 5000 newborn boys.[1] The mean age of diagnosis is 5 years, although symptoms usually present themselves before this age. The clinical presentation of the disease is characterized by progressive muscle wasting and muscle weakness, starting in the proximal muscles and extending toward the distal muscles. Typically, the muscles of the lower extremity show clinically apparent weakness in an earlier phase compared to the muscles of the upper extremity.[2] Most boys with Duchenne muscular dystrophy become wheelchair-confined by the age of 12, with a mean age of 10 years if untreated with corticosteroids.[3,4] Soon after boys become wheelchair-dependent, their arm function declines.[5] Although there is no cure yet, life expectancy has improved to a median of 30 years because of use of corticosteroids and respiratory support.[4,6]

Regular physical activity is important to maintain good health. Furthermore, it is important for maintaining functional abilities and is also beneficial for quality of life and social participation.[7] Nevertheless, physical inactivity is fairly common in children with a disability.[8] They are more likely to develop a sedentary lifestyle compared to their healthy peers. For example, children with cerebral palsy are less physically active than their healthy peers.[9] For boys with Duchenne muscular dystrophy, the literature shows lower physical activity in ambulant boys compared to healthy boys from a young age onward. They made fewer steps and spent fewer minutes at moderate and high step rate compared to healthy boys.[10,11] However, for boys with Duchenne muscular dystrophy, regular mildly intensive physical activity has been shown to prevent disuse and other secondary complications of inactivity. Jansen et al[12] showed that assisted physical training with dynamic support, for example an electric bike, can avoid disuse. It is feasible, safe and helpful to preserve optimal physical capacities. Alemdaroglu et al[13] showed that upper extremity training can increase upper extremity muscular endurance, protect

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proximal muscle strength and is critical to improve and preserve functional levels. Despite the importance, little is known about physical activity in boys with Duchenne muscular dystrophy and whether physical activity decreases when the disease is progressing.

Various methods are used to assess physical activity including a diary, pedometry, accelerometry, and heart rate monitoring. Although they provide objective assessment of physical activity, they can be time consuming, uncomfortable and expensive. More importantly, they may not be reliable or suitable in persons with gait anomalies or in nonambulant persons.[7] When measuring large groups of boys with Duchenne muscular dystrophy, the method should be feasible for both ambulant and nonambulant boys. Physical activity questionnaires are a feasible method in large scale studies because of their low cost, convenience and low burden for the participant.[14] Moreover, a questionnaire can provide subjective assessments, for example why someone is physically active.

The primary aim of this study was to describe physical activity and the participant's perception of physical activity in boys with Duchenne muscular dystrophy compared to healthy boys. The secondary aim was to describe the physical activity in the different stages in the course of Duchenne muscular dystrophy.

Methods

Participants

The questionnaire was completed by boys with Duchenne muscular dystrophy, healthy boys or the parent/caregiver. Exclusion criteria were reported diagnosis with Becker muscular dystrophy or any other muscular dystrophy. Also, girls with Duchenne muscular dystrophy were excluded. Because the questionnaire was anonymous, no diagnosis of Duchenne muscular dystrophy on DNA level was available. The authors attempted to avoid including boys with Becker muscular dystrophy or a clinical intermediate profile by excluding boys who did not meet the diagnostic criteria of age at loss of ambulation. Since the use of prednisone, the age at loss of ambulation has increased from 10 years (SD 1.5 years) with approximately 2 standard deviations to 13 years.[17] The authors chose to add 1 standard deviation and exclude all boys with an age of loss of ambulation of $\geq$14.5 years. For the late nonambulatory group the authors excluded all boys with an age of loss of ambulation of $\geq$13.0 years, because these boys are older and did not all use corticosteroids. Exclusion criteria for healthy boys were being in a wheelchair or having a condition which influences the amount of physical activity, such as asthma. The Duchenne muscular dystrophy population was divided in 4 subgroups based on the Vignos[15] and Brooke scales.[16] Ambulant boys were in the early ambulatory (Vignos 1-3) or the late ambulatory stage (Vignos 4-8). Wheelchair-dependent boys are divided in an early nonambulatory stage with relative good arm function (Vignos 9-10, Brooke 1-3) and a late nonambulatory stage with a limited arm function (Vignos 9-10, Brooke $\geq$4).

