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## Supplementary Online Content

Hawken N, Hakimi Z, Aballéa S, et al. Elicitation of health-related quality-of-life concepts associated with overactive bladder: a qualitative study. *JHEOR* 2016;4(2):127-40

### **Supplementary Appendix A**

Assessing the Impact of Overactive Bladder on Quality of Life

Discussion Guide for Interviews

**Supplementary Table 1.** Summary of Concepts from Qualitative Studies

**Supplementary Figure 1.** Conceptual Framework from Literature Review

This supplementary material has been provided by the authors to give readers additional information about their work.

## Supplementary Appendix A

### Assessing the Impact of Overactive Bladder on Quality of Life Discussion Guide for Interviews

#### OPENING (5 MINUTES)

- Introduce interviewer
- Remind participants of the purpose and format of the interview

“During this interview, we would like to discuss with you the impact of overactive bladder (OAB) on people’s lives. We want to identify existing and/or develop new patient-reported outcome (PRO) questionnaires to assess health-related quality of life (HRQoL) for patients confronted with OAB. This questionnaire will reflect the views and concerns of people like you to help us better understand the effect of these treatments on people’s lives. We want to hear about your experiences with OAB; for example, how the disease is affecting your day-to-day life, how your life has changed since you have developed the disease and how you could improve it.”

- Confidentiality:

“As researchers we would like to assure you that all of the information that you share with us today will be treated as confidential by Creativ-Ceutical. We will type up transcripts from the recordings but any names or other personal identifiable information will be removed from these. We will use the transcripts to compile results from all of the participants but it will be reported in such a way that no individuals can be identified.”

#### HISTORY OF OAB (10 MINUTES)

Perhaps we can start by thinking about when the disease appeared and how you were diagnosed? Can you describe which OAB symptoms you experience (urgency, frequency, incontinence)?

- When did you first start feeling the first symptoms?
  - Did they change/evolve? If so, how and when?
- When did you first see a health professional in relation to OAB?
  - Who did you see?
  - What prompted you to see them?
  - Who else have you seen since?
- Have you talked to anyone else about your condition? If so, who? If not, why?
- What things have you done or tried to do to deal with OAB?
  - Have you tried medication?
  - Have you tried non-pharmacological treatments?
  - How have these things worked for you?

## **IMPACT OF OAB (30 MINUTES)**

### **General Discussion**

We would like to understand more about the impact that OAB has on you and your life. But first, what does quality of life mean to you?

Prompts:

- What makes life good?
- What makes life bad?

How is your life affected by OAB?

Prompts:

- What is life like when you have OAB?
- How different was your life before the disease developed?
- Does OAB stop you from doing anything you would otherwise be able or want to do?
  - If so, what?
- How do you feel about the impact that OAB has on your life?

What is it like to be suffering from OAB?

Prompts:

- How do you feel about yourself since you suffer from OAB?
- Do you have the feeling that the disease affected the way you see yourself?
  - If so, in what way?

### **Exploration of Specific Areas of Impact**

How does OAB affect your relationships with people in your life?

Prompts:

- What do you think it is like for the people in your life?
- Do you think something has changed since you were diagnosed with OAB?  
Potential areas to cover:
  - Partner (sexual life)
  - Children
  - Friends

How does OAB affect the types of things you do?

Prompts:

- Did things change since you have OAB?  
Potential areas to cover:
  - Family/social/leisure activities
  - Work (travel, meetings)

How does OAB affect the way you feel in yourself?

Prompts:

- Did things change since you have OAB?

Potential areas to cover:

- Way you feel about yourself
- Ability to concentrate
- Energy
- Shame
- Motivation to do things
- Satisfaction/happiness
- Stress/anxiety

How does OAB affect your ability to rest?

Prompts:

- Did things change since you have OAB?

Potential areas to cover:

- Sleep (frequent awakening because of OAB)
- Recovering from physical activities

### **IMPORTANCE OF AREAS OF IMPACT (10 MINUTES)**

*NOTE: Discussion to be based around the key areas discussed in Section 3.*

“Thinking about the issues we have been talking about today, which are the most important to you?”

Ask participants to select the three most important issues for them. What would be a valuable improvement of your quality of life? What is the smallest improvement of the symptoms you discussed that would contribute to an improvement of your quality of life?

### **SUMMING UP (5 MINUTES)**

- Ask about any issues not discussed

“Is there anything I should have asked today but didn’t?”

