

## **QUALITY OF LIFE IMPACTS OF INCONTINENCE AND THE ROLE PLAYED BY ABSORBENT PRODUCTS**

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Following so many scientific papers covering the highly technical properties of nonwovens and composites of which they are a part, it seems appropriate to end the day's session bringing into perspective a widespread application for your products; namely: managing adult incontinence. Earlier this year, the National Association For Continence, or NAFC, completed two nationwide surveys of consumers. One intercepted the general public in retail malls across 20 U. S. cities and the other was conducted by telephone among NAFC's consumer members. I am here today to present to you highlights from both pieces of consumer research, as well as relevant highlights from earlier surveys we've conducted. More importantly, I am here to challenge those of you in marketing and product development to raise the bar on performance characteristics of your materials so that outstanding needs and concerns of the end-users of your products can be better addressed.

By way of background, NAFC is a national, non-profit 501(c) (3) corporation dedicated to improving the quality of life of people with incontinence, or loss of urinary control. We are the world's largest and most prolific consumer advocacy organization devoted exclusively to incontinence. Our mission has three prongs: consumer education and outreach, information dissemination through networking and collaboration, and advocacy on behalf of our constituency. We publish and distribute a quarterly newsletter, a comprehensive directory of products and services, and extensive literature on a variety of pertinent topics. I encourage you to pick up sample copies of these materials that I have with me today.

NAFC confidentially manages a database comprised of 140,000 names of individuals who have contacted us for help, as well as an interactive website receiving thousands of visitors each month. Our networking activities keep us in close touch with key healthcare providers so that incontinence is among their priorities, while collaboration with other organizations allows us to continually expand our sphere of influence. In addition, we routinely initiate contact with government agencies and elected officials to educate them on the need for approvals of new products and technology and for broader funding of research and coverage of options for consumers.

The mall study, the first of its kind focusing exclusively on bladder health among both men and women, consisted of a total of 1,001 completed interviews. Conducted by well known research firm Yankelovich, the survey utilized a stratified random methodology of soliciting participation across all adult age groups to yield a composite of survey respondents considered to be representative of the U. S. Census (1990) demographic data by age and gender. The slide you see depicts the demographic profile of survey respondents. Its costs were funded by a grant from Pharmacia Corporation, marketers of Detrol LA, a prescription drug used in the treatment of symptoms associated with urge incontinence, frequency of urination, and urgency to urinate. In lay terms, these symptoms may be collectively referred to as an "overactive bladder."

A similar, stratified random approach was taken in the pre-selection of potential participants for the telephone survey. However, its pool of 500 potential respondents was drawn exclusively from NAFC's membership, as opposed to the general American public as in the Yankelovich survey. This second study was funded by American Medical Systems, marketers of medical devices for treating urinary and fecal incontinence as well as erectile dysfunction. Each of the 500 randomly pulled names was mailed an invitation by NAFC to participate in an anonymous telephone interview. A total of 123 telephone interviews was completed and cross-tabulated. As you can see from the slide, the mean age of the self-selected participants in this latter survey was older than that of the mall interviews, or 56.1 years compared to 46.8 years of age. This difference is believed due primarily to the free long distance calling incentive that was offered to the telephone survey respondents, which may have been more attractive to older than younger people.

Both studies confirmed key beliefs and findings from previously completed consumer research; namely:

- The majority of American people are ill-equipped to address urinary health problems as they arise, and they remain ignorant about bladder health in general. Our research, for example, shows that two-thirds of all Americans have NEVER spoken to a healthcare professional about their bladder health. And among those who report symptoms of a problem, over half still haven't been to a doctor.
- Urine leakage and overactive bladders causing urge and frequency of urination are at least as devastating to young adults as this condition is to older adults. While we've seen evidence from past research of how socially isolated individuals feel, our research methodology in these two studies allowed us a glimpse into the lives of the young as well as old. We can now put ourselves in the place

of a 36-year-old woman who told her interviewer, “I am very self-conscious out in public. I don’t go out much. Especially if there is a lot of walking and [I’m] not very close to many bathrooms.”

- People, and especially women, need encouragement and support to seek out proper diagnosis, treatment, and management advice from healthcare professionals trained in continence care. In our research, for example, 79% of women surveyed said that they had experienced a gradual onset of symptoms over a period of years, and as a result, 68% reported they “tolerated” their incontinence. This contrasts sharply with men, 67% of whom reported a sudden onset of symptoms. Half of the men surveyed said they sought medical attention for their problems almost immediately.

By way of background, it is estimated by experts in the field that as many as 25 million adult Americans are affected by incontinence, or the involuntary loss of urine. This means leakage of any amount. Without a heightened level of public education, without new research into the etiology and possible prevention of incontinence, U. S. Census projections suggest that this number will easily increase to nearly 30 million people by 2020.

Incontinence is not a disease but rather a symptom of an underlying medical condition. It may even be the outcome of a degenerative disease process. It is fairly common in young women during pregnancy and up to three months post-partum. It represents a chronic health problem for the elderly, as suggested by such statistics as the fact that:

- One in five adults ages 40-49 living independently in the community leaks urine, increasing to nearly one in three for those 60-69 years old.
- Approximately one-third of all of those residing in assisted living communities experience episodes of incontinence.
- Well over half of those in nursing homes are incontinent.

