

ARTICLES

Incontinence After Prostatectomy: Coping With Incontinence After Prostate Cancer Surgery

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Purpose/Objectives: To describe the nature of postprostatectomy urinary incontinence, determine how men manage postsurgery urinary incontinence, identify men's perceptions of adequacy of preoperative counseling, and identify men's expectations regarding the probability of postsurgery incontinence.

Design: Survey.

Setting: United States.

Sample: Members of US TOO International, who experienced urinary incontinence after surgery.

Methods: Copies of the survey (N = 370) were mailed to all chapters of US TOO International, a prostate cancer support group, for distribution to members. A letter of invitation also was posted on the US TOO International Web site and in the monthly newsletter. Men who desired to complete the survey (N = 130) called the researcher's office, and a copy of the survey and a stamped return envelope was mailed to them. Surveys returned to the researchers from June 1998 to January 1999 were included in the analyses.

Main Research Variables: Urinary incontinence, management of urinary incontinence, and coping.

Findings: 166 men returned surveys. The majority was Caucasian (95%) and married (83%). The median age was 67 years, 87% of the men rated their health as good or excellent, and 114 men (69%) reported becoming incontinent after surgery. Most men experienced stress incontinence symptoms. The majority (89 of 111 men) reported that they were told preoperatively that urinary incontinence was a possible complication. Overall, regardless of length of time since surgery, men (74%) thought that incontinence was an important problem to resolve. Men used containment devices such as pads, special undergarments, and even sanitary napkins as management strategies. The majority of men (54%) used pelvic muscle exercises, especially those who were fewer than two years postsurgery (72%).

Conclusions: Urinary incontinence is a prevalent postoperative complication for men, even up to five years after surgery, and a source of great distress for some. Men reported stress and urge incontinence symptoms and used an array of strategies to contain their urine. Finding effective treatments for postprostatectomy urinary incontinence and receiving adequate information before surgery is important to these men.

Implications for Nursing: As the number of men who undergo surgical treatment for prostate cancer increases, nurses need to be equipped with the necessary knowledge and information to answer preoperative concerns and provide effective strategies for managing postoperative urinary incontinence.

Key Points . . .

- Urinary incontinence is a significant problem for men after prostate cancer surgery.
- Men use behavioral interventions (e.g., pelvic muscle exercises) and containment devices (e.g., absorbent pads) to manage their incontinence.
- Despite the length of time since surgery, men find incontinence an important problem to resolve.

As the U.S. population ages and public awareness of prostate cancer and the use of blood testing for prostate-specific antigen (PSA) increase, prostate cancer likely will be detected in its early stages more frequently (Haas & Sakr, 1997; Kao et al., 2000). For localized and well-differentiated tumors, the treatment goal is cure, usually through radical surgery (Scher, Isaacs, Fuks, & Walsh, 1995), which has a high 10-year survival rate (Gerber et al., 1996). Researchers have demonstrated that surgical treatment offers a cure (as defined by an undetectable PSA) for select patients

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with clinical stage T1c or T2 tumors, a serum PSA level of less than 10 ng/ml, a biopsy Gleason score of less than eight, and a reasonable likelihood of living 10–20 years after surgery (Potter & Partin, 2001). This has been supported in several case series in which PSA progression-free survival is equal to or greater than 70% at 10 years postprostatectomy (Pound, Partin, Epstein, & Walsh, 1997). The combination of PSA level, clinical stage, and Gleason score has been shown to be predictive of pathologic stage (Feneley & Partin, 2000). Researchers have learned that men aged 70 and older with a PSA greater than 20 ng/ml and a Gleason score of 8–10 have an 85% chance of metastatic disease. Men aged 50 and younger with a PSA lower than 4 ng/ml and a Gleason score lower than seven have a 24% chance of having extracapsular disease (Gilliland et al., 1999).

Two traditional surgical approaches, retropubic and perineal, are used to remove the prostate gland. Because of the density of tissue in the compact space of the pelvic basin and the need to completely remove diseased tissue, damage to the surrounding nerves and striated muscle of the internal urethral sphincter mechanism is possible using either approach. Two major consequences of radical prostatectomy surgery are erectile dysfunction and urinary incontinence.

Urinary continence is a complex, physiologic process of storing and emptying urine involving anatomic structures of the male urinary and genital tracts, peripheral neural pathways, hormonal influences, and central nervous control. Continence is maintained as long as the pressure in the urethra remains higher than the pressure in the bladder. Dysfunction in either the storage or emptying of urine can lead to incontinence. Urinary incontinence, the involuntary loss of urine sufficient enough to be a problem (Fantl et al., 1996), has many causes. These include incompetent sphincter mechanism, detrusor (bladder smooth muscle) instability, and bladder neck obstruction.

Winters, Appell, and Rackley (1998) noted that sphincter insufficiency is the most commonly noted mechanism contributing to incontinence after radical prostatectomy. Groutz et al. (2000) supported this finding among 83 men who had undergone radical prostatectomy. Junemann (1999) found that although detrusor instability typically is present after prostate cancer surgery, it does not strongly influence continence status. This finding further supports Winters et al. in that although detrusor instability is present in many men, it is the sole cause of postprostatectomy incontinence in very few men. Therefore, new pure urge incontinence should be present in very few men postprostatectomy.