Procedure

Boys with Duchenne muscular dystrophy were recruited from the members database of the Dutch patients' organization Duchenne Parent Project. Healthy boys were recruited from a local elementary and high school and a university. A filled in and returned questionnaire was considered as an informed consent, as agreed on with the medical ethics committee. The study was approved by the local medical ethics committee. All data were handled according to the guidelines of good clinical practice.

Development of the Questionnaire

A physical activity questionnaire was constructed out of existing physical activity questionnaires, since, to the authors' best knowledge, there is no existing questionnaire which assesses physical activity in boys with Duchenne muscular dystrophy. A literature search in PubMed contained the following search terms: questionnaire (MeSH Term), physical activity, sedentary behavior, child (MeSH Term), neuromuscular disease (MeSH Term) and Duchenne muscular dystrophy (MeSH Term). Thirty questionnaires were identified (see online Appendix A). After reviewing these questionnaires, 3 were selected which were suitable for use in healthy children and concerned physical activity or sedentary behavior. The final physical activity questionnaire consisted out of questions in 6 different domains:

1. Participant characteristics: the age, use of medication, diseases and participation in school or work. For boys with Duchenne muscular dystrophy, the Brooke and Vignos scale, comorbidities, age of wheelchair confinement, presence of scoliosis, and corticosteroid use were also assessed.
2. Transportation to school or work: questions about duration (in minutes) and the way of transportation (active or passive) to school or work were distracted from the Flemish Physical Activity Computerized Questionnaire.[18] Active transportation consisted of walking, cycling, hand biking or using other nonmotorized vehicles, and using a manual/e-motion wheelchair. Passive transport consisted of use of an electric wheelchair, a car, public transport, or a nonmotorized vehicle that is pushed by someone other than the boy himself.
3. Therapy: for the Duchenne muscular dystrophy population, questions about frequency, duration and type of therapy were added.
4. Physical activity intensity and type: the Modifiable Activity Questionnaire was used for questions about physical activity and exercise.[19] Frequency of engagement in different categories of physical activity were assessed: light physical activity (activities which do not increase heart rate or breathing, like normal walking or relaxed cycling), more strenuous physical activity (activities which increase heart rate and breathing, like running or dancing), and sports on a competitive level. Because the Modifiable Activity Questionnaire assesses physical activity and exercise in a healthy population, questions were modified to be relatable for the Duchenne muscular dystrophy population (eg, wheelchair hockey and swimming).
5. Screen time: the Healthy Lifestyle in Europe by Nutrition in Adolescence questionnaire was used to measure sedentary minutes spent on screen time-based and leisure time activities.[20]
6. Perception of physical therapy: questions were extracted from the Flemish Physical Activity Computerized Questionnaire to assess benefits and barriers of being physically active.[18]

Analysis

Descriptive statistics were used to calculate frequencies. Independent-samples *t*-tests were used to compare differences between boys with

Table 1. Participant Characteristics.

	Total Duchenne muscular dystrophy group (n = 84)	Early ambulatory stage (n = 24)	Late ambulatory stage (n = 9)	Early nonambulatory stage (n = 21)	Late nonambulatory stage (n = 30)	Healthy boys (n = 198)
Age (years) mean (SD)	15.5 (6.4)	8.9 (3.6)	13.1 (2.5)	16.1 (3.7)	21.1 (5.2)	14.0 (4.3)
Corticosteroid use (%)	66.2	81.0	88.9	78.9	39.3	—
Scoliosis (%)[a]	17/28/55	4/8/88	0/36/64	16/26/58	36/43/21	—

[a]severe scoliosis/mild scoliosis/no scoliosis.

Duchenne muscular dystrophy and healthy boys. One-way ANOVA with post hoc tests were used to compare differences between the subgroups of the Duchenne muscular dystrophy population. Statistical analyses were done with SPSS Statistics version 20.0 for Windows with a significance level set at $P < .05$.

