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## Research

# What Americans Understand and How They Are Affected by Bladder Control Problems: Highlights of Recent Nationwide Consumer Research

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Over the last 5 years, the National Association For Continence (NAFC) has sponsored epidemiologic surveys of adults across the United States in order to quantify the prevalence of bladder control problems in the community, to understand how quality of life of those people experiencing these medical disorders is affected, and what beliefs people in general hold surrounding bladder health. While key statistics from each of these studies have been shared with the media in interviews, news releases, and briefings, no single published report has attempted to capture highlights of these substantial pieces of consumer research. Such is the objective of this article.

Each project was funded by a single company either marketing or developing a product for treating or managing urinary incontinence (UI). In every project, NAFC was involved deeply in the formation of questions, the scope of questions asked, and in analysis and interpretation of

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findings. The surveys were fielded or conducted by nationally recognized research firms specializing in such demographic research.

Two of the studies looked at bladder control issues without focus on a single diagnostic category, while another surveyed only women about overactive bladder symptoms. A fourth looked in-depth at stress UI among women of all ages. All individuals who were interviewed lived independently in the community, as opposed to institutional settings. It is by these three groupings that results of the research are discussed here.

### General Bladder Control Issues

During the fourth quarter 2000, 1,001 adults ages 30 to 70

were interviewed in retail malls. Twenty major cities were represented. Weighted by age and gender to reflect national census data, the responses were statistically significant within +/- 3%. The survey was conducted by Yankelovich Partners and funded by Pharmacia Corporation, now owned by Pfizer. The company markets tolterodine (DetrolLA®) for symptoms of overactive bladder (OAB).

The purpose of the study was to examine bathroom-related attitudes and behaviors and their relationship to bladder control problems. Analysis was completed in the first quarter 2001, and NAFC issued a news release in April 2001 with key findings spotlighted. The research documented the following:

- The bathroom is a personal place for most people, a

**Table 1.**  
**Summary of Symptoms by Gender: Ages 30-70**

Symptoms	Sudden Urge to Urinate	Leakage When Coughing/Sneezing/Laughing	Both Urge and Leakage	Symptom Free	Total
Female	13%	14%	22%	51%	100%
Male	24%	2%	4%	70%	100%
Both	19%	8%	13%	60%	100%

**Table 2.**  
**Symptoms by Age Group**

Symptoms	Sudden Urge to Urinate	Leakage When Coughing/Sneezing/Laughing	Both Urge and Leakage	Symptom Free	Total
Total ages 30-70 (n=1,001)	19%	8%	13%	60%	100%
Ages 30-39 (n=262)	15%	7%	10%	68%	100%
Ages 60-70 (n=224)	25%	10%	19%	46%	100%

haven for those seeking happy or peaceful refuge. This finding was supported by the numbers of people who have pleasurable experiences in their bathroom. More than half (53%) of survey respondents read in the bathroom. Nearly half (47%) say they think about serious issues. One-third (33%) of these surveyed admit they retreat to the bathroom to talk on the telephone. More than one-quarter (27%) of respondents aged 30 to 39 revealed they make love in the bathroom.

- For others, the bathroom represents a symbol of incarceration because of the preoccupation with needing to be near toilet facilities due to bladder control problems. An astonishing 62% of respondents indicated they routinely scout out restrooms when visiting an amusement park. Similarly, 61% look for restroom facilities when they go to the movies, on average less than a 3-hour excursion from home and back.
- The use of public restrooms — cleanliness, ease of accessibility, and privacy — is a con-

cern for many Americans, women more than men and older people more than younger adults. Three-fourths (75%) of all respondents think that public restrooms are not clean enough. Women are much more cautious than men when using public facilities, as almost half of all women (49%) say they always use seatcovers in public restrooms, compared to only 38% of men who were interviewed.

- Privacy in the bathroom, whether at home or in public, becomes more important as people grow older. This has major implications for how older people feel about using public restrooms especially if they have bladder control problems or voiding disorders, adding still another reason for them to remain at home and isolated.
- Forty percent (40%) of all respondents admitted that they experienced urgency/frequency or leakage of urine, or both. Table 1 breaks this statistic down by gender and by age group, revealing how disproportionately older people are affected. As expected,

women emerged as sufferers of stress urinary incontinence (SUI), or leakage when coughing, sneezing, or laughing. Men were more likely to experience a sudden urge to urinate than they were to leak with SUI. However, more than one in five (22%) women responded that they experience both urgency and SUI, compared to just 4% of men who self-reported both types of symptoms (see Tables 1 & 2).

