

When is better really better? Individuals' experiences of treatment for OAB with anticholinergic medication

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ABSTRACT

Overactive bladder (OAB) has been found to have a number of psychological consequences, including anxiety, depression and shame. However, there is little research on how drug treatment, which has been found to be effective at reducing physical symptoms, impacts on these psychological effects. This study aimed to examine patients' experiences of anticholinergic treatment for OAB, and the impact of both OAB and its treatment on psychological well-being. A cross-sectional, qualitative interview design with a secondary care outpatient sample was used. The approach was idiographic and sought to understand the detailed complexities and nuances of patient experiences. This small-scale qualitative study found that, even where there had been symptom reduction, patients did not feel 'better', and found it difficult to let go of worries and fears around OAB. These findings suggest that a person with OAB may need support even after a 'successful' treatment, as OAB continues to be at the centre of patients' lives.

Key words: Chronic illness • Health psychology • Overactive bladder • Psychology • Quality of life • Urinary incontinence

INTRODUCTION

Overactive bladder (OAB) has an estimated prevalence of between 16 and 17.5% with expectations that this will rise to 20% by 2018 (Lee et al., 2013). Rates are similar between men and women (Milsom et al., 2001) and increase with age. Symptoms are urinary urgency, with or without incontinence, usually with urinary frequency and nocturia (Abrams et al., 2003). The psychological correlates of OAB have been found to be wide-ranging, including anxiety, depression, obsessive compulsive disorder and embarrassment/shame (Kinsey et al., 2016; Vrijens et al., 2015; Ahn et al., 2016). Nicolson et al. (2008) found that OAB had an all consuming effect on people's self esteem which was a consequence of the fear and worry around leakage and its related embarrassment.

OAB is typically treated with anticholinergic medication and some form of bladder training. Anticholinergics have been found to be effective in treating the symptoms of OAB (Herbison et al., 2003) and to improve health-related quality of life (HRQL; Khullar et al., 2006). However, HRQL is, in essence, a measure of impact and not distress and it is unclear how changes in symptoms relate to subjective, patient satisfaction with the outcomes of their treatment (Khullar et al., 2006). Indeed, compliance rates with anticholinergic drugs have been found to be low, with 43–83% of patients discontinuing medication within the first 30 days (Sexton et al., 2011). This appears to be related to the fact that improvements following treatment may not be sufficient to eliminate the bothersomeness of symptoms and may not outweigh the perceived disadvantages of treatment which include side effects and inconvenience (Sexton et al., 2011). There is little research which examines how drug treatment impacts on these psychological effects of OAB, if at all.

A recent study by Pretorius et al. (2014) found that, following drug treatment, there was no direct relationship between symptom severity and anxiety or depression in OAB. Controlling for age, the relationship between severity and depression was mediated by the person's perceptions of their personal control over, and the consequences of, OAB; the relationship between severity and anxiety was mediated by the person's perceptions of their personal control over OAB. This suggests that while medication is effective at alleviating symptoms and their physical impact, it may not improve OAB's psychological effects.

To date there is a lack of understanding of patients' experiences of taking anticholinergic medication, their decisions to continue or discontinue treatment and the related psychological issues. Sexton et al. (2011) identify a need for further research to understand patient expectations and decision making relating to anticholinergic treatment. This study aimed to examine patients' experiences of anticholinergic treatment for OAB, and the impact of both OAB and its treatment on psychological well-being.

METHOD

Design

This study used a cross-sectional, qualitative interview design with a secondary care outpatient sample. The approach was idiographic and sought to understand the detailed complexities and nuances of patient experiences. A small sample size was therefore deemed appropriate (Robinson, 2014).

Participants

Participants were recruited from a local urology outpatient clinic. They were eligible for inclusion if they had been diagnosed with OAB and were over the age of 18. Locally, Solifenacin is the most frequently used treatment therefore, in order to control

for the potential differences between drug treatments, only patients who had been prescribed Solifenacin 3 months previously were included.

Six eligible participants consented to being invited for interview, of whom four took part. Of the two who dropped out, one started a new job and no longer felt they had the time; the other did not give a reason. All participants were female with an age range 35–59. Including Solifenacin, one participant had tried five different medications, two had tried two and one had tried one. Two participants described themselves as single, one as married and one as widowed. Two had no formal qualifications, one left school at 16 (with General Certificates of Education), and the other had a degree. One participant was employed full-time, two part-time and one was unemployed.

