Journal of Public Health Medicine

Vol. 22, No. 3, pp. 427–434
Printed in Great Britain

An epidemiological study to establish the prevalence of urinary symptoms and felt need in the community: the Leicestershire MRC Incontinence Study*

Sarah Perry, Christine Shaw, Philip Assassa, Helen Dallosso, Kate Williams, Katherine R. Brittain, Fiona Mensah, Nigel Smith, Michael Clarke, Carol Jagger, Christopher Mayne, C. Mark Castleden, Jeremy Jones, Catherine McGrother and the Leicestershire MRC Incontinence Study Team

Abstract

Background The aim of the study was to establish the prevalence of urinary symptoms and felt need in adults. This paper discusses problems with setting thresholds to distinguish cases from non-cases in this field of research. Few studies have provided detailed age- and sex-specific prevalence estimates for felt need in relation to urinary symptoms.

Methods A cross-sectional postal survey was carried out of 15 904 community-dwelling adults aged 40 years or more registered with general practitioners in Leicestershire. Subjects were selected randomly by household from the Leicestershire Health Authority Register. The postal questionnaire consisted of questions on general health, urinary and bowel symptoms, quality of life, service use and demographic characteristics.

Results Thirty-four per cent of the sample reported clinically significant symptoms. The prevalence and severity of symptoms increased with age. However, only 2 per cent of the sample reported symptoms that were clinically significant, bothersome and socially disabling.

Conclusion Urinary symptoms are very common in adults over 40 years of age living in the community. However, symptom-based estimates probably overestimate the level of need for health care in the community. It may be more effective and efficient to target services, in the first instance, on those people who report clinically significant symptoms that are bothersome or socially disabling. A consensus on thresholds and definitions of urinary symptoms is required to standardize clinical and research work and to target services more appropriately.

Keywords: urinary symptoms, prevalence, felt need

Introduction

In the past, research on urinary symptoms has tended to concentrate on urinary incontinence in women[1–14] and symptoms associated with bladder outflow obstruction in men.[15–18] More recent work, however, has reported on the prevalence of lower urinary tract symptoms in adults generally.[19–21] Estimates of need for health care for urinary symptoms have focused on the prevalence of symptoms and patterns of service utilization. For example, reviews of the literature suggest that approximately 35 per cent of women experience some urinary incontinence[22–27] and, on average,

* The Leicestershire MRC Incontinence Study is a series of interrelated multi-stage projects designed to explore the prevalence and incidence of urinary symptoms and the effectiveness of different types of service provision and treatments.

[1] Leicestershire MRC Incontinence Study, Department of Epidemiology and Public Health, University of Leicester, 22–28 Princess Road West, Leicester LE1 6TP.

[2] Department of Medicine for the Elderly, [3] Department of Obstetrics and Gynaecology, Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW.

Sarah Perry,[1] Research Associate

Christine Shaw,[1] Research Fellow

Philip Assassa,[1] Senior Clinical Researcher

Helen Dallosso,[1] Research Fellow

Kate Williams,[1] Research Fellow in Nursing

Katherine R. Brittain,[2] Research Associate

Fiona Mensah,[1] Research Associate

Nigel Smith,[1] Senior Clinical Research Fellow

Michael Clarke,[1] Professor of Epidemiology and Public Health

Carol Jagger,[1] Senior Lecturer in Epidemiology and Public Health

Christopher Mayne,[3] Honorary Senior Lecturer in Urogynaecology and Consultant Gynaecologist

C. Mark Castleden,[2] Professor of Medicine for the Elderly

Jeremy Jones,[1] Lecturer in Health Economics

Catherine McGrother,[1] Senior Lecturer in Epidemiology and Public Health

Address correspondence to Dr Sarah Perry.
E-mail: sip1@leicester.ac.uk

one in four women with incontinence seek medical help.[1,5–7,9,10,12,14,28–30] These two estimates, however, may exaggerate the level of need and unmet need for health care in the community. The prevalence of socially disabling incontinence in women (i.e. felt need) is much lower at about 2 per cent.[6,9,10,14,31]

Bradshaw[32] distinguished between four types of need for social care: normative need, felt need, expressed need and comparative. The International Continence Society's (ICS) definition of incontinence as 'the involuntary loss of urine which is objectively demonstrable and a social or hygienic problem' incorporates aspects of normative need (i.e. the presence of clinically significant symptoms) and felt need (i.e. an individual's perception of problematic or socially disabling symptoms).[33] Felt need is a particularly important concept in the case of urinary symptoms for a number of reasons: (1) symptoms are rarely life threatening and only a minority or people with symptoms find them disabling; (2) fairly non-invasive treatments require motivated individuals to comply with treatment; (3) definitions of clinically significant urinary symptoms vary tremendously across studies and between professionals working in this area.

