Health care sought and received by men with urinary symptoms, and their views on prostatectomy

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SUMMARY

Background. Urinary symptoms are common among middle aged and elderly men.

Aim. A study was undertaken to describe the health care sought by men aged 55 years and over with urinary symptoms, the action taken by general practitioners and urologists, and the men's views on prostatectomy.

Method. A postal questionnaire was sent to 516 men aged 55 years and over in the North West Thames Regional Health Authority, with previously identified mild, moderate or severe urinary symptoms.

Results. The response rate among eligible subjects was 83%. Of 420 respondents 45% had seen their general practitioner for their symptoms. General practitioners had referred 62% of these men to a urologist, reassured 21% and prescribed medication to 17%. The probability of a man seeking medical advice increased with increasing symptom severity. In contrast, the decision to refer was independent of symptom severity. Of the men referred to a urologist, the majority (71%) were offered and accepted surgery. The remainder were reassured (17%), or received a prescription (4%). Eight per cent were offered surgery but declined. When presented with details and information on the risks and benefits of prostatectomy, 22% of men with symptoms would probably or definitely refuse treatment, while a further 47% of men were unsure.

Conclusion. There are many men who do not seek treatment for urinary symptoms and, of those who do, subsequent referral is not associated with symptom severity. There is scope for improving the referral process through the shared development of guidelines between general practitioners, hospitals and commissioning agencies.

Keywords: urination disorders; prostate diseases; men's health; patient self referral.

Introduction

MODERATE or severe urinary symptoms affect up to 25% of middle aged and elderly men. 1-3 These are commonly due to benign prostatic hyperplasia, a condition for which an

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effective intervention exists.^{4,5} However, many men with symptoms do not receive treatment.³ The relationship between the need for and use of health care involves a chain of events in which intervention rates are influenced by: whether individuals seek medical advice; whether clinicians judge the intervention to be appropriate; and if, when presented with information about the intervention and its risks and benefits, individuals choose to receive it. Planning and purchasing of health care require an understanding of this process.

Little information on these three steps is available. First, as regards whether or not individuals seek medical advice, a Danish study found that a third of healthy men with urinary frequency, post-micturition dribbling, and a weak urinary stream believed that these symptoms did not justify seeking treatment.6 Secondly, variation in clinical judgement about the appropriateness of surgery is believed to account for much of the variation in prostatectomy rates within countries although this view is based largely on studies of men undergoing prostatectomy, with no information about those who have symptoms but do not undergo surgery.⁷ Thirdly, even after being offered treatment, men may not wish to accept it. In a British study, 30% of 107 men with minimal symptoms who were on a waiting list for prostatectomy declined surgery after being reassured about the natural history of prostatic obstruction.8 An American study to validate a quality of life questionnaire among men awaiting prostatectomy had to exclude 37 men (55%) who elected not to have surgery. Preliminary results from studies in the United Kingdom and the United States of America of symptomatic men considering prostatectomy found that many declined surgery after viewing an interactive video disc that provided information on the risks and benefits of treatment. 10,11

While these studies give some indication of the importance of these factors in different countries, there is little information about their overall effect on the relationship between need and use in a defined population. This study sought to: determine the advice-seeking behaviour of men with mild, moderate or severe urinary symptoms; describe their subsequent management by general practitioners and urologists; and determine whether these men would choose surgery when provided with information about the outcomes of prostatectomy. This paper describes the results of a two-stage survey, the first stage of which is being reported elsewhere.³

Method

A two-page questionnaire was sent to 2000 men over the age of 55 years selected from eight randomly chosen general practices in North West Thames Regional Health Authority in 1992. With the exception of the smallest practice, where the entire list was used, 265 men were randomly sampled from the whole of each practice's list to create a database of 2000 names and addresses. The purpose of the survey was to measure the prevalence and severity of urinary symptoms. The survey achieved a response rate of 77.7% (1480) among eligible respondents. Questions on urinary symptoms were taken from the American Urological Association symptom index, with some minor modifications to the wording of some questions to make them more appropriate for a British population. ¹²

A symptom index, ranging from 0 to 30, was calculated by adding together the scores of six urinary symptoms (fuliness, frequency, intermittency, urgency, poor flow and hesitancy) where each symptom was assigned one of the following values: 0 = 1 never, 1 = 1 hardly ever, 2 = 1 less than half the time, 3 = 1 about half the time, 4 = 1 more than half the time and 5 = 1 almost always. The symptom index was categorized into five levels of severity: none (0), very mild (1-6), mild (7-9), moderate (10-18) and severe (19-30). These cut-off points were derived from information gained from the results of a consensus panel that considered the appropriateness of indications for treatment. Further details of the method are described elsewhere.

