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Treatment-seeking behaviour and stated preferences for prostatectomy in Spanish men with lower urinary tract symptoms

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Objectives To determine whether men in the community with lower urinary tract symptoms sought treatment, would choose to have a prostatectomy, and the factors that might influence their decision.

Subjects and methods The study was a cross-sectional population survey using interviewers in the autonomous community of Madrid and comprised 2002 men aged ⩾50 years. The main outcome measures were self-reported International Prostate Symptom Scores (IPSS), treatment-seeking behaviour and the patients' stated preference for prostatectomy.

Results The response rate among eligible subjects was 68.1%; overall, 38.2% of men sought medical advice for their lower urinary tract symptoms. Whether a man sought medical advice was related to symptom severity, 'bothersomeness', interference in daily activities and his perception of the future; of these, bothersomeness and interference in activities were more likely to determine whether or not a man consulted his doctor. Most men in the sample (84.9%) reported that they would choose a prostatectomy, although this value depended on whether they had had a previous prostatectomy, were younger, and on the content of the information presented. Men were more likely to report that they would accept surgery if their doctor recommended it and less likely when presented with information on the outcomes of treatment.

Conclusion Many Spanish men with lower urinary tract symptoms do not seek medical advice for their symptoms, although most stated that they would accept a prostatectomy on the recommendation of their doctor. Further research should examine whether reported patient preferences correspond to actual behaviour and what is the most appropriate type of information to give to potential patients.

Keywords Lower tract symptoms, treatment-seeking behaviour, prostatectomy

Introduction

Lower urinary tract symptoms (LUTS) affect 20–30% of middle-aged and elderly men [1–6]. Although the presence of symptoms is an important reason for seeking treatment, it is not the only one; some men with severe symptoms never seek treatment while others with relatively mild symptoms do so early. Whether a man will eventually undergo treatment depends on a sequence of events that includes: (i) the impact of symptoms on health status and quality of life; (ii) treatment-seeking behaviour and; (iii) informed patient preference.

Few population-based studies have determined the impact of symptoms on health status, bother and quality of life. In Scotland, the USA and France, studies report that a substantial proportion of men in the community are bothered by their urinary symptoms, have less general well-being and experience interference in their activities of daily living [7–9]. The only study to use a validated, generic measure of health status, the Medical Outcomes Study 36-item short-form health survey (SF-36), found that increasing symptom severity was associated with a worsening in physical role, social functioning, vitality, mental health and perception of general health status, while bothersomeness was associated with a worsening in all dimensions of the SF-36 [10]. A study examining how the impact of symptoms on general health status (measured using the Nottingham Health Profile) influenced the use of prostatectomy concluded that the impact of symptoms on health status may be the determining factor in treatment-seeking behaviour and in the decision to accept surgery [11].

Many men in the community tolerate their LUTS and do not seek treatment for them. In the USA, only 4.4% of men with mild, moderate or severe urinary symptoms had seen a doctor for their symptoms [12]. This compares with 11.3% of Scottish men with BPH, defined using a combination of symptom scores, flow rates and prostate size, who reported that they consulted a doctor

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for their symptoms [13]. Those men who did so were significantly more likely to report a greater impact on their daily living activities [13]. Of British men with mild, moderate or severe urinary symptoms, 45% reported that they had seen a GP for their symptoms [14]. The results of these studies suggest that many men do not perceive their symptoms to be serious enough to warrant treatment or have different perceptions about the associated risks of surgery.

Whether or not a man would choose to have a prostatectomy is limited to evidence from case-series of men referred for prostatectomy and from one population-based study of self-reported patient preferences for prostatectomy. Studies of men waiting to undergo prostatectomy have shown that the proportion of men declining surgery ranged from 15% in Denmark [15], 16% and 30% in the UK [16,17] to 55% in the USA [18]. Recently, a study in the USA, using an interactive video-based shared decision-making program, found that most (86%) moderate or severely symptomatic men elected to decline surgery and opt for ‘watchful waiting’ [19]. That study also showed that symptom severity was not enough to explain the patients’ choice; bothersomeness appeared to be a better predictor. The only population-based study to determine the extent to which men with LUTS reported that they would accept treatment when presented with details and information on the risks and benefits of prostatectomy, found that 22% reported that they would probably or definitely refuse treatment and a further 47% were unsure whether they would choose prostatectomy [14].