John, Sullivan, Bangerter, Hauri, and Yalla (2000) investigated the before and after urodynamic function in men who underwent a radical prostatectomy. They found no difference in functional sphincter length (defined as “the distance between the first increase in urethral pressure above baseline and maximal urethral pressure,” p. 1762) between continent and incontinent men. They did note, however, that pressure transmission and maximal urethral closure pressure were altered significantly immediately after surgery; improvements in these functions were correlated with restoration of continence.

The Present Study

Incontinence is associated with feelings of embarrassment and shame, and the fear of incontinence can lead to avoidance of valued social activities (Wyman, Harkins, Choi, Taylor, & Fantl, 1987). These negative effects have been documented

extensively in the incontinence literature, but most of the studies to date have been conducted with women. Much less is known about the experience of incontinence among men, including how incontinence affects their daily lives and what men do to manage incontinence. Outside of anecdotal reports (Korda, 1996), little information is available about the effects of incontinence in men following radical prostatectomy. The present exploratory study was undertaken to learn more about this potentially devastating complication to help minimize the effects of prostate cancer and its treatment on survivors’ physical, psychological, and social functioning. The specific purposes of the present study were to better understand the nature of postprostatectomy urinary incontinence, men’s perception of postoperative incontinence, and methods men use to manage urinary incontinence.

Methods

Sample and Instrument Development

Men who were members of US TOO International, a prostate cancer support group, and lived in the United States were invited to participate in the study. A letter explaining the study was attached to an eight-page survey with 31 multiple-choice and 4 open-ended items. The principal investigators developed the survey based on information from previous research and a literature review. Content validity was established through consultation with content experts. The open-ended and multiple-choice items were reviewed by several prostate cancer nursing specialists, oncologists, and members of the US TOO International support group outside the sampling frame. The readability level of the cover letter and survey were grades 7.5 and 7.0, respectively, using Microsoft® Word (Microsoft Corporation, Redmond, WA). The University of Maryland’s institutional review board approved the study. Written informed consent was not required because return of the completed survey implied consent to participate.

Procedure

Two recruitment strategies were used. In the first, support group facilitators (N = 370), identified by US TOO International headquarters personnel, were mailed the cover letter and survey and asked to distribute these items at support group meetings. In the second strategy, a letter of invitation to complete the survey was posted on the US TOO International Web site and in the monthly newsletter. Men desiring to participate in the study (N = 130) called the researcher’s office, and a copy of the survey and a stamped return envelope were mailed to them. Surveys returned to the researchers from June 1998 to January 1999 were included in the analyses.

Research Variables and Measures

The main research variables were urinary incontinence, management of urinary incontinence, and coping. The item “Have you started leaking urine since your surgery?” assessed urinary incontinence. Men who reported that they leaked urine prior to surgery or were continent after surgery were excluded from the quantitative analyses.

Management of urinary incontinence was assessed by a multiple-choice item where participants could check all that applied: “How do you manage your urinary leakage? Tissue paper, pads, sanitary napkins, special undergarments, bed pan, limit fluids, extra fluids, voiding schedule, medication, condom

catheter, indwelling catheter, intermittent catheter, pelvic muscle exercises, sit to void, penile clamp, other—please specify.” Urinary incontinence and management strategies were explored in men who were two years or fewer from surgery, two to five years from surgery, and five years or more from surgery.

In keeping with the exploratory nature of the study, coping was assessed with a two-part, open-ended question. In the first part, respondents were asked to list and describe any problems they had experienced related to accidental urine loss since their surgery. In the second part, respondents were asked to think about the worst problem they had experienced that was related to accidental urine loss since their surgery and describe what they had done to manage it, including what worked and what did not.

The survey also assessed men’s perceptions regarding the adequacy of preoperative counseling (“Do you feel that you received enough information to prepare you about the possibility of urinary incontinence after surgery?”) and thoughts about what additional information would have been helpful. The information that men were provided with about the probability of incontinence after surgery was assessed with two items: “Were you told prior to surgery that urinary leakage was a possible complication?” and “Before your surgery, what did your doctor tell you about urinary symptoms that might occur after your surgery?” Finally, two items assessed beliefs regarding the likelihood of successful treatment of incontinence (“Do you think you can get better?”) and how important it was for respondents to resolve their urinary incontinence.

Analysis Plan

Survey data were entered and analyzed using the SPSS® 9.0 Statistical Software Package (SPSS Inc., Chicago, IL). Frequencies were run and univariate statistics (mean, standard deviation) were computed for each variable. Cross tabs with chi-square statistics were calculated to compare the association between number of years postsurgery (one to two years, three to five years, and more than five years) and the following variables: symptoms of reported urine loss, self-reported management strategies for urine loss, and men’s perceptions after surgery regarding chance of urinary incontinence improvement, adequacy of postoperative information regarding urinary incontinence, and importance of resolving urinary incontinence problems.

All responses to open-ended questions were typed in Microsoft Excel 97. All responses were reviewed within each question. For each question, a set of codes was developed to reflect common themes. Each response was assigned at least one theme code. Open-ended data were summarized according to themes.