- Those who do not suffer from symptoms of urgency or leakage, or both, feel the need to urinate on average 5.9 times per day (during a typical 24-hour period), whereas those with mixed symptoms need to urinate 8.1 times a day. Urgency/frequency are overactive bladder symptoms likely to begin surfacing after age 50, such that by age 80, men and women are nearly equally affected.
- This is one of the few nationwide studies that attempted to quantify nocturia, or frequent awakenings to use the toilet. Among those who revealed they are aroused from sleep during the night

to go to the bathroom, almost two in five (38%) have to get up twice or more, fitting the clinical diagnosis of nocturia. One in eight (13%) of these say they sometimes do not make it to the bathroom in time and thus lose urine on the way to the toilet. While beyond the scope of this survey, weekly or more frequent urge incontinence has been associated independently with an increased risk of falls and non-spine, non-traumatic fractures in older women (Brown et al., 2000). In assessing the economic consequences of urge incontinence in combination with nocturia, health economists may well underestimate the costs of urgency and incontinence in connection with falls that occur.

Other interesting highlights from the survey data include:

- Only one in five (20%) people say they are very comfortable using restrooms and bathrooms besides the one in their own home. Regardless of age, people rate gas station restrooms with the lowest comfort rating of all public locations. Younger people are more critical of public restroom cleanliness than older people.
- One-third (33%) at least sometimes wait until nobody else is in the restroom, and one in five (21%) sometimes run the faucet while using the toilet in public places. Almost half (45%) of women at least sometimes flush the toilet so other people will not hear what they are doing as they urinate.
- Toileting accidents are frequent among people who suffer urinary health problems. Fifteen percent of people who suffer from sudden urges to urinate and just as many who leak urine sometimes do not make it to the bathroom in time. Among those who suffer from a mix of urgency and leakage, two in five (40%) have such accidents.

- Two-thirds (66%) of all respondents, regardless of whether they had bladder control problems, said they had never discussed their bladder health with a doctor. This was true for 71% of men and 61% of women. Among those reporting symptoms, 26% said they had discussed them with a doctor (18% of men and 33% of women). Of this same group, only half (52%) said they were “very comfortable” with the idea of discussing their symptoms with their doctor (50% of men and 55% of women).

A second general survey was conducted by Harris Interactive among U.S. adults to better understand attitudes and experiences with loss of bladder control, or urinary incontinence. In addition, we sought to understand whether people with bladder control loss are managing their symptoms, and, if so, in what way. Another key objective was to understand how diagnosis of the problem affects people’s lives. The research was undertaken with funding from Kimberly-Clark Corporation, marketers of Depends® and Poise® absorbent products. A total of 1,420 online interviews were conducted: 1,025 interviews with a national sample of U.S. adults ages 30 to 70; 297 interviews with women pre-identified with loss of bladder control ages 30 to 70; and 98 interviews with men pre-identified with loss of bladder control ages 50 and older. All interviews were conducted in May 2004. The margin of error for the total sample for this survey was +/- 3%.

Respondents were categorized as “having symptoms” of bladder control problems if they indicated that they had ever experienced at least one of the following: loss of bladder control during physical activity such as lifting heavy objects, changing positions, or exercising; loss of bladder control while sneezing, coughing, or laughing; loss of bladder control as a result of not making it to the bathroom before wetting garments or the floor;

**Table 3.**  
**Percentage of Adults Ages 30 to 70 Who Indicate an Awareness of the Following Conditions**

Allergies	80%
Diabetes	72%
Cancer	70%
Ulcers	69%
Epilepsy	68%
Kidney disease	68%
Urinary incontinence	67%
None of these	16%

wearing any kind of protective pads because they regularly leak urine; or the noticeable loss of a few drops of urine throughout their day.

This second survey showed that nearly one-third (32%) of Americans ages 30 to 70 have experienced loss of bladder control symptoms at some point in their lives, with women three times more likely to be among those having symptoms than men. Seventy-three (73%) of these respondents were women compared to 27% men.