There is accumulating evidence that men with LUTS do not always seek treatment and may not elect to undergo a prostatectomy, an effective treatment for their symptoms. The present study aimed to identify the prevalence of men in the community with symptoms who would choose to consult a doctor for their symptoms and would accept a prostatectomy. The existence of a group of men in the community who do not seek treatment for their symptoms could have important implications for those involved in planning health services. Thus, the aims of this study were to determine: (i) whether Spanish men sought treatment for their LUTS; (ii) whether they would choose to have a prostatectomy; (iii) the factors that influence their decision and; (iv) whether the content of the information influenced the stated preferences.

Subjects and methods

A three-page questionnaire was used to collect information from 2002 men in Madrid aged ⩾50 years; the questionnaire was administered by interview. The purpose of the survey was to measure the prevalence and severity of reported LUTS and the methods have been reported in detail elsewhere [6]. Briefly, the sample was selected using a three-step sampling process stratified by census district, house and individual. Of a total of 3485 census districts (the smallest unit of the census) 243 were selected randomly, reflecting inner-city, suburban and rural areas. In each district, one of four households was contacted until 8–10 households had replied. The estimated response rate among eligible responders was 68.1% and the age-structure of those responding differed from the male population of Madrid in that men aged 50–59 years were under-represented, while men aged 65–74 years were over-represented. The other demographic characteristics (education and area) in the sample were similar to that of the population of Madrid [6].

Questions on urinary symptoms, bothersomeness, interference in activities and perception of the future were taken from the Spanish translation of the IPSS [20]. Although other translations were available, this version was chosen because it had been re-translated to assess the validity of the original translation. A symptom index, ranging from 0 to 35, was calculated by summing the scores of seven urinary symptoms (fullness, frequency, intermittency, urgency, poor flow, hesitancy and nocturia) where each symptom was assigned one of the following values: never = 0, hardly ever = 1, less than half the time = 2, about half the time = 3, more than half the time = 4 and almost always = 5. The symptom index was categorized into four levels of severity; none (0), mild (1–7), moderate (8–19) and severe (20–35). Responders were also asked about how bothersome any trouble with urinating had been in the preceding month (possible responses = no problem, very small problem, small problem, medium problem, big problem), the extent to which they experienced interference in their daily activities (possible responses = never, some of the time, most of the time, all of the time) and how they would feel if they had to spend the rest of their life with their current level of symptoms (delighted, pleased, not bothered either way, unhappy, terrible). Responders were asked if they had ever consulted their doctor for their symptoms.

Establishing patient preferences

To determine whether men would accept treatment or not, they were asked three questions that varied in the content of the accompanying information. The wording of the first format was: ‘Urinary problems are often caused by the prostate. Prostate enlargement is a common problem in men of your age. The most common treatment for this problem is surgery. If your symptoms were found to be due to an enlarged prostate and you

were offered surgery for it, which of these phrases best represents your attitude?'. To assess whether providing information about surgery might influence choice, participants were provided with currently available evidence about the outcomes of treatment. The wording of the second format was: 'We will now give you some information: the surgery involves a hospital stay of five days. The majority of patients improve, although some worsen. Sometimes, it can result in permanent problems such as impotence, infertility or incontinence requiring the use of pads for the rest of your life. Which of these phrases best represents your attitude?'. Finally, participants were asked whether they would choose surgery if their doctor recommended it to them.

Respondents were asked to score their preferences on a scale of 1–5 (1 = would choose surgery, 2 = would probably choose surgery, 3 = I do not mind one way or the other, 4 = would probably not choose surgery, 5 = would not choose surgery). Data were analysed as frequency distributions; CIs for proportions were calculated at the 95% level using the method of Fleiss [21]. All analyses were conducted using procedures written in SAS [22], with odds ratios (ORs) calculated using the Statcalc procedure in EpiInfo [23].

Results

Overall, 38.2% (635/1662) of men with mild, moderate or severe urinary symptoms reported that they sought medical advice; this proportion increased as symptom severity increased from mild to severe (Table 1). Similar increases were seen for bothersomeness, interference in daily activities and perception of the future (Table 1). The data were categorized into dichotomies (i.e. none/mild versus moderate/severe) to calculate ORs; these varied for symptom severity, bothersomeness, interference in daily activities and perception of the future (Table 2).

Table 3 shows the distribution of stated patient preferences for treatment with the information content accompanying the question on choice, listed for several factors. Overall, 84.9% of men reported that they would probably or definitely choose surgery, 13.6% would probably or definitely not choose surgery and only 1.5% were unsure. There was no clear increase in the proportion of men who reported that they would choose treatment as the symptom severity or bothersomeness increased (Table 3). The proportion of men choosing surgery was significantly related to whether a man had had previous prostate surgery, although a previous episode of acute retention did not appear to affect their choice for surgery (Table 3). In general, older men were less likely to choose surgery.