Results

A convenience sample of 166 men returned surveys^a. Forty men (24%) had been either incontinent prior to their surgery or

^a Calculating a reliable response rate for either recruitment technique is not possible for several reasons. First, 130 responses to the US TOO International Web site and newsletter announcement were received; however, the number of men who read the notice is not known. Regarding the second recruitment method, 370 surveys were known to be sent to group facilitators. However, the number actually distributed is not known.

were dry after surgery and therefore were excluded from the quantitative analysis. Twelve men (7%) were excluded from analyses because of missing data. Thus, data from 114 men (69%) were used in the quantitative analyses. However, many of the 40 men claiming to be dry after surgery provided open-ended responses that were relevant to the study questions. Their answers were often inconsistent with actually being “dry.” Therefore, open-ended responses from all 154 men who answered the open-ended questions were summarized.

Sample Characteristics

Table 1 displays the demographic characteristics of the sample. The majority was Caucasian (95%) and married (82%). The average age was 66 years (SD = 7.6), and 87% rated their health as good or excellent. Thirty-five percent of the men were two to five years from surgery.

Symptoms of Reported Urine Loss

Many men experienced stress incontinence symptoms, especially with lifting (77%), coughing (72%), and sneezing (72%) (see Table 2). No statistically significant differences existed among the groups on the prevalence of stress and mixed incontinence (i.e., stress with urge) symptoms. Men in the group that was more than five years postsurgery experienced

Table 1. Sample Demographics

Variable	n	%
Age (years)		
Range = 43–82	–	–
\bar{X} (SD) = 66.4 (7.6)	–	–
Median = 67	–	–
Race		
Caucasian	108	95
African American	3	3
Other	1	1
Missing	2	2
Marital status		
Married	94	82
Divorced	10	9
Widowed	7	6
Single	3	3
Health status		
Excellent	49	43
Good	50	44
Fair	14	12
Poor	–	–
Missing	1	1
Time since surgery (years)		
≤ 1–2	36	32
2–5	40	35
> 5	37	32
Missing	1	1
Hormonal therapy before surgery		
No	96	84
Yes	16	14
Do not know	2	2
Radiation therapy after surgery		
No	88	77
Yes	25	22
Do not know	1	1

N = 114

Note. Because of rounding, not all percentages total 100.

Table 2. Symptoms of Reported Urine Loss Among Men

Type of Incontinence	Whole Group Responses ^a		No Response Given		Subgroup 1 ^b (n = 36)		Subgroup 2 ^c (n = 40)		Subgroup 3 ^d (n = 37)	
	n	%	n	%	n	%	n	%	n	%
Stress										
Lift	88	77	1	1	27	75	32	80	28	76
Cough	82	72	3	3	24	67	32	80	26	70
Sneeze	82	72	2	2	23	64	31	78	28	76
Exercise	71	62	5	4	20	56	26	65	24	65
Walk	60	53	3	3	17	47	22	55	20	54
Laugh	42	37	4	4	12	33	16	40	14	38
Climb stairs	31	27	8	7	11	31	10	25	10	27
Urge										
Sense of urgency	76	67	5	4	25	69	27	68	23	62
When sleeping	47	41	4	4	16	44	12	30	19	51
While in shower or tub	42	37	3	3	12	33	9	23	20	54
Hearing running water	28	25	4	4	4	11	10	25	13	35
When hands are in water	20	18	4	4	3	8	7	18	9	24
When place key in doorlock	12	11	5	4	2	6	5	13	5	14
Mixed										
Bend	63	55	6	5	17	47	22	55	24	65
Standing up	58	51	4	4	20	56	22	55	16	43
Jog or run	52	46	14	12	15	42	17	43	19	51
During sexual relations	31	27	22	19	10	28	11	28	10	27

^a Total number of responses given. Percents total more than 100 because subjects could have experienced more than one type of incontinence.

^b Subgroup 1 = ≤ 1–2 years

^c Subgroup 2 = 2–5 years

^d Subgroup 3 = 5+ years

urge incontinence when in the shower or tub more than men in the other groups, 54% versus 33% and 23%, $p = 0.022$. Two men experienced solely urge symptoms.

Self-Reported Incontinence Management Strategies

Containment devices such as pads, special undergarments, and even sanitary napkins were used by the men as management strategies (see Table 3). Pelvic muscle exercises reportedly were used by the majority of men (54%), especially those who were two years or fewer postsurgery (72%). No statistically significant differences existed ($p > 0.05$) among the groups for the management strategies, except pelvic muscle exercise.

Incontinence-Related Stressors

One of the primary study objectives was to determine what men who have undergone prostate cancer surgery view as the most important stressors related to incontinence. Twenty-seven men did not respond to the item that asked them to “Please list and describe any problems you have had related to accidental urine loss since your surgery.” Another 22 men indicated that they either had not experienced accidental urine loss since surgery or had none to speak of.

One hundred five respondents described a wide range of problems related to incontinence. When these respondents described their problems, they typically discussed the degree of incontinence they experienced, precipitants of incontinence, and how incontinence affected them socially, emotionally, or physically.

Degree of incontinence: Incontinence ranged from temporary and mild to long lasting with a total lack of control. One man described his experience in the following narrative.

When exercising, flow is increased. Dripping is increased if I have not had a normal bowel movement. Decreases after evacuation. Once I have urinated and stripped urethra, I still lose a small quantity of urine shortly thereafter. Use Depends pads for men. They are adequate except sometimes slip off center with dampening of underwear as result. I am somewhat fastidious, so change pads frequently, using at least three or more per day.