Results

Participant Characteristics

The questionnaire was sent to 225 boys or men with Duchenne muscular dystrophy, 89 boys with Duchenne muscular dystrophy completed the physical activity questionnaire (response rate is 40%). Five questionnaires were excluded; 1 was filled in by a girl with Duchenne muscular dystrophy, 1 was an outlier because of the age of 49, and for 3 boys the age of wheelchair dependency was too high. The average age of wheelchair confinement was 11.1 years (SD = 1.7) for the early nonambulatory stage and 9.3 years (SD = 1.5) for the late nonambulatory stage. Two hundred seven healthy boys completed the questionnaire. Nine boys were excluded; 7 boys had asthma, 1 boy had juvenile idiopathic arthritis, and 1 boy had acquired brain impairment. Table 1 shows the participant characteristics.

Transportation to School or Work

The majority of healthy boys (93%) used active transportation to go to school or work (cycling or walking) whereas only a small percentage of boys with Duchenne muscular dystrophy (13%) used active transport. The percentage of boys using active transport decreased when the disease is progressing. Healthy boys spent less minutes on transportation than the total Duchenne muscular dystrophy group ($P < .001$), the late ambulatory stage ($P = .003$), the early nonambulatory stage ($P = .003$), and the late nonambulatory stage ($P < .001$). Also, boys in the early ambulatory stage spent less minutes on transportation than the late nonambulatory stage ($P = .022$). The mean time spent on transportation to school or work and the way of transportation are listed in Table 2.1.

Therapy

Table 2.2 shows an overview of therapy type, therapy frequency, and duration in boys with Duchenne muscular dystrophy. The majority (86%) of the boys engaged in physical therapy. The mean duration of therapy was 50 minutes (SD = 45). There was no difference in therapy duration between the different Duchenne muscular dystrophy stages (all $P > .05$).

Physical Activity Intensity and Type

For boys with Duchenne muscular dystrophy, the percentage of boys who did not engage in light or strenuous exercise increased with disease progression ($P < .01$) (see Figure 1). All boys in the early and late ambulatory stage engaged in light exercise, for example riding their wheelchair or cycling at an easy pace. Of those in the early ambulatory stage, 9% did not engage in strenuous exercise like wheelchair hockey or swimming. More than a third of the boys in the late ambulatory stage did not engage in strenuous exercise. In the early nonambulatory stage a small percentage reported not to engage in light (5%) and strenuous exercise (10%). In the late nonambulatory stage the percentage of boys which reported not to be engaged in light exercise increased to almost 50%. Two-thirds of this group did not engage in strenuous exercise.

Table 2.4 shows the engagement in sport activities and competition over the last year. A higher percentage of healthy boys (88%) played sports over the last year compared to boys with Duchenne muscular dystrophy (69%). More than 80% of the healthy boys played sports in a competition compared to almost 40% of boys with Duchenne muscular dystrophy. The percentage of boys with Duchenne muscular dystrophy playing sports decreased when boys become nonambulant and when arm function is declining, although not significantly. However, in the early nonambulatory stage almost two-thirds of the boys still played sports in competition. In this group, the most commonly played sports were wheelchair hockey, swimming and table tennis.

More than half of the school going boys with Duchenne muscular dystrophy participated in physical activity classes at school, whereas all of the school going healthy boys had physical activity classes at school, see Table 2.5. Almost half of the school going healthy boys and a third of the total Duchenne muscular dystrophy group practiced swimming at school. This was the highest in the early nonambulatory stage, as almost half of these boys engaged in swimming at school.

Screen Time

Table 2.6 shows screen time and leisure time activities. Boys with Duchenne muscular dystrophy had higher screen time

Table 2. Physical Activity Questionnaire Outcomes.

