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Understanding help-seeking behaviour in older people with urinary incontinence

Vethanayagam, Natalie; Orrell, Alison; Dahlberg, Lena; McKee, Kevin; Orme, Susan; Parker, Stuart; Gilhooley, Mary

Health and Social Care in the Community

DOI:

[10.1111/hsc.12406](https://doi.org/10.1111/hsc.12406)

Published: 01/05/2017

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Vethanayagam, N., Orrell, A., Dahlberg, L., McKee, K., Orme, S., Parker, S., & Gilhooley, M. (2017). Understanding help-seeking behaviour in older people with urinary incontinence: An interview study. *Health and Social Care in the Community*, 25(3), 1061-1069. <https://doi.org/10.1111/hsc.12406>

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Understanding help-seeking in older people with urinary incontinence: An interview study

Journal:	<i>Health & Social Care in the Community</i>
Manuscript ID	HSCC-OA-16-0227.R1
Manuscript Type:	Original Article
Keywords:	Older People, urinary incontinence, help-seeking behaviour, comprehensive geriatric assessment, General Practice, attitudes to ageing

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Understanding help-seeking in older people with urinary incontinence: An interview study

Abstract

The prevalence of urinary incontinence (UI) increases with age and can negatively affect quality of life. However, relatively few older people with UI seek treatment. The aim of this study was to explore the views of older people with UI on the process of seeking help.

Older people with UI were recruited to the study from three continence services in the north of England: a geriatrician-led hospital outpatient clinic (n=18), a community based nurse-led service (n=22) and a consultant gynaecologist-led service specialising in surgical treatment (n=10). Participants took part in semi-structured interviews, which were transcribed and underwent thematic content analysis.

Three main themes emerged: *Being brushed aside*, in which participants expressed the feeling that general practitioners did not prioritise or recognise their concerns; *Putting up with it*, in which participants delayed seeking help for their UI due to various reasons including embarrassment, the development of coping mechanisms, perceiving UI as a normal part of the ageing process, or being unaware that help was available; and *Something has to be done*, in which help-seeking was prompted by the recognition that their UI was a serious problem, whether as a result of experiencing UI in public, the remark of a relative, the belief that they had a serious illness, or the detection of UI during comprehensive geriatric assessment.

Greater awareness that UI is a treatable condition and not a normal part of ageing is needed in the population and amongst health professionals. Comprehensive geriatric assessment appeared an important trigger for referral and treatment in our participants. Screening

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3 questions by health care professionals could be a means to identify, assess and treat older
4
5 people with UI.
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8 Keywords: older people, urinary incontinence, help-seeking behaviour, comprehensive
9
10 geriatric assessment, general practice, attitudes to ageing
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13
14 *What is known about this topic*
15

- 16 • The prevalence of UI increases with age.
- 17
- 18 • UI negatively affects older people's quality of life.
- 19
- 20
- 21
- 22 • Few older people with UI seek help.
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- 24

25
26 *What this paper adds*
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- 28 • There is a lack of awareness amongst older people and health professionals that UI is a
29
30 treatable condition and not part of the normal ageing process.
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- 32
- 33 • There was a strong view that general practitioners did not recognize or prioritise
34
35 participants' concerns regarding UI.
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- 37
- 38 • Comprehensive geriatric assessment and screening questions have the potential to
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40 identify older people with UI and trigger appropriate referral and treatment.
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Introduction

Urinary incontinence (UI) is defined by the International Continence Society as the complaint of any involuntary leakage of urine (Abrams et al., 2010). UI decreases quality of life (e.g. Aguilar-Navarro et al., 2012) and is a predictor of higher mortality, especially among older people (John, Bardini, Combescure, & Dallenbach, 2016). The study reported here aims to explore help-seeking behaviour in older people with UI. The study forms part of a larger project examining the views of older people with UI on the continence care they receive.