Typically, men described a gradual process of regaining bladder control: a fairly substantial lack of control right after the catheter was removed postsurgery shifted to good control six months to a year postsurgery, with a periodic lack of control often related to stress or unusual circumstances. For example, one man said,

Right after surgery, accidental urine loss was frequent. Over a period of six months, it became less and less. I started out with depends [sic] for men. Then went to posse [sic] pads, and now just get by with sports underwear, which get slightly damp during the day.

Of the 105 who answered questions about incontinence-related problems and strategies, 11 (10%) reported no incontinence problems at the time of the survey; however, they indicated having problems at one time. From 18 of the 105 (17%) respondents who described incontinence problems, it was not clear if problems persisted or if these respondents currently had incontinence problems. Twelve percent of respondents reported an enduring complete lack of control. However, the majority reported lesser problems, such as

Table 3. Self-Reported Management Strategies for Urine Loss

Strategy	Whole Group Responses ^a		No Response Given		Subgroup 1 ^b (n = 36)		Subgroup 2 ^c (n = 40)		Subgroup 3 ^d (n = 37)	
	n	%	n	%	n	%	n	%	n	%
Behavior										
Pelvic muscle exercises	61	54	17	15	26	72	20	50	14	38
Sit to void	32	28	20	18	7	19	12	30	13	35
Voiding schedule	26	23	19	17	10	28	10	25	6	16
Limit fluids	21	18	21	18	5	14	7	18	9	24
Extra fluids	1	1	24	21	—	—	1	3	—	—
Containment										
Pads	60	53	14	12	19	53	23	58	18	49
Special undergarments	20	18	21	18	10	28	7	18	3	8
Sanitary napkins	10	9	23	20	6	17	3	8	1	3
Tissue paper	7	6	21	18	3	8	2	5	2	5
Penile clamp	8	7	22	19	1	3	4	10	3	8
Condom catheter	4	4	23	20	—	—	1	3	3	8
Bed pan	1	1	23	20	—	—	—	—	—	—
Invasive										
Medication	16	14	22	19	—	—	5	13	8	22
Indwelling catheter	1	1	23	20	—	—	1	3	—	—
Intermittent catheter	1	1	23	20	—	—	—	—	1	3

^a Total number of responses given. Percents total more than 100 because subjects could have used more than one strategy.

^b Subgroup 1 = ≤ 1–2 years

^c Subgroup 2 = 2–5 years

^d Subgroup 3 = 5+ years

stress-related incontinence (20 of 105 respondents, 19%) while lifting, bending, or rising from a chair. Many reported using one to two pads (16 of 105 respondents, 15%) or three to four pads (6 of 105 respondents, 6%) per day, or a pad as needed (n = 3), for example, when they expected to be away from home for long periods. Others reported leakage (n = 5), minor dribbling (n = 4), or occasional unexpected wetness (n = 7). Some reported very minimal problems (n = 6). For example, one man

just wore a regular pad for two weeks, and then only when around people. Leaking gradually diminished until it stopped (meaning that leaks amounted to one drop maybe as often as once a week). I feel very lucky to have so few problems.

Three men were only incontinent at night and then only occasionally.

Precipitants of incontinence: In describing incontinence problems, many described the situations under which incontinence most often occurred. As noted previously, many men reported either current or a history of stress-related incontinence and many described activities that were antecedents of incontinence, such as playing tennis, golfing, doing yard work, and dancing. Others reported losing bladder control only when their bladder was very full or after drinking alcohol or caffeinated beverages. For many, long car or train trips or long shopping outings were risky activities.

Effects of incontinence: The problems the men described that were a direct effect of incontinence generally fell into three major categories: social, emotional, or physical effects. Of course, problems in one category could overlap with another category, and, often, the social or emotional effects somehow were implicated in the description of the physical effects without being explicitly stated. One man said,

The worst problem is no control. Skin irritation is a small problem—odor is a concern—finding a pad was a problem—disposing of the pad away from home is a problem—people are not very understanding of incontinence.

For this respondent, “no control” may have meant feeling out of control of his body, no control over the social impression he makes, or simply the physical effects of having no control over his bladder. Also, the respondent implied having faced public intolerance but did not describe those episodes. Again, the responses often hint at a richness of experience but only offer the slightest glimpse.

Social effects most commonly were mentioned and appeared to be the most troubling. This category included descriptions of the social limitations caused by surgery and the immediate postsurgery recovery period. One man described that he missed a funeral and other important social functions because of his inability to control his bladder. Another said that following surgery,

There was no way I could go out to dinner, go out to a show without having to worry about getting my clothes wet. I tried all types of pads and briefs with plastic liners. Most of them had to be changed within an hour. If I sat in a chair I could hold a portion of the urine and could void some urine. The best and least expensive was a pad sold by Wal-Mart called Assurance. I saved over 1/3 of the major brand. Penile clamp did not work.

The fear of discovery of the incontinence was a common theme. For example, one man was self-conscious of the continual dripping he experienced in public showers. Another was embarrassed to urinate in public restrooms because of wearing

a pad. Still another described, "It's been three years since my surgery and I still suffer from incontinence. Constant flow while coughing and, at times, *odor*—not knowing if people around me are obvious of the odor!"

Many men described a social event at which they lost control of their bladder, such as in a bar, at a wedding, or while shopping. One man's experience illustrates the frustration men feel faced with their own lack of control and a lack of understanding by the public: "With great urgency in a shopping mall, unable to locate an open bathroom, I jumped over the 'Closed' sign, greatly angering a janitor! The guy was such a complete jerk that I [urinated] on the hallway floor."