Only one in eight (13%) of people with symptoms, and only 4% of the total population of adults ages 30 to 70, self-report that they have been diagnosed as having the medical condition by a health care provider. Despite its prevalence, nearly two-thirds (64%) of those who have experienced symptoms are not currently using any treatment or product to manage their incontinence. In fact, awareness of the condition is not as high as it is for other medical conditions and diseases, such as allergies and diabetes, as reflected in Table 3.

Findings from the study illustrate that diagnosis actually improves knowledge, communication, and successful management of the condition (see Table 4).

On several of these questions, responses from women varied significantly from men regardless of whether they had been diagnosed, as reflected in Table 5. Women also differ signif-

**Table 4.**  
**Effect of Diagnosis on Knowledge, Communication, and Management**

	Diagnosed	Not Diagnosed But Having Symptoms
Feel my quality of life has improved	47%	32%
Feel a higher sense of self-esteem now that I am managing symptoms	40%	21%
Find sexual life is fulfilling	20%	13%
Feel a sense of relief from stress	54%	40%
Likely to discuss my condition with my spouse/partner	62%	27%
Likely to discuss my condition with a doctor or nurse	95%	31%
Likely to discuss my condition with family members	52%	17%
Seeking information about the condition	24%	3%
Managing the symptoms	97%	44%
Have greater awareness of the absorbent products available for managing symptoms	67%	38%

**Table 5.**  
**Diagnosis Characteristics of Men and Women**

	Men	Women
Likely to discuss my symptoms with my spouse/partner	43%	40%
Likely to discuss my symptoms with a doctor or nurse	55%	57%
Likely to discuss my symptoms with family members	14%	36%
Likely to discuss my symptoms with friends	12%	32%

icantly from men in their health-seeking behavior. While they are more likely to ultimately seek out a diagnosis for their symptoms (43% of women vs. 29% of men), they surprisingly wait longer than men to do so. Women experience symptoms for 6.5 years before being diagnosed, compared to 4.2 years for men. This is despite the fact that women

report, on balance, more severe symptoms than men and begin experiencing symptoms at an earlier age than men (39 years vs. 46 years).

Misconceptions influence health-seeking behavior and responses that people have to their symptoms of bladder control loss. Four out of ten (41%) of those surveyed think that loss of

bladder control is a disease. Still worse, nearly an equal number (38%) believe that it is a natural part of aging. On a related question, the majority of respondents ages 30 to 70 believe that loss of bladder control first occurs around age 60, when those actually reporting symptoms report that they first exhibited loss of bladder control around age 40.

As might be expected, those with less-severe symptoms rate their quality of life higher, in that 77% with slight leakage rate their quality of life as being excellent/good, compared to 69% with moderate symptoms and 62% of those describing their symptoms as severe. Nearly half (45%) of those with mild or slight symptoms indicate they are not pursuing any treatment or using any commercial products to help manage their symptoms, compared to 23% with moderate symptoms and just 7% who consider their symptoms to be severe.

### **Stress Urinary Incontinence In Women**

In 2002, NAFC sponsored a landmark study on SUI in women. It represented the first such nationwide study specifically on this diagnostic category and was especially important because it represented the first time that women as young as 18 were asked about a common medical condition they may share with women in their 70s and 80s. Harris Interactive conducted the nationally representative survey consisting of telephone interviews, and 1,029 women completed interviews. The stratified random technique allowed age groups to mirror the most recent U.S. Census data. The project was funded by Eli Lilly and Company, a global pharmaceutical company developing a drug for treating symptoms of SUI. The objectives of the research were: (a) to quantify the prevalence of SUI across women of all ages, (b) to determine how well the condition is understood, and (c) to examine the behavior of women with symptoms.

*Prevalence.* While we have known for some time that SUI affects millions of Americans, the large majority of whom are women, this survey documents that the condition is truly widespread. The survey also dispels the myth that only older women are affected.

One-fourth (26%) of women ages 18 and older reported experiencing an involuntary loss of urine when coughing, sneezing, laughing, or during physical activity during the immediately preceding 30 days. Among women ages 25 to 44, 24% experienced these symptoms, while 33% of women ages 45 to 64 experienced them.

