

# What prevents older people from seeking treatment for urinary incontinence? A qualitative exploration of barriers to the use of community continence services

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**Background.** Urinary incontinence is a significant health problem for older people. Many people with incontinence do not seek services. Simple and effective treatments exist in primary care.

**Objectives.** Our aim was to explore reasons why older people living in the community do not present for help with problems of urinary incontinence and to identify ways in which they may be assisted to access continence services.

**Methods.** In-depth interviews lasting an average of 1 h were conducted with 20 people aged over 65 years living in the community, purposively selected from a sample of patients who volunteered to be interviewed.

**Results.** Older people described ageing as a natural, degenerative process and had reduced health expectations. Urinary incontinence was commonly viewed as an inevitable aspect of ageing and, as such, something to be accepted and managed independently. Shame and embarrassment combined with generational differences in attitudes to disclosure about personal matters also prevented people from seeking advice. Relatively successful strategies to manage incontinence enabled people to contain their symptoms, although this was at a social, psychological and, in some cases, health cost. Older people in this sample had considerable co-morbidity, in many cases resulting in mobility problems. Despite regular contact with primary care professionals, they had seldom disclosed their urinary incontinence.

**Conclusion.** A combination of personal attitudes and practical barriers prevent older people from seeking help for urinary incontinence. It is possible that older people would be more likely to seek help if asked specifically about urinary leakage by primary health care professionals.

**Keywords.** Older people, service use barriers, urinary incontinence.

## Introduction

The International Continence Society (ICS) has defined urinary incontinence as “a condition in which involuntary urine loss which is objectively demonstrable,

is a social or hygienic problem”.<sup>1</sup> Although this definition is not uniformly accepted,<sup>2</sup> there can be little doubt that urinary incontinence is a significant health problem with potentially serious physical, psychological and social consequences.<sup>3–7</sup> Simple and effective treatments for urinary incontinence are available in primary care,<sup>8–12</sup> but research has shown that many older people who have incontinence do not seek services.<sup>13–15</sup> For instance, even amongst those with severe symptoms, one study found that only about one-third had accessed health services for their problem.<sup>14</sup> Withdrawal, resignation and low expectations have been found to be reasons why older people living in the community do not seek help for a variety of health and social needs.<sup>10</sup>

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A review of research relating to the management of urinary continence identified a lack of qualitative research that sought the views of elderly people.<sup>16</sup>

Promotion of continence forms part of the remit of community nurses and health visitors for the elderly, with training, support and clinic services provided by specialist continence nurses. In the past, an assessment of continence was carried out in general practice annually as part of the 'Over 75 years check'. However, following health policy changes, this health check is no longer a requirement for general practice and there is variation in the extent to which it is carried out by primary care staff. Recent initiatives have attempted to promote high standards of care and access to services for older people, including the promotion of best practice in continence services.<sup>17,18</sup>

Relatively little is known about why older people, who are frequently in contact with the primary health care team, do not seek help for their incontinence. The present study was undertaken in parallel with a cross-sectional postal survey which investigated prevalence of urinary incontinence and determinants of service use in older people registered with four general practices in a relatively deprived urban area in the South West of England.<sup>19</sup> This study found an overall prevalence of 39% older people with urinary incontinence, of whom only 15% had accessed services. Moreover, two-thirds of those reporting urinary leakage several times per week to all the time and up to two-thirds of those reporting moderate or large volumes of leakage had not accessed services. In the present study, it was hoped to explore in depth the reasons why older people do not access community continence services. A further aim was to establish how they could be assisted to access such services given the important social and psychological costs of incontinence. An exploration of this type lent itself methodologically to a qualitative approach.