Perhaps the most poignant example of this social intolerance was offered by a man (age 42) who reported that he "wet pants on a bus from the airport in Helsinki to town. The driver stopped and kicked me off the bus when a mother and her daughter complained of the smell. I sat at the roadside and cried." Although this was by no means common, the fear of such an event seemed to linger behind the words of many respondents when they discussed their worst event. For example, one man said his worst problem was "mostly fear of other people finding out and embarrassment regarding sexual relations."

A subcategory within the broader social category was problems related to sexual relations. Eleven of 105 men (10%) reported incontinence while sexually aroused, attempting sex, or having sex. For one man, the problem was enough to prevent him from having a relationship with a woman.

The worst problem has been attempting any sexual activity. I was in a relationship with a woman at the time of the electrovaporization procedure, and we had made adequate accommodations for my impotency and were looking forward to subsequent developments, such as MUSG [sic] and Viagra. However, after I became incontinent, I had to wear a pad at all times and the sexual activity diminished and finally the relationship ended for that reason, but not that reason alone. In the past three years, I have dealt with this by not having or trying any sexual activity. Really, I am afraid to get into another relationship.

The **physical effects** of incontinence included skin irritation, sores, and reddening of the skin from exposure to urine as well as rashes from incontinence briefs. Others reported side effects from medications taken for incontinence.

Men described many **practical problems** related to incontinence. These included having quick access to a restroom at all times, carrying a change of clothes or several changes of incontinence briefs or pads, finding a place to dispose of pads, and finding the correct pad size. One man said, "My biggest problem was experimenting with different pads, undergarments, etc. Especially when flow was strongest in the first two to three weeks after catheter removal." One man reported having to buy two new cars in two years because of incontinence.

Only a few men described explicitly the **emotional effects** of incontinence. For example, one man said that wetting the bed was degrading. Another said, "The incontinence has been dealt with by medication, careful diet, and stoic tolerance." One man said, "Incontinence has become a problem for me that is more devastating than the fact that I am surviving stage D-1 cancer that has a good chance of returning." Another described depression until he found others who shared his experiences.

The worst problem I had was dealing with the loss of control of my urine! I got very depressed, miserable, self-pity—there were times I wanted my cancer back! In support groups, I've met others with similar feelings. I sought counseling and eventually realized I was grieving for the loss. Two years after the [radical prostatectomy].

Efforts to Manage Incontinence-Related Stressors

The strategies that men reported using to manage incontinence-related stressors fell into four general categories depending on the problem they had: preventing incontinence, improving incontinence, anticipating leakage, and dealing with complete lack of bladder control. Men generally described specific activities or behavioral strategies they used to confront incontinence rather than socioemotional adjustments. As was generally true for all the open-ended responses, men often were very matter-of-fact when describing their strategies. For example, in response to the question asking how they dealt with their worst problem, one man said, "I changed pad, underwear, and trousers. What else is there?"

Preventing incontinence: The most frequent techniques to prevent incontinence were vigilance and frequent voiding. For example, "I must remember to void more frequently if I am upright for prolonged time, especially if it is cold; also when I might have alcohol and be out dancing, etc." Many men described needing to pay close attention to anticipate when to change their pad to prevent wet trousers. Others tried to schedule visits to the bathroom to keep their bladder empty, particularly on trips or during social events. One man reported that keeping his bowels empty also helped with bladder control. Another man reported getting as much information as possible before surgery about the things he could do to reduce the risk of incontinence.

I had time to prepare, checked out the pads, and got ready. Read all I could and asked the urologist any and many questions. I was worried about incontinence, about as much as the cancer. Learned Kegel exercises and made a real effort to be patient and work through the problem. He gave me the best operation possible for a good start.

Several men reported that drinking more or less water, avoiding alcohol, not drinking close to bedtime, and avoiding sitting on the floor were ways to prevent events of incontinence. One man, whose only problem with incontinence was while sleeping said,

First, replaced queen-size bed with two single beds, thus ensuring wife was not affected. Second, purchased and placed plastic absorbent sheets below low sheet in the critical area. Third, endeavor not to drink any fluids after 8 pm and always void immediately prior to going into bed (11–11:30 pm).

Improving continence: Men described two main methods of improving continence. The first was by strengthening muscles using Kegel exercises. Many men reported using Kegel exercises; some men reported success but others did not find them successful. One man said, "Upon an unofficial suggestion, I found that taking an enema and holding the water worked very well to strengthen my pelvic muscles."

Anticipating leakage: Those with enduring incontinence problems, which was the majority of respondents, reported ways that they had learned to anticipate leakage to avoid problems.

Many men had developed strategies to keep supplies close at hand when they needed them most, such as in their golf or tennis bag. Many men kept a change of clothes and pads in their car trunk. One man described that he,

on occasion, went to public bathroom and used layers of paper towels as substitute pad. Poor results. Solution: I always carry a spare pad folded in my hip pocket. If wearing a suit jacket, I put pad in inside pocket. Also, if I expect increased flow (e.g., playing golf), I wear double pads. I also carry supply of pads in my car and golf bag.

Another man said “I carry backup supplies all the time, and I know where every public restroom in my entire area is located and the hours it’s open.”