Overall, almost half (47%) of women reported knowing someone who has experienced these symptoms. This percentage increased slightly with age; 54% of women ages 45 to 64 reported knowing someone. Women in the South were more likely to know someone with SUI symptoms than women in the Northeast (52% vs. 39%). Only 33% of African-American women reported knowing someone, whereas 50% of Caucasians and 51% of Hispanics reported knowing someone, even though there was no statistical difference in prevalence reported among races.

*Onset of symptoms.* When asked about the age that women typically begin to suffer from symptoms, 75% of women expressed the belief that women begin to experience these symptoms at age 40 and older, while 57% believe that it is age 50 and older. Only 13% of women believe that a woman could develop leakage symptoms before the age of 40. In reality, women who had experienced leakage during the past 30 days indicated very different findings, as 40% of women first experienced their SUI symptoms before the age of 40 and almost two-thirds (63%) before the age of 50. Nearly one-quarter (23%) reported that they first experienced symptoms before the age of 30. The average age of women when they first experienced symptoms

was 44. Women with children were more likely to be experiencing SUI and initially at an earlier age than women without children. Symptoms of SUI affected women regardless of household income or education level.

*Knowledge of risk factors.* Other studies have confirmed the association of urine leakage with aging. In this study, over half (54%) of women strongly agreed or somewhat agreed that urine leakage is a normal part of aging.

However, survey findings document for the first time nationally the fact that SUI is widely misunderstood by women overall and as a result remains underdiagnosed and undertreated, based on the following statistics.

- Fully one-third (34%) do not believe that childbirth puts a woman at risk for involuntary urine leakage. Even 26% of those with SUI symptoms do not think childbirth puts women at risk.
- Forty-two percent of women believe that drinking a lot of liquids puts a woman at risk, with over half (52%) of younger women ages 18 to 24 believing this myth. Statistics are virtually identical for women actually reporting symptoms.
- Over one-quarter (26%) stated that feeling stressed in the office or home puts a woman at risk, with 36% of younger women ages 18 to 24 believing this myth.
- While 10% of women overall believe that having too much sex is a risk factor, younger women ages 18 to 24 were twice as likely (20%) to believe this to be true. In fact, nearly one-third (29%) of women ages 25 to 34 with symptoms of SUI also erroneously believe too much sex puts a woman at risk.

There were no significant differences across regions or race in what women believe are risk factors. Public health education needs to be targeted especially at younger women because their basic lack of understanding of

SUI exceeds even that of middle-aged and older women.

*Worries/Fears about leakage.* Women in general expressed a high degree of concern with embarrassment if they were to experience symptoms of SUI, with 78% indicating that the smell of urine would be among the most embarrassing factors. An equal percentage feared the embarrassment of accidentally soiling upholstered furniture in a friend's home.

Other forms of embarrassment include the following (% feeling embarrassed if):

- 78% if the smell of urine was present.
- 78% if furniture was soiled in a friend's home.
- 74% if other people knew.
- 68% if having to wear absorbent briefs or pads.
- 66% if having to carry a change of clothes.
- 66% if leaving places suddenly because of an accident.

Nearly 9 out of 10 (87%) of all women interviewed said they would be constantly worried about having an accident if experiencing SUI, with an even higher percentage of younger women ages 18 to 34 expressing this fear (93%).

*Behavior of women experiencing symptoms of SUI.* Despite its widespread prevalence, of those women experiencing symptoms, only half (50%) had ever consulted with their doctor about their symptoms. This, however, varied with age. Older women (ages 65 and older) were more likely (64%) to have consulted with their doctors than younger women ages 25 to 34 (54%). There were no significant differences across region or race. Unlike other surveys, even in recent years, women with symptoms on average reported they had waited only 1.2 years before speaking to their doctor.

Those who had not consulted their doctor gave the following explanations:

- 64% – Not enough of a problem.
- 34% – Something that is supposed to happen with age.

- 22% – Not asked by their doctor.
- 19% – Dealing with it by wearing absorbent pads.
- 17% – Not aware something could be done.
- 17% – Too busy.
- 10% – Don't have a doctor.

One-quarter (25%) of women with symptoms had not spoken to anyone about their leakage. Those who had approached the following:

- 37% – Female friend.
- 37% – Female family friend.
- 28% – Spouse or significant other.
- 18% – Nurse.
- 15% – Co-worker.
- 10% – Children.
- 4% – Male friend.
- 3% – Pharmacist.