	Total Duchenne muscular dystrophy group (n = 84)	Early ambulatory stage (n = 24)	Late ambulatory stage (n = 9)	Early nonambulatory stage (n = 21)	Late nonambulatory stage (n = 30)	Healthy boys (n = 198)
2.1 Transportation						
Active/passive transportation (%)	13/87	36/64	0/100	5/95	0/100	93/7
Transportation time in minutes per day (SD)	83.5 (85.7)	33.2 (33.5)	105.0 (115.9)	80.6 (50.9)	117.1 (108.5)	32.7 (41.6)
2.2 Therapy type, frequency and duration in boys with Duchenne muscular dystrophy						
No therapy (%)	7	13	11	0	7	—
Physiotherapy (%)	86	83	78	95	83	—
Occupational therapy (%)	29	25	33	24	33	—
Hydrotherapy (%)	32	30	22	53	23	—
Music therapy (%)	12	8	22	19	7	—
Play therapy (%)	4	0	0	10	3	—
Other forms of therapy (%)	10	29	0	5	0	—
Mean therapy time in minutes (SD)	50 (41)	52 (54)	40 (36)	62 (51)	43 (35)	—
2.3 Light and strenuous exercise in the last 2 weeks						
Light exercise						
No exercise (%)	18	0	0	5	47	4
1 to 5 days (%)	34	13	44	53	33	30
6 days or more (%)	59	87	56	43	20	66
Strenuous exercise						
No exercise (%)	33	9	33	10	67	5
1 to 5 days (%)	51	52	56	81	30	34
6 days or more (%)	16	39	11	9	3	61
2.4 Sport activities						
Playing sports (%)	69	73	90	65	61	88
Sport competition (%)	39	21	46	57	61	82
2.5 Physical activity and swimming at school (only school going boys)						
Physical activity at school (%)	76	90	50	81	67	100
Minutes per class (mean ± SD)	44 (14)	44 (11)	36 (10)	43 (21)	48 (7)	56 (25)
Swimming (%)	33	32	30	44	22	47
Minutes per class (mean ± SD)	38 (11)	45 (13)	38 (11)	33 (6)	30 (0)	43 (10)
2.6 Screen time and leisure time activities						
Screen time (hours per day), mean (SD)	5.9 (4.0)	3.5 (3.3)	4.9 (3.5)	6.4 (2.6)	8.3 (4.6)	4.5 (3.0)
Playing an instrument (%)	10	5	20	12	8	25
Time spent on video games						
Minutes per weekday, mean (SD)	94 (90)	42 (26)	93 (106)	110 (86)	133 (109)	77 (69)
Minutes per weekend day, mean (SD)	153 (147)	93 (95)	138 (117)	159 (116)	221 (210)	109 (93)
2.7 Perception of physical activity						
% of boys not enough physical activity	32	13	11	30	56	11
2.8 Benefits and barriers of physical activity						
Benefits						
Having fun (%)	88	96	100	90	73	94
Making friends (%)	69	68	78	74	60	51
Better physical condition (%)	69	71	67	80	55	86
Getting a kick from winning (%)	42	17	63	63	41	55
Feeling less anxiety (%)	27	35	22	33	14	31
Losing weight (%)	21	22	11	32	15	38
Barriers						
Lack of sport facilities (%)	31	22	22	53	26	5
Insufficient health (%)	23	4	18	28	38	6
Large distance to facilities (%)	17	19	11	29	9	3
No interests in sport/PA (%)	14	17	0	6	24	13
Lack of time (%)	6	4	0	6	9	29
Too expensive (%)	4	0	0	17	0	5