The prevalence of UI has been found to increase with age, although the true prevalence of UI is not accurately known due to variations in study populations, definitions and measurements of UI, and study methods (Hunskaar et al., 2005). A multi-national study (Irwin, Kopp, Agatep, Milsom, & Abrams, 2011) has estimated that there are approximately 350 million people worldwide with UI. This study also confirmed that UI is more common among older than younger people and in women than men, with a prevalence of up to 20 percent in women aged over 60 years (see also Gibson, Wagg, & Hunter, 2016). In the United Kingdom (UK), a cross-sectional postal survey of patients aged over 65 years and registered with four urban general practices (Peters, Horrocks, Stoddart, & Somerset, 2004) found an overall UI prevalence of 39 percent, although many of these patients reported leaking less than once a week. Only a minority of those patients with UI were found to have accessed services, and this is a finding replicated in other studies (e.g. Simeonova, Milsom, Kullendorff, Molander, & Bengtsson, 1999; Teunissen, van Weel, & Lagro-Janssen, 2005). If we are to increase access to continence services among older people with UI, we need to improve our understanding of their help-seeking behaviour.

Findings from research on help-seeking patterns in older people with UI are inconsistent.

Older people have been found to seek help less than younger people (Irwin, Milsom, Kopp,

1
2
3 Abrams, & Grp, 2008) and older women to seek help less than older men (Li, Cai, Glance, &
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5 Mukamel, 2007). Another study found that older women are *more* likely to seek help than
6
7 younger women, and the authors suggest that this may be explained by higher levels of
8
9 comorbidity among older people present opportunities to address the problem to health care
10
11 staff (Shaw, Das Gupta, Williams, Assassa, & McGrother, 2006). It has been shown that how
12
13 bothersome people find UI is a stronger predictor of help-seeking than the severity of UI (Xu,
14
15 Wang, Li, & Wang, 2015). Still, older people who may be in frequent contact with health
16
17 care professionals often do not seek help for their UI despite the fact that it affects general
18
19 well-being, self-esteem and social functioning (Lagro-Janssen, Smits, & Van Weel, 1992;
20
21 Robinson et al., 1998; Simeonova et al., 1999) and recent research shows that women with
22
23 stress-related UI delay consultation and treatment for their condition for over a decade
24
25 (Grzybowska, Wydra, & Smutek, 2015). Despite increasing evidence that effective
26
27 management of UI is possible, older people are frequently neither assessed nor treated (Wagg,
28
29 2013), partly due to a lack of awareness of the potential for treatment among both patients and
30
31 professionals (Gibson & Wagg, 2014; Gibson et al., 2016).
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37 A UK national audit of continence care for older people, which sampled acute and
38
39 rehabilitation hospitals, found poorly integrated continence services and an inconsistent
40
41 screening for UI or adequate assessment by service providers (Wagg, Harari, Husk, Lowe, &
42
43 Lourtie, 2010). Other research has found a need for improvements in service capacity, for
44
45 example, regarding staff training and inter-service collaboration (Orrell, McKee, Dahlberg,
46
47 Gilhooly, & Parker, 2013). Importantly, the national audit did not capture the views of
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49 services users on why they sought help.
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53 Some qualitative studies have sought to explore in depth the views of older people with UI on
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55 the process of help-seeking. Findings indicate that: UI is commonly perceived to be a normal
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3 part of the ageing process (Horrocks, Somerset, Stoddart, & Peters, 2004); there is a lack of
4
5 knowledge about the condition and available treatments (Shaw, Tansey, Jackson, Hyde, &
6
7 Allan, 2001); and older people only seek help when their UI has become severe, either in
8
9 terms of bothersome symptoms or that UI is perceived as part of a life threatening disease
10
11 (Lammers, van Wijnhoven, Teunissen, Harmsen, & Lagro-Janssen, 2015; Teunissen et al.,
12
13 2005). These studies sampled older people, of which some had little or no experience of
14
15 continence services, and it is important that further work explores how contact and
16
17 involvement with such services impacts on help-seeking.
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21 The present study employed a qualitative approach to explore the views of older people with
22
23 UI on their help-seeking behaviour. Such an approach offers the greatest potential for
24
25 developing an in-depth understanding of a phenomenon which is currently poorly understood.
26
27 All participants in our study were already receiving help from continence services. Our study
28
29 also adds substantially to previous work as it considered the views of older people with UI on
30
31 the process of help-seeking in three different service settings: a geriatrician-led hospital
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33 outpatient clinic specialising in care of older people, a community-based nursed led service
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35 operating across a large UK city and a consultant gynaecologist-led service specialising in the
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37 surgical treatment of UI.
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42 **Methods**

