

Report of a Survey of Women with Bladder Control Disorders

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- Bladder control disorders such as urinary incontinence (UI) and overactive bladder (OAB) have been referred to as the “last real taboo of the 20th century”.
- These conditions affect nearly 200 million people worldwide, and estimates in the United States are as high as 33.3 million persons.
- These disorders affect more than twice as many women as men and are felt to be a significant health issue for aging women.
- Very little is known about a patient’s perception of the severity of incontinence, associated absorbent incontinence product use, and interaction with health care professionals.

A qualitative mail survey was conducted to understand the current health care professional/patient relationship and determine ways of increasing communication between individuals with incontinence and health care providers. A thirty-three (33) item questionnaire was mailed by a mail order catalog company Home Delivery Incontinent Supplies Co., Inc. (HDIS) located in St. Louis to 1,500 women. The final sample consisted of 422 responses with 405 women aged 56 and older. The majority of these women reported moderate urinary incontinence, with urge and mixed being most common, for 5 years or less.

The attached table addresses the respondents’ degree of comfort with bladder disorder terminology, onset and nature of symptoms, impact on quality of life, management strategies, interaction with health care professional and patient education needed.

This survey indicated that respondents who experienced mixed urinary incontinence felt it adversely affected their quality of life. Respondents sought assistance from the family doctor who made a referral to a specialist, usually a urologist. Although embarrassment was typically not an issue, most respondents want the professional, both doctors and nurses, to initiate all discussions of the bladder and incontinence.

A significant percentage of respondents believe that professionals need to become more knowledgeable and provide a greater depth of information in many areas, including the selection of incontinence products.

This survey identified the barriers that are surmountable, providing that nurses and other health care professionals take appropriate steps. It is evident that these respondents, adult women with incontinence, want more information related to the cure or management of bladder disorders, especially as they relate to quality of life. The professionals who provide it, perhaps in partnership with the drug and medical product industry, have an opportunity to break down the perceived barriers between consumers and treatment.

Women in this survey reported urine loss on a daily basis; they freely admitted the impact of bladder dysfunction on their quality of life and how they coped with the problem. While the majority of respondents who sought professional assistance were satisfied with their doctors and aware of treatment options, they still desired more information about the causes and treatments, as well as coping with the situation and learning how others cope. Since respondents are getting information through consumer advertising, a partnership between the healthcare community and the drug and medical product industry to produce information on incontinence would be ideal.

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Table 1

Understanding of Current Terminology:

It has been suggested that when promoting awareness of bladder control disorders, simple language and terminology (e.g. bladder health, bladder control, and overactive bladder) should be used. However, when asked to rate as “very comfortable, somewhat comfortable, or not at all comfortable,” respondents noted they were:

- 51% were very comfortable using the terms - “overactive bladder” and “incontinence”
- 39% said they were very comfortable with loss of bladder control,
- 33% with leaks,
- 26% with accident
- 23% with incident
- Roughly one fourth (23%) of respondents said they were not “very comfortable” using any of the terms listed above when discussing their condition/situation.

Onset of Incontinence:

When questioned about length of time incontinence had been a problem:

- Approximately one-third (34%) experienced incontinence two years or less
- One-third (31%) experienced incontinence between three and five years
- One third (25%) experienced incontinence six years or more
- Ten percent (10%) experienced incontinence for over 20 years

The results of this survey indicated that urge and mixed were the most common clinical types of incontinence. This was interpreted as an indication of more than one symptom, mixed UI.

- 68% “leak on the way to the bathroom”
- 58% “leak with physical activity such as coughing, laughing, bending, exercising”
- 38% “leak with strong urinary urge”
- 21% “leak without awareness”

Nature of symptoms:

Urinary frequency was reported as 52% respondents typically use the bathroom between five and eight times per day and 53% reported nocturia, voiding two to three times per night. Eighty-two percent (82%) of the respondents leaked urine during the day and 80% leaked urine at night. Nocturnal enuresis was seen in this group, with 53% saying they leak urine during the night at least once a week and 39% saying they leak urine every or almost every night.