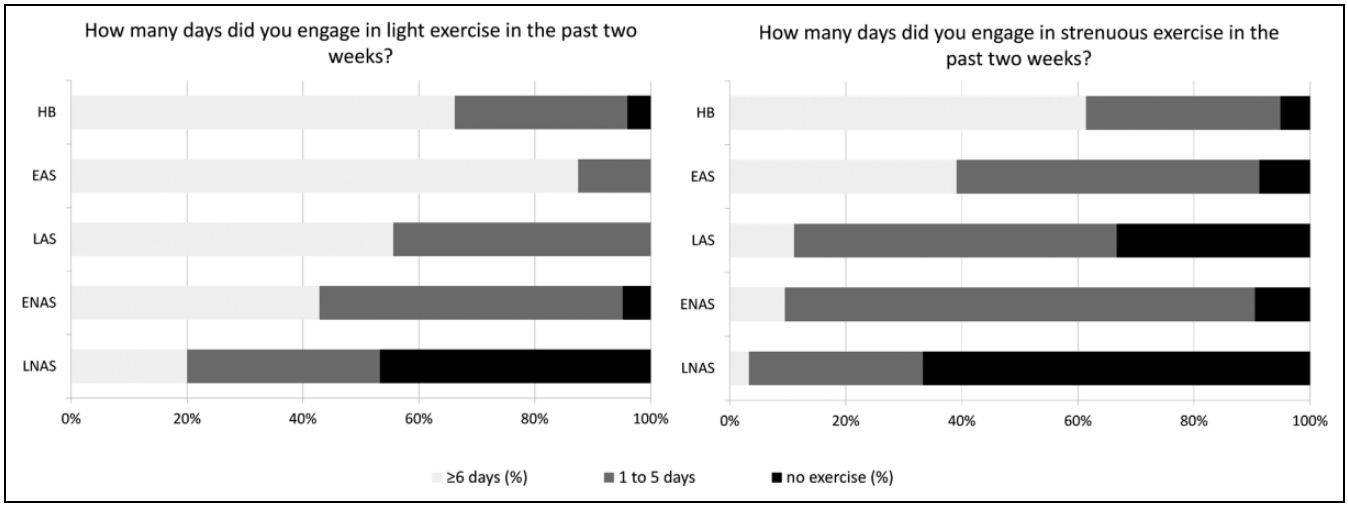

Figure 1. The frequency of light and strenuous exercise in the last 2 weeks. Abbreviations: EAS, early ambulatory stage; ENAS, early nonambulatory stage; HB, healthy boys; LAS, late ambulatory stage; LNAS, late nonambulatory stage.

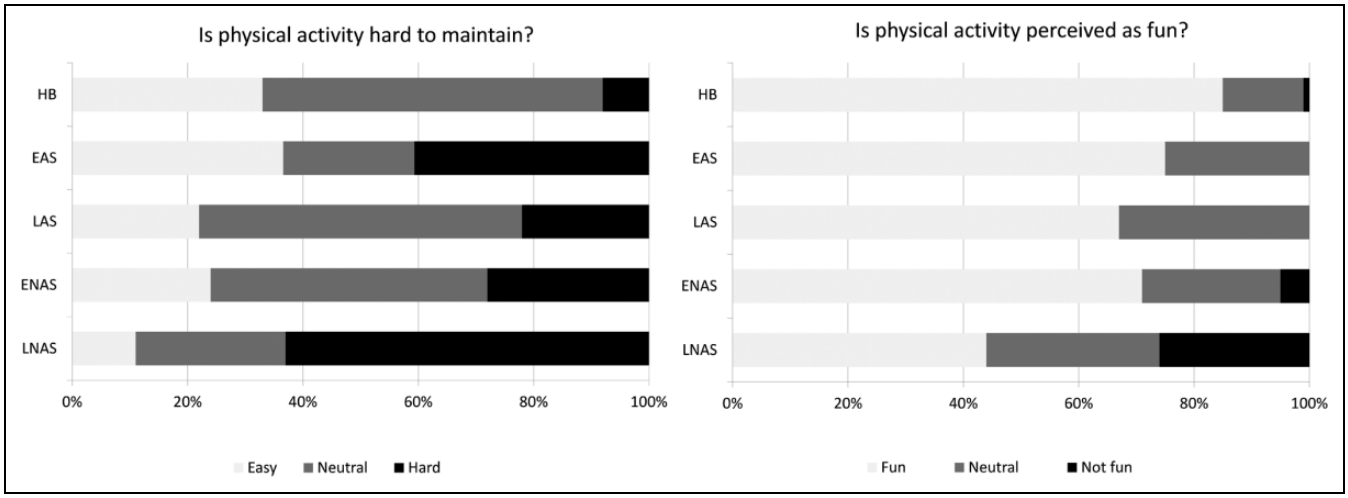

Figure 2. Perception of physical activity. Abbreviations: EAS, early ambulatory stage; ENAS, early nonambulatory stage; HB, healthy boys; LAS, late ambulatory stage; LNAS, late nonambulatory stage.

than healthy boys ($P = .004$). Also, the late nonambulatory stage had a higher screen time than the healthy boys ($P < .01$), the early ambulatory stage ($P < .01$), and the late ambulatory stage ($P = .03$).