The follow-up survey involved 516 men (34.9%) in the initial survey who reported a symptom index score of seven or more, that is mild, moderate or severe symptoms. They were sent a second questionnaire six weeks after the initial survey that sought information about their health behaviour and views on prostatectomy. The seven page questionnaire was sent together with a personal covering letter from the man's general practitioner and a stamped, addressed envelope for reply. All non-respondents were sent a reminder letter and a second questionnaire one month later. Participants were asked whether they had sought advice for their urinary symptoms and from whom, whether they had visited their general practitioner or urologist, and what had been the results of these consultations.

To investigate the possible effects of response bias, the nonrespondents were compared with the respondents in terms of age, severity of symptoms, previous surgery and previous episodes of acute urinary retention, using data from the initial survey.

In order to discover whether men would accept treatment or not, participants were presented with currently available evidence about the outcome of treatment and a simple description of the procedure. The information was worded as follows: 'The most common treatment for urinary problems caused by enlargement of the prostate gland is surgery. This involves passing an instrument like a small telescope up the penis to clear the blockage. It usually involves a hospital stay of about eight days. About 80% of men experience an improvement in their symptoms following surgery, about 15% are unchanged and 5% worse off. Some men will also have difficulty getting an erection after surgery. In addition, about 10% have complications, such as bleeding, infections and leakage of urine, which normally clear up within a few weeks. If your urinary symptoms were found to be due to an enlarged prostate and you were offered surgery for it, feeling the way you do now, would you choose to have it?

Respondents were asked to score their preference on a scale of zero to five (0 = definitely want, 1 = probably want, 2 = not sure but inclined to yes, 3 = not sure but inclined to no, 4 = probably do not want, 5 = definitely do not want).

Data analysis consisted of frequency distributions. Confidence intervals for proportions were calculated at the 95% level using the method of Fleiss. ¹⁴ The significance of observed differences was tested using chi square statistics calculated using procedures

written in SAS. Wilcoxon matched-pairs signed-ranks were calculated to test for a change in bothersomeness and urinary frequency between the initial and follow-up surveys using procedures written in SPSS.

Results

Characteristics of the sample

Of the 516 men with mild, moderate or severe symptoms who were sent a questionnaire, eight had died and three had moved, so that the final study population was 505. Seventy two questionnaires were not returned and a further 13 were returned without response, so that the response rate was 83.2%. A comparison of non-respondents and respondents showed little difference in mean age (69.5 years versus 67.1 years, respectively). Respondents were significantly more likely than non-respondents to have moderate or severe symptoms (239/420 respondents versus 7/85 non-respondents, Mantel Haenszel $\chi^2 = 70.2$, 2 degrees of freedom, P<0.01). Respondents were also more likely than non-respondents to have had previous prostate surgery, and to have experienced an episode of acute urinary retention, although these differences were not significant. In total, 420 men with mild, moderate or severe symptoms were included in the analyses.

To test the extent to which men's urinary problems may have changed between the initial survey (from which their symptom index scores were derived) and the follow-up survey (from which patient preference was determined), questions on bothersomeness and urinary frequency were included in both. The results of a Wilcoxon matched-pairs signed-ranks test suggested that while there was no significant change in the measures of bothersomeness, urinary frequency decreased between the two surveys (Z = -3.02, P < 0.05).

Advice-seeking behaviour

The pattern of the advice-seeking behaviour by men with urinary symptoms is shown in Table 1. About half the men had not sought any advice for their symptoms; this was more common among those with mild or moderate symptoms than among those with severe symptoms. Of those seeking advice, the principal source was their general practitioner (88.8% of those with moderate symptoms, 97.2% of those with severe symptoms). The percentage of men who sought advice from their general practitioner about their symptoms increased from 40.3% of those with mild symptoms to 64.8% with severe symptoms.

Action by general practitioners and urologists

Of the 175 men who had consulted their general practitioner and for whom data were available, 21.1% were reassured, 16.6% were prescribed medication, and 62.3% were referred to a surgeon or urologist (Table 2). The percentage referred to a urologist or surgeon did not vary with symptom severity. Of the 109 men who were referred, nine were still waiting to see their sur-

Table 1. Source of advice used by men with urinary symptoms, by symptom severity.

