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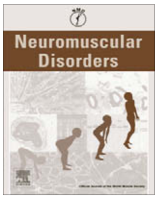

Prevalence and psychosocial impact of lower urinary tract symptoms in patients with Duchenne muscular dystrophy

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ABSTRACT

Patients with Duchenne muscular dystrophy (DMD) frequently report lower urinary tract symptoms at the outpatient rehabilitation clinic. The purpose of this study was to determine the prevalence of lower urinary tract symptoms in the Dutch male DMD population and their effect on quality of life. A postal questionnaire was sent to members of Dutch DMD patient organisations. 199 male patients with confirmed DMD and over the age of 3 years were included. 170/199 (85%) patients reported one or more lower urinary tract symptoms. Generally, post micturition dribble, straining and feeling of incomplete emptying were most frequently mentioned. 42% of patients (range 18–76%) experienced the symptoms as a problem. In 49/170 (29%) patients, it reduced quality of life. In conclusion, lower urinary tract symptoms in DMD patients are under reported and under diagnosed. However, the vast majority of male DMD patients with symptoms experience them as a problem, often reducing quality of life.

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1. Introduction

Duchenne muscular dystrophy (DMD) is caused by a genetic X-linked disorder in which defects in the dystrophin gene lead to absence or very low concentration of the protein dystrophin in the myocyte. DMD is characterized by progressive striated muscle weakness that initially manifests itself around the pelvic girdle, but eventually involves every striated muscle in the entire body. On average, DMD patients become wheelchair confined around the age of ten and develop life-threatening respiratory insufficiency and heart failure in the early twenties [1]. However, due to improved medical and technical treatments, such as ventilatory support, the life expectancy has increased for DMD patients [2].

DMD patients frequently report lower urinary tract symptoms (LUTS) when specifically asked for it at the outpatient rehabilitation clinic. Examples of LUTS are urinary incontinence, frequency, urgency and feeling of incomplete emptying. In the general Dutch male population the prevalence of urinary incontinence is 0.27% for age-group 5–14 years, 0.02% for age-group 15–24 years and 0.04% for age-group 25–44 years. The prevalence for frequency is 0.14%, 0.05% and 0.11%, respectively. The prevalence of other LUTS are 0.09%, 0.05% and 0.1%, respectively [3]. There are few studies which have investigated urinary problems in small DMD populations [4,5]. MacLeod and colleagues interviewed 88 DMD patients (age range 3–25 years) of whom 46 of 74 respondents (62%) had urinary problems [4]. Uchikawa et al. described a population of 27 boys with DMD (age 7–14 years) and found a prevalence of 43% for urinary incontinence based on the Functional Independence Measure [5]. However, the prevalence of LUTS in the Dutch male DMD population is still unknown.

The pathophysiology of LUTS in DMD patients has not been fully elucidated yet. For example, urinary retention may be caused by functional obstruction during the micturation (due to the sitting position or constipation) or alternatively due to voiding postponement [6]. Urgency and incontinence in DMD patients may also be related to neurogenic bladder disorders, which may be caused by severe scoliosis or as a complication of spinal fusion surgery. This underlying cause of LUTS may respond well to treatment with anticholinergic medication [4,7].

Involvement of the smooth muscles has also been described in DMD patients regarding gastrointestinal disorders and it could be possible that smooth muscles are also involved in urinary disorders as well [8].

In both patients with spina bifida and neurologically healthy children, LUTS have been reported to importantly affect quality of life [9,10]. The extend to which LUTS affect participation in activities and quality of life in DMD patients is currently unknown.

The aims of this study were: (1) To investigate the prevalence of LUTS in the Dutch population of DMD male patients; (2) To explore whether LUTS are related to age, wheelchair confinement, spinal surgery, voiding postponement, constipation or micturition in

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sitting position; and (3) To evaluate the impact of LUTS on participation in daily and social activities and quality of life.

2. Methods

2.1. Patient selection

DMD diagnosis was established by muscle biopsy, DNA sampling or according to the Emery criteria [11]. All male DMD patients older than 3 years were included and subdivided into four age groups; 4–5 years, 6–12 years, 13–18 years and 19+ years. The age-group of patients between the age of 4–5 years was created since children ought to be toilet trained just before this age and therefore a higher prevalence of LUTS is assumed (e.g. urinary incontinence). Patients who had a catheter à demeure were excluded to avoid bias while a catheter may be used to manage LUTS but also for convenience (e.g. to reduce transfers).

A postal questionnaire was sent to two Dutch DMD patient organisations (Dutch Parent Project and Vereniging Spierziekten Nederland, which is the Dutch Patient Association of Muscle Diseases) who distributed the questionnaire among their members. The questionnaires were anonymously returned to the investigators.

The study was approved by the Medical Ethics Committee.