On both weekdays and weekend days, the times spent playing video games increased with disease progression ($P < .001$). Boys with Duchenne muscular dystrophy in the late nonambulatory stage spent more time playing video games than healthy boys (weekdays: $P = .04$, weekend days: $P = .001$) and boys with Duchenne muscular dystrophy in the early ambulatory stage (weekdays: $P = .002$, weekend days: $P = .00$).

Perception of Physical Activity

Perception of whether physical activity was easy or hard to maintain and fun is shown in Figure 2. Exercising was easy to maintain for healthy boys. The percentage of boys with Duchenne muscular dystrophy who found it hard to maintain exercising increased with the disease stage. The majority of the healthy boys perceived physical activity as fun. The percentage of boys with Duchenne muscular dystrophy who perceived physical activity as fun was highest in the early ambulatory stage and in the early nonambulatory stage. As the disease is progressing, more boys with Duchenne muscular dystrophy perceived physical activity as not fun. This is highest in the late nonambulatory stage, where almost a quarter of the boys perceived physical activity as not fun.

The majority of the healthy boys felt they have sufficient physical activity, see Table 2.7. This was comparable to boys with Duchenne muscular dystrophy in the early and late ambulatory stage. However, this percentage decreased when boys become nonambulant. In the late nonambulatory stage almost three-quarters of the boys found it hard to maintain enough physical activity.

Benefits and barriers of physical activity are listed in Table 2.8. The most important advantages of physical activity for all groups were a better physical condition, making friends and having fun. For the total group of boys with Duchenne muscular dystrophy, the most important barriers were lack of sport facilities, insufficient health and a large distance to the sport facilities. The percentage of boys who perceived these factors as barriers is highest in the early nonambulatory stage. For healthy boys, the most important barriers for physical activity were lack of time and no interests in sports or physical activity.

Discussion

The aim of this study was to describe physical activity and perception of physical activity in boys with Duchenne muscular dystrophy compared to healthy boys. The secondary aim was to describe physical activity in the different stages in the course of Duchenne muscular dystrophy. The results showed that the intensity and amount of physical activity was lower in boys with Duchenne muscular dystrophy compared to healthy boys and decreased with disease stage, as expected. As the disease progresses, it becomes more difficult to maintain enough physical activity. Lack of sport facilities was the most mentioned barrier for physical activity in boys with Duchenne muscular dystrophy. Still, physical activity was perceived as fun, even for the majority of the more affected boys. Having fun and making friends were the most mentioned benefits of physical activity.

According to the WHO guidelines, children should be physically active for at least 60 minutes each day at a moderate to vigorous intensity.[21] A large part of the healthy boys in the study does not meet these criteria. Also, the boys with Duchenne muscular dystrophy in the study do not meet these criteria, especially in the late nonambulatory group. Bendixen[22] also showed that the amount of time boys with Duchenne muscular dystrophy engage in an activity decreased as boys grow older. Interestingly, in this study, a large part of the early nonambulatory boys report to engage in strenuous activities. This might be explained by the popularity of wheelchair hockey in the Netherlands. Boys in the early nonambulatory phase use a hand hockey stick, and thus perform arm activity. For boys with Duchenne muscular dystrophy this can be considered as strenuous activity, since they use a higher percentage of their maximal possible muscle contraction compared to healthy boys.[23] Physiotherapy and hydrotherapy contribute to the amount of physical activity in boys with Duchenne muscular dystrophy. The results show that the majority of the boys with Duchenne muscular dystrophy have physiotherapy. In contrast, the percentage of boys who have hydrotherapy or do swimming at school is very low, while swimming is highly recommended by Bushby for boys in the ambulatory and early nonambulatory stage.[24] Furthermore, the results show that boys with Duchenne muscular dystrophy spend more than the recommended time on sedentary behavior (computer use and/or watching TV/DVD).[21]