Although age- and sex-specific prevalence estimates for urinary symptoms have been published widely, few studies have reported on age- and sex-specific prevalence estimates of felt need. Those that have, have concentrated on felt need in a subsample of respondents with clinically significant incontinence[34] or men with lower urinary tract symptoms.[19,21] Only Sommer *et al*.[35] assessed age- and sex-specific felt need in the whole sample surveyed. This is important, because some people who do not meet the criteria for clinically significant symptoms (e.g. incontinence several times a month or more often) may report felt need. Other studies have concentrated on the associations between felt need and severity of symptoms.[1,8,10,17,18,36,37]

This paper will illustrate the dilemmas faced when measuring normative and felt need by presenting data from an epidemiological study on urinary symptoms. Various estimates of need will be presented and guidelines for future research discussed.

Methods

Normative need is defined in terms of the prevalence of clinically significant urinary symptoms. Unfortunately, there is no consensus regarding thresholds for distinguishing between cases and non-cases for urinary symptoms. The American Urological Association symptom index for benign prostatic hyperplasia (AUA7) and the ICS*male* questionnaire identify seven and 20 urinary symptoms, respectively.[38,39] Although well-validated and good measures of severity of symptoms, neither questionnaire provides thresholds for individual symptoms. Both assign numbers to response categories (generally 0–5 for the AUA7 and 1–5 for the ICS*male* questionnaire) and scores on individual items are summed to produce a severity index (0–35) in the AUA7. The scoring procedure for the ICS*male* questionnaire is not clear, but it appears that responses are dichotomized and thresholds are set fairly low, resulting in high prevalence estimates. For example, in a community sample of men aged 40 years or more, 78 per cent reported terminal dribble, 51 per cent hesitancy and 20 per cent urge incontinence.[21] In an attempt to standardize terminology in this field, the International Continence Society (ICS) has produced definitions for symptoms, but these definitions are descriptive and do not attempt to quantify abnormal and normal symptoms. For example, it is not obvious at what level of frequency going to the toilet to pass urine is regarded as a symptom of urinary frequency rather than normal behaviour.

The process of setting definitions and thresholds for the different measures of need used in the study were based on reviews of the literature, the expertise of the multi-disciplinary study team, which included clinicians and health services researchers, and the advice of the steering committee to the study. When the literature was sparse or ambiguous, the setting of thresholds was based on the level at which symptoms were considered to have an impact on an individual's lifestyle, although this will vary from individual to individual. For example, going to the toilet every 2 h is probably easily managed by most people, but hourly or more frequent visits to the toilet are probably inconvenient, noticeable and disruptive.

In reviews of the literature on the prevalence of incontinence, Thom and Hampel[22–24] found that studies tend to assess either the prevalence of any incontinence (i.e. 'ever' incontinent or incontinent 'ever in the past year) or the prevalence of more severe incontinence (i.e. clinically significant), which is generally based on the frequency of incontinent episodes. The threshold for severe or regular incontinence tends to be weekly episodes (i.e. more than once a month). In this study, then, incontinence was regarded as a clinically significant symptom if it occurred several times a month or more often.

Clinically significant thresholds for frequency, nocturia, urgency, pain and straining are less easy to identify in the literature. The AUA7 question on frequency asks: 'Over the past month, how often you have had to urinate again less than two hours after you finished urinating?' In this study, then, the threshold for clinically significant frequency was going to the toilet hourly or more often. The threshold for nocturia was set at going to the toilet two or more times during the night. Other researchers have used the same definition.[20,21,40] It was difficult to establish, from the literature, thresholds for urgency, straining and pain. Urgency was treated as clinically significant if respondents usually experienced an overwhelming urge to pass urine or had difficulty holding urine most of the time. Straining to pass urine and pain in the bladder or on passing urine was treated as clinically significant if it occurred most of the time. These definitions, based on the frequency of

occurrence, reflect severe symptoms.[19] Because the setting of thresholds is somewhat arbitrary, all levels of severity will be presented in the first instance.