Interviews

All interviews were conducted on an individual basis by one of two research assistants. Interviews were semi-structured, using an interview schedule as a basis. The interview schedule was developed partly from an examination of the literature on the psychological consequences of OAB (Kinsey *et al.*, 2016), in particular the qualitative study by Nicolson *et al.* (2008). It was also based on Pretorius *et al.*'s (2014) quantitative study which found that illness perceptions (in particular the perception of personal control) mediate the relationship between symptom severity and psychological distress. From this literature an interview schedule was developed to explore patients' experiences of the effect of OAB and its treatment on their psychological well-being, quality of life and relationships? The interview schedule is given in Appendix 1.

Procedure

Ethical approval was obtained from the local NHS Research Ethics Committee and the relevant Trust R&D department.

Clinical nurse specialists working in a urology outpatient clinic in a NHS trust in the north of England identified eligible patients from their records. Once identified, potential participants gave permission to be contacted by a research assistant, who then invited them to an interview. If they agreed, a convenient time and place was arranged. Before the interview began, participants were given an information sheet to ensure they completely understood the purpose of the interview, and gave written consent to take part after they had read it and had the opportunity to ask questions. Interviews lasted between 45 and 75 min.

Data analysis

The interviews were recorded and transcribed verbatim. Data were then analysed using thematic analysis as outlined in Braun and Clarke (2006) by three of the authors. Briefly, this involves familiarizing your- self with the data, generating initial codes, collating codes into potential themes, and reviewing and defining themes. This study takes a critical realist approach, in which themes are identified in a theoretical way

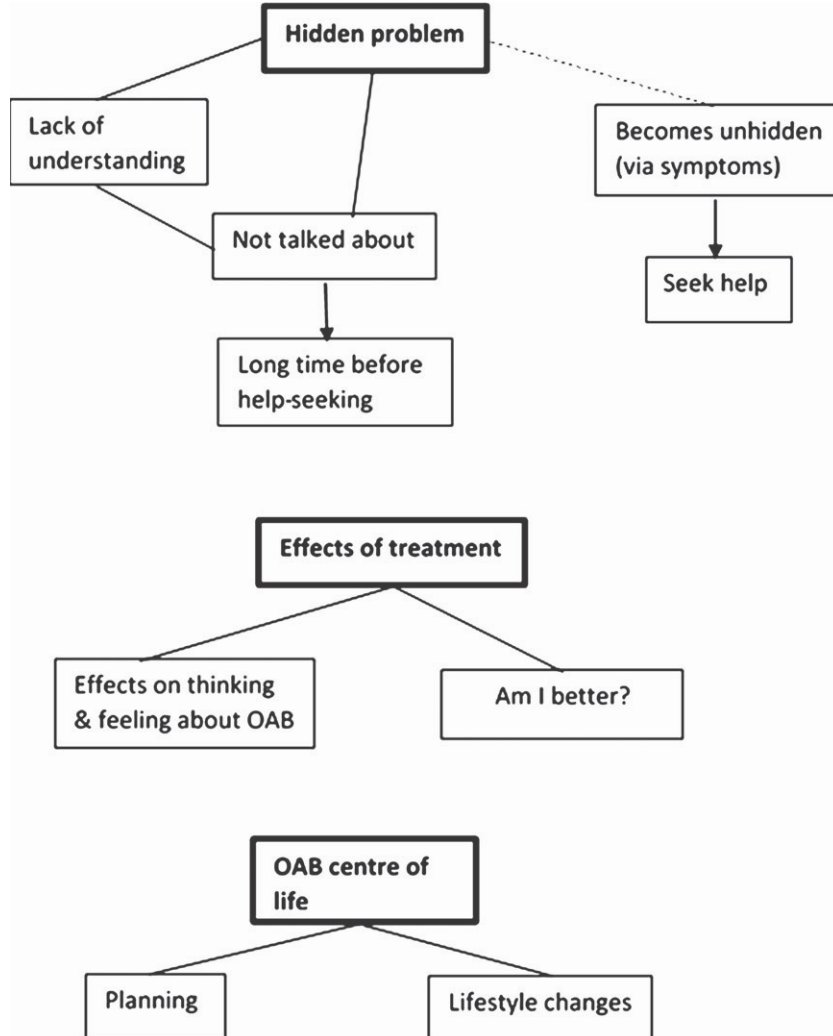


Figure 1. Map of themes

and at a semantic level (i.e. identified using existing literature as a framework and within the explicit meanings of the data; Braun and Clarke, 2006). Each of three authors (DK, TA & LG) read all transcripts and made initial notes and identified tentative themes. Discussion between the authors led to the agreement of the final themes.