*Lifestyle/Attitudinal changes.*

Fifty-eight percent (58%) of women experiencing symptoms of SUI reported having to make some type of change in their lifestyle, a trend that increased with age. These included such adjustments as: (a) having to always know where the closest toilet is (31%), (b) having to wear absorbent pads and briefs every day (23%), and (c) drinking less water and fewer beverages for fear of leaking in public (19%). Nearly one in five (18%) reported feeling less confident because of their symptoms.

**Overactive Bladder In Women**

In 2003, a nationwide on-line survey was conducted by Harris Interactive on behalf of the NAFC and the National Women's Health Resource Council. It was funded under a research grant provided by Watson Pharma, Inc. The company recently launched Oxytrol™, offering transdermal drug delivery of oxybutynin for treating symptoms of overactive bladder.

The research examined the impact of health on lifestyles, specifically quantifying the extent to which sufferers of OAB experience compromised quality of life because of other health disorders. The study also looked at medication compliance to better understand why and when

**Table 6.**  
**Co-Morbidities Related to OAB Treatment**

Medical Disease/ Disorder	Control Group	Self-Reporting OAB Current Rx Users	Self-Reporting OAB Lapsed Rx
Gastrointestinal	13.9%	32.2%	28.4%
Hypertension	15.2%	35.1%	36.8%
Obesity	17.1%	39.1%	39.0%
Arthritis	19.9%	42.5%	45.7%

patients elect to stop using oral medication for OAB. In addition, questions were asked to understand more fully the relationship between a patient and her "regular doctor" in the context of how OAB concerns are discussed and managed between the two parties.

Included in the survey were women in the United States ages 40 to 65 with a household income of \$35,000 or higher and at least a high school education. A total of 1,228 women were interviewed in-depth by telephone, allowing for a +/- 3% error from the norm within a 95% confidence interval. The data were weighted to be representative of the U.S. population using demographic and propensity score weighting. Among those respondents who currently experience OAB symptoms, three subgroups were analyzed: (a) treated sufferers who were using the medication for their OAB, (b) those who formerly took medication for their OAB, and (c) those who have never been treated with medication for their OAB. Among the total, a control group without symptoms of OAB was isolated for comparative purposes.

Two in five (42.5%) revealed OAB symptoms. Over a third (36.2%) reported symptoms of stress urinary incontinence but no urge incontinence. An additional 14.4% revealed mixed incontinence, or a combination of both stress and urge incontinence, while only a small fraction (3.9%) indicated symptoms of only urge incontinence as part of their OAB symptoms. Such statistics underscore the importance of a full and comprehensive diagnosis so that appropriate patient

expectations can be framed by the health care provider when a medication is being prescribed as a form of treatment for OAB.

Often, primary care providers may struggle with the question of whether OAB is enough of a "bother" to be addressed if a patient doesn't initiate questions about it. Clearly, this survey indicates that for most middle-age women, it is a big "bother." Three quarters (77.3%) who have never used OAB medication but who report symptoms indicate so. These same women are equally as likely (37.8%) to fear taking still another prescription drug, as they are influenced by their embarrassment (37.7%) and concern of public disclosure (31.2%), all factors in whether the dialogue with physicians is opened by them.

Co-morbidities are statistically more likely to occur in patients reporting OAB symptoms than those free of OAB symptoms, explaining their reluctance to add still another daily pill. In fact, the biggest potential benefit of a transdermal delivery vehicle for OAB expressed by surveyed participants is the lower likelihood of interaction with other medications. In essence, women with OAB are significantly more likely to suffer from other compromising health disorders than those who do not experience OAB (see Table 6).

Making health matters worse, the survey revealed that, whether current or lapsed users of medications for OAB, patients were statistically less likely to go for long walks or exercise regularly, contributing further to their compromised health status. For example, although nine out of ten women

wish to go for long walks, only two in three currently taking medication for OAB ever do, compared to four in five who are non-OAB sufferers.

OAB sufferers are two to three times more likely than non-sufferers to very often experience disturbed sleep, difficulties concentrating, tiredness, overeating, and lack of self-esteem, according to survey responses.