Still, aging does not cause incontinence. The aging process, however, precipitates changes that do negatively affect the bladder. Its capacity can be reduced, leading to frequency. Others experience flaccid bladders that fail to fully empty, causing recurrent urinary tract infections and overflow incontinence. Still others experience spasticity of the bladder triggered by idiopathic signals to the brain, leading to sudden urgency. Meanwhile, gender-specific changes, such as an enlarged prostate in men causing blockage to the bladder outlet and reduced estrogen and weakened pelvic floor muscles in women causing stress urinary incontinence, do occur. Mobility issues, as well as side effects and interactions from multiple prescription drugs, can also be culprits.

Incontinence can also be the result of trauma or a disease process. Examples include:

- Spinal cord birth defects such as spina bifida
- Injury during surgery, such as a radical prostatectomy in men in which the sphincter is damaged or severed
- In women, injury from childbirth
- Spinal cord injuries such as from diving and other sports or traffic accidents
- Strokes which leave neurological damage
- Multiple Sclerosis
- Cerebral Palsy
- Parkinson’s Disease
- Diabetes
- Alzheimer’s Disease and Dementia

To entice consumers to participate in the research, our mall intercept study purposely opened dialogue with shoppers on a lighter note, how they view time spent in the bathroom. We learned that the bathroom is a personal place for most people, a haven for those seeking refuge from busy lives. But it’s a prison for those plagued with bladder control problems. And we learned that people who suffer from urine leakage are less comfortable using public restrooms than others, apparently afraid of being discovered. For those of you in the absorbent products market, this also has implications for how important product disposal factors are to consumers using your products. This feedback also underscores the importance of “quiet” absorbents. Afraid of using public toilets or being heard in public, these people live lives of isolation and embarrassment.

In fact, we have surveyed our membership from time to time about the effects of incontinence on lifestyle. In 1996, 14.5% of respondents indicated that their incontinence was a major problem. Three years later, the comparable figure was 19.9%, with virtually no difference between how strongly men versus women characterized its impact on their lives. Those in the lowest income bracket were disproportionately most seriously affected, as were those under age 45. Those who did consider their incontinence to be a jor problem were more likely than others to use a catheter or reusable absorbents as management

products.....and to be suffering from bowel as well as urinary incontinence. Meanwhile 57.8%, or nearly two-thirds of all respondents to the 1999 membership survey expressed the opinion that in their day to day lives their bladder or bowel problem was "bothersome, but management."

Those who do venture out are preoccupied by the need for public toilets. Millions of people are thus "toilet mapping" when they go anywhere in public. We know this is true because 62% of all of the mall shoppers interviewed revealed that they scout out restrooms when visiting an amusement park. A similar percentage (61%) look for restrooms when they go to the movies.

Women are more likely than men to simply tolerate their incontinence, in part out of necessity. Two-thirds (68%) of all women with incontinence have lived with its problems for three years or more, whereas only half (50%) of all men with incontinence have experienced unabated symptoms for three years or more. This is true even though the mean number of daily episodes of incontinence is approximately the same for women that it is for these men. Despite this fact, we found in our research that men are more likely to pay out of pocket for treatment when health insurance coverage is denied or not available to them. This may have implications as well for how women and men view the cost of products used for managing incontinence. Women, for example, may place greater value on management products because they have already elected to forego the cost of diagnosis and treatment. The male attitude towards absorbent products, on the other hand, could be quite different for very subtle reasons that relate to how low their tolerance is for loss of bladder control.

From previous research, we have learned that NAFC members claim to have spent out of pocket \$946 (\$1998) managing incontinence. However, 57.0% indicated they had spent less than \$500. This includes absorbent products, urethral inserts, catheters, and pessaries. Those in the highest income bracket tend to spend less than those in the lowest income category.

How absorbent products are both designed and marketed needs to take into account how and when different genders experience symptoms of urine loss. Women are more likely to experience stress urinary incontinence, or the leakage of urine upon coughing, sneezing, or laughing. This is largely because of pelvic floor muscle weakness. This also explains the gradual onset of symptoms. Men, on the other hand, are more likely to experience a sudden urge to urinate – or difficulty urinating because of blockage or nerve damage. In our survey, more than one in five (22%) women reported that they experience both symptoms, or mixed incontinence, compared to just 4% of men responding to the survey. These very different characteristics call for very different absorbent products.

