

# Needs assessment of women with urinary incontinence in a district health authority

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## SUMMARY

**Background:** The prevalence of urinary incontinence in women is difficult to estimate because definitions vary between researchers and among women, for whom thresholds of complaint differ. However, studies have also shown that only about a quarter of women affected by urinary incontinence consult a doctor for their symptoms, despite evidence of effective treatments and better management of the condition in primary care.

**Aim:** To assess the perceived needs of women with urinary incontinence living at home.

**Design:** Cross-sectional community survey.

**Setting:** A 1% stratified random sample of women living at home, registered with a local GP, and aged 45 years and over (n = 720) in a north London district health authority with a total population of 308 000.

**Results:** Out of 720 questionnaires, 489 were returned completed (68%). A total of 227 (46%) women had symptoms of significant urinary incontinence. Seventy-eight (16%) had significant symptoms which they said were not a problem, and 149 (30%) of the total number of responders acknowledged that they had significant symptoms and that these symptoms were a problem for them; of these, 48 (32%) sought help from their GP; 16 out of the 48 consulting their GP were happy with the treatment given, and the remaining 101 women who considered their incontinence to be a problem had not consulted their GP and 76 of those had also not told anyone else that they had a problem. The commonest reasons given by the 101 women who admitted having a problem and who had not consulted their GPs were that they thought that they should cope on their own (43 [42.6%]), that incontinence was inevitable with age (26 [25.7%]) or that it was embarrassing to talk about the problem to their GP (14 [13.8%]).

**Conclusions:** Despite the existence of effective interventions for urinary incontinence, many women who are incontinent do not seek help even when they perceive their incontinence to be a problem. Half of the women who did consult their GP did not find the treatment offered helpful. Achieving health gain for women with urinary incontinence will require a more active approach than currently exists to inform people that better care is available, to help counteract the stigma attached to the problem, and to ensure that primary care professionals are able to provide effective services.

**Keywords:** urinary incontinence; needs assessment; women.

## Introduction

URINARY incontinence is common in women and yet is still a taboo subject. Prevalence data varies from estimates of 14% of all women<sup>1</sup> to occasional stress incontinence in 50% of pre-menopausal women.<sup>2</sup> Prevalence is difficult to estimate because definitions vary between researchers and among women, for whom thresholds of complaint differ.<sup>3,4</sup> The main causes of urinary incontinence in women over 45 years of age are urethral sphincter incompetence and an overactive bladder.<sup>5</sup> Urinary incontinence in women has been shown to be managed effectively in primary care.<sup>5-7</sup> In urethral sphincter incompetence, pelvic floor exercises have been shown to improve function in 80% of cases.<sup>8</sup> An overactive bladder, the second commonest cause of urinary incontinence in women, can be treated successfully with bladder retraining, with or without bio-feedback.<sup>9,10</sup> Pharmacotherapy has also been shown to be effective in overactivity although side-effects are common.<sup>11</sup> Oestrogen replacement therapy can be useful in post menopausal women.<sup>6,12</sup> However, studies have also shown that only about a quarter of women affected by urinary incontinence consult a doctor for their symptoms<sup>13</sup> despite evidence of effective treatments and better management of the condition in primary care.<sup>14-16</sup> O'Brien *et al* found that fewer than 30% of all regularly incontinent women discuss the problem with a GP or nurse.<sup>12</sup>

We conducted a study, in a district health authority, to assess unmet need and to explore attitudes to seeking medical help of women with urinary incontinence who currently lived at home.

## Method

The study was carried out in a north London health authority district with a population of 308 000. A postal questionnaire was administered to a 1% random sample of all women aged 45 and over who were registered with a local general practitioner (GP) and who lived at home. The sampling frame was the District GP register (nursing and residential homes were excluded). The sample was stratified for age and used age-specific prevalence rates to calculate sample size.<sup>18</sup> The resulting sample size was 720.

A previously piloted self-completion questionnaire was sent to all women. Responses were confidential and an accompanying letter explained the purpose of the study and offered assistance with completion if desired. The study was approved by the local ethics committee. The questionnaire was in two parts: the first was designed to identify women with significant symptoms of incontinence and the second part explored perceived needs of symptomatic women, whether or not they had sought help, and how satisfied they were with any help received. Women were also asked to

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**HOW THIS FITS IN***What do we know?*

There is strong evidence that effective treatments for urinary incontinence in women exist and can be provided in primary care.