Previous studies have assessed felt need by asking individuals if their symptoms are bothersome or socially disabling, or if they want help.[41–47] These aspects of felt need were included in the postal questionnaire. If symptoms were 'a lot' of bother or a 'moderate' to 'severe' problem they were classified as bothersome. Symptoms were defined as socially disabling if they had 'a lot' of impact on daily activities, social life, relationships, feelings or overall quality of life. Reporting 'a little' impact on these items was not regarded as a sufficient indication of felt need. It is unlikely that respondents would perceive themselves to have a serious problem and it would be difficult to assess improvements to quality of life as a result of treatment. Respondents were also asked if they wanted help with urinary symptoms.

The postal questionnaire was presented as a confidential health survey and included questions on general health, disabilities, urinary and bowel symptoms, health-related quality of life, service use and demographic characteristics. The questionnaire consisted of closed questions with a range of set answers. Examples of questions asked in the questionnaire are as follows:

Q: Do you ever leak any urine when you don't mean to? (this means anything from a few drops to a flood during the day or night)

A: Continuously, Several times a day, Several times a week, Several times a month, Several times a year, Never/rarely.

Q: How much of a problem would you say you have with your urinary symptoms?

A: Severe, Moderate, Mild, No problem.

Q: Do your urinary symptoms interfere with your daily activities?

A: A lot, A little, Not at all.

Piloting of the questionnaire indicated that respondents found the questions clear and easy to complete.

During an 8 month period starting in October 1996, 15 904 people aged 40 years or more were mailed a postal questionnaire developed by the study team. Patients registered with 137 (90 per cent) general practices in Leicestershire and Rutland were randomly selected by household from the Leicestershire Health Authority list. People living in institutional settings (e.g. residential and nursing home) were excluded from the sampling frame. Non-responders were sent a second questionnaire 2 weeks after the first mailing.

Results

Of the 15 904 questionnaires posted, 1304 (8.2 per cent) were excluded because the person no longer lived at the address, had moved to a residential or nursing home or was deceased. Of the remaining 14 600 questionnaires mailed, 10 226 were returned (70 per cent) and of these 10 116 (99 per cent) were analysable. Response rates were lowest in the youngest and oldest age groups (i.e. 40–49 years and 80+ years) and slightly lower in men (see Table 1).

The distribution of responses to the urinary symptom questions are shown in Fig. 1. Most adults report that they never or rarely experience symptoms. Thus, 79 per cent, 83 per cent and 89 per cent of adults never experience incontinence, pain and straining, respectively. Figure 1 also illustrates how the estimated prevalence of symptoms will vary depending on the definitions used. If, for example, the threshold for clinically significant nocturia is set at twice a night or more often, 20 per cent of adults report this symptom. Raising the threshold to three times a night, however, lowers the prevalence to 7 per cent of adults.

The definitions and prevalence estimates of need used in this study are summarized in Table 2. Prevalence estimates of need varied depending on the definition used (normative or felt). Thus 34.1 per cent of the sample reported clinically significant symptoms, 7.2 per cent bothersome symptoms and 2.7 per cent socially disabling symptoms. Approximately 4 per cent of the sample wanted help with their symptoms. There were significant age and sex patterns in the prevalence of clinically significant urinary symptoms. Urinary incontinence, frequency and urgency were much more common in women than in men, whereas the prevalence of nocturia, straining and pain were similar in men and women.