While "dry mouth" is often cited as a leading side effect of oral OAB medications, those categorized as lapsed users were more likely to speak to their prescribing physician about their gastrointestinal problems (30.7%) than any other adverse side effect. It is interesting, however, that the highest percentage of lapsed users revealed problems with dry skin (58.2%), more so than any other negative side effect.

Lapsed users reported no less severe symptoms than those classifying themselves as current users of medication for OAB. However, nearly half of all lapsed users gave up in 3 months or less. In fact, one-third of all lapsed users blamed side effects and an equal proportion blamed lack of efficacy for their overall reason in stopping use of the medication.

The large majority (84%) of all current and lapsed users of medication had seen their regular health care provider, as opposed to a specialist or subspecialist, about their problems with OAB symptoms. This underscores the need for the primary care provider to be well informed about diagnostic categories and the realm of treatment options. According to the survey, only one in four (25.8%) patients being prescribed medications believe that their provider understands how deeply the symptoms of OAB truly affect their lives. Nine out of ten patients who discussed their OAB symptoms with their physician disclosed that they were the party initiating discussion, as opposed to the physician.

It is clear we still have much more work to do in diagnosing and treating OAB. While statistically significant yet self-reported

consumer data from a slice of the population leave us with additional questions, this research represents a landmark, quantitative study with respect to understanding the middle-age, female with overactive bladder.

### Conclusion

As recently as 4 years ago, several nurses published results of surveying 70 women to learn more about their beliefs and lack of knowledge regarding urinary incontinence and how this might influence their utilization of health care services (Bush, Castellucci, & Phillips, 2001). Such work, as well as NAFC's own in-house surveys of its newsletter readers in earlier decades, planted the seeds for subsequent, more substantial research, as reflected by the work spotlighted in this article.

Collectively, these nationwide surveys offer statistically significant documentation of how widespread, how far-reaching, how misunderstood, and how real are the symptoms of urinary incontinence and related symptoms of overactive bladder. While self-reported consumer data obtained by such methodology can leave us with additional questions, this body of research marks a monumental leap in understanding the prevalence, the needs of public education outreach, and the gaps in the health care delivery system. At NAFC, we trust that it lays a foundation to support future investment in research, education, and collaboration. ■

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## Urologic Nursing Editorial Board Member Elected Nurse Practitioner of the Year



The Michigan Council of Nurse Practitioners has elected **Susanne A. Quallich, APRN, BC, NP-C, CUNP**, as its Nurse Practitioner of the Year. Ms. Quallich has been a valued member of the Michigan Urology Center, Division of Andrology and Microsurgery since 2002, and is one of only 38 nurse practitioners in the country with a specialty certification in urology (CUNP). Her unique clinical focus in the areas of male sexual and reproductive health have made her a thought leader and expert among her peers in these areas, and she has published a variety of book chapters and journal articles on these topics.

Ms. Quallich is an editorial board member and regular columnist for the peer-reviewed journal, *Urologic Nursing*, as well as an executive board member of the Certification Board for Urologic Nurses and Associates, the agency that certifies non-physician professionals in urology. She is president of the local chapter for the Society of Urologic Nurses and Associates, and is an active member in various other professional societies that include the American Society for Reproductive Medicine, the American Academy of Nurse Practitioners, the Michigan Council of Nurse Practitioners, and Sigma Theta Tau.

Ms. Quallich serves as a lecturer and clinical preceptor for the University of Michigan School of Nursing, and has spearheaded the use of the Michigan Urology Center Web site to provide patient and provider-friendly information on specific clinical programs.

Ms. Quallich received her BSN and MSN degrees from the Frances Payne Bolton School of Nursing at Case Western Reserve University in Cleveland, Ohio. She also holds a Bachelors of Science in Biology from John Carroll University in Cleveland.

Other consumers follow a similar process, but different people, no matter how similar they are, make different purchasing decisions. You might be very interested in purchasing a Smart Car, but your best friend might want to buy a Ford F-150 truck. What factors influenced your decision and what factors influenced your friend's decision? Research shows that "strategic fragrancing" results in customers staying in stores longer, buying more, and leaving with better impressions of the quality of stores' services and products. Mirrors near hotel elevators are another example. Check out this Heineken commercial, which highlights the differences between "what women want" and "what men want" when it comes to products. Figure 3.2. Marketing to men is big business.