RESULTS

Three superordinate themes were identified from the interviews: hidden problem, effects of treatment and OAB centre of life. Links between the subthemes emerged from participant accounts and are presented in chart form below (see Figure 1). Arrows are used where the direction of the effect was made explicit by the participants; where no arrow is given, direction was not clear. A dotted line indicates the subtheme was linked to the superordinate theme but there was no direction. 'Hidden problem' is linked to subthemes 'lack of understanding' and 'not talked about' (which are also linked to each other). 'Not talked about' leads to sub-theme 'long time before help-seeking'. 'Hidden problem' is also linked to subtheme 'OAB becomes unhidden' (in which OAB becomes noticeable to others via symptoms), which leads to subtheme 'seek help'. The second superordinate theme, 'effects of treatment', had two subthemes: 'effects on thinking and feeling about OAB' and 'am I better?'. Similarly, the superordinate theme 'OAB centre of life' also had two subthemes: 'planning' and 'lifestyle changes'. Themes are described below and illustrated by quotes from the participants. The participant number and line numbers are given in brackets following each quote [for example, (P6: 35–37)].

Superordinate theme 1 – OAB as a hidden problem

The thing is, it...it's just you. Unless you tell somebody else it's just you who knows that you have a problem. (P1: 228–229)

Participants talked about OAB as a condition being largely hidden from others – other people did not realize there was a problem, or, if they did know, they did not realize that it was on their minds much of the time. Two participants talked about how this meant, prior to help-seeking, they did not realize other people had similar symptoms:

... you get talking to people that specialise in the condition, you find you're not the only one – there's more people out there. (P4: 201–203)

Subtheme – OAB not talked about

Because OAB is a largely hidden condition, it is not talked about, both by the person with OAB and other people without OAB, prior to and post help-seeking (which also contributes to OAB being hidden). This seemed to be in part about an embarrassment in talking about urinary problems. For example, one participant said:

Sometimes it's just hard going, there are people, there are things you don't want to talk about when there are other people around you. (P1: 169–171) And another:

I don't know if it's ... if there are other people my age that do go through it, because it's not the sort of thing that people talk about really, you know? (P3: 389–390)

Subtheme – lack of understanding

OAB as a hidden problem appeared to link to a lack of understanding from others about both the condition itself and, most importantly to participants, what it is like to live with the condition.

I don't think it goes through their minds, you know what I mean? It doesn't happen to them, does it? And they don't know the situation. They do know of the situation, but they don't ... whereas you can be thinking about it because it's happening, they...they're not aware of it. (P2: 131–134)

This lack of understanding of the participants' needs due to their OAB, and because they did not talk about the issues they faced with others, sometimes led to difficulties in day-to-day life:

... my husband goes, you know, he wouldn't think, "well I'll park there because [P4] needs the toilet", you know. (P4: 149–150)

It also meant, before help-seeking, the person with OAB lacked understanding about what their symptoms meant. Participants variously attributed their symptoms to having a hysterectomy, drinking alcohol, stress or childbirth:

I think it's me having a weak pelvic floor when I'd had the children. I think, I was saying to her, that I've not done my exercises properly or something (P4: 12–14)

Subtheme – long time before help-seeking

This lack of understanding about what their symptoms meant, and that other people also experience the same symptoms, meant that all participants did not seek for a number of years. They talked about it being something they had just 'put up with'.