	Mild (n = 181)	Moderate (<i>n</i> = 185)	Severe (n = 54)	Total (n = 420)	95% CI
Sought no advice	56.9	51.9	33.3	51.7	46.8 to 56.3
Consulted GP	40.3	<i>42.7</i>	64.8	44.5	39.7 to 49.2
Other ^a	2.8	5.4	1.9	3.8	2.3 to 6.0

n = number of men in group. CI = confidence interval. *Other = friends, relatives, practice nurse.

geon. The majority (71.4%) had been offered and accepted surgery (Table 2). Of the remainder, 15 had been reassured, four had been prescribed medication and seven had been offered and declined surgery. There was no significant difference between symptom severity and action by the urologist, but the numbers were small.

Men's views on prostatectomy

The distribution of men's views on prostatectomy, by symptom severity is also shown on Table 2. At their current level of symptoms, 30.6% of men would definitely or probably choose to have a prostatectomy, while 22.1% would probably or definitely not want treatment. Nearly half of men (47.3%) were unsure what they would choose, although more men were inclined to have the operation than not (32.0% versus 15.3%). Overall, men were more likely to choose surgery (62.6% versus 37.4%). The proportion of men choosing surgery was not significantly related to symptom severity, a history of previous prostate surgery or of an episode of acute urinary retention (Table 3).

Using data from all 420 respondents, a separate analysis was undertaken of only those men who expressed a firm view about surgery (that is, that they definitely or probably would or would not choose it). In this group, men who had consulted their general practitioner were more likely to have indicated that they definitely or probably would choose surgery (63, 71.6%) than those who had not consulted their general practitioner (64, 57.1%). Although this difference was small, it was statistically significant ($\chi^2 = 4.4$, 1 df, P < 0.05).

Discussion

This study has described the pattern of advice-related behaviour of middle-aged and elderly men who experience mild, moderate or severe urinary symptoms, and the response made by clinicians. Slightly fewer than half of men with symptoms (45%) reported that they had consulted their general practitioner, of whom the majority (62%) were referred to a surgeon, and of these the majority (71%) reported that they were offered and accepted surgery. However, a substantial proportion (22%) of men said that in theory they would choose to accept their symp-

Table 3. Choice of whether or not to have a prostatectomy, by symptom severity, previous prostate surgery and a previous episode of acute urinary retention.

	% of men choosing		
	prostatectomy	95% CI	
Symptom severity ^a			
Mild $(n = 122)$	<i>60.7</i>	51.4 to 68.5	
Moderate (n = 128)	64.1	55.1 to 71.5	
Severe (<i>n</i> = 31)	64.5	45.4 to 77.6	
Previous prostate surgery ^b			
Yes (n = 14)	71.4	42.0 to 86.0	
No (n = 266)	62.4	<i>56.3</i> to <i>67.8</i>	
Acute urinary retention ^c			
Yes (n = 22)	<i>68.2</i>	45.1 to 82.0	
No (n = 253)	61.3	<i>54.9</i> to <i>66.9</i>	

n = number of men in group. CI = confidence interval. *Data missing for 34 men. *Data missing for 35 men. *Data missing for 40 men.

toms and forego surgery, and a further 47% were unsure whether or not to go for surgery.

Before any conclusions may be drawn, two aspects of the method need to be considered: the response rate and the validity and reliability of the questions about symptoms and preferences. The response rate in the initial survey had been 78% and in this survey was 83%. Although the response rate was high, it is of concern that respondents to this survey were more likely than non-respondents to have moderate or severe urinary problems. This means that the proportions of the population seeking and receiving treatment may have been slightly overestimated.

The way in which the questions were phrased could bias the results. The symptom index used has been extensively tested and shown to be internally consistent and have good test-retest reliability, as judged by the Pearson correlation coefficient. The question about men's views on prostatectomy was developed specifically for this study and has not been tested for its reliability and validity, in particular, its power to predict the decision that a man will take in practice. Eleven per cent of respondents

Table 2. Action taken by general practitioners and by urologist or surgeon, and patient choice for surgery.

