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Editorial by XXX on pp. x–y of this issue

Qualitative Exploration of the Patient Experience of Underactive Bladder

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Article info

Article history:

Accepted March 29, 2017

Associate Editor:

Christian Gratzke

Keywords:

Detrusor underactivity
Patient reported outcomes
Qualitative
Quality of life
Underactive bladder

Abstract

Background: Underactive bladder (UAB) is considered the symptom complex associated with the urodynamic diagnosis of detrusor underactivity.

Objective: The aim of this research was to investigate the patient reported experience of the symptoms, signs, and impact of UAB. This research is also part of the initial qualitative phase for the development of a new patient reported outcome measure for the assessment of UAB.

Design, setting, and participants: Qualitative methods were used to understand the experience of UAB from a patient perspective, in a purposive sample of male ($n = 29$) and female ($n = 15$) patients aged 27–88 yr (mean: 64 yr), diagnosed with a primary diagnosis of detrusor underactivity, with or without coexisting urological conditions. Semistructured interviews were conducted in Bristol, UK.

Results: Male and female patients reported a variety of lower urinary tract symptoms and associated impact on quality of life. Storage symptoms of nocturia, increased daytime frequency, and urgency, and the voiding symptoms of slow stream, hesitancy, and straining were reported by over half of the patients. A sensation of incomplete emptying and postmicturition dribble were also frequently described. Most had a post void residual >30 ml ($n = 34$, 77%, median: 199 ml) with many reporting urinary tract infections, a history of self-catheterisation, and some experiencing occasional acute retention episodes. These symptoms and signs can have a broad impact on quality of life including having to plan their daily activities around the location of toilets, disruption to sleep, social life, and associated effect on family and friends.

Conclusions: Knowledge of the lived experience of UAB obtained in the current study will be used for the development of a new patient reported outcome measure and help inform the current working definition of UAB.

Patient summary: The symptoms, signs, and impact on quality of life of underactive bladder are described by patients with the condition.

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<http://dx.doi.org/10.1016/j.eururo.2017.03.045>

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Please cite this article in press as: Uren AD, et al. Qualitative Exploration of the Patient Experience of Underactive Bladder. Eur Urol (2017), <http://dx.doi.org/10.1016/j.eururo.2017.03.045>

1. Introduction

Underactive bladder (UAB), which is considered to be the symptom complex of urodynamically diagnosed detrusor underactivity (DU), is a condition that is relatively under-researched. The current working definition describes UAB as “characterised by prolonged urination time with or without sensation of incomplete bladder emptying, usually with hesitancy, reduced sensation on filling, and a slow stream” [1].

In men and women presenting with lower urinary tract symptoms (LUTS) and referred to urodynamic studies, the prevalence of DU has been shown to be up to 40% in men and 13% in women [2] and as much as 48% in particular groups such as male patients over 70 yr of age [3]. In men, DU has been reported alongside coexisting bladder outlet obstruction or detrusor overactivity (DO) in 47% of subjects, and with coexisting DO or urodynamic stress urinary incontinence in 73% of female patients [2]. It is recognised that there is an overlap of LUTS associated with these conditions and UAB, such as slow flow, nocturia, increased urinary frequency, and incontinence [1,4,5]. The symptomatic burden of LUTS associated with DU [5–7] and known impact of LUTS on quality of life [8,9] highlight the requirement to understand how patients with UAB feel and function for clinical outcome assessment purposes.

Currently, no fully validated patient reported outcome (PRO) measures exist for the assessment of UAB. In order for a PRO instrument to be used in patient management, exploration of the reported symptoms, signs, or other functional aspects should be carried out in a sample of patients known to have the condition, using accepted qualitative methodology. In this type of study an exact representative sample is not required, but a good spread of participant characteristics is advantageous in order to capture all relevant backgrounds and experiences of the condition [10]. There is no definitive sample size for a study such as this but 30 or 40 interviews are typical [9,11,12]. To our knowledge, this is the first qualitative research study which focuses on elucidating the patient reported experience of UAB. This study also aims to contribute essential evidence of content validity for a new PRO measure [13,14], for the assessment of the symptoms, signs, and impact of UAB in research and clinical practice.

2. Materials and methods

Qualitative methods were employed in order to understand the experience of UAB from a patient perspective. Semistructured interviews

were conducted with a purposive sample of male and female patients with a primary diagnosis of DU. Patients with DU alone and in combination with other common coexisting urological conditions, were interviewed to ensure the relevance of the PRO instrument to all patients with the condition. The primary objective to the interviews was to elicit the symptoms, signs, and impact of UAB, with an emphasis on capturing key idiomatic expressions and language used to describe their symptoms.

Interviews were conducted by trained qualitative researchers either in-person at the patient’s home, in situ at the hospital, or over the phone. Informed written consent was obtained to participate and audio record the interviews, which were then transcribed verbatim and organised using qualitative research software package NVivo v10 (QSR International, Victoria, Australia). Following the first exploratory interviews, an inductive approach [15] to analysis of the transcripts revealed concepts that contributed to the ongoing development of a coding framework. Concepts identified early on in the coding process were followed-up in subsequent interviews through iterative revisions of an interview schedule. Data collection and analysis continued concurrently, using a reflexive and constant comparison approach [16]. Concepts relating to symptom or impacts which were spontaneously reported in the interview (without prompting by the interviewer) were given particular attention. Towards the end of data collection, concepts were coded by urologic defined symptoms (eg, “hesitancy,” “increased urinary frequency,” “urgency”) which categorized the data within the current urological and theoretical context [17,18]. Discussion meetings between researchers evaluated discrepant codes to achieve consensus and consistent coding across transcripts. Interviews continued until the dataset was considered saturated, that is, when it was considered that no further concepts relevant to DU were likely to be found by conducting further interviews. Ethics approval was granted as a substantial amendment of an existing project: Reference 087/99.

2.1. Sample inclusion criteria

Male and female patients of 18 yr of age or over with a slow stream associated with a weak bladder contraction, were selected by retrospective review of the urodynamic reports of patients referred for pressure flow studies (PFS). Table 1 shows the urodynamic criteria used to select patients with a primary diagnosis of DU. The patients were grouped by the presence or absence of coexisting urological conditions.

3. Results

A total of 44 semistructured interviews were conducted in Bristol, UK, from January 2014 to December 2014. Table 2 summarises the demographic and clinical characteristics of the sample. All patients were Caucasian, and came from a variety of educational backgrounds (ranging from school leaver at 16 yr or younger, to college or university educated) and occupations (manual, service, and professional).

Table 1 – Diagnosis group inclusion criteria and number of patients per diagnosis group

All DU patients included in the study (n = 44)			
Males:	BCI < 100 BOOI < 20	Females:	P _{det} Q _{max} < 20 cmH ₂ O Q _{max} < 15 ml/s
DU without coexisting urological conditions (n = 19)			
DU + coexisting urological conditions (n = 25)			
Mild SUI/USI (n = 7)	Mild DO (n = 8)	BOO-E (n = 5) BOOI ≥ 20 to <40	BOO (n = 5) BOOI ≥ 40

BCI = bladder contractility index; BOO = Bladder Outlet Obstruction; BOO-E = Bladder Outlet Obstruction in the Equivocal Range; BOOI = Bladder Outlet Obstruction Index; DO = Detrusor overactivity; P_{det}Q_{max} = detrusor pressure at maximum flow; Q_{max} = maximum flow rate; SUI = Stress Urinary Incontinence; USI = Urodynamic Stress Incontinence.

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