

Barriers to help seeking in people with urinary symptoms

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Background. Urinary incontinence is a common problem but, for those experiencing significant clinical symptoms, help seeking has been reported to be as low as 20%. As many of these people could be helped by simple interventions, there is a clear need to identify barriers to help seeking and develop interventions to overcome these barriers.

Objectives. This study explores help-seeking behaviour in people with urinary symptoms such as leakage, frequency, nocturia and urgency in order to identify barriers to service use.

Method. Thirty-one people who either had agreed to treatment as part of an intervention study or who were receiving treatment at a hospital out-patient clinic for their urinary problems took part in unstructured, taped interviews. Respondents were questioned about their views on help seeking for urinary problems and their personal experiences of consultations. The data were transcribed, coded and thematic analysis carried out.

Results. The most common theme to emerge was a lack of knowledge of the condition and of available treatments. Urinary symptoms frequently were considered a normal part of ageing or childbirth, or it was felt that these types of symptoms were inappropriate for medical intervention. Older people were not only more likely to accept symptoms but were also less likely to want to bother their GP. Patients did not always communicate their concerns about urinary symptoms to their GP, through either embarrassment or misconceptions of what is a 'medical problem'.

Conclusions. There is a clear need for health education and health promotion in this area. Future work should explore professionals' knowledge and views of these types of conditions with the aim of providing guidelines for management in primary care.

Keywords. Family practice, health behaviour, health services accessibility, urinary incontinence.

Introduction

Lower urinary tract symptoms such as incontinence, urgency, frequency and nocturia are common complaints, particularly in the elderly, with ~34% of the population experiencing clinically significant symptoms.¹ However, relatively few people are likely to consult their GP for incontinence. Help seeking has been estimated as 20,² 35,³ 37.6,⁴ 41,⁵ 52,⁶ 57⁷ and 83.1%.⁸ Of those with severe symptoms (daily leakage), only about half seek help.^{4,9} People who consider the symptoms to be problematic or bothersome are more likely to consult but, again, only about half report speaking to a doctor.⁴

A number of studies have examined reasons for not seeking help. People often consider their symptoms to be too trivial or not problematic enough, irrespective of objective severity.^{10,11} Other, often quoted, reasons are that urinary symptoms are believed to be a normal part of ageing,¹² or the natural result of childbirth.⁵ These beliefs are accompanied by a lack of knowledge of treatment options,¹⁰ embarrassment¹¹ and fear of invasive investigations.¹³ People who do seek help can be unsuccessful in acquiring treatment for their condition if communication between doctor and patient fails.¹⁴ There is a clear need to identify the barriers to help seeking for those who could benefit from appropriate advice and intervention.

This study aims to examine reasons why people do and do not seek help in order to shed light on barriers to acquisition of treatment and advice. This analysis is part of a larger qualitative study of satisfaction with care for

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urinary symptoms and is a preliminary investigation for a more in-depth study of help-seeking behaviour. Access to care was found to be one aspect of satisfaction with the care event, but it also warrants examination in relation to equity of service use and provision. Some people may never wish to take part in treatment, no matter how severe their symptoms, and so this study interviewed people who had agreed to treatment as part of a large-scale intervention study, but who had either not sought, or who had not acquired treatment successfully for themselves in the past. These people were considered to have an unmet need for services. A small sample of women were also interviewed who had successfully sought help and were being treated in a gynaecology out-patient clinic.

Methods

In-depth interviews were carried out by four trained interviewers. Thirty-one participants were recruited to the study, 23 female (mean age 57 years, range 38–86) and eight male (mean age 59 years, range 41–74). Twenty-six participants were taking part in the pilot phase of a randomized controlled trial assessing a continence nurse practitioner service. These participants were identified initially by postal survey as having storage abnormality symptoms such as frequency, nocturia, urgency or leakage. Outcomes of the trial were assessed by home interview at 3 and 6 months. Consent to take part in the qualitative study was sought by the interviewer at the final outcome assessment. As the qualitative study was also exploring patients' views of care, particularly experiences of urodynamic investigations, participant selection was based on consent to urodynamics, with half having undergone urodynamics and half not. Consecutive patients were approached until sufficient numbers were acquired, with all those approached agreeing to take part. As part of the purposeful sampling, five participants were recruited from a gynaecology out-patient clinic in order to include the views of people who had been successful in obtaining treatment for their urinary problems. These participants were selected randomly from clinic lists which covered a period of 3 months. Twelve women were approached, with consent gained from five. All respondents were, therefore, either undergoing or recently had completed treatment at the time of interview.

Respondents were interviewed in their own homes and the interviews were taped and then transcribed verbatim into QSR Nud*ist 4 (Qualitative solutions and Research Pty Ltd) software for analysis. The interviews lasted ~1 hour and covered topics related to satisfaction with all aspects of the care they had received. An interview guide was used which was based on a review of the satisfaction literature.