	% of men with symptoms				
	Mild	Moderate	Severe	Total	95% CI
Action taken by GP®	(n = 69)	(n = 71)	(n = 35)	(n = 175)	
Reassured patient	17.4	25.4	20.0	21.1	15.5 to 27.5
Prescribed a drug	20.3	11.3	20.0	16.6	11.6 to 22.5
Referred patient	62.3	63.4	60.0	<i>62.3</i>	54.6 to 68.9
Action taken by urologist/surgeon ^b	(n = 39)	(n = 35)	(n = 17)	(n = 91)	
Reassured patient	10.3	20.0	23.5	16.5	9.8 to 24.8
Prescribed a drug	0	11.4	0	4.4	1.4 to 10.0
Offered surgery:					
Patient declined	10.3	<i>5.7</i>	<i>5.9</i>	7.7	3.4 to 14.3
Patient accepted	<i>79.5</i>	62.9	70.6	71.4	60.9 to 79.2
Men's views on prostatectomy ^c	(n = 122)	(n = 128)	(n = 31)	(n = 281)	
Definitely want	13.9	17.2	25.8	16.7	12.7 to 21.3
Probably want	14.8	14.1	9.7	13.9	10.2 to 18.2
Not sure, inclined to yes	32.0	<i>32.8</i>	29.0	32.0	26.7 to 37.5
Not sure, inclined to no	13.9	16.4	16.1	15.3	11.4 to 19.8
Probably do not want	8.2	<i>6.3</i>	12.9	7.8	5.1 to 11.4
Definitely do not want	17.2	13.3	6.5	14.2	10.5 to 18.6

n = number of men in group. CI = confidence interval. *Data missing for 12 men. *Data missing for nine men; another nine men still waiting to see urologist. *Data missing for 34 men; excludes those seen by a urologist.

did not answer this question and, of those who did answer, 47% were unsure whether they would choose surgery. It is unclear whether this uncertainty arises from the wording of the question, insufficient information being provided, or from the difficulties in deciding about treatment. Studies of patient preference are susceptible to variations in the amount of data presented and the way that questions are framed (that is, whether the question refers to the probability of a good or adverse effect). 15 Most of the published work about patient preferences has been applied to cancer patients where trade-offs between quality of life and life expectancy are made using methods taken from econometrics. Other studies have found low levels of test-retest reliability. 16 Among the substantial proportion of men who were unsure if they would choose to have surgery it is likely that some have what has been termed an 'external locus of control' 17 and would transfer the decision to treat to the surgeon.

Few men in the present survey reported seeking advice from relatives, friends or the practice nurse for their symptoms. This may be because they believed that lay carers and nurses have little to offer for urinary problems or it may reflect under-report- having received advice from family or friends to see their general practitioner, they only reported that they saw a general practitioner. It is also possible that there was some reporting bias because they viewed these sources of advice in a less formal way. It has been estimated that 25% to 75% of symptoms are dealt with by patients themselves or friends and family 18,19 and that the decision to consult a general practitioner is dependent on the influence of advisers, the effectiveness of self-care and the need for information.²⁰ Many men may consider their urinary symptoms as part of the normal ageing process and thus do not consider their condition worthy of consulting their general practitioner. A study in Denmark found that men aged 70 years and over with voiding difficulties did not consult a doctor for their urinary symptoms.21

Although men were more likely to visit their general practitioner if their symptoms were more severe, the decision of the general practitioners to refer appeared to be independent of symptom severity. This study confirms the important gatekeeper function of general practitioners: 38% of the men who went to see their general practitioner were not referred on to a surgeon. This is consistent with the considerable volume of work done on the referral decision that shows that a wide variety of factors, and not just the patient's condition are important.²² Semi-structured interviews with family physicians in Canada found that of nonmedical factors in the decision to refer, patients' wishes were the most important.²³ Difficulties with travel, access to a consultant, and family wishes also influenced the decision.²³

Some men were prescribed medication for their urinary symptoms, either by their general practitioner (17%) or their urologist (4%) despite a lack of any definitive evidence of the efficacy of such treatments and the recommendation that prostatectomy is still the treatment of choice for benign prostatic hyperplasia.²⁴⁻²⁷ During the period of the study, finasteride (Proscar®, MSD), was being marketed and some men may have been prescribed it as participants in studies to evaluate the drug.

How will the results of the study be used? When combined with information on clinicians' views of appropriateness of prostatectomy¹³ and population estimates of the prevalence of urinary symptoms from the initial survey,3 these data will provide evidence of the level of provision of treatment a population requires and thus inform planning and commissioning of urological services. The findings are being applied to the purchasing process. This involves collaboration between general practitioners, urologists and the commissioning agency to set agreed activity levels and develop referral guidelines. The results of this process will be reported in a separate paper.

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