Common daily activities, such as transportation to school are also more passive for boys with Duchenne muscular dystrophy. Boys with Duchenne muscular dystrophy use almost no active modes of transportation to go to school or work, whereas the majority of healthy children use an active mode of transport. In healthy children, literature shows positive associations between active transportation and being physical active.[25] It would be very useful to explore whether this also applies to boys with Duchenne muscular dystrophy. An example of an active mode of transportation is using a wheelchair with power assisted wheels. Boys with Duchenne muscular dystrophy often go to schools for children with a disability, which are not always as close by as regular schools. This explains longer distances to their school or work, or a long pickup route and transfer time. Extra attention must be paid to compensate for this passive behavior for a significant amount of time each day.

This study has several limitations. First, the total questionnaire is new and not yet validated. However, the major part of the questionnaire contained parts of already existing, validated questionnaires. Second, the authors did not have a confirmation of the Duchenne muscular dystrophy diagnosis because they used an anonymous questionnaire. However, the authors tried to avoid including boys with Duchenne muscular dystrophy with a clinical intermediate profile or with Becker muscular dystrophy by excluding boys who had a relative high age of wheelchair dependency. Third, boys with Duchenne muscular dystrophy were scored on the Brooke and Vignos scale by their parents or themselves (if the boy was adult) and not by a professional. This may have had some influence on the placement in the subgroups. Fourth, the number of boys within each subgroup was relatively small. Finally, the questionnaire was subjective. It is possible that the amount of physical activity is overestimated.

It is not surprising that the amount and the intensity of physical activity is lower in boys with Duchenne muscular dystrophy, since loss of strength and decreased mobility limit the options to be physically active. This study helps to quantify poor engagement in physical activity by boys with Duchenne muscular dystrophy, and demonstrates factors that contribute to it. Sufficient physical activity may optimize physical functioning, prevent diseases related to physical inactivity and avoid disuse. Literature shows a positive effect of exercise in boys with Duchenne muscular dystrophy, however, these studies showed benefit of exercise over a short period of time (24 weeks and 8 weeks respectively).[12,13] More (long-term) studies on the effect of exercise in boys with Duchenne muscular dystrophy are necessary. Furthermore, engagement in physical activities positively influences the sense of self-worth, belonging to a group and forming peer relationships. Hence, more attention must be paid to this decreased physical activity since the consequences of inactivity are significant for both the physical and the emotional aspect. This study emphasizes the need of promoting and maintaining sufficient physical activity in boys with Duchenne muscular dystrophy, especially when the disease

progresses. Exercise needs to be stimulated and facilitated, particularly in boys in the late nonambulatory stage. Group activities are preferred over home-based activities, since the social element is a very important aspect of being physically active for boys with Duchenne muscular dystrophy. Team sports such as wheelchair hockey, table tennis, and swimming are recommended.

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Author Contributions

All authors meet the authorship criteria and nobody who qualifies for authorship has been omitted from the list. All contributors have been properly acknowledged. Authors and contributors have approved the acknowledgment of their contributions. IJMD designed the study protocol and was responsible for supervision of the project. NV designed the questionnaire, handled data collection, and did preliminary analysis. MJ revised the questionnaire, handled data collection, and supervised data analysis. LH handled data collection and final analysis and wrote the final manuscript, which was revised by IJMD, NV, and MJ. All authors read and concurred with the content of the final manuscript. All authors had complete access to the study data.

Declaration of Conflicting Interests

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Ethical Approval

The study was approved by the Medical-Ethics Committee of the region Arnhem/Nijmegen (http://www.cmoregio-a-n.nl/). A filled in and returned questionnaire was considered as an informed consent, as agreed upon with the medical ethics committee.

Supplemental Material

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