43 *Sample and Recruitment*

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46 Participants were recruited via three continence service settings: a geriatrician-led continence
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48 service (Service A), a community based continence nurse-led service (Service B) and a
49
50 consultant gynaecologist-led service specialising in surgical treatments of UI (Service C).
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53 **People could either self-refer or be referred by their general practitioner (GP) to the**
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3 community based nurse-led service (Service B), while services led by a consultant geriatrician
4
5 (Service A) or a gynaecologist (Service C) accepted referrals from GPs and other specialists.
6
7 The only remaining type of service in the area which people with continence problems could
8
9 be referred to was a hospital urology department, but we were unable to establish access to
10
11 participants through this service.
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13

14
15 All three services were based in one geographical location, a large city in the north of
16
17 England, serving a population of just over 800 000 people (Office for National Statistics,
18
19 2016). Three different service settings were targeted to enable a maximum-variation sample
20
21 of older people attending continence services.
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24
25 The interview study was part of a larger survey study on UI. Participants were eligible for
26
27 recruitment to the survey study if they were aged over 50 years, had UI and were able to give
28
29 informed consent to participate in a study. Potential participants who fulfilled the inclusion
30
31 criteria for the larger, survey study were initially identified on presentation at the given
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33 service by the practitioner who saw them. Potential participants were then asked to speak to a
34
35 dedicated project research nurse attached to the service. As part of the process of gaining
36
37 informed consent, potential participants were asked if they would also be willing to take part
38
39 in a face-to-face interview to explore their experiences in more detail. Those participants who
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41 had indicated a willingness to be interviewed were contacted by phone by a member of the
42
43 research team (AO) and consecutively invited for interview. A total of 50 participants took
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45 part in a face-to-face interview, the point at which a preliminary consideration of interview
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47 transcripts indicated that data saturation had been reached. The refusal rate to take part in the
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49 interviews was low (approximately 10%).
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Materials and Procedure

Semi-structured interviews were conducted outside the clinical setting in locations chosen by the participants. Most interviews took place in participants' homes, although some were held on university premises.

As is standard with semi-structured interviews, the interview schedule was composed primarily of topics and issues of importance to the study, with no specifically-worded questions and flexibility regarding the order in which the topics could be addressed during the interview. An initial set of topics drawn from the study aims and objectives was adjusted and honed following a review of relevant literature. The final interview schedule consisted of four main topic areas: history of UI; process of help-seeking; management and treatment of UI; and attitudes and views about UI services. Within these areas a series of sub-topic remarks, reminders and prompts ensured that the interviews dealt with each topic in detail. All interviews were digitally recorded and transcribed verbatim. This study reports on the interview data related to the topic 'process of help-seeking'.

Information on the characteristics of participants was collected via the larger, survey study. This included standard items on gender, age, education and occupational status as well as items assessing quality of life and urinary symptoms. Quality of life was measured via the item "How would you rate your overall quality of life in the last week?" (response scale from *very poor* (1) to *excellent* (5)). Urinary symptoms over the past four weeks were measured via the following items: frequency of leaking urine (response scale from *never* (1) to *all the time* (6)); amount of urine usually leaked (response scale from *none* (1) to *a large amount* (4)); and how much leaking urine interferes with everyday life (response scale from *none at all* (0) to *a great deal* (10)).