Skin integrity is another important issue related to the effects of incontinence. Eight years ago, Diane Storer Brown conducted a study of adult hospitalized patients at a Kaiser Permanente Medical Center and found perineal dermatitis in up to 33% of patients. This is caused by irritation from ammonia contained in urine and by acidic urine or residual antiseptics, soaps or detergents. The condition is exacerbated by heat, moisture, friction and occlusive clothing. In fact, while diapers have improved incontinence containment problems, some have impede the evaporation of moisture from the skin, causing friction and leading to skin maceration. At the time, this researcher concluded that diapers be used only while patients were ambulatory - with polymer diapers as the product of choice. When patients are bedridden, the product of choice would be polymer underpads, preferable both in terms of cost and skin integrity. It was concluded that the nonpolymer underpad should no longer have a place in incontinence management. Still, they continue to be used, especially in home care environment who launder supplies for reuse. It is therefore no surprise that in our own membership surveys that we find people with skin problems to be those in the lowest income bracket and those using reusable absorbents for management. There is a significantly higher prevalence of skin problems associated with incontinence among men (52%) than women (43%) in community dwelling, as opposed to institutional, environments.

Nocturnal enuresis (i.e., bedwetting or waking up during the night to urinate) is a problem that plagues especially older people. Among those who say they get up during the night to go to the bathroom, almost two in five (38%) have to get up twice or more. Witness the comment of one 52 year old female respondent who revealed "It affects my sleep pattern. I wake up tired because I have to go to the bathroom 5-6 times a night." In fact, one in eight (13%) of all respondents say they sometimes do not make it to the bathroom in time. This is significant because clinical research demonstrates a direct connection between incontinence and falls and subsequent injuries.

We learned from our research that the willingness is present on the part of most consumers to speak to their doctor about their urinary symptoms, but many don't because their physicians haven't opened the door for dialogue. Only one in ten (11%) said that they would not be comfortable having such a discussion with their doctor. This has some very important messages to the medical community and public health officials alike. OB-GYN doctors in particular need to sit up and take note, as 42% of all women surveyed said that their first physician of choice for this conversation is their OB-GYN. The younger the women, the more this is true. Meanwhile, nearly one-third (29%) of all respondents feel that there need to be more public messages encouraging visits to the doctor. This, they say, would motivate them to seek out professionals for diagnosis and treatment.

Women in particular feel strongly that the public needs to hear and see evidence that incontinence “affects many people.” Certainly, you marketers in the audience should be thinking about whose waiting rooms should house your product literature.

Still, even when some speak to their doctor, they aren’t being carefully diagnosed and thus end up receiving inappropriate treatment. Some doctors may be too quick to dash off a prescription on the first report of a “bladder problem.” For example, 20% of all female respondents in our mall survey who reported symptoms associated exclusively with stress urinary incontinence were prescribed a pharmaceutical ordinarily used to treat urge/frequency, to no avail. It’s therefore not surprising to us when we hear from consumers how frustrated or disappointed they are, even after visiting a doctor.

While we’re pleased to find in the research evidence that NAFC members are more proactive (>80%) about seeking treatment than non-members (<50%), it’s alarming that some of our educational messages are still falling on deaf ears. For example, we learned from the in-depth telephone interviews that 20% of our members report that they continue to restrict their fluid intake to control loss of urine. This is despite our educational literature that promotes hydration for good bladder health. Dehydration, of course, is a serious issue particularly for the elderly because it can result in disorientation, mild dementia, and falls.

Regardless of gender or age, quality of life is seriously and negatively impacted by incontinence. This is made clear by the revealing and very personal remarks from those interviewed about how restricted they feel:

“[The problem with urinary incontinence is one of] not feeling feminine, not spontaneous. I feel damp and like I am sweating all the time.”

- Female, Age 52

“The whole thing is aggravating. It’s frustrating. It limits your freedom of your social life and leaving the house. I don’t think anybody can understand how it is.”

- Male, Age 42

“My bladder control problems have caused me to change my life. I sometimes feel that I am captive.”

- Male, Age 78

“It is embarrassing, time consuming, smelly, messy, and inconvenient.”

- Female, Age 83

While NAFC as a national organization can encourage consumers to get educated about bladder and bowel health and to pursue diagnosis and treatment if they experience symptoms, we still need to get out simple preventive messages such as:

- Following sensible dietary habits such as drinking plentiful amounts of water, eating high fiber foods, and restricting caffeine and alcohol
- Faithfully doing pelvic floor muscle exercises, seeking out instruction, biofeedback therapy, electrical stimulation, or other forms of clinically proven physical therapy
- Staying active and getting regular physical exercise to maintain mobility and weight control
- Remaining alert to potentially undesirable side effects from medications, or drug interactions, with the help and advice of a pharmacist or physician
- Discussing all of the surgical options that are applicable and revisiting periodically the question of treatment as new procedures, devices, and technology become available.

We have found from earlier research that approximately half of all male and female respondents with moderate to severe incontinence rated non-surgical, non-invasive, non-prescription drug avenues of treatment to be the most helpful treatment they’ve received. Pain more so than recovery time was the larger complaint of those electing surgical intervention, in women as well as men, in all cases except for the choice of injectible bulking agents. And while new medical technology and advances are bringing more acceptable treatment options to consumers every year, absorbent products remain central to management of these symptoms for many. Because millions are affected, many of whom are not candidates for surgery or even medications, this leaves a tremendous challenge for on-going innovation by your industry. I hope that what I’ve shared this afternoon has triggered new creative energy among you so that your future product development and marketing ingenuity can put living back into life for so many.