



Bladder and bowel dysfunction affect quality of life. A cross sectional study of 60 patients with aquaporin-4 antibody positive Neuromyelitis Optica spectrum disorder



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ABSTRACT

Background: Transverse myelitis (TM) associated with Neuromyelitis Optica (NMO) can be severe and is well known to reduce mobility early in the disease. However the burden of bladder and bowel dysfunction is unknown and overlooked. We studied the frequency of bladder and bowel dysfunction and their impact on quality of life.

Methods: A cross-sectional study of 60 patients who had AQP4-IgG positive NMO associated TM was performed using the Bladder Control Scale, Lower Urinary Tract Quality of Life, Bowel Control Scale and Neurogenic Bowel Score, Short-Form-36 Health Survey and EDSS. The relationships between the variables were analysed with multiple linear regression.

Results: Fifty women and 10 men participated. 78% (47/60) patients reported bladder symptoms and a similar number reported bowel problems. 87% (52/60) patients reported either bladder or bowel dysfunction. 65% (39/60) developed residual symptoms after the first episode of myelitis and the remaining by the second episode. Both bladder and bowel dysfunction reduced quality of life and required modification of lifestyle in 83% (39/47) and 70% (33/47) respectively.

Conclusion: Bladder and bowel dysfunction is very common in NMO associated myelitis developing early in the disease and significantly affects quality of life.

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1. Introduction

Neuromyelitis Optica (NMO) is an autoimmune inflammatory astrocytopathic disorder of the central nervous system (CNS) with predilection to affect the optic nerves and spinal cord. A specific antibody AQP4-IgG, against aquaporin-4, the astrocyte water channel, is involved in the pathogenesis in up to 90% of patients and its detection in the sera facilitates diagnosis and early treatment (Lennon et al., 2005). Patients with single or relapsing longitudinally extensive transverse myelitis (LETM) with AQP4-IgG are classified as NMO spectrum disorders (NMOSD). The estimated

prevalence in the United Kingdom is 7.2–19.6 per million (Jacob et al., 2013). The typical age of onset is in the fourth decade (though all ages can be affected) male to female ratio has been reported to range between 1:4 and 1:8 (Jacob et al., 2013; Cabrera-Gomez et al., 2009).

Frequent relapses of LETM lead to accumulation of neurological deficits affecting motor, sensory, bladder, bowel and sexual function (Kitley et al., 2012). The aim of this study was to (a) determine the frequency of bladder or bowel dysfunction (BBD) in NMO and (b) explore the impact on quality of life.

2. Methods

All AQP4-IgG positive NMO patients (Wingerchuk 2006 criteria (Wingerchuk et al., 2006)) who had an episode of transverse myelitis and attended an outpatient appointment between April 2013 and March 2014 at the Walton Centre NMO clinic (one of the two national referral centres in the UK) were asked to participate

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in the study. All questionnaires have been independently validated and were appropriate for assessment of bladder, bowel symptoms and quality of life.

2.1. Assessment of bladder and bowel dysfunction

Initial assessment used the Bladder Control Scale (BLCS) and Bowel Control Scale (BWCS) (Fischer et al., 1999). These self-reported questionnaires evaluate BBD for continence, constipation and subsequent restrictions on activities and lifestyle during the previous four-week period.

BLCS has 4 items and the final scores can range from 0 to 22, with higher scores indicating greater bladder control problems and worse restrictions. BWCS has 5 items and the final score can range from 0 to 26, with higher scores indicating greater bowel control problems and worse restrictions.

Patients who reported bladder or bowel symptoms in the above questionnaires then completed further detailed questionnaires. Those with bladder symptoms completed further self-assessment questionnaires using the International Consultation on Incontinence Questionnaire Female/Male Lower Urinary Tract Scale (ICIQ FLUTS, MLUTS) (Avery et al., 2004, 2007; Jackson et al., 1996).

FLUTS has 15 questions relating to filling symptoms, 12 questions on voiding symptoms and 12 related to incontinence. MLUTS has 20 questions relating to voiding symptoms and 24 questions relating to incontinence. Each question has four options on how the urinary symptom affects them: “not at all/ slightly/ moderately/a lot” and a ‘bothersome score’ out of 10.

Similarly patients who reported bowel problems completed the Neurogenic Bowel Scale (NBS) (Krogh et al., 2006). Score ranges from 0 to 6 (minor bowel problems), 10 to 13 (moderate), and 14 (severe).