The content of the information presented to the responders had an effect on whether or not a man reported that he would choose surgery. In general, regardless of symptom severity or level of bothersomeness, the reported preference for surgery was highest if the responder accepted the advice of his doctor, and lowest if provided with information about the possible outcomes of prostatectomy (Table 3). A similar pattern was observed as age increased (from 89.8% to 64.9% for men who were told that their symptoms were related to the prostate) and 91.8% to 80.0% for men if they were advised to have prostatectomy by their doctors.

Table 1 Proportions of men seeking treatment ($n = 698$), by symptom severity, 'bothersomeness', interference with daily activities and perception of future, for men aged ⩾50 years in Madrid in 1995

	n *(%) [95% CI]*
Symptom severity	
None	39 (13.5) [9.8–17.7]
Mild	296 (27.7) [25.1–30.4]
Moderate	246 (52.2) [47.6–56.6]
Severe	93 (76.9) [68.1–83.1]
Total	674
Missing	24
Bothersomeness	
No problem	316 (22.8) [20.6–25.1]
Small problem*	225 (52.1) [47.3–56.6]
Medium problem	108 (87.1) [79.6–91.6]
Big problem	49 (86.0) [73.7–92.1]
Total	698
Interference in activities	
Never	535 (30.6) [28.5–32.8]
Some of the time	125 (64.1) [56.9–70.3]
Most of the time	20 (87.0) [65.3–94.3]
All of the time	12 (85.7) [56.2–94.3]
Total	692
Missing	6
Perception of future	
Delighted	219 (20.3) [18.0–22.8]
Pleased	297 (44.5) [40.7–48.2]
Not bothered	103 (72.0) [63.8–78.4]
Unhappy	48 (67.6) [55.3–76.7]
Terrible	27 (84.4) [66.5–92.1]
Total	694
Missing	4

*Very small problem and small problem combined.

Discussion

Overall, 38.2% of the subjects reported that they sought medical advice; the proportion who did so increased as symptom severity, bothersomeness, interference in activities and perception of the future increased. Of these, bothersomeness and interference in activities were the strongest predictors. However, these factors did not

Table 2 Factors determining whether a man sought treatment for men aged ⩾50 years in Madrid in 1995

	Reported consulting a doctor (n)			
	Yes	*No*	*Odds ratio*	*95% CI**
Symptom severity				
Moderate/severe	339	253	4.09	3.32–5.05
None/mild	335	1023		
Bothersomeness				
Medium/big problem	157	24	15.44	9.75–24.63
No/small problem	541	1277		
Interference in activities				
Most/all of the time	32	5	12.44	4.60–36.48†
Never/sometimes	660	1283		
Perception of future‡				
Unhappy/terrible	75	28	4.66	2.92–7.47
Delighted/pleased	516	897		

*Cornfield 95% CIs. †CIs may be inaccurate because one value is < 5. ‡143 who were 'Not bothered' about the future were excluded from table.

explain why a man stated that he would choose surgery. Overall, 84.9% of men stated that they would choose to have a prostatectomy, although their stated preference for surgery depended on the content of the presented information. More men reported that they would choose surgery if their doctor advised it, with fewer men choosing surgery when presented with information about the risks and benefits of prostatectomy.

Before drawing conclusions, possible limitations of the method are considered. Surveys are subject to sampling and response bias; the possible contributions of bias in this survey have been discussed elsewhere [6]. Men who respond to surveys may differ in some way from those who do not. In this survey, there was no information assessing the characteristics of those who did and did not respond. It is possible that men with symptoms were more likely to respond, although this is unlikely because non-responders did not know the purpose of the interview. The wording of the questions could also bias the results. The IPSS used to measure LUTS has been extensively tested for validity and reliability [24]. The Spanish version used here has been shown to be valid in Spain [20]. The question about patient preference is a modification of a question developed in the UK for a similar population-based study of patient preferences and has not been tested for validity and reliability [14]. Nevertheless, it was discussed extensively with researchers who have considerable experience in questionnaire design. It was decided not to quantify the risks and benefits of surgery in the information accompanying the choice question because we were advised not to do so by the urologists who reviewed the questionnaire and by the sociological and research company that collected the data. However, in retrospect we would have done so, because the experience of the shared decision-making program of men appropriate for prostatectomy found that patients were not overwhelmed by the amount of information [19].