Analysis

Transcripts were read and re-read and main concepts identified. The text was then examined line by line, and each expressed concept was interpreted and given a category code. Codes were developed that related to the structure and process of the care event, patients' views of illness, views of health care, feelings and person characteristics. The data were also read 'horizontally' by reading extracts collected under each category code and the text deconstructed further by identifying subcategories. In this way, a hierarchical coding frame was developed of main categories and subcategories. Text searches were also carried out to locate specific words relating to each category code. Analysis and data collection ran concurrently to inform sampling and to allow emergent themes to be pursued in subsequent interviews. Analysis was carried out by the first author, but interpretation and coding were agreed with the interviewers as the study progressed to ensure reliability. Data coded under the main category 'access to care' were extracted for the present analysis. Themes were developed based on the hierarchical nature of the coding scheme and on relationships observed between the 'access to care' codes and all other codes. The techniques used in the analysis were based on those developed by Strauss and Corbin.¹⁵ Sampling was continued until no new categories pertaining to the areas of interest emerged.

Results

Respondents in this study reported two main reasons for help seeking. One was the fear of serious underlying disease such as cancer, and the other was the presence of significant distress or impact on quality of life. Pain was considered a symptom that warranted medical intervention, as this was thought likely to signify disease, and was expected to be treatable. Urinary symptoms such as leakage, frequency and nocturia generally appeared to fall into the second category, although men often viewed the symptoms as indicative of serious pathology because of their awareness of prostate cancer. Women were less likely to consider these symptoms a disease state and often were completely unaware of available interventions. Respondents had their own representations of a legitimate 'medical problem' and often considered these types of symptoms too trivial to present to their GP.

"There was nothing really wrong with me and I felt that it was just a muscle problem." (Respondent 1)

Representations of a 'medical problem' were not necessarily dependent on severity of symptoms. One woman was wet every day when she had a cough, but on consulting the doctor she only mentioned the cough.

Few people talk openly about these types of symptoms and so lay knowledge is poor. There was greater awareness in men about prostate problems but awareness of

treatment for urinary symptoms in general was often non-existent. The woman mentioned above explained that she had not reported her urinary symptoms to the doctor because she had no knowledge of these issues from her social circle and so was unaware that treatment was available.

As symptoms were not considered a medical problem, they tended to be normalized, and management strategies incorporated into the patients' lifestyles. A passive, accepting attitude was adopted.

"I'd just accepted it that it was part of, well part of life I suppose." (Respondent 24)

The insidious onset of symptoms contributed to the normalization process. Respondents often experienced symptoms for many years, sometimes since childhood. If they had not actually had problems there was the perception that they had always had a weak bladder. However, even if symptoms were accepted and coping was relatively successful, people still felt a need for help.

"She said 'Somebody can help you' and I thought 'Oh I wish'." (Respondent 7)

Help seeking often was triggered by worsening of symptoms, creating greater impact on quality of life and/or fear for the future. All respondents considered symptoms to be long term and progressive, resulting in a fear of becoming 'incontinent' in older age, especially when there was prior experience of this.

"and my grandmother was incontinent and I can remember her smell was terrible and I can't end up like that, just cannot." (Respondent 5)

Other triggers to help seeking were specific events such as leaking during sex, or leaking in public. This undermined the illusion of coping.

Older people were less likely to seek help. This was viewed as a generational difference, as older people had been children pre-NHS, and were brought up with the attitude that the doctor was only consulted in extreme circumstances. They were more prepared to 'put up with things' and 'get on with life', and felt that this was a habit that was difficult to break.

Some people were unsure about consulting and sought help indirectly by 'just mentioning' symptoms whilst attending for regular health checks. If the GP did not respond, the patient was often too embarrassed to broach the subject again, or decided against it because they feared physical examinations or invasive treatments. Some respondents realised that they should be more explicit or persistent in help seeking but refrained for the same reasons.

"I supposed if I had nagged on they would have eventually found it wouldn't they, but I was worried I might have to be cut again" (Respondent 29)

Some interpreted the doctor not addressing the issue in these circumstances as an indication that no treatment

was available, and made assumptions about the doctor's views of the causes and treatments of urinary symptoms.

"I mentioned it to the doctor but he never picked up on it, never gave me any advice . . . It seems to be 'oh, you have had children, it's something you have to put up with' so I never took it any further." (Respondent 14)

When the GP did discuss the symptoms, the patient sometimes failed to communicate their concerns. If asked how problematic the symptoms were, the patient's interpretation of the word 'problem' took on a different frame of reference. One respondent told the doctor that symptoms were not a problem (interpreted as a serious health threat) but later claimed they had sufficient impact to require treatment, as their sleep frequently was disturbed. However, the doctor did occasionally give poor advice, making suggestions such as

"The more you go the more you are clearing your fluids out." (Respondent 21)

A commonly reported occurrence was failure to revisit the doctor, even when symptoms deteriorated. The respondent quoted above reported a gradual worsening of symptoms but felt that he should not seek help again, until he received a questionnaire as part of the present study. Similarly, if treatment was not acceptable, due to side effects for example, patients sometimes did not return for further advice. Patients were very responsive to the doctor's approach and could be either encouraged or discouraged from discussing sensitive issues.