## Methods

### *Participants*

Following the principles of qualitative inquiry, the research focused on a relatively small sample selected purposefully.<sup>20</sup> The sample comprised a selection of individuals who had responded to the survey questionnaire in the first study above. The survey provided the opportunity for respondents to volunteer to be interviewed. Interviewees for the present study were selected from those who had reported urinary incontinence and had volunteered for interview. The sample size was not predetermined, rather additional participants were recruited until all relevant avenues of enquiry had been explored and continued data analysis failed to reveal new themes. Selection ensured that the participants reflected a range of characteristics, namely age, sex, severity of symptoms, living circumstances and

use of services. In addition, both confirming and disconfirming accounts were sought (i.e. older people who had positive and negative experiences of urinary incontinence and services), a qualitative technique that is recognized to strengthen and ensure the robustness of data generated.<sup>21</sup>

### *Ethics*

An interview involving disclosure of intimate personal details with a person from a potentially vulnerable group raises ethical issues about both confidentiality and informed consent. Furthermore, the safety implications of perhaps frail elderly persons being visited at home by a researcher were taken into account in preparation for the study. It was decided that details of the professional background of the researcher would be important in assuring participants of the confidentiality of the research and help allay fears of talking about the personal and sensitive topic of urinary incontinence. For these reasons, it was decided to introduce the interviewer (SH) as a research nurse. The United Bristol Healthcare Trust Local Research Ethics Committee granted ethics approval.

### *Interviews*

Semi-structured interviews were conducted at the participant's home or doctor's surgery according to the preference of the participant. Each interview was taped and transcribed. A topic guide based on current research into barriers to utilizing health services was used to give overall direction to the interviews, but each interview varied in accordance with the priorities set out by the participant (Box 1).

### *Analysis*

Transcripts were analysed by SH using constant comparison derived from grounded theory techniques.<sup>22</sup> This involved an iterative process of data collection, coding and analysis. A preparatory list of themes and categories relating to the factors that interviewees perceived to be relevant to their experience of incontinence and its management was drawn up, and modified as analysis proceeded and new ideas and concepts emerged. A comprehensive list of themes and categories was derived and the data reread, coded and checked by another researcher (MS). Conclusions were drawn concerning the range of experiences, beliefs and understandings of the participants. The analysis was validated by writing to participants detailing the main points arising from their interviews and asking for corrections if these were not as remembered by the participant.

## Results

### *Participants*

From the survey sample of 915 (69% response rate), 120 people with urinary incontinence volunteered to be

interviewed. Twenty people between the ages of 66 and 94 years were purposively selected as described above. Seven participants lived alone, and two lived with relatives other than their husband or wife. Participants included nine men between the ages of 66 and 82 years

and 11 women between the ages of 68 and 94 years. Two of the men had permanent indwelling urinary catheters. Six participants had at one stage used the specialist continence service, but only three participants said they were current users, and for most this was in relation to the supply of continence pads. A further three participants had been referred to the local hospital urology department but had not received a referral to specialist community continence services.

**Box 1** *Schedule of content of the interview (the exact content and order varied according to responses)*

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Questions asked by the interviewer

1. How would you describe your general health at the moment?
2. I noticed from your questionnaire that you experience some urinary leakage. When did you first become aware that this was happening? How did you feel about it?
3. What did you think was the cause?
4. Did you speak to anyone about it? What sort of support or advice did you receive?
5. How helpful did you find it?
6. Let's move on to what is happening currently—can you tell me how you are managing now?
7. Can you tell me how problems with leakage have affected your daily life?
8. And what about contact with friends and family? How has this affected your relationships with others?
9. (*If living with a partner*): How has your urinary leakage affected your husband/wife/partner? What about the intimate side of your life, how has it affected your marital life/sex life?
10. What would you say is the worst thing about having this problem?

*Or (if patient has other health problems):* How is having this problem compared with (patient's other problems)

11. Can we talk about the ways that you think you could have been helped? Tell me what you think would have been most helpful to you in dealing with your leakage of urine. What problems did you have with getting care?
12. How do you think people who have similar problems to yours should be helped?
13. Why do you think people who have similar problems to yours sometimes find it difficult to get the help they need?