Data analysis

Demographic data were analysed using descriptive statistics. A thematic content analysis of the interview data was conducted (Babbie, 2016). Two members of the research team (NV and AO) read the interview transcripts several times to become familiar with their content after which initial impressions of the data were discussed and notes were made to capture important features of the data. An initial framework for the analysis of the transcripts was then generated. Two researchers were involved in this process to enhance the validity and reliability of the findings and to guard against researcher bias.

The first author, who was not involved in conducting the interviews, went through an iterative process using the analysis framework to become familiar with the full content of the interview material, focusing specifically on the material that related to the topic 'process of help-seeking'. Thereafter key themes were identified. These themes were developed and refined in order to code all the relevant interview material, with sub-themes subsequently being developed. This framework was then used to explore the relationship of the key themes across the data. Each stage of the analysis was conducted by the first author. To improve inter-rater reliability for the data coding, a selection of transcripts was reviewed by another member of the team (AO) to check for bias and alternative interpretations of the data.

Ethical approval

This study was approved by Bradford Research Ethics Committee and research governance approval was obtained from each of the NHS trusts responsible for continence services included in the study.

Results

As shown in Table 1, 18 participants were recruited from Service A (mean age 70.06 years, SD=9.69), 22 participants from Service B (mean age 68.36 years, SD=7.44) and a further 10 participants from Service C (mean age 63.7 years, SD=10.07.) The majority of participants were women and White British, had low level of education and were retired. The majority of participants reported having a fair or good quality of life. Regarding UI, most of the participants reported leaking every day or at least several times a week. Furthermore, the majority of participants reported leaking a moderate amount and felt that leaking urine interfered with their daily life.

Table 1 about here

Three main themes emerged from the data: *Being brushed aside*; *Putting up with it*; and *Something has to be done*. Within the latter two themes, some sub-themes also emerged. These main themes and sub-themes are reported in Table 2, with illustrative quotes. Additional quotes are presented in the subsequent text to fully reveal the themes.

Table 2 about here

The first theme was *Being brushed aside*. Some participants had a negative experience of seeking help for their UI from their GP. Participants commonly attributed an apparent indifference of GPs to their UI, neither prioritising nor recognising the participants' concerns:

“First of all they, well I had so many other things that she [GP] had to deal with I think that was put to one side you know until I asked her two or three times you know.” [Interview 31, Female 78, Service B]

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3 Of course, some negative cases were noted where participants sought help from their GP and
4
5 were referred to continence services in response. Nevertheless, this sense of ‘being brushed
6
7 aside’ emerged quite clearly from the data.
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10 The second theme was *Putting up with it*. Within this theme, various sub-themes emerged
11
12 related to how participants lived with their continence problems but did not seek help.
13
14 Embarrassment emerged as a dominant experience, explaining why older people did not seek
15
16 help for their UI. The participant quoted below repeatedly mentioned this feeling, which
17
18 perhaps indicates the depth of the emotion experienced:
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22 “I think it were a bit, a bit embarrassing you know? You’re a bit
23
24 embarrassed....I think it’s more about the embarrassment.” [Interview 5,
25
26 Male 62, Service A]
27
28

29 A number of the participants developed coping strategies to manage their problem, such as
30
31 wearing incontinence pads. Participants also strongly expressed a belief that UI was a normal
32
33 part of ageing and this attitude influenced their decision not to access health care. The study
34
35 also identified that older people were unaware that treatment was available. This theme and
36
37 its sub-themes emerged from the data with no apparent variation related to the three settings
38
39 from which participants were recruited.
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43 The third theme identified was *Something has to be done*. Participants sought help for UI due
44
45 to experiencing a significant event, insight or process that highlighted the seriousness of their
46
47 problem. Many examples were given, but the experience of being incontinent of urine in
48
49 public emerged as a reoccurring experience, and this triggered participants to access the
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51 continence service.
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3 “I went to Kwiksave [a shop] and I said to [daughter] I want a wee...so they
4
5 asked her on the cash desk if they've got a toilet...she says we have but it's
6
7 not for anybody to go but because they explained they let me go but it were
8
9 too late, I were drowned. She [daughter] said you've got to do summat about
10
11 it and that's when I went [to the doctors].” [Interview 11, Female 70,
12
13 Service A]
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16
17 As can be understood from the above quote, being prompted by a relative to do something
18
19 about their continence problems was also a powerful motivation for participants. Another
20
21 example of this follows:
22
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24 “My grandbairn came up and she says, “You smell Grandad.”, so I thought
25
26 that’s it. So next time I went to clinic I think I asked.” [Interview 5, Male 62
27
28 years, Service A]
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30