2.2. Questionnaire design

In this study, a multiple choice questionnaire was used which was based on a questionnaire designed to investigate LUTS in children between the age of 12–18 year who had undergone kidney transplantation [12]. Questions related to the transplantation were removed. We added extra questions for DMD patients; diagnosis details (DNA sampling, muscle biopsy or Emery criteria), lower extremity function according to the Brooke scale [13], current health situation, medication, history of spinal surgery, use of artificial ventilation, aids, special (house) facilities and the need of personal assistance with toileting.

The classification of LUTS was based on the International Continence Society (ICS) standards [14] and subdivided in four categories; symptoms during storage, voiding or post micturition and lower urinary tract pain. LUTS during the storage phase were: increased daytime frequency, nocturia, urgency, urinary incontinence, enuresis and reduced bladder sensation. LUTS during the voiding phase were: slow stream, intermittent stream, hesitancy and straining. LUTS post micturition were: feeling of incomplete emptying and post micturition dribble. Lower urinary tract pain symptoms were: bladder and urethral pain. For each symptom it was asked whether it had occurred in the previous 4 weeks.

Except for questions about the storage phase symptoms and hesitancy the answers were stratified into; 1 – never, 2 – occasionally, 3 – regularly, 4 – often and 5 – always. For analysis the answers were dichotomised. Those dichotomised options were “not present” (never) and “present” (occasionally-always).

Regarding the storage phase, the presence of frequency was dichotomised to two groups; 1–7 micturitions per day as “not present” and eight or more micturitions per day as “present”. The answers for urgency and hesitancy were the previous mentioned options 1–5 but for further analysis, the used option reduction was different namely “not present” (never-occasionally) and “present” (regularly-always). For nocturia, urinary incontinence and enuresis the options were “yes” or “no”. The question about bladder sensation (“do you feel when you need to go to the toilet”) was dichotomised in “reduced” (never-often) and “normal” (always).

We added extra questions, not mentioned in the ICS standards, involving bladder infection (dichotomised into: “never” and “once or more times”), use of catheter (“yes” or “no”), use of aids for micturition (“yes” or “no”) and voiding postponement (“yes” (regularly-always) or “no” (never-occasionally)).

Questions concerning the presence of constipation were also added. Constipation was defined as a defecation frequency less than two times a week and hard stool.

We also inquired if LUTS occurred after decline in lower extremity function [13], after spinal surgery or after needing personal assistance for micturition.

For every individual LUTS, it was asked if it was experienced as a problem. The five possible options were reduced to “no” (1 – “no, it’s not a problem”), ”yes” (combination of 2 – “yes, it is a bit of a problem”, 3 – “yes, it is quite a problem” and 4 – “yes, it is a serious problem”) and “not applicable”.

There were three additional questions on the influence of LUTS on daily activities (“yes” or “no”), social activities (“yes” or “no”) and how they would feel if they had to live forever with those complaints. The options for this last question were stratified into three groups: “satisfied” (combination of the answers 1 – very satisfied, 2 – satisfied, 3 – mainly satisfied) and “unsatisfied” (combination of the answers 4 – mixed feeling, 5 – mainly unsatisfied, 6 – unsatisfied, 7 – very unsatisfied) or “not applicable”.

2.3. Statistical analysis

Analysis of variance (Kruskal–Wallis) was used to determine if differences were occurred in the prevalence of LUTS between age-groups. Spearman’s ρ was used to identify a correlation between LUTS and age/age groups, wheelchair confinement, spinal surgery, voiding postponement, constipation and micturition in sitting position. A correlation coefficient >0.7 was regarded strong, 0.5–0.7 as moderate, and <0.5 as poor. A p-value of <0.05 was considered statistically significant.

SPSS version 14.0 was used for statistical analysis.

3. Results

The patient organisations sent the questionnaires to 589 patients, of whom 214 responded. One hundred ninety-nine of 214 respondents (aged between 4 and 40 years, mean 14.6 years) were included. Reasons for exclusion were: other or unknown diagnosis ($n = 10$), female gender ($n = 2$), boy with a suprapubic catheter which was inserted for LUTS management ($n = 1$) and unknown age ($n = 2$).

Twenty-four patients completed the questionnaire themselves, 58 with assistance of another person (mostly a parent), 111 only by parents and of 6 it is unknown.

Patient characteristics are presented in Table 1. Of all patients, 32% (64/199) used laxatives and only 3 patients had constipation of whom 2 did not use a laxative. Out of 121 boys who were sitting during micturition 104 were wheelchair confined and required an aid and 104 needed personal assistance (encompassing walking and wheelchair confined patients).

Details about micturition are presented in Table 2. Of the 140 boys who required an aid, 116 used a urinal, 5 a condom catheter, 4 the combination urinal and condom catheter, 1 the combination of urinal and intermittent catheterization once a day, 2 the combination urinal and diaper at night, 1 the combination condom catheter and diaper at night, 1 the combination condom catheter and intermittent catheterization once a month, 3 a diaper throughout the day and 7 only at night.

3.1. Prevalence of LUTS

One hundred seventy patients (85%) reported to have one or more LUTS, 140 (70%) two or more LUTS and 113 (57%) patients had 3 or more LUTS (see Table 3). Most frequently mentioned LUTS

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