*What does this paper add?*

This study reminds us that women are reluctant to seek help themselves and that achieving health gain for urinary incontinence requires a more active approach from health care professionals than currently exists.



give details of why they had not sought help.

Significant incontinence was taken to be a positive response to both 'often leaking when laughing, coughing or getting up from a chair' and 'leaking before reaching the toilet'. Women who answered 'yes' to significant incontinence were then asked to state whether or not their incontinence was a problem for them that required help. Analysis was carried out on responders who had significant incontinence and for whom symptoms were a problem requiring help. One postal reminder was sent to study participants who had not responded initially.

**Results**

Replies were received from 489 women (68%). Two hundred and twenty-seven (46%) women indicated that they had significant symptoms of urinary incontinence. Of these, 78 (34%) did not feel their symptoms to be a problem, 149 (66%) did and also felt that they needed help (Table 1).

Analyses of the 149 women for whom incontinence was a problem showed that for all ages, 32% asked their GP for help with the problem. Over two-thirds had not sought help from their GP and 51% were unable to tell anyone that they were incontinent (Table 2). There were no significant differences between the age groups with regard to whether or not they consulted their GP ( $P = 0.122$ ).

Forty-eight women had asked their GP for help. Thirty-three per cent felt that treatment had been effective and 50% felt that it had not; eight were still being treated (Table 3). Table 4 describes the different types of help offered by GPs. The 101 women who had not asked their GP for help were asked to describe the reasons for this. Responses were grouped together and are described in Table 5.

**Discussion**

The study reveals some of the characteristics of women aged 45 and over who live in their own homes and who suffer from urinary incontinence. It confirms that symptomatic urinary incontinence is common. The study also illustrates the difficulties around treating this problem, highlights a large body of unmet need, and describes the extent of incontinence that is not revealed to GPs.

The low response rate to the survey could have introduced bias, particularly if the characteristics of the non-responders were significantly different from the responders. It is possible that there was a positive bias towards women

responding, if they already suffered from incontinence. It was not possible to study the non-responders separately and, as a result, the analyses concentrate on the characteristics of the responders only and make no assessment of prevalence rates within the study area. Women aged 18 to 44 years were also surveyed but were excluded from the analyses because the response rate was low.

Sixteen per cent (78/489) of women had significant symptoms of incontinence but replied that they did not require help with the problem. This finding has been shown in other studies where the prevalence of the condition does not equate with the requirement for treatment.<sup>1,19,20</sup> The definition of urinary incontinence used in the survey means that this group of women are often wet. It is unlikely that they are happy with their condition and their responses may indicate that they do not know that treatment is possible. Unrecognised need results in a decreased demand for services.

There was no real difference in willingness to seek help between the two age groups. It is unlikely, therefore, that reluctance to seek help can be attributed to age, particularly the stoicism often thought to be inherent in the older generation. Differences in perception of seriousness of symptoms between patients and clinicians has been described in other studies. In a large survey of patients in a health centre, Hannay reported that patients' perceptions of troublesome symptoms from a number of different pathologies differed significantly from their clinicians' assessments. He calls this the 'symptom iceberg'.<sup>21</sup> Crosland has also reported variations among patients in reporting rectal bleeding to their GP.<sup>22</sup>

Of the 149 women who felt that their symptoms did require help, only 32% actually discussed the problem with their doctor. Over two-thirds did not seek medical help and 51% of this group were also unable to talk to anyone else about their problem. Older women were more likely to tell their doctors than younger women although the difference was not statistically significant. We not only have unrecognised need but also the recognised need is not fully reflected in the demand for services.

Only 33% of the women who did seek help from their doctor felt that the treatment they received had made a difference and they no longer needed further help. More older women were satisfied with treatment than younger women, which may reflect better treatment or lower expectations.

A greater percentage of younger women were referred to a specialist although incontinence is more common in older women, tends to be more severe, and can cause more disability in older women. Older women were more likely to be given incontinence pads and drugs than the younger age group, although the study evidence for this is based on small numbers.