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32 Another experience that was identified was participants perceiving the cause of their UI to be
33
34 life threatening. Participants from the consultant gynaecologist-led service specialising in
35
36 surgical treatments (Service C) also sought help when they discovered a vaginal prolapse.
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39 Finally, some participants in the geriatrician-led continence service (Service A) and the
40
41 community based continence nurse-led service (Service B) did not seek help but had their UI
42
43 identified through comprehensive geriatric assessment (CGA). For example, a participant in
44
45 Service B [Interview 29, Female aged 68] had her UI identified as part of CGA by an
46
47 occupational therapist during an assessment for falls, while a participant in Service A had his
48
49 UI identified as part of CGA by a geriatrician in clinic.
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3 “I saw the Doctor that I see all the time...she's carer of the elderly...she put
4 me straight in touch with the continence nurse who happened to be in same
5 building...” [Interview 5, Male 62, Service A]
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10 Discussion

11 *Main findings*

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16 Help-seeking behaviour often occurs after a long sequence of events and experiences related
17 to a health problem. As such, to understand help-seeking behaviours one must seek to
18 understand the chain of events that leads up to that ultimate action. Help-seeking behaviour in
19 older people with UI is influenced by factors both internal and external to the person. Several
20 factors such as embarrassment, believing continence problems to be part of getting old, and
21 ignorance of treatment options, all inhibited our participants from help-seeking. Experiencing
22 incontinence in public or perceiving symptoms as potentially life-threatening, on the contrary,
23 served as motivation to seek help, as did a prompt from a relative.
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35 There was a difference across services sampled in that some participants from geriatrician-led
36 and community based nurse-led services (Services A and B) had not sought help at all, but
37 had their UI identified through CGA. Contact with services designed for older people thus
38 helped to highlight continence problems and was an important trigger for help-seeking.
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42 However, of great concern is the key experience for our participants that during contact with
43 their GP their UI-related symptoms and concerns were brushed aside and regarded as low
44 priority.
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50 *Barriers to and facilitators of help-seeking*

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53 Our study indicates quite clearly that the experience of UI has many and various implications
54 for the quality of life of older people (Horrocks et al., 2004; Shaw et al., 2001; Teunissen et
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2
3 al., 2005). Embarrassment about disclosing UI to health care professionals was a powerful
4
5 emotion for our participants and shows that there is still a stigma attached to UI (Garcia,
6
7 Crocker, & Wyman, 2005). Embarrassment has been found to prevent people from seeking
8
9 help for UI in some, but not all, previous qualitative studies (Horrocks et al., 2004; Shaw et
10
11 al., 2001), with variation in the emotion's significance for help-seeking related to cultural
12
13 differences (Teunissen et al., 2005). However, one American survey of older people found
14
15 that only 3 percent of those with UI reported embarrassment as a reason for not discussing the
16
17 issue with their primary care provider (Dugan et al., 2001).
18
19

20
21 Other reasons for putting up with UI among the participants of our study included attributing
22
23 UI to the ageing process (cf. Dugan et al., 2001; Roin & Nord, 2015) and the development of
24
25 coping strategies in the hope that the condition will go away. This shows that there is not only
26
27 a stigma around UI, but also a lack of awareness that this condition is not part of normal
28
29 ageing and that treatment is available (cf. Teunissen & Lagro-Janssen, 2004). Some