The questions about the subject's stated preferences for prostatectomy varied in the content of the accompanying information; the order of the questions could have led to a 'learning effect'. If so, it would be expected that the proportion of men reporting that they would have chosen surgery would have increased across the categories. This issue could be examined in future studies by randomly allocating the questions to the interviewees.

Although men in the survey reported that they would definitely or probably choose treatment, it is unknown whether their attitude towards treatment would correspond to their actual behaviour. The men in this sample could be followed to determine whether reported preferences for treatment corresponded with their behaviour when offered surgery. There is little information about this, because published research relates to patients' preferences for treatment alternatives, as part of the interaction between patient and physician, rather than about the provision of information by questionnaire as a basis for decisions about treatment preferences.

A substantial proportion of Spanish men (38.2%) reported that they sought advice for their mild, moderate or severe symptoms. This value was higher than those published for men in the USA (4.4%) and Scotland (11.2%), but lower than in England (45%) [12–14]. However, there are important differences among these studies in their design, the age-groups examined and in the definition of urinary symptoms. For example, the USA and Scottish studies were based on community samples selected for detailed urological investigations and it is possible that several men in the community with mild or moderate symptoms refused to visit the clinic and were therefore excluded from the study (i.e. the USA study reported a response rate of only 55%). In addition, both of these studies excluded men because of a previous or imminent prostatectomy, and it is likely that the latter group would be symptomatic [12,13]. Both of these groups are likely to have symptoms, the former because their original prostatectomy was ineffective and the latter because their urinary symptoms were the reason that they were having a prostatectomy. The UK studies differed from the present study in that the questionnaires were administered by post rather than by interview [14].

There may be real differences among countries; that

Table 3 Stated preference for having a prostatectomy, by symptom severity, bothersomeness, age-group, previous prostate surgery, and acute retention, in men aged ⩾50 years in Madrid in 1995

		Format of information	
	Prostate % yes (95% CI)	*Outcomes information % yes (95% CI)**	*Doctor's advice % yes (95% CI)*
Symptom severity			
None	82.5 (77.4–86.3)	75.3 (69.7–79.8)	90.5 (86.3–93.2)
Mild	84.1 (81.7–86.1)	71.6 (68.7–71.6)	90.8 (88.8–92.3)
Moderate	75.1 (70.8–78.7)	59.7 (55.1–64.0)	84.4 (80.7–87.3)
Severe	77.7 (69.0–83.8)	63.3 (54.0–71.0)	80.8 (72.4–86.5)
Bothersomeness			
No problem	82.9 (80.8–84.8)	70.7 (68.2–73.0)	90.0 (88.3–91.5)
Small problem†	74.9 (70.5–78.7)	62.3 (57.5–66.8)	84.0 (80.1–87.1)
Medium problem	78.9 (70.4–84.8)	63.4 (54.2–71.0)	85.4 (77.6–90.2)
Big problem	82.8 (70.1–89.7)	70.7 (57.1–80.1)	84.5 (72.1–91.0)
Previous prostate surgery			
Yes	90.7 (78.9–95.4)	81.5 (68.1–88.9)	88.9 (76.7–94.2)
No	74.4 (70.4–77.8)	58.9 (54.6–62.9)	84.1 (80.7–86.9)
Acute urinary retention			
Yes	81.0 (70.6–87.4)	73.8 (62.9–82.5)	85.7 (76.0–91.2)
No	74.9 (70.8–78.3)	58.4 (54.0–62.5)	84.4 (80.8–87.2)
Age group (years)			
50–54	90.7 (78.9–95.4)	59.2 (44.3–70.9)	91.8 (79.5–96.2)
55–59	84.2 (71.6–90.8)	52.6 (39.1–64.2)	86.0 (73.7–92.1)
60–64	79.1 (69.8–85.3)	61.9 (51.9–70.2)	85.7 (77.2–90.8)
65–69	76.0 (67.5–82.2)	65.9 (57.0–73.2)	83.7 (76.0–88.8)
70–74	73.3 (63.7–80.4)	61.0 (50.9–69.3)	84.8 (76.1–90.0)
75–79	70.7 (58.9–79.2)	62.7 (50.7–72.1)	80.0 (68.9–87.0)
80–84	64.6 (49.4–75.7)	54.2 (36.3–66.5)	85.4 (71.6–92.0)
85+	64.0 (42.6–78.2)	60.0 (38.9–75.0)	80.0 (58.7–89.8)

*Yes, men stated that they definitely or probably wanted a prostatectomy. †Very small problem and small problem combined.

there are such differences in the impact of urinary symptoms is supported by the results of a comparison of Scottish and American men suggesting that the latter experience greater interference in daily activities than the former for similar levels of symptom severity [8]. It is known that only 5.4% of Spanish men reported that their symptoms interfered with their daily activities, compared with 36.9% of British men [2,6].