I've put up with it, not talked to anyone about it. So I'd say about two years [before seeking help.] (P4: 2–3)

Subtheme – OAB becomes unhidden

Despite OAB being perceived as a hidden condition, the participants only sought help when their symptoms became 'unhidden' and they were prompted by an outside source. For example, one participant had been experiencing OAB symptoms for a number of years, but only went to the doctor after moving in with family members because her frequent night-time trips to the toilet disturbed them:

I've seemed to have noticed it more the last couple of years cos I moved in with my [family]. And I didn't realise, but I was maybe getting up two or three times in the night. (P3: 6–8)

Previously, she said she had just 'put up with' the symptoms and thought it was just that she had a weak bladder. Similarly, another participant was prompted to seek help by her mother, after experiencing symptoms

for 2 years, because she had an episode of urgency while out shopping with her and was unable to reach the toilet in time. She also spoke of her children telling her that

You need to get it sorted cos it's not right, you know, going to the toilet as often as you've been. (P4: 196–198)

Before the episode of incontinence and her sons beginning to tell her the level of urinary frequency was not normal, she attributed her symptoms to childbirth and had not thought to seek help. One participant only sought help after seeing a television advertisement for an information helpline for OAB, and realized her symptoms could be a 'problem':

I didn't realise it till I saw an advertisement on TV about wanting to go to the loo that sometimes I thought, 'maybe I have a problem.' (P1: 6–7)

Superordinate theme 2 – effects of treatment Participants reported a varied effect of treatment on their symptoms. One participant said that the medication had improved both her urgency and frequency:

So... everything seems to be getting better. (P4: 248–249)

However, the other participants reported mixed results. For example, one participant said it had helped reduce her frequency, but it had not had an effect on her urgency or leaking (which were her main concerns). Another said it helped her urgency but had not helped her frequency and, as frequency (particularly at night) was her main concern, she said:

Basically, I don't really feel like I've got any- where. (P3: 17–18)

Subtheme – effects on thinking and feeling about OAB

Participants also reported a varied effect of treatment on their thinking about OAB. Two participants talked about how the treatment working has led to positive psychological change. Both talked about 'less stress' and 'less worry' about needing to plan around going to the toilet when they were out of the house. However, the participant who felt 'everything was getting better' also said despite this she was still lacking in confidence when leaving the house:

Because I've gone through all this, I think it'll take a while to adjust. (P4: 108–109)

She said she felt her confidence would improve as time went on:

I've got to... not be brave, but try and get confidence back in myself at thinking I'm not going to have an accident and I'm not going to leak. (P4: 45–47)

However not all participants experienced a positive change. For example, one participant talked about how treatment had led to more worry and stress due to the lack of effect of the medication on her frequency and attempting to hold off going to the toilet longer as part of her bladder training:

I'm conscious of it now. More conscious that... at one time I would have just like go and not really think of it. It's just that I've got a weak bladder, you know. But now I'm conscious of it all the time. (P3: 259–261)

Subtheme – am I better?

There was also variability in what the participants hoped to get from treatment. Sometimes these goals were vague such as a 'normal working bladder' (P1:189–190). Two participants talked about goals relating to psychological functioning (rather than the bladder itself), such as:

Being able to go out and enjoy without having to worry about, you know, wanting the toilet all the time. (P4: 94–96)

None of the participants, including those who felt the treatment had worked very well for them, felt that their main goals had been met. For example, one participant had found her urgency had improved after treatment but still struggled with night-time frequency:

Well basically, what I've always ... this is why I went to see the GP in the very very first place, I just would like to get a full night's sleep. That's basically all I've really wanted out of it. (P3: 197–198)

And so, despite some improvement in urgency, felt that the treatment had not worked for her:

Basically, I don't really feel like I've got any- where, if you know what I mean. But I know I have during the day because I can hold it, but yeah. (P3: 17–19)

Because of the variability in outcomes and what the person hopes to get from treatment, there was some confusion about what 'better' means. The two participants who talked about the medication and bladder training working very well for them did not also feel that they were 'better'. One was still experiencing some leakage, and the other felt that she was still trying to 'get her life back':

It would just be nice, like I just said, to get my life back and start enjoying myself a bit instead of being stressed out about the toilet. (P4: 101–102)

Both participants who felt the treatment was not working well for them, and one who still experienced leakage, talked about how they did not think OAB could be treated or 'cured'. For example, one said:

... that's the sad part that, it's not going to get better. (P1: 187)

Most also viewed OAB as a chronic condition to be worked around:

A way of life, yeah. (P2: 202)

This appeared to lead to a sense of acceptance and perseverance around OAB:

You just know your situation, you know what you've got to do. (P2: 179)

It's just learning and living with the condition isn't it? (P1: 160)

Superordinate theme 3 – OAB centre of life

The participants talked about OAB as being at the centre of their lives in terms of thinking, planning and making changes to their lifestyles. While the subtheme 'effects on thinking and feeling about OAB' above refers specifically to treatment, this theme refers to OAB more broadly across life. All participants, including those who felt they had a good outcome from treatment, talked about OAB being on their minds much of the time:

Even though I'm on those tablets, I'm still feeling like my life is ruled by wanting to go to the toilet all the time. (P3: 15–16)

and:

It doesn't really leave your mind. You're sort of planning and thinking. (P2: 220–221)

All participants planned around their OAB, particularly when leaving the house, by, for example, knowing where the toilets are going to be or taking precautions such as taking extra underwear:

I know that if I do do anything different I've got to think about it. (P2: 240–241)

... because I go to the toilet before I go, and then when I go to somewhere, like Tesco's, I know there's a toilet and I know where it is. (P3: 31–32)

They also changed aspects of their lifestyle to cope, for example by moderating fluid intake or not drinking caffeinated drinks. This remained even after a successful treatment:

I just reassess my lifestyle and see what can make it worse or what can make it better em, so... It's just reassessing maybe my lifestyle, you know change it, just to make it better, hmm, to make my condition better uh to make it more ... manageable. (P1: 316–319)

If I try and just limit my toilets and drinks I'm not too bad. (P2: 47–48)

Participants talked about coping strategies (such as humour and drinking less) being both helpful and unhelpful. For example, humour was described as being both helpful and unhelpful. One participant, at different points in the interview, said:

My son-in-law, he's quite good. He makes a joke of it. (P3: 242)

But later:

Some people think, you know, that it's just a bit of a joke because you need to go for a wee all the time, but it's not. (P3: 333–335)

Two participants appeared to feel some shame about the coping strategies they use (such as carrying extra underwear). In the interviews, they looked away from the interviewer and whispered when talking about these coping strategies. One participant had never experienced incontinence but was worried she would when out of the house:

[Whispers] But I do always wear panty liners just in case. (P3: 179)

Another had experienced an episode of incontinence, but had no further episodes since taking medication. She still took spare underwear with her when leaving the house just in case:

I mean nobody knows about [taking spare underwear]. Just kept it to myself. (P4: 282)

Participants also talked about it sometimes being difficult to manage lifestyle changes. For example, one participant talked about restricting her fluid intake so she would not need the toilet as often, but finding it difficult to balance this with drinking enough:

If I drink more, I know that I'm never gonna be thinking about not wanting to go for a wee, you know what I mean? So it's real hard. It's a right catch-22. (P3: 59–60)

And she said my blood pressure was low because I'm not drinking enough. You know what I mean? So I think well what, what. You know? I just don't know what to do. (P3: 66–68)

DISCUSSION

This was a small-scale interview study which aimed to explore the experience of people who had received anticholinergic medication to treat their OAB with a view to developing understanding and opening up avenues for further research. While the themes which emerged seem consistent with other studies of OAB (e.g. Nicolson *et al.*, 2008), they also shed light on the factors connected with patients' decisions about, and experience of, anticholinergic medication.

Although previous studies have suggested that treatment with anticholinergics has improved the quality of life of people with OAB (Khullar *et al.*, 2006), this study suggests that, whilst people are able to do more, a more complex picture exists. The notion of 'better' is an interesting one, and, in an age of patient-led care, it is particularly important to note that what is better for one person might not be better for another as it depends on the individual's own situation and lifestyle. None of the participants in this study felt they were 'better', including those who described positive changes after treatment, and there was some confusion over what 'better' meant. One factor contributing to this may be that none of the participants felt their main treatment goals were met, so even if there were significant improvements in other areas they did not feel 'better'. This is consistent with Reynolds *et al.*'s (2015) findings which suggest that symptoms of OAB are not completely resolved following treatment. It may be that a complete 'cure' is not a possibility for people with OAB, and so looking at how to support people in managing ongoing issues seems important, and to ensure expectations about treatment are realistic. In addition, this feeling of not being 'better' may link to participants still feeling that OAB was at the centre of their lives after treatment. If OAB is at the centre of life, it may be reasonable to assume that there is a fear underlying the need to constantly plan and think about OAB. As participants discussed planning around where toilets are located and trying to prevent needing the toilet so often, it may be that a fear of leakage or incontinence underlies this planning. Indeed, previous studies have identified fear of leakage and associated anxiety