Table 1 Response rates to the postal survey by age and sex

	Men			Women			Total		
Age group (years)	Eligible sample (*n*)	Responder (*n*)	% of eligible	Eligible sample (*n*)	Responder (*n*)	% of eligible	Eligible sample (*n*)	Responder (*n*)	% of eligible
40–49	2039	1197	58.7	2063	1390	67.4	4102	2587	63.1
50–59	1930	1254	65.0	1886	1376	73.0	3816	2630	68.9
60–69	1455	1073	73.7	1573	1208	76.8	3028	2281	75.3
70–79	1083	843	77.8	1310	993	75.8	2393	1836	76.7
80+	434	315	72.6	827	577	69.8	1261	892	70.7
Total	6941	4682	67.5	7659	5544	72.4	14600	10226	70.0

The prevalence of symptoms tended to increase with age, although the pattern is slightly different in men and women. For example, the prevalence of urinary incontinence in women peaked in the early 50s, declined in the 60s and then rose in 75+ years olds. In men, however, the prevalence of incontinence increased steadily with age (see Fig. 2). The prevalence of incontinence, frequency, urgency and nocturia was much lower in men than in women in the youngest age groups. The difference was less marked in the older age groups. In the elderly (70+ years), nocturia was more common in men than in

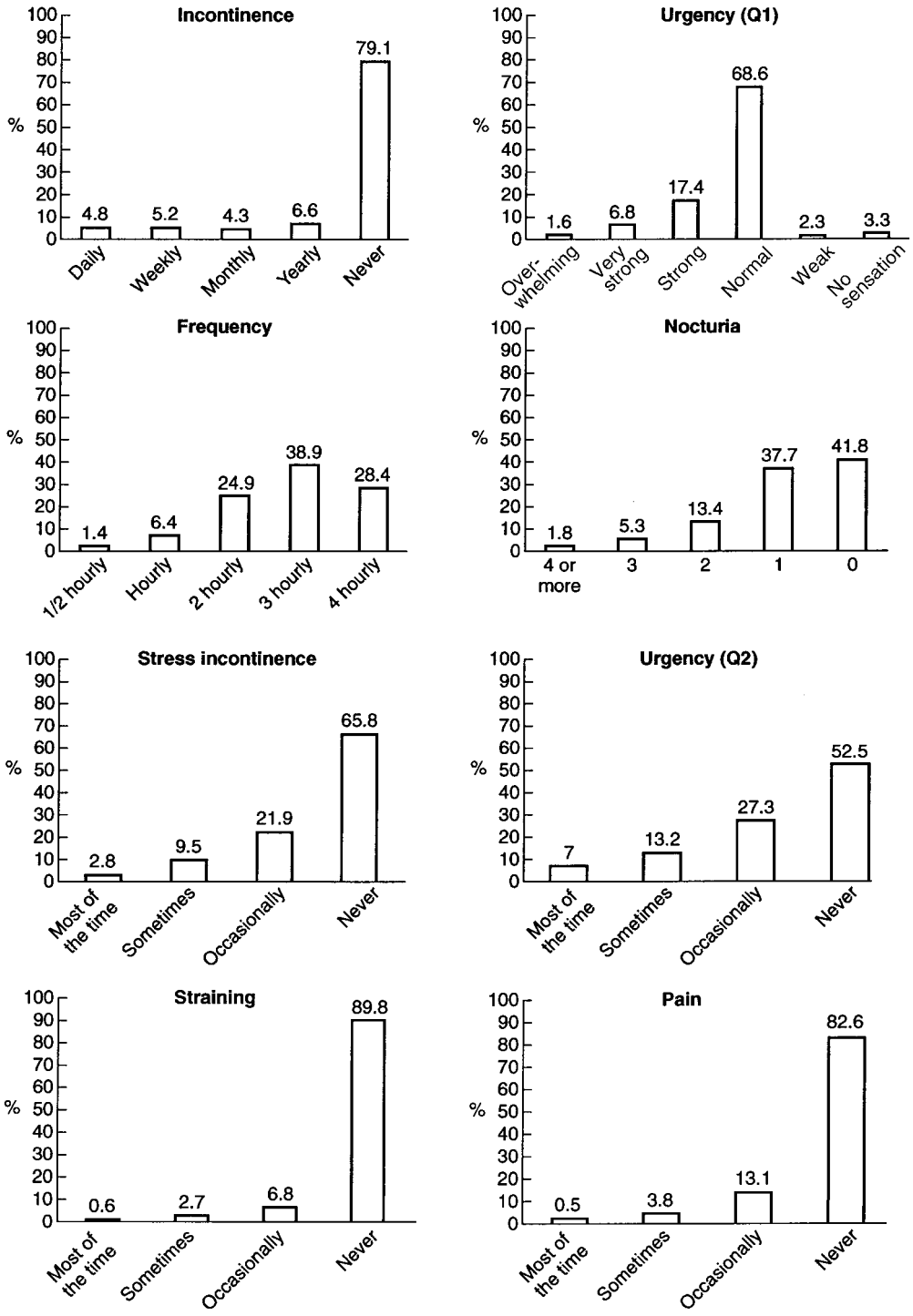

Figure 1 Distribution of urinary symptoms in adults aged 40 years or more.

Table 2 Definitions and prevalence of need in adults aged 40 years and over living in the community

Definition of need	Threshold for cases	Prevalence (%)			
		Men	Women	Total	95% CI of total
NORMATIVE NEED					
Clinically significant symptoms	Any of the below	28.5	38.8	34.1	33.1, 35.1
Nocturia	Twice a night or more often	19.9	20.9	20.5	19.7, 21.3
Any urinary incontinence	Several times a month or more often	8.9	20.2	14.9	14.1, 15.7
Urgency	Most of the time or overwhelming	5.4	8.8	7.3	6.7, 7.9
Frequency	Hourly or more often	6.1	9.1	7.8	7.2, 8.4
Straining	Most of the time	0.7	0.5	0.6	0.4, 0.8
Pain (bladder/passing)	Most of the time	0.4	0.5	0.5	0.4, 0.6