*Findings*

The dominant themes that emerged from the qualitative analysis are illustrated in Figure 1. Represented in the figure are the likely barriers to seeking help and the potential opportunities for accessing community continence services. The participants' responses to their incontinence seemed to be closely associated with their attitudes about ageing and beliefs about the cause of incontinence. These attitudes influenced whether or not services were accessed. In addition, the use of self-management strategies enabled them to cope with the problem (at some personal psychological and social cost) without seeking outside help. There was evidence that increasing exposure in advertising and magazine features discussing urinary incontinence has influenced attitudes, beliefs and knowledge about incontinence. However, the majority of participants were in regular contact with primary health care professionals and this offers opportunities to improve access to services. Below we present findings that attempt to describe why people do or do not access continence services under the following headings: attitudes and beliefs; reactions to incontinence; independent management; and practical barriers.

*Attitudes*

Older people's attitudes about ageing underpin their beliefs regarding the cause of urinary incontinence. Participants reflected on the physical process of ageing and the deterioration in their ability to carry out

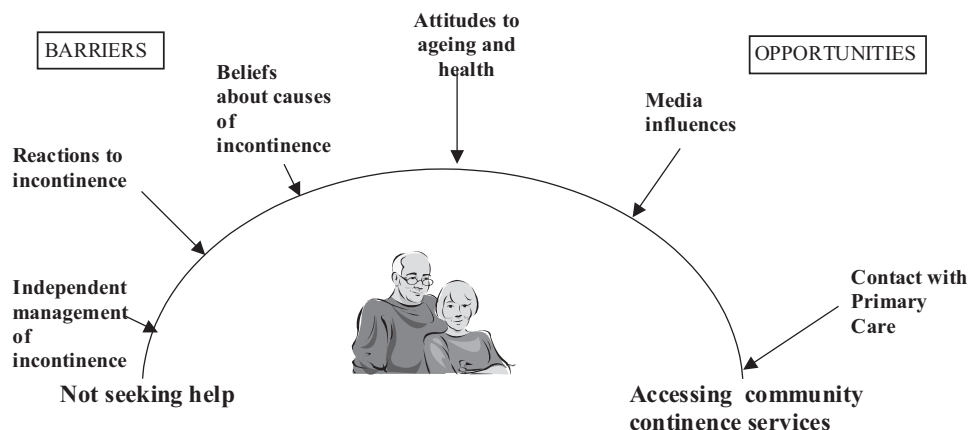


FIGURE 1 *Factors influencing older people's access to continence services*

activities and hobbies. Ageing was equated with muscles being weakened or worn out, responses being slowed and resilience broken down. Like a disease, ageing was seen to reduce strength and resistance to any threatening health problems.

Related to their attitudes to ageing, older people appeared to have low expectations with regard to their own health. Urinary symptoms were normalized as a consequence of ageing and most participants accepted the daily restrictions and discomfort of urinary leakage as inevitable. Continued deterioration was feared but also accepted as part of 'getting older'. Perhaps unwittingly, health professionals contributed to older people's reduced health expectations by their own attitudes to, and simplified explanations of, the cause of urinary incontinence.

#### *Reduced health expectations*

"Well, I thought at 82 I don't expect to be like I was at 52. Of course, the doctor said everything's worn out and yet I went to 'Keep Fit' I until I was 70, I played skittles until I was 70, 3 or 4 times a week." (P6, female, 83 years)

Participants frequently commented that their generation was not used to discussing private bodily functions and might be inhibited about discussing personal problems with health professionals. There was also a perception that older men might be the most reluctant to disclose that they have a urinary incontinence problem, partly because of beliefs about the association of leakage and female gender and partly because of advertising that frequently features women only.

#### *Disclosure*

"If it's a male incontinent—they're the ones who don't like to talk..."

"You think it's more difficult for a man?"

"Yes. They don't like talking about it even to a doctor, I reckon." (P13, female, 73 years)"

"I think there's quite a few men about, like what you've talked to, have got to have one [pad] but men don't talk to each other, do they? They keep their problems quiet." (P14, male 69 years)

Many female participants believed that female gender and its association with pregnancy and childbirth were a major determinant of incontinence problems. In addition, many reported chronic health problems of varying severity and felt these were causal in their own incontinence. Hypertension, strokes, heart and prostate problems were the major conditions reported. Restricted mobility affected about half the sample. Participants often reported that their urinary leakage was either caused or exacerbated by surgery such as

hysterectomy or medication such as diuretics prescribed for other health problems.