Coping with complete lack of control: By far, the most energy went into dealing with having no, or very little, control. Men tried a variety of techniques including collagen injections, medications, Cunningham clamps, leg bags, bed bags, and urine drip pockets to control their problem.

I leak constantly while standing, so I use protection all the time. I have used diapers, pads, condom catheters, penile clamps, and a new product—the zip control system. I have had numerous problems involving a premature failure or unanticipated reaching of the capacity of the product I was using, with the result being wetting my clothes to various degrees, things I was sitting on at the time, and just plain dripping urine onto the floor. The diapers, such as Depends, require changing several times during the day. This means tremendous expense; therefore, the so-called Texas condom with the leg bag is preferred. Even with this, the daily shower and resulting daily change of condom is rather expensive. Sometimes, the leg bag develops a kink, which stops the liquid; when it backs up, the trousers get wet. I must always wear black (dark) trousers to help hide any wet spots on the trousers. The expense of dry cleaning is a real problem. Now, I only buy washable trousers, leaving all my various colored suits and trousers (other than black) hanging in the closet.

Many of the solutions men found seemed to reflect a great deal of trial-and-error efforts, and they required substantial tailoring for their particular needs. One man reported,

The external catheter with a skin prep, twice per day, with a leg bag connected to the catheter with thick-walled tubing is 98% effective. A strap to keep the tubing to the side of the leg keeps it from the bending knee. The external catheter with bed bag is 98% effective at night with clip to prevent the bed bag from pulling the external catheter off. This avoids getting up many times at night.

The road to finding an acceptable solution for total incontinence was often quite long and circuitous. One man said that “lately, I found out by accident about the ‘Cunningham Incontinence Clamp.’ My urologist never mentioned it. Wearing this clamp when I go to social functions helps a lot.”

Several men went through many procedures to try to correct their incontinence. Particularly for those who were very active before surgery, the desire to regain control and live the way they did previously motivated them to search for an acceptable solution. For example, one man said,

Worst problem—not being able to exercise (i.e., playing golf, racquetball, etc.) and the simple household chores—because of excessive drainage. Admittedly, I did not pursue the Kegal [sic] exercise routine like my urologist would have liked me to, so two and a half years after surgery and use of a Cunningham clamp. I had two separate collagen injections—first lasted 36 hours. Second injection—six days—then had AMS sphincter 800 urinary prosthesis implanted. It has now been 13 months since that operation—leakage (bad) has been controlled and would recommend procedure to anyone who has uncontrollable drainage. Coughing or sneezing may cause a drop or two of urine to escape onto a paper towel folded into underwear—my quality of life concerning incontinence is much better than before.

Many men described very active lives despite incontinence. For example, one man was completely incontinent but said, “I am very active—ride my motorcycle on long trips—California, Colorado, Mexico, etc. Am on hormonal therapy for three plus years and PSA is 0.0.” Another man described overcoming barriers to achieve the activity level he wanted.

Use two to three napkins per day. Sleep interrupted four to five times nightly, which results in my being tired the next day. Started using imipromine [sic] (10 mg) about three months ago. Has helped a great deal—only get up two times nightly. Am not so tired in daytime. My activity has not changed much since my surgery. Am very active and do just about everything I want. My sexual drive is still strong, but have to use vacuum tube—works great but somewhat embarrassing. May start using Viagra.

Overall, men describe accommodations to their life, trying to balance being incontinent with having rid their body of cancer through surgery. One man said,

Only problem now is stress incontinence. I exercise on a regular basis, run—very slow—5K road races, still very active. By holding an elective position in community and in auto racing . . . I now have padded briefs—my “life insurance underwear”—which I wear on occasion. I am very contented as I got rid of the *cancer*.

Still, many of those who still struggle with how best to deal with incontinence indicated that they still are searching for a better solution. One man said,

I still have leakage. I do not let it interfere with my life. I wear pads, two a day, and I am used to them. I look forward when something better comes available. . . . I see my doctors every three months, usually about my PSA readings. He has suggested many times, possible solutions. After examination, I decline again, hopeful that something better will develop someday.

Men’s Perceptions After Surgery

Overall, men ($n = 84$, 74%) thought urinary incontinence was an important problem to resolve, regardless of length of time since surgery (see Table 4). About 45% of respondents indicated that they thought their urinary incontinence could get better, although the proportions reporting this decreases as a function of time since surgery ($p = 0.05$). The majority (80%) reported that they were told preoperatively that urinary incontinence was a possible complication. However,

Table 4. Men's Perceptions After Surgery

Perception	Total Group Responses ^a		No Response Given		Subgroup 1 ^b (n = 36)		Subgroup 2 ^c (n = 40)		Subgroup 3 ^d (n = 37)	
	n	%	n	%	n	%	n	%	n	%
Think urinary incontinence can get better	51	45	6	5	23	64	16	40	11	30
Received enough information	69	61	6	5	26	72	27	68	15	41
Resolving incontinence is important.	84	74	5	4	27	75	29	73	27	73

^a Total number of responses given. Percents do not total 100 because subjects could have more than one perception about incontinence.

^b Subgroup 1 = ≤ 1–2 years

^c Subgroup 2 = 2–5 years

^d Subgroup 3 = 5+ years

39% of the men said they did not receive enough information to adequately prepare them for urinary incontinence after surgery, and the reported adequacy of information was associated with time since surgery ($p = 0.01$). The majority (59%) of men who had surgery more than five years prior reported not having received enough information.