FELT NEED					
Bothersome symptoms	Either of the below	6.2	8.0	7.2	6.6, 7.8
A bother	A lot	2.1	3.2	2.7	2.3, 3.1
A problem	Moderate or severe	5.6	7.0	6.4	6.0, 6.8
Socially disabling symptoms	Any of the below	2.2	3.2	2.8	2.4, 3.2
Daily activities	A lot	1.0	1.7	1.4	1.2, 1.6
Social life	A lot	1.3	1.8	1.6	1.4, 1.8
Relationships	A lot	0.6	0.8	0.7	0.5, 0.9
Upset or distress	A lot	1.1	2.0	1.6	1.4, 1.8
Quality of life	A lot	1.3	1.9	1.6	1.4, 1.8
Want help	Yes	3.8	3.8	3.8	3.4, 4.2

women. The number of respondents reporting pain and straining was relatively low and very similar at the thresholds set.

The prevalence of felt need is shown in Fig. 3. The prevalence pattern for socially disabling symptoms and wanting help was similar. About twice as many people reported bothersome symptoms as wanted help. As with the reporting of clinically significant symptoms, the prevalence of felt need increased with age. Sommer *et al.*[35] found that 4.6 per cent, 7.7 per cent, 9.2 per cent and 8.1 per cent of women in their 40s, 50s, 60s and 70s, respectively, reported felt need. Similar findings were found in this study in relation to the reporting of bothersome symptoms (5.6 per cent, 7.1 per cent, 7.7 per cent, 8.5 per cent, respectively). The reporting of felt need increases steadily with age in men. In women, felt need is fairly stable across age groups until they reach very old age (80 year or more), when the percentage of those reporting felt need doubles.

The majority of people with clinically significant symptoms did not find them bothersome or socially disabling (see Fig. 4). Although 34 per cent of the population reported clinically significant symptoms, only 2 per cent reported clinically significant symptoms that were bothersome and socially disabling. About a third of those with bothersome symptoms found them socially disabling. A very small percentage of the population

