

## PATIENTS' AND SUFFERERS' EXPERIENCES AND PERCEPTIONS OF LIVING WITH SYMPTOMS OF OVERACTIVE BLADDER (OAB): A FOCUS GROUP STUDY OF QUALITY OF LIFE

### Hypothesis / aims of study

The objective of the study was to examine the psychosocial impact of overactive bladder symptoms on patients and sufferers. The aims were to a) identify the range and depth of patients' and sufferers' experiences of the symptoms, b) to explore patients' and sufferers' perceptions of the impact of these symptoms and related experiences on their quality of life, c) to identify patients' and sufferers' perceptions of health care.

### Study design, materials and methods

The study was designed to collect in-depth qualitative data from both women and men in three British cities. Focus Group data provides rich, contextual evidence to address the aims and objectives stated above while complementing previous studies that have employed objective validated measures of QoL.

The inclusion criteria were based on recognised symptoms (described by Abrams, 2003).

The sample comprised people who were self-identified as OAB sufferers (and not necessarily patients at the time of the interviews) recruited through a local publicity campaign and then screened against the inclusion criteria before being admitted to the study ( N = 13) i.e. the 'sufferers'. Current patients (N = 22) were referred to the study by their general practitioners.

The sample comprised seven single-sex groups, four male and three female with an average of five people in each group. The average age was 64.6 years (with a range of 51-85 years) with the mean age for men being 59.1 years and for women 71 years.

In order to ensure data that was of key concern to the patients and sufferers specifically, it was collected via focus group discussions.

Full MREC approval and research governance was achieved and informed consent obtained in advance from all participants. The focus groups were all conducted by the PI and recorded and transcribed verbatim. The groups lasted from between 50 and 90 minutes with the majority lasting for around 70 minutes. Data were then analyzed to identify themes emerging around the psychosocial aspects of disease impact and health care.

### Results

The majority of patients and sufferers reported the impact of the condition in multiple thematic areas of QoL as exemplified below in extracts from the group interviews. Severe psychosocial difficulties were identified by all groups which related to their negative perceptions of treatment,

a sense of the inevitable worsening of the condition compounded by low expectations of medical care, particularly among the 'sufferers'.

<i>Main theme</i>	<i>Findings</i>
Age and health	<i>I always assumed that the problem was largely due to my age</i>
On-going fear of incontinence	<i>I have this fear of being incontinent when I'm out.</i>  <i>It's about the control of when it comes out.</i>
Embarrassment	<i>The problem I've got is not detrimental to my health - it's just embarrassment and worry.</i>
Exhaustion from broken nights	<i>I can't remember when I last slept through the night.</i>

The 'psychology' of urgency	<i>I think I'll go to the toilet anyway and as you get closer to the cloakroom it becomes not just important it's imperative.</i>
Reduced self-esteem	<i>I work harder than some of the younger guys so I can maintain it [self-esteem] I still have the physical strength.</i>
Relationships and sexuality	<i>I actually want to feel like I was right, you know, thoroughly clean – do you know what I mean? If I felt there way any kind of smell on me, I would not want to go anywhere near my husband.</i>
Strategies for coping	<i>I will go a different way maybe because I know there is a garage with a loo. I carry spares [underwear and trousers] just in case.</i>
Perception of health care	<i>We think doctors know a lot, but really they don't. The doctors actually don't care.</i>

#### Interpretation of results

In general, the outcome of the focus groups suggests a patient and sufferer population who consider themselves to be faced with severe psychosocial difficulties that impact upon their quality of life. Those currently identified as patients have greater optimism if their experience of medical care is positive. However, all are aware that the diagnosis is not a life-threatening one. They tend to accept the fact that the condition is somehow 'secret'; one in which they feel that their bodies are out of control, they are constantly tired and assume an age-related inevitability. These factors and the fear of incontinence and embarrassment about addressing the symptoms, lead them to develop elaborate coping strategies which involve a reduction in their daily activities e.g. they have to plan their working and social lives around opportunities for urination. Their sense of low self-esteem and embarrassment is particularly worrying for those seeking sexual partners and for those with existing partners the fear of odour and being unclean is a major anxiety especially for women. On the whole, the low self-esteem and the belief that the condition is somehow their fault leads many to accept their experience of medical consultations as one in which their concerns are dismissed. There is also a general level of ignorance about the reasons for the condition and treatments available.

#### Concluding message

OAB has a substantial psychosocial impact on affected individuals particularly on their self-esteem, sexual, family, work and social relations. Under-diagnosis and under-treatment are compounded by a culture of embarrassment and ignorance. Clinicians are encouraged to be more proactive in identifying individuals with OAB and cognizant of the impact of the physical symptoms on patients' and sufferers' quality of life.

Abrams P. Describing bladder storage function: overactive bladder syndrome and detrusor overactivity. *Urology* 2003; 62(5 Suppl 2):28-37.

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