Respondents ($n = 44$, 39%) who answered “no” to the question, “Did you receive enough information to prepare you about the possibility of urinary incontinence after surgery?” were asked, “What additional information would have been helpful?” Answers fall into three general categories.

Greater information accuracy, detail, or precision: More than half of the responses ($n = 23$; 52%) suggested that men wanted information that was more accurate, more detailed, or more precise. Regarding information accuracy ($n = 4$, 9%), one man reported that incontinence “seems to occur more frequently than stated and last indefinitely,” and another would have wanted “information that some leakage is bound to occur in nearly all cases.” A few responses reflected a sense that information was withheld purposely. One man wanted “the truth about incontinence and impotence risk,” whereas another wanted “honesty.”

Eleven men wanted more detail about incontinence issues. Some wanted general information (e.g., “information in more detail,” “some literature and details to prepare for incontinence,” “a more accurate and comprehensive talk,” “a thorough discussion and a plain forthright oral statement”). Others wanted more detail about specific topics, such as “more detail on what constitutes ‘stress’ incontinence” or “thorough and informed directions on Kegel exercises.”

Seven respondents wanted more statistics or more accurate statistics. For example, one man wanted “to know [the] true percentage of people who have urinary leakage problems after surgery.” Another said, “I believe that the percentages quoted [as to the possibility of incontinence] by the doctors and the books I’ve read to be vastly understated.” Yet another stated that he “would have been better prepared had I known that the chances were greater than just a possibility.”

A small number of respondents wanted the additional information in written form ($n = 5$; 11%), such as “a booklet explaining the possibility of incontinence” or “written article explaining incontinence.”

Information on strategies to deal with incontinence: Fourteen (32%) respondents reported wanting information about specific strategies to prevent, control, or accommodate incontinence. The most popular topic, which 10 men men-

tioned, was learning more about pelvic muscle exercises or “Kegels.” Respondents desired more detailed information about these exercises (e.g., “more information on when and how to use Kegel exercises to strengthen the sphincter muscle”) as well as specific information such as “how soon to start Kegal [sic] exercise after surgery.”

Three respondents wanted more detailed information on “methods of controlling incontinence” and “information on retraining.” One man would have wanted more information about pads. Two men wanted information about “different ways of living with incontinence.”

Information on the treatment process: Only three patients specifically reported wanting more information about the process involved in treatment. All treatments and tests through the urethra were very painful. Another patient said, “getting rid of the catheter was a BIG problem!”

One patient, who reportedly was poorly prepared by his physician for the possibility of incontinence, leaked constantly after treatment because his sphincter was destroyed during surgery. He had the most comprehensive and thoughtful response to this question. In his response, he touched on nearly all areas mentioned by all respondents, and his answer reflected the extent to which information might have armed him for the battle he was to face.

- (1) A more accurate and more comprehensive talk on what has been observed and what has been reported on in the literature, and what the outlook is for me, and what the probabilities are for the various possible outcomes (long-term leakage, totally incontinent, totally dry, etc.)
- (2) When doctors talk about dry, they don’t really mean dry—they mean leakage that doesn’t require more than two diapers or pads per day (socially dry). They should tell me that, instead of expecting me to know it. (When I’m told odds of my being dry after a few weeks are very high, I expect to be “DRY”—no leakage whatsoever.)
- (3) What to expect when the catheter is taken out, and how to prepare for it, and how to cope with it.
- (4) A list of relevant literature (for men after prostate cancer treatment) to read, a list of relevant Web sites.
- (5) Available resources: continence centers or continence specialists, support groups, lists of phone numbers of others who have the problem and are willing to discuss their experiences.
- (6) The pros and cons of doing kegals [sic] as soon as the catheter is taken out, the controversy over how best to do them (men), and how useful they have been proven to be (no scientific-quality proof exists).
- (7) A summary-type overview on what can be done if I turn

out to be one of those who has some (or a lot) of long-term incontinence, along with rough probabilities of success that can be expected and some of the types of side effects that came along with the treatments.

Discussion

Urinary incontinence is a prevalent problem that can last many years after prostatectomy. In total, 69% of the men responding to the present survey reported becoming incontinent since their surgery.

Limitations

Sampling techniques: Several important factors must be considered when interpreting the results from this study. The first concerns the sampling technique used in the study. A convenience sample, rather than a random sample, was used, which may limit the generalizability of the findings. For example, only patients who were particularly distressed by urinary incontinence may have chosen to respond or the results may apply only to men who are involved to some degree in support groups. Few African American and men of other ethnic groups responded to this survey; therefore, care needs to be taken to interpret these findings for culturally diverse groups. Given that this is an early exploration into the area of urinary incontinence in this population, with the goal of describing the range of urinary incontinence problems and management techniques (and not the prevalence of problems and techniques), a convenience sample is acceptable but less than ideal.

Changes in surgical techniques: Nerve-sparing techniques devised to minimize the incidence of these conditions have been used since the 1980s (Walsh, Marschke, Ricker, & Burnett, 2000). Evidence suggests that nerve-sparing surgery promotes sexual potency and urinary continence (Catalona, Carvalhal, Mager, & Smith, 1999). Walsh et al., for example, found that 93% of patients undergoing anatomic radical prostatectomy were continent by 12 months postsurgery. They also noted that prevalence of self-reported continence and sexual potency is high when experienced surgeons performed the surgery.