about planning around toilet breaks in people with OAB (e.g. Nicolson *et al.*, 2008). This underlying fear may therefore perpetuate habitual worries and coping strategies, even where they are no longer necessary. This may also become cyclical – the person with OAB has had variability in their treatment outcomes and does not feel ‘better’, so they still feel like OAB is at the centre of their lives (and so must continue planning around it), which contributes to them feel they are not better.

Participants talked about OAB being a hidden condition which was not talked about by others or them- selves. Sexton *et al.* (2011) similarly found that participants in their study of older adults with OAB were reluctant both to speak about their problems and to seek help. Urinary problems are generally perceived to be embarrassing and a taboo subject, and are therefore not discussed. However, considering what under- lies this silence is important. For example, Rozmovits and Ziebland (2004) discuss how gaining control of bodily functions is equated with becoming a civilized, socialized adult and so losing control over, for example, your bladder means you are no longer a civilized adult. Similarly, Mitteness and Barker (1995) discuss how incontinence is seen as a sign of incompetence, as the only older people with incontinence who are visible are those who have been unable to manage their incontinence (due to physical or cognitive issues). Within this cultural context it is unsurprising that people experiencing urinary problems, particularly leakage, do not discuss it with others. It is possible that dealing with a sense that an identity as a ‘civilized adult’ has been lost is too distressing and embarrassing to reveal. The unacceptability of the symptoms is therefore likely to contribute to the hidden quality of the condition, and the fact that people do not seek help or even realize there may be help. It may also contribute to the underlying fear of incontinence which, as discussed above, may also perpetuate other difficulties associated with the condition. Future research might usefully explore the sense of self in people with OAB in order to shed further light on the processes which underlie the unspeakable nature of the problem.

When the symptoms become ‘unhidden’ it may be embarrassing for people with OAB as others have noticed symptoms or there has been an episode of public incontinence. As discussed above, for some there may be embarrassment due to a sense that their ‘uncivilized’ self has been discovered. There may also be anxiety about what is actually wrong (e.g. anxiety that it is cancer) if there is a general lack of understand- ing about OAB as a condition. Addressing the issue of ‘unhiding’ may be important as a way of addressing the fears of it happening again. It may be that until people can have confidence in their bladder, and that the treatment will continue to work, they will not feel able to let go of their coping strategies and worries, and it may be that lack of confidence which also feeds into not knowing what is ‘better’. Raised awareness has been identified as a key factor in why people seek help for urinary symptoms (Brittain *et al.*, 2001).

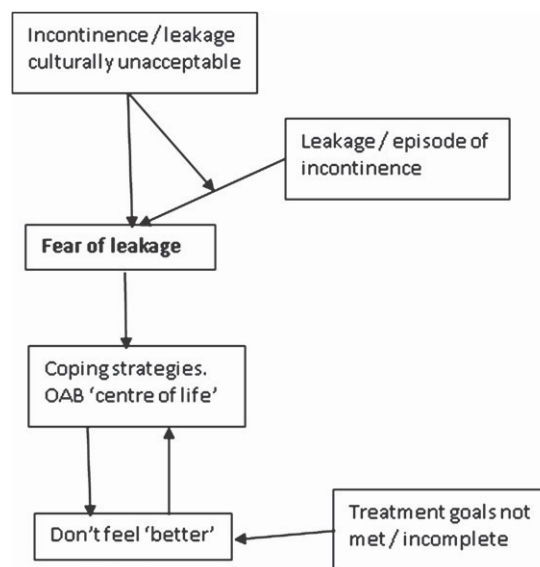


Figure 2 Tentative model of process after overactive bladder (OAB) treatment.

It may be helpful to make OAB more widely known and discussed to make it more acceptable. Indeed, one participant was prompted to seek help after seeing an advertisement for OAB.