#### *Reactions to incontinence*

Extremes of response were reported, ranging from acceptance and resignation to shame and even disgust. Some participants expressed deep-seated fears that incontinence was the harbinger of future frailty and dependence. Women in particular expressed concerns about cleanliness and personal hygiene, and worried that others might be aware of their leakage. Negative reactions such as embarrassment and shame contributed to concealment of incontinence problems from family, friends or health professionals.

Participants commonly described feelings of self-consciousness, embarrassment, humiliation and disgust associated with incontinence. Powerful feelings of shame were heightened by secrecy that traditionally surrounded discussion of personal matters. Negative feelings led to painstaking concealment of the problem. Coupled with an acute sense that personal hygiene may be a problem, feelings of shame and embarrassment reinforced the difficulties participants felt in disclosing their problem, either to family or to health professionals, as they feared the negative reactions they themselves associated with incontinence.

#### *Shame*

"By the time I've got out of bed and just got round there ... I thought oh no. That is what makes you feel old and ashamed of yourself. I know you shouldn't and losing my movements. Am I getting through to you what I mean, I'm losing me." (P18, female, 68 years)

"Well, I think it makes you feel conscious. I'm thinking to myself, I hope I'm clean. I mean some people don't worry or nothing about it, but I shouldn't like that." (P6, female, 83 years)

However, some participants, especially those who viewed their incontinence as a natural outcome of ageing or a consequence of sickness or infirmity, tended to feel that it was not a medical problem and accepted the restrictions it imposed. They reported less severe symptoms and tended to manage their incontinence problems independently. For participants with major medical conditions, urinary incontinence was the least of their problems and again was not a precursor to seeking help. In other words, there seemed to be an awareness that the physical and social restrictions of severe urinary symptoms were less evident when lives were already limited by illness or restricted mobility. This goes some way to explain the minimization of comparatively severe urinary symptoms. Furthermore, continued control of personal bodily functions and self-management of incontinence, if it occurred, were important contributors to the maintenance of self-esteem when disabling medical problems dominated participants' lives.

*Resignation and minimization of symptoms*

“I get caught out many a time. Yes. But I don’t have an active enough life not to keep it under control.” (P5, female, 69 years, restricted mobility and speech problems following three strokes)

“I haven’t ever been to the doctor about it at all. I belong to the school where you think you can’t keep worrying the doctor for every small thing.” (P9 male, 82 years, arthritis)

“It’s like anything, I’ll have to put up with it, won’t I? It’s a hindrance sometimes I suppose, but a lot of people is a lot worse off.” (P17, male, 79 years)

*Independent management*

Participants frequently described self-imposed daily routines, restricted drinking and choice of clothing to manage their urinary leakage. Avoidance of unknown social situations, careful planning and maintenance of strict routines and judicious use of continence pads were the management strategies most often described. Men and women expressed contrasting attitudes towards the use of continence aids. Men frequently thought pads were for women’s use only. Two men expressed strong repugnance for pads because of negative associations with increasing dependence. Succumbing to use of pads or other aids seemed to undermine men’s self-image in a fundamental sense not described by the female participants. Women did not express negative feelings towards pads, perhaps due to familiarity with sanitary towels.

*Continence pads*

“I think I’m wearing a pad and I’m telling you now and I’m not ashamed of it but I feel that I’m in control.” (P18, female, 68 years)

“The only thing you read about and you see advertised is incontinence underwear and that. I’ve never felt that I’d like to start using things like that, no.” (P9, male, 82 years)

“I’ve seen these pads and the like. I know there’s such a thing as a bag that will take urine. I don’t want to buy one of those because I think once you start wearing that you tend to say I’m alright, so I guess I’ll stop trying...I don’t want to have to come to it until I’ve got to... Because I’m a firm believer in that once you start supporting something you’ve got to maintain it.” (P2, male 75 years)

“I know that the facility (wearing pads) is there but put it from my mind because it is a path I *really* don’t want to go down and that’s not because (pause) of course it’s pride. I was going to say that it’s not that, ‘course it’s pride.” (P12, male, 74 years)