Variations in Prevalence Reports

Unfortunately, reports of postoperative prevalence of urinary incontinence are conflicting (Palmer, 2000). These variations can be caused by the different surgical techniques used, the definition of urinary incontinence, different methodologies in data collection, and source of incontinence information. Wei and Montie (2000) reported that incontinence rates in patient self-reports varied from 13% (when continence was defined as one or less pad per day) to 65% (when incontinent episodes were more frequent than one per day) when different definitions were used. However, physicians' and patients' reports of urinary incontinence had little agreement. Of note, agreement between men and physicians increased with men who reported having "moderate to big problems" (kappa coefficient = 55%, indicating moderate agreement).

Some evidence in the current study's data indicated that the lack of agreement between physicians and patients might be in part because of what patients mean by incontinence. More than half of the men—18 of 35—who answered "no" to the question, "Have you started leaking urine since your surgery?" provided open-ended responses indicating that they

did experience incontinence. Although these respondents were excluded from the results reported (based on the criteria), noting the quality of those responses here is worthwhile. Most of the answers (12 of 18) suggested that these men had said they were not incontinent because they believed what they experienced was "just normal." The following answers were typical: "I think I had the normal problems after surgery. It was not a problem for me"; "No problems. Only occasional squirts when allow bladder to be too full"; and "On rare occasions, I have a small release related to straining. . . . I've been fortunate . . . the releases I have are so small I ignore them." Apparently, expectations of duration and severity of leakage can influence patients' perceptions of what deserves the label "leaking urine." A few men reported more obvious problems such as "minor dribbling when standing. The problem is worse with alcohol, requiring frequent voiding. Then I use extra Depends." Or, "It's mostly during the day I have a problem. At night I have more control." One man who had declared himself continent said, "I use three plus pads per day now." These inconsistencies between the closed- and open-ended responses offer some insight into why prevalence rates in the incontinence literature can vary so widely and why physician and patient agreement may be so poor.

Men reported stress, urge, and mixed incontinence symptoms. However, very few men reported pure urge incontinence symptoms; this lends further evidence to the claim that very few men should report pure urge incontinence (Winters et al., 1998).

Management Strategies

The men in this sample used a variety of management strategies. Behavioral strategies such as pelvic muscle exercise (i.e., Kegel exercises) were used, although usage appeared to decline over time. Sitting to void, a method to effectively empty the bladder, was used by all groups, although its usage appeared to increase over time from surgery. More than half of the men used containment strategies such as pads. Containment strategies help men achieve social continence (Fonda, 1990), by which men attempt to control wetness and odor and, most importantly to these men, avoid detection by others.

Despite the number of years since surgery, finding a solution to incontinence remains an important issue to these men. In response to the open-ended query about the coping strategies they used, participants described a wide range of practical solutions, many of which seem to have been identified through trial and error. Some of the coping strategies likely were discovered through informal discussions with other men dealing with the same basic problems. An obvious next step would be to formalize these techniques by way of offering a menu of practical management strategies to men postprostatectomy. In this regard, more systematic study of the range of coping strategies is needed, with input from affected men as to the relative effectiveness of the various strategies.

Need for Information

Men who participated in the study indicated that they would have wanted more information preoperatively. Several said that frank, open dialogue and accurate information about incontinence would have helped them. Having information may help the men cope with incontinence and minimize its impact on their daily lives (Palmer, 2002). In another study, only 37% of men said that they received

adequate information about incontinence (Fitch, Gray, Franssen, & Johnson, 2000). Moore and Estey (1999) noted that men found that they did not process information about incontinence preoperatively because they were overwhelmed with the cancer diagnosis.

Implications for Practice

Clearly, oncology nurses will interact with men with prostate cancer both pre- and postsurgery. Giving men information only once about the possible consequences from prostate cancer surgery is not sufficient. Men react differently to being incontinent and may need additional follow-up information, emotional support, and practical assistance with management strategies. They should be referred to local chapters of support groups. Some self-care strategies that may improve urine control include maintaining an adequate fluid intake, avoiding caffeinated beverages and alcohol, and making sure bowels move regularly (Palmer, 2002). In addition, pelvic muscle exercises (i.e., repetitive contraction and relaxation of specific pelvic floor muscles) have proven effective when performed correctly in helping men regain urine control (Moorhouse, Robinson, Bradway, Zoltick, & Newman, 2001). Effective containment of urine is important so that men can function socially. The National Association for Continence (www.nafc.org) has a resource guide that men can use to select ab-

sorbent products to meet their needs. Finally, nurses should read Michael Korda's book (1996), *Man to Man: Surviving Prostate Cancer*, for a moving first-person account of a man coming to terms with a cancer diagnosis, surgery, and its consequences. The book also provides a vivid portrayal of a man's struggle to cope with incontinence.

Conclusions

As procedures to treat prostate cancer evolve, 100% preservation of urinary continence may become a reality and urinary incontinence caused by prostate cancer treatment may become a moot issue. Meanwhile, many men will live long lives as a result of the successful treatment of their cancer; however, they also will live valiantly with incontinence. Oncology nurses must be sensitive to their informational and treatment needs and devise effective pre- and postoperative interventions to help them cope, manage, and treat incontinence.

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