The survey confirmed that women's reasons for not seeking help were based on embarrassment, belief that nothing could be done or a belief that incontinence came with age and should be accepted as normal. These findings reflect a lack of knowledge about the causes of urinary incontinence and the availability of treatment, as well as the social stigma and embarrassment that is attached to the condition. Despite the existence of better treatment for urinary incontinence, many women continue to suffer, apparently leading

Table 1. Response to survey.

| Age (years) | Response rate (%) | Number with symptoms of incontinence (%) | Number with symptoms for whom symptoms were a problem (%) | Number with symptoms for whom symptoms were not a problem (%) |
|-------------|-------------------|--|---|---|
| 45–64       | 195/360 (54)      | 95 (49)                                  | 60 (31)   | 35 (18)   |
| 65+         | 294/360 (82)      | 132 (45)                                 | 89 (30)   | 43 (15)   |
| All ages    | 489/720 (68)      | 227 (46)                                 | 149 (30)  | 78 (16)   |

Table 2. Asking for help.

| Age (years) | Number for whom symptoms were a problem | Number who told their GP (%) | Number who did not tell their GP (%) | Number who did not tell GP or anyone else (%) |
|-------------|---|------------------------------|--------------------------------------|---|
| 45–64       | 60                                      | 15 (25)                      | 45 (75)                              | 35 (55)                                       |
| 65+         | 89                                      | 33 (37)                      | 56 (63)                              | 41 (46)                                       |
| All ages    | 149                                     | 48 (32)                      | 101 (68)                             | 76 (51)                                       |

Table 3. Satisfaction with treatment.

| Age (years) | Total | Better (%) | Not better (%) | Still being treated (%) |
|-------------|-------|------------|----------------|-------------------------|
| 45–64       | 15    | 3 (20)     | 7 (47)         | 5 (33)                  |
| 65+         | 33    | 13 (39.4)  | 17 (51.5)      | 3 (9.1)                 |
| All ages    | 48    | 16 (33)    | 24 (50)        | 8 (17)                  |

Table 4. Type of help offered.

| Age (years)  | Specialist referral (%) | No perceived help given (%) | Pelvic floor exercises (%) | Incontinence pads (%) | Drugs (%) |
|--------------|-------------------------|-----------------------------|----------------------------|-----------------------|-----------|
| 45–64        | 8 (53)                  | 4 (27)                      | 2 (13)                     | 0 (0)                 | 1 (7)     |
| 65+          | 9 (27.3)                | 10 (30.3)                   | 4 (12.1)                   | 6 (18.2)              | 4 (12.1)  |
| All ages (%) | 17 (35.5)               | 14 (29)                     | 6 (12.5)                   | 6 (12.5)              | 5 (10.5)  |

Table 5. Reasons for not going to GP for help.

| Reason   | Number (%) |
|--|------------|
| Believed they should cope with the problem themselves  | 43 (42.6)  |
| Thought that incontinence came with age/was inevitable | 26 (25.7)  |
| Were too embarrassed to go to GP                       | 14 (13.8)  |
| Felt doctors were too busy                             | 4 (4)      |
| Did not want treatment                                 | 1 (1)      |
| No reason given  | 13 (12.9)  |

independent lives — the study sample excluded women in institutional care. They do not seek help even when they perceive their incontinence to be a problem.

We have seen that not all need is recognised for services for incontinence, not all recognised need results in demand and, indeed, not all demand results in supply. Only half of the women who sought help felt that they received adequate treatment. Yet we know that better management and sometimes effective treatment is possible in primary care for many people with urinary incontinence.<sup>14–16</sup>

A study<sup>23</sup> carried out on the current provision of continence promotion in primary care and the training requirements of GPs and practice nurses throughout the UK in 1993, showed that the majority of GPs thought that it was their role to identify and assess urinary incontinence. However, only 30% assessed themselves as competent to

do so and 80% of GPs thought that their training in continence/incontinence was inadequate. In 1998, Grealish published the results of a qualitative study examining GP attitudes to female urinary incontinence.<sup>24</sup> The author found that many GPs avoided dealing with the problem because they found it difficult to treat. Our study has also shown that a significant proportion of incontinence is not revealed to GPs.

If we are to achieve health gain for women with urinary incontinence we need to achieve three main outcomes: the removal of the social stigma attached to the problem, the education of the public on the availability of effective treatment, and the training of health care professionals on the treatment of incontinence. Perhaps the solution to these three problems lies in tackling them in reverse order. If primary care clinicians were trained in the prevention, identifi-

cation, assessment, treatment, and management of urinary incontinence, then they would be ideally placed to promote continence, screen for incontinence when it may be hidden, and discuss the solutions openly with sufferers, offering effective treatment and thereby perhaps helping to dispel some of the embarrassment and stigma attached to the condition.

Currently, no single specialty in the health service takes responsibility for dealing with urinary incontinence.<sup>25</sup> It seems likely that the large body of identified unmet need illustrated in this study will remain unmet, until we change the current system. Given that we actually have research evidence for better management of this socially embarrassing condition, we have little excuse for ignoring it.

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