There are several possible reasons why men do not seek medical advice for their urinary symptoms. First, men may consider their symptoms to be an inevitable consequence of ageing and do not believe they would benefit from consulting their doctor or from treatment. A Danish study investigating this issue found that men aged ⩾70 years and with voiding difficulties did not consult a doctor for their symptoms [25]. It has been suggested that many men do not seek medical advice for their symptoms because they recognize that their symptoms remit spontaneously and that they believe their symptoms are temporary [13], although there is no direct evidence for this hypothesis. Alternatively, fears related to surgery or to the perceived outcome of treatment could influence a man's decision to seek treatment for his symptoms. Whether or not men with symptoms who do not seek treatment will go on to develop acute retention is unknown and should be studied.

A high proportion of asymptomatic men reported that they would choose to have a prostatectomy. This finding was unexpected and suggests that either the men misunderstood the question or that it was irrelevant to them. It is possible that these men did not carefully consider the risks of the treatment because they realized that they were unlikely to require a prostatectomy. There has been one other study, in the UK, that assessed the extent to which men in the population with urinary symptoms reported that they would choose to have surgery, when presented with information about the procedure [14]. Although broadly similar proportions in both countries sought medical advice for their symptoms (38.2% and 45%), more Spanish men reported that they would choose surgery than did men in the UK (84.9% and 30.6%, respectively) while British men were more uncertain about their preferences (47% and 1.5%) [14].

There are three possible explanations for these differences. First, the British study was conducted by post, while the present study used interviewers; this may have lead to a bias, with men reporting that they would choose surgery, to please the interviewer. Second, the questions were not identical, in that the UK questionnaire provided estimates of the relative risks and benefits of surgery. Third, there could be cultural differences between English and Spanish men in the way they react to authority figures (i.e. doctors), a legacy of an authoritarian government, although this is only speculation.

The content of the accompanying information was an important factor in whether or not men stated that they would choose to have a prostatectomy. Men reported they would be more likely to choose surgery on the recommendation of their doctor, than when told their symptoms were 'due to the prostate' or when presented with information about the risks and benefits of prostatectomy. Studies of patient preferences in medical decision-making are dependent on the amount of information presented and on the way the questions are asked (i.e. whether the question refers to a good or a bad effect) [26]. One possible explanation for the present result is that the content of the question with information about outcome also included impotency and infertility; a recent study investigating treatment preferences in men referred for prostatectomy in the USA found that patients' attitudes toward sexual dysfunction as a potential outcome was an important predictor of whether a man would choose surgery or opt for watchful waiting [19].

Although the bothersomeness of symptoms was an important factor in determining the likelihood of a man seeking medical advice for his urinary symptoms, it was not as important as whether a man stated that he would choose a prostatectomy. These findings are inconsistent with those of the shared decision-making programme which found that bothersomeness and attitudes towards post-operative sexual dysfunction were the most important predictors of whether or not a man would choose to have a prostatectomy [19].

Men were asked if they would choose prostatectomy, an effective treatment for LUTS [27]. However, alternative treatments such as medical therapy, watchful waiting and laser therapy are emerging for the treatment of these symptoms. It is possible that the men who did not wish to undergo prostatectomy would prefer one of these options instead. In retrospect, questions about these options would have been included, although when the questionnaire was developed there was little evidence of their efficacy. It was surprising that some men without symptoms would still elect to have surgery if offered, despite having been informed about the potential risks. The reasons for this are unclear and warrant further study.

In conclusion, the finding that many men with LUTS do not seek medical advice for their symptoms and that some would decline prostatectomy when offered raises several issues. First, there are important implications for those involved in planning and providing urological services. Whether or not efforts should be directed towards persuading these men to seek medical advice for their symptoms, with the potential increased demand on the healthcare system, remains unclear. Should a man with bothersome mild symptoms be able to choose prostatectomy despite the recommendation that such men are inappropriate for surgery [27]? Second, we intend to combine these results with those from a consensus panel that established the appropriate indications for surgery in Spain, using a survey of the prevalence and severity of LUTS, to estimate the number of prostatectomies required in Madrid [6,14]. Third, a follow-up survey has been planned to compare reported treatment preferences with actual behaviour.

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