A tentative model of the process underlying the continued distress for people with OAB after treatment, illustrating the above, is given in Figure 2.

All participants in the study were female, despite similar prevalence rates in men and women (15.6 and 17.4%, respectively; Milsom *et al.*, 2001), and evidence that women do not seek treatment for OAB more often than men (Apostolidis *et al.*, 2012). It

is unclear why only women agreed to take part. Further research should not only seek to confirm the findings from this study on a wider scale but also to include male participants, to establish whether there are significant gender differences.

This study suggests that the complexity of successful treatment for OAB lies in the fact that, with such deeply ingrained cultural norms around incontinence, it is difficult to let go of worries and fears around the condition, particularly in the absence of a complete removal of symptoms. Findings also suggest that a person with OAB may need support even after a 'successful' treatment, as OAB continues to be at the centre of patients' lives. A more holistic approach, such as that outlined by Ussher (1999) in relation to gynaecological problems, which addresses not just the material elements of OAB, but also the social constructions around incontinence and the intrapsychic elements of worry and anxiety about the condition, may be useful to help reduce unnecessary coping strategies and habitual worries after successful symptom reduction through medication. Further research should explore the best format and manner of implementing this kind of support.

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WHAT IS KNOWN ABOUT THIS TOPIC

- OAB has been found to have a number of psychological consequences, including anxiety, depression and shame.
- There is little research on how drug treatment, which has been found to be effective at reducing physical symptoms, impacts on these psychological effects.

WHAT THIS PAPER ADDS

- People with OAB find difficulty in letting go of worries and fears around the condition, particularly in the absence of a complete removal of symptoms.
- A person with OAB may need support even after a 'successful' treatment, as OAB continues to be at the centre of patients' lives.

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APPENDIX 1 – INTERVIEW SCHEDULE

Treatment History

When did you first experience bladder problems?

Prompts:

How long ago did this occur? How did you feel about it?

At what stage did you consider seeking medical advice and care?

Prompts:

When you did, why?

If you did not immediately, why not?

How long after noticing your symptoms?

How long ago did you seek medical advice and care? How did you feel about it?

Route to Treatment

How did you go about obtaining treatment?

Prompts:

Who did you first see? for example G.P./practice nurse

What happened when you did?

What did your GP prescribe, if anything?

What was your experience of the referral process to the urology clinic?

Treatment, Efficacy and Adherence

What treatments have you received for OAB?

Prompts:

How many treatments have you received? Do you remember their names?

In what order did you receive them? Have you received bladder training?

(if more than one treatment): What made you change treatments?

Prompts:

How long did you take 'drug X' for? Why did you change?

Were there any times you stopped treatment (medication or bladder training) without speaking to a doctor/nurse first?

What were your thoughts about the treatment?

How did you feel about the treatment?

What were your hopes/aspirations for a successful treatment?

Prompts:

How did you hope it would improve your symptoms?

How did you hope it would improve your life?

How effective has your treatment been in treating your symptoms?

Prompts:

How satisfied are you with your treatment? What affect has it had on your symptoms?

Quality of Life and Psychological Well-being

Before you were given treatment: How did OAB affect your daily life?

Prompts:

What words do you use to describe the symptoms/things that bothered you?

What were the most important aspects of your difficulties?

Being 'caught short'

Precautions taken to prevent this

Relationship Sexually Psychologically

How did this make you feel?

Embarrassment

Body image

Sexuality/feeling of being sexually attractive

Self esteem General mood Anxiety/distress/depression

Since commencing treatment, how have the effects on your daily life changed, if at all?

Prompts: As per question 9

Personal Control

How much do you think you can do, aside from taking medication, to control your overactive bladder symptoms?

Prompts:

What things can/do you do?

What particular measures you take to improve or maintain your symptoms, if any?

Age related perceptions

What do you think about having OAB at the age you are now?

Prompts:

What in particular led you to think about OAB and age in this way?

Are there things that have happened in the course of your life that you think have contributed to your condition?

How does the impact of OAB on your life compare with other medical conditions from which you suffer?/Or from conditions you might suffer in the future?

How do you think that your experiences of your illness would be different if you were older/younger, if at all?

Prompts:

In what way would you deal with the illness any differently if you were older/younger, if at all? (prompts: medication/treatment seeking)