*Practical barriers*

In response to questions seeking views about how people could be helped to access services, participants outlined a number of perceived practical barriers that could potentially be addressed by service providers. For example, participants were sometimes unaware of the availability of treatments and unsure whom to contact for advice. Concern about the doctor’s workload was given as a reason for not consulting about their non-emergency urinary problems. Even those participants in contact with their GP made their other health problems a priority, especially those who found talking about urinary problems embarrassing. For these participants, the length of consultation was felt to be too short to broach and explain personal matters. For others, there was a fear that repeated consultations might lead the doctor to suspect malingering, and hence older people who held this view implicitly rationed the number of times they felt able to consult.

*Contact with GPs*

“I can’t control it unless I have something done to it and I don’t want to trouble the doctor with it because I go there with so many problems, you know what I mean. He could turn round and say ‘is he putting that on or he isn’t putting that on’.... It’s embarrassing. As I said I can’t go round all the time because you don’t know how doctors’ minds work, because they may think is he genuine or whatever. You’ve got to be careful what you do. You’ve got to have a proper complaint to go round there. The doctor might think that you might be ‘jamming it’—you’ve got to be careful what you do.” (P14, male, 69 years)

“He’s been seeing me with other things and I thought let’s get one thing sorted out at a time which he has done.” (P8, female, 73 years)

The doctor’s gender was an important barrier to women, though this did not seem so significant to the male participants. Housebound patients reported that they were unable to mention their urinary problems to the doctor whom they saw for emergency house calls only, when it was inappropriate to raise other health problems. Opportunities for seeing leaflets or publicity about local clinics were significantly reduced as community nurses and social services provided routine care and monitoring to housebound patients.

Contact with health professionals, especially community nurses, did not seem to be associated with increased disclosure of urinary problems. Participants who reported repeated contact with practice nurses and district nurses because of complex health problems said they either had not been asked about urinary leakage or had chosen not to ask for help.

*Contact with nurses in primary care*

“The nurses do come and see you from time to time because of your leg. Have they ever asked you whether or not you have any problems with urinary leakage?”

“No, they just come and dress me leg.”

“They’ve never asked you?”

“No. They’ve asked me what caused it, like, the ulcers.” (P15, female, 86 years, with leg ulcers dressed by district nurses)

“Has the nurse ever asked you about leakage of urine?”

“No. no. Until it came up on that survey of yours. Actually, to be honest I think they’ve got enough on their plate. When we go down there and look into the surgery you look at the people and there’s thousands of records, isn’t there? Well, I wonder how they get by.” (P2, male, 75 years, attends local surgery for regular BP monitoring and blood tests).

Embarrassment was considered to be the major reason why people did not present themselves for care. The perceptions of high standards of privacy and confidentiality were fundamental to use of any relevant services. This was especially true where people attended their local surgery and could be known both to surgery staff and to other patients.

*Perceptions of confidentiality*

“I had to wait in the queue and there was few behind me. And when I asked she said no there was no parcel for you. She said what is it and so I said incontinence pads, she said who’s it for. Well, I had people behind me who I knew so I said it was for my mother, and I couldn’t say it was for Mrs J. because I’m Mrs J. and they knew it! I just walked out because I was too embarrassed. I just walked out. I did see the nurse on the way out and I said I’ve just been for those pads and she said she’d forgotten all about that. So I’m not going to bother again I’ll go and buy them.” (P19, female, 69 years attempting to collect incontinence pads from a health centre)

**Discussion**

This study explored in depth reasons why older people with urinary incontinence may choose not to access continence services. Although previous qualitative studies have explored barriers to care with participants who are receiving treatment,<sup>23</sup> studies that enquire why

participants have not sought help are underdeveloped.<sup>16</sup> One possible limitation of this study is that the volunteer sample, although chosen to reflect a wide range of characteristics, may differ from those who chose not to volunteer for interview, and this may affect the extent to which the findings are transferable. However, a particular strength of this qualitative study is that the participants had not already elected to accept treatment, which was a potential bias of Shaw’s study. In addition, it included groups who have been under-researched in the past, namely men and very elderly people.<sup>24</sup>