Answers to questions that are similar between questionnaires were cross-checked for consistency of response for each patient.

2.2. Assessment of quality of life

All patients completed the Short Form 36 Health Survey (SF36) used to assess health status and quality of life (Hays et al., 1993). Scores were transformed into the standard 0 to 100 scale using the RAND algorithm (Hays et al., 1993; Jenkinson, 1999). Higher scores indicate better quality of life. Physical Component Summary Score (PCS) and Mental Component Summary Score (MCS) were calculated.

In addition, those with bladder dysfunction completed an additional QOL questionnaire—Lower Urinary Tract Scale Quality of life (ICIQ LUTS QOL) (Bright et al., 2014) that specifically assesses the impact of urinary symptoms on quality of life. A summary score out of 76 is calculated from 19 items with greater values indicating increased impact on quality of life. Each question also has a ‘bothersome score’ to indicate impact of individual symptoms for the patient. The final question rates the overall interference of urinary symptoms with everyday life.

2.3. Neurological disability

Assessed and scored using the Expanded Disability Status Scale (EDSS) by a neurologist (LE).

3. Results

Ethical approval was obtained as part of the NMO UK study from the National Research Ethics Committee. All participants

gave written informed consent before participating in the study. Statistical analyses were performed using STATA12. Data was tested for normality and Spearman's correlation was used for non-parametric data. $P < 0.05$ was deemed statistically significant.

3.1. Participant data

74 patients with AQP4-IgG positive NMO or NMO spectrum disorders attended the clinic during the study period. Seventy patients satisfied the inclusion criteria (4 had only optic neuritis). 10 did not participate, citing personal reasons. The remaining 60 patients (50 females and 10 males) completed self-administered questionnaires. The median age was 49 years (range 18–81). 47 patients were diagnosed with NMO (optic neuritis and myelitis) and 13 patients were diagnosed with NMOSD (myelitis in the presence of serum anti AQP4 IgG). The median duration of disease (from first attack) was 6.5 years (range 4–468 months). The median number of relapses of any type was 3.5 (range 1–13). The median number of myelitis episodes was 3.2 (range 1–10). The last relapse was at least 2 months prior to completing questionnaires. Neurological disability was assessed by EDSS, with a mean score of $4.83 \pm 1.85.78$ % (47/60) patients reported bladder symptoms and a similar number reported bowel problems. 87% (52/60) patients reported either bladder or bowel dysfunction; Five each had only bladder or bowel symptoms. 13% (8/60) were asymptomatic. 65% (39/60) of those who had a myelitis developed residual bladder or bowel symptoms after the first ever episode of myelitis and the remaining by the second episode. Of the affected patients 83% (39/47) and 70% (33/47) patients altered overall lifestyle due to bladder or bowel symptoms respectively.

3.2. Bladder dysfunction

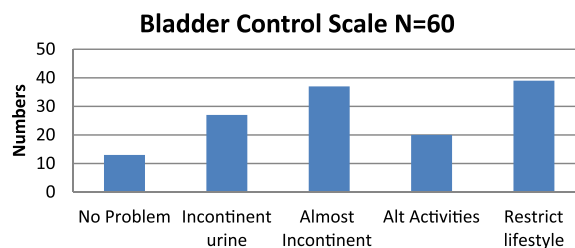
3.2.1. Bladder Control Scale (BLCS) ($n=60$) (Graph 1)

47/60 (78%) patients reported bladder symptoms (41 were women). The BLCS total score ranged from 0 to 22; 16/47(34%) patients scored higher than 11 indicating greater impact on lifestyle. During the preceding four weeks 27/47 (57%) had been incontinent; 37/47 (79%) were almost incontinent; 20/47(43%) altered activities because of bladder symptoms and 39/47(83%) restricted lifestyle due to bladder problems.

3.2.2. Incontinence questionnaire Female/Male Lower Urinary Tract Scale (ICIQ FLUTS) ($n=41$) and MLUTS ($n=6$)

All 41 females completed FLUTS questionnaire, the most problematic urinary symptoms were leakage of urine 19/41(46%) and urgency of micturition 18/41(44%). The most common and distressing (bothersome) urinary symptoms were urgency 25/41 (60%), hesitancy 20/41(49%), incontinence 19/41(47%), and nocturia 16/41(39%).

Six males completed MLUTS; the most problematic urinary symptom was hesitancy and interrupted flow (5/6) and the possibility of incontinence (4/6) bothered the men most.



Graph 1

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