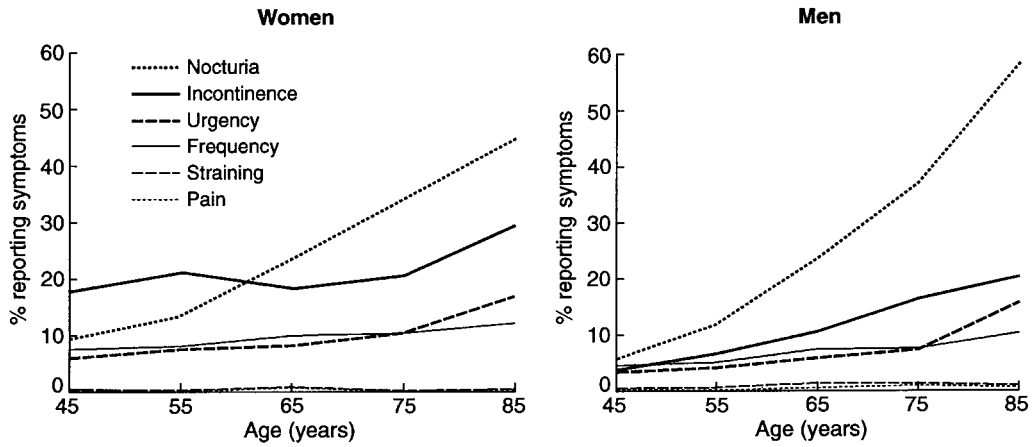

Figure 2 Prevalence of clinically significant urinary symptoms in women and men.

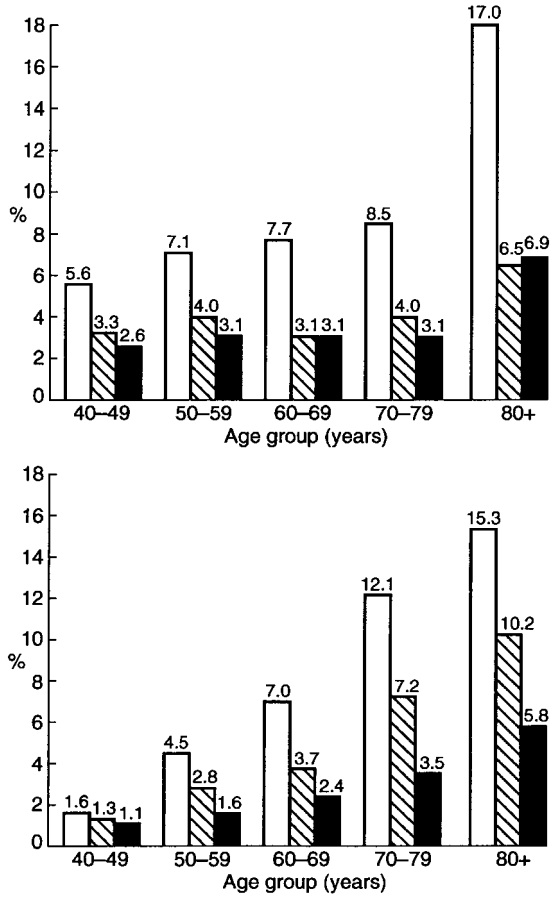

Figure 3 Prevalence of felt need in adults by age; white bars, bothersome symptoms; striped bars, want help; black bars, socially disabling symptoms. Top, women; bottom, men.

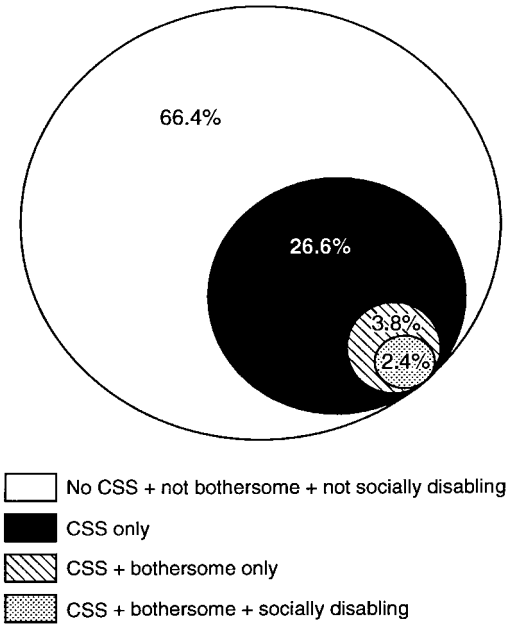

Figure 4 Relationships between measures of need. CSS, clinically significant symptoms. Groups < 1 per cent not shown: bothersome only, 0.4 per cent; socially disabling only, 0.1 per cent; socially disabling and bothersome, 0.1 per cent; CSS and socially disabling, 0.2 per cent.

(0.6 per cent) reported symptoms that were bothersome and/or socially disabling but did not report clinically significant symptoms.