The commonly held belief that incontinence is a natural and inevitable consequence of ageing was a major factor that prevented participants seeking help for urinary leakage. It is known that variations in health beliefs about cause influence the behaviours of people once they perceive they have a health problem. The importance of participants’ views about causation and the consequent action taken in seeking help in relation to osteoarthritis, another chronic, socially disabling condition that varies in severity, has been reported.<sup>25</sup> Participants in our study frequently described ageing as an inevitable process of slowing down and decay. The belief that health problems are inevitable due to the natural degenerative effect of ageing explains older people’s reduced health expectations and acceptance of comparatively severe urinary symptoms. Moreover, health professionals sometimes confirmed older people’s beliefs that incontinence was an inevitable consequence of ageing in their own attitudes and explanations of the cause, a finding that was also observed in Sanders’ study.

Seeking professional advice for a chronic health problem may not be a clear-cut process. Individuals may have symptoms for a long time before seeking medical help. During this period, accommodation or adaptation to the symptoms occurs, with a gradual increase in the threshold for tolerance occurring. It is only when this accommodation breaks down that people actually seek help.<sup>26</sup> Older people in this study reported they had managed their symptoms, often for years, without recourse to the doctor. Regular visits to the toilet, strict daily routines and restrictions on type and colour of clothing, type and number of drinks consumed and some social activities were tolerated in order to self-manage urinary leakage. In some cases, older people may have unintentionally worsened their problem and put their own health at risk by restricting fluid intake and altering regimes of prescribed medication, especially diuretics.

Incontinence is a distressing condition with profound social and psychological sequelae. Participants in this study often commented on perceived generational differences in attitudes about the acceptability of talking about personal matters such as bodily functions. Seymour has written about the shame and stigma associated with loss of control over bodily functions that

relates to cultural values and beliefs about cleanliness and control around toilet training.<sup>27</sup> Evidence from the interviews showed loss of control over bodily functions being feared as the threshold for loss of independence. Ironically, since incontinence is often a precipitating factor for people being admitted to residential or nursing care homes, fear of institutionalization may be one of the factors preventing people seeking help for incontinence.<sup>5</sup> This barrier might be particularly true of older people living alone. Another study has found that older people considered incontinence a sign of personal incompetence and that this forced them to adopt strategies so as not to compromise the appearance of competence in the eyes of others.<sup>28</sup> The stigma associated with being unable to control bodily functions and the fear of other people's reactions, including those of health professionals, led to people preferring to conceal their problem and manage independently as long as they were able. Based on research reported above and affirmed by our findings, it would seem that concealment of the problem might be preferred to seeking help if people believe that the condition is an inevitable aspect of ageing and disclosure of urinary incontinence could lead to being thought unable to live independently.

#### Practice implications

Since the majority of participants were in regular contact with the primary care team, there would seem to be many opportunities to improve access to continence care. However, some patients saw their GP relatively rarely, usually for an episode of acute illness. It was generally felt inappropriate to raise the problem of incontinence during such a consultation. Nursing staff and other support services carry out most of the routine care for housebound patients, but they may not typically carry out a continence assessment. In short, the evidence of this study shows that despite frequent contact with health services at home, older people tend not to disclose their incontinence problems. The reason for this may relate to the fear of loss of control of bodily functions and institutionalization discussed above, or it may be that in comparison with the rest of their problems, the incontinence is not bothersome.

In conclusion, we suggest that community nurses and other health professionals ask older people in their care whether they experience urinary leakage. Professionals need to be aware of the high prevalence of incontinence in older people, especially those with mobility problems and the housebound. Our study enhances the findings of the prevalence survey by describing the practical barriers to accessing care experienced by older people. Addressing issues such as lack of information about continence services, especially for the housebound, and improving people's perceptions of the confidentiality of existing services are essential to enable people to seek help for this distressing but manageable condition. A more direct

approach from health professionals is likely to result in more older people seeking continence services.

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## Declaration

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