Severity was the important factor running through all accounts. There was variation in how severe the condition was before people were unable to cope with symptoms. The benefits of treatment had to be perceived to overcome emotional costs, such as embarrassment.

Discussion

The most common theme to emerge from this research was lack of awareness about the condition, its causes and its treatments. Such barriers to help seeking are not specific to urinary symptoms. Facione,¹⁶ in a review of help seeking for breast cancer, found lack of awareness of the significance of symptoms a common theme reported by investigators, and people who seek help promptly for cardiac symptoms have been found to have greater cardiovascular knowledge than those who delay.¹⁷ Lack of awareness of available treatments or fear of invasive treatments has also been reported in other conditions. Ansong *et al.*¹⁸ found that only 27.6% of men identified as impotent were aware of the availability of treatment, and 16.2% of those not seeking help believed that treatment was risky or harmful. The present research suggested that sensitive conditions such as incontinence are not discussed frequently in social situations, reducing

opportunities for informal acquisition of information. People are also less likely to discuss stigmatizing conditions with a doctor. As in the present study, shame and embarrassment have been reported as barriers to help seeking in conditions such as alcohol abuse,¹⁹ impotence,¹⁸ hearing impairment²⁰ and depression.²¹ Health promotion and education should be directed at these more 'taboo' areas in order to allay fears and misconceptions, and promote awareness of symptoms and treatments.

In line with previous research, urinary symptoms were considered by participants as a normal part of ageing.¹² As well as being more reluctant to access professional help, older people may have a more general acceptance of deteriorating health.²⁰ Older persons delay longer in seeking help for all types of cancer compared with younger people,¹⁶ and accept conditions such as hearing impairments as being a part of normal ageing.²⁰ Of course, elderly people are more likely to have poorer health and a greater number of co-morbidities, with urinary dysfunction being a result of conditions such as stroke, dementia, Parkinsons disease, etc. However, even if urinary symptoms appear insignificant in the presence of other pathologies, alleviation of these symptoms could have a major impact on the quality of life of both patient and carer. However, urinary dysfunction is also common in the fit elderly, and health professionals should target at-risk groups for investigation of possible urinary disorder.

The main trigger to help seeking identified in this research was the impact of symptoms on quality of life. Although this is likely to be dependent on severity of symptoms, the relationship between severity of symptoms and help seeking is not strong.⁴ It is, perhaps, impact that is of greater predictive value in estimating the need for service provision. The degree of impairment in daily activities has been found to be associated with help seeking in other similar non-life-threatening conditions.^{21,22} In the present study, the failure of the patient to communicate the extent of impact was a barrier to treatment provision. One reason for this is that patients often present indirectly by consulting with other, less bothersome symptoms. Depression is a missed diagnosis in 50% of individuals who consult a physician, as the primary motive for consultation is rarely depressed mood, but a symptom of depression such as sleep disturbance or somatic complaints.²³ Similarly, nocturia may be presented as sleep disturbance, or incontinence may be the real problem when frequency or urinary tract infections are the primary reason for consultation.

As well as using an indirect approach, patients also reinterpret the impact of the symptoms during the consultation. Their symptoms suddenly seem insignificant and trivial. However, the doctor can only make an assessment of the severity of the symptoms based on patients' reports. A solution would be a simple severity of symptoms and quality of life scale that is quick and easy to complete, allowing detailed assessment with the minimum of

embarrassing probing. Such a scale should be sensitive to a wide variation in symptoms and also to change, so that treatment outcomes could be assessed.

Attitudes of men and women to help seeking were very similar, apart from the finding that men were more aware of prostate problems and were more likely to seek reassurance that there was no serious underlying pathology. Both men and women were embarrassed at reporting symptoms, were unaware of treatment options and fearful of surgical interventions, and were just as likely to consider symptoms a normal part of ageing.

The present research considered help seeking for urinary problems from the patient's perspective, but the findings indicated a need also to explore the knowledge and attitudes of professionals. Treatment for urinary dysfunction can be simple but time consuming. However, in milder cases, self-help information concerning bladder re-education or pelvic floor exercises may be sufficient. The primary care team should be aware of the availability of specialist services such as continence advisory services and continence helplines as a possible first line intervention. There is a need for evidence-based guidelines in relation to urinary symptoms for use in primary care by both doctors and nurses.

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