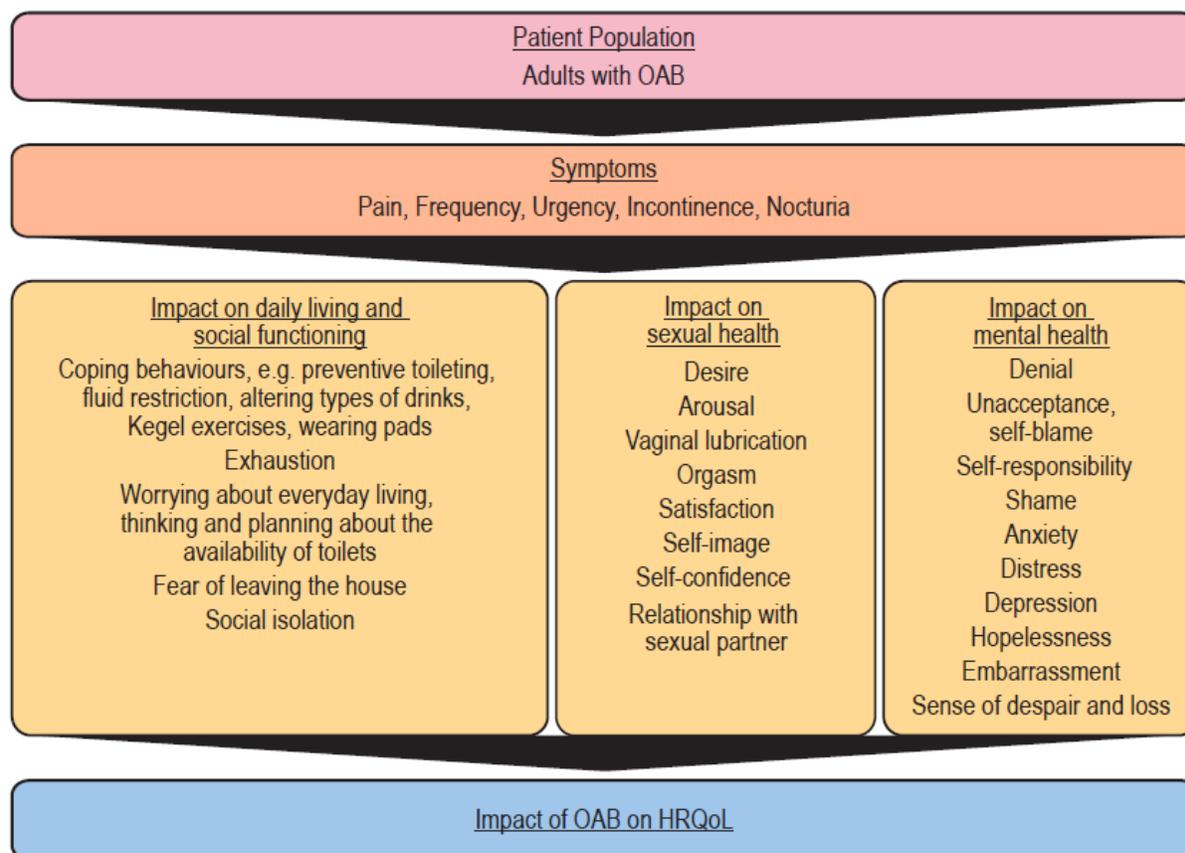
- Remind participant that everything he/she has said will be kept confidential
- Close the interview

“Thank you for taking the time to share your thoughts and experiences with us. If you have any further concerns or questions following on from today, please do not hesitate to contact me. Thank you again.”

**Supplementary Table 1.** Summary of Concepts from Qualitative Studies

Reference	Symptom Concepts	Impact Concepts
Coyne et al. 20071	<ul style="list-style-type: none"> <li>• Pain</li> <li>• Frequency</li> <li>• Urgency</li> <li>• Incontinence</li> </ul>	<ul style="list-style-type: none"> <li>• Sexual desire</li> <li>• Sexual arousal</li> <li>• Vaginal lubrication</li> <li>• Orgasm</li> <li>• Sexual satisfaction</li> <li>• Self-image/self-confidence</li> <li>• Relationship with sexual partner</li> <li>• Coping behaviors</li> </ul>
Anger et al. 20111	<ul style="list-style-type: none"> <li>• Nocturia</li> <li>• Frequency</li> <li>• Urgency</li> <li>• Incontinence</li> </ul>	<p>Triggers for Incontinence</p> <ul style="list-style-type: none"> <li>• Running water</li> <li>• Standing from sitting</li> <li>• Putting the house key in the door</li> <li>• Sleeping longer than usual</li> <li>• Undoing pants in preparation for using the bathroom</li> </ul> <p>Medications and Side Effects</p> <ul style="list-style-type: none"> <li>• Ineffective in controlling wetness</li> <li>• Unpleasant side effects</li> </ul> <p>Impact of OAB on Quality of Life</p> <ul style="list-style-type: none"> <li>• Movies, airplane trips, car trips</li> <li>• Nocturia</li> <li>• Inability to fall back asleep</li> <li>• Fatigue during the day</li> </ul> <p>Strategies to Control Wetness</p> <ul style="list-style-type: none"> <li>• Preventive toileting</li> <li>• Fluid restriction</li> <li>• Altering type of drinks</li> <li>• Kegel exercises</li> <li>• Wearing pads</li> </ul>
Nicolson et al. 20083	<ul style="list-style-type: none"> <li>• The experience of urgency</li> <li>• Frequency</li> <li>• Incontinence</li> </ul>	<ul style="list-style-type: none"> <li>• Fear and coping strategies</li> <li>• Anxiety about everyday living</li> <li>• Depression and hopelessness</li> <li>• Embarrassment</li> <li>• Self-esteem, sexuality and embodiment</li> </ul>

OAB: overactive bladder

**Supplementary Figure 1.** Conceptual Framework from Literature Review

HRQoL: health-related quality of life; OAB: overactive bladder

**REFERENCES**

- <sup>1</sup> Coyne KS, Margolis MK, Jumadilova Z, et al: Overactive bladder and women's sexual health: what is the impact? *J Sex Med* 2007;4(3):656–66.
- <sup>2</sup> Anger JT, Nissim HA, Le TX, et al: Women's experience with severe overactive bladder symptoms and treatment: insight revealed from patient focus groups. *Neurourol Urodynam* 2011;30(7):1295–9.
- <sup>3</sup> Nicolson P, Kopp Z, Chapple CR, et al: It's just the worry about not being able to control it! A qualitative study of living with overactive bladder. *Br J Health Psychol* 2008;13(Pt 2):343–59.