Discussion

Although population estimates of need are useful for calculating the level of burden in the community, age–sex prevalence estimates uncover possible differences in need and thus allow better targeting and perhaps take-up of services. The prevalence of urinary symptoms, in particular nocturia and incontinence, was found to be very high in adults and becomes more severe with age. The age–sex prevalence patterns of frequency, urgency and nocturia were similar, demonstrating the importance of investigating symptom groups rather than symptoms in isolation. Indeed, just over a third (36.9 per cent) of respondents reported more than one symptom. These symptom groups may indicate the presence of specific underlying conditions. Alternatively, they may represent individuals' methods of coping with symptoms, which may result in the management of one, but the aggravation of another. For example, to avoid incontinence an individual may go the toilet more frequently and thus report urinary frequency.

Assessing need and planning services accordingly is difficult in the absence of agreed thresholds for distinguishing between cases and non-cases. The definitions for clinically significant symptoms used in this study were based on reviews of the literature and the expertise of a multi-disciplinary team. Nevertheless, setting thresholds to define cases is somewhat arbitrary and raising or lowering thresholds can have a dramatic impact on prevalence estimates. The same applies to setting thresholds for felt need. Validation of the questionnaires used in the survey are being carried out on community samples and further analyses will enable us to investigate relationships between different definitions of need and service uptake, compliance and ultimately treatment outcomes.

It is unrealistic to base service need predictions on normative definitions, as this study found that 46 per cent of the sample aged 60 or more years of age report clinically significant urinary symptoms. Normative need provides no information about the level of disability experienced as a result of urinary symptoms. In the case of non-life-threatening conditions, compliance with treatment is likely to be low if symptoms are not perceived to have an impact on an individual's quality of life. It may be wiser to base service planning on the number of people with bothersome or socially disabling and clinically significant symptoms. If results from this study are projected to the population of Great Britain over 40 years of age,[48] about half a million people would have

urinary symptoms that are clinically significant, bothersome and socially disabling. Although a substantial number, a general practitioner with 1800 patients could expect to have 16 such adults. Primary care services would probably find this level of need manageable.

Response rates to the postal survey were lowest in the youngest age bands, where the prevalence of symptoms is lowest. Our estimates of normative need may, as a result, be higher than expected. On the other hand, the survey excluded people living in institutional settings, where the prevalence of incontinence is known to be much higher than in community populations.[6,49] Unfortunately, very little is known about the prevalence of felt need among people living in institutional settings. It is difficult, therefore, to make the necessary adjustments to our calculations. Correction factors for possible non-response bias and people living in institutional settings will be investigated in future work.

Symptom-based estimates probably overestimate the level of need for services in the community. It may be more effective and efficient to focus services, in the first instance, on those people who report clinically significant symptoms that are bothersome, or socially disabling symptoms. Symptom severity and bothersomeness have been shown to be good indicators of post-surgical improvement in symptoms and quality of life for prostatectomy.[50] Additionally, services should be targeted towards the elderly, who report the greatest need for health care whatever definition is applied. Subsequent reports on the study will investigate in greater detail the prevalence of different types of incontinence (e.g. stress, urge, mixed, unconscious and functional incontinence, post-micturition dribble and nocturnal enuresis) and additional voiding symptoms (e.g. hesitancy, intermittency, weak flow and incomplete emptying) in adults living at home and in residential or nursing home settings.

Acknowledgements

We thank the general practitioners of Leicestershire who gave their support to the study; the MRC Steering Committee, which includes Professor P. Abrams, Professor N. Black, Professor M. Bland, Dr C. McArthur, Dr L. O'Toole, Dr J. Roberts, Professor B. Roe and Dr P. Rhodes; Usman Azam, Clinical Research Fellow on the study; collaborators on the study – Professor K. Woods, Mr D. Osborn, Ms E. Herring, Ms K. Caywood, Professor G. Parker, Professor J. Lindesay, Ms H. Duffin, Dr R. Baker, Ms C. Pope, Dr A. Wilson, Ms P. Robinson, Dr F. Cheater; and lastly respondents to the survey. This project is funded by the Medical Research Council.

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Accepted on 2 November 1999