The survey attempted to determine severity of incontinence with the following results:

- 47% described their incontinence as moderate
- 28% described their incontinence as mild
- 18% described their incontinence as severe

The degree of incontinence was not correlated to age but it was directly related to how long the respondent had experienced incontinence. That is, those experiencing mild incontinence were significantly more likely to have only been incontinent two years or less, while those experiencing severe incontinence were significantly more likely to have been incontinent for more than 10 years.

Impact on Quality of Life (QoL):

Overall, 58% of the respondents said incontinence had a negative impact on their life with 38% noting that incontinence negatively impacted their lives on a daily basis. Twenty-three percent (23%) said the negative impact began immediately after the onset of incontinence. Respondents’ frustrations with UI have been segmented into four main areas that were all fairly equal in representation -

- Mental frustrations (embarrassing, no control).
- Inconvenient (difficult to be away from home/bathroom, have to go all the time).

- Discomfort (wet pants, need to change pad often, odor).
- Problems with protection/products (have to wear, carry extra, money spent on).

The survey asked respondents to describe the first experience with loss of bladder control with an open-ended question. The following are examples of the more disturbing answers:

- Came home after church and wet pants before I could enter the bathroom.
- After having two children leaked when I jumped around at an activity.
- Just couldn't control it.
- Wet in my pants and was not too happy about it. Embarrassed me so much.

Additionally respondents were asked to share thoughts and experiences related to loss of bladder control, the most frustrating part of being incontinent, and what they would like healthcare professionals to know. Respondents noted the following:

- Just let people know that it is a way of life and they aren't the only ones it has to so there is no reason to be ashamed.
- Have to learn to live with it and adjust lifestyle.
- It's a real drag on my emotions.
- It's hell.

Management Strategies:

Respondents were asked about disposable incontinence products used. Women used lower-cost products such as menstrual pads rather than specific incontinence pads. The type of pad did relate to UI severity since "no protection and panty liners" were worn significantly more by those experiencing mild incontinence; "disposable underwear/pull-ups and diaper type products" were worn significantly more often by those experiencing moderate and severe incontinence.

Consultation with a Health Care Professional:

This group tended to seek help from their physicians fairly quickly after onset of UI:

- 14% said they sought professional advice immediately after their first loss of bladder control incident
- 19% sought professional advice within the first three months
- 12% within 4-6 months
- 5% within seven months to a year
- 15% said it was over a year before they sought professional advice

Survey respondents noted that the family doctor/general practitioner was the doctor consulted first for almost two thirds (64%) of those who sought professional advice and it was usually (41%) that sought advice during a regular visit. A urologist was consulted second for almost 50% of the patients. Respondents (71%) noted that a female doctor was the healthcare professional with whom women are most comfortable discussing UI, 54% with a female nurse, 45% with a male doctor, and only 14% with a male nurse.

Regardless of the type of doctor consulted, respondents indicated that she (the respondent) initiated the discussion on UI the majority (57%) of the time. Only 18% of respondents said they filled out a form (e.g. screening questionnaire) that contained questions about bladder control.

Patient Education:

The preferred method for dispersing information on UI were brochures/handouts (74%) and educational videos to take home (39%) provided by healthcare providers. The specific information respondents would like to see addressed in these materials included information on:

- treatments (68%)
- products (50%)

- guidelines for normal urinary frequency (45%)
- guidelines for assessing results of various treatments (39%)
- incidence/expectations for incontinence as a result of other diseases/conditions (38%)
- medical research (37%)

Respondents (48%) learned about incontinence or bladder control products on TV, in a magazine and other advertising followed by seeing and reading information on store shelves (42%), from a friend or relative (29%), from a doctor or healthcare professional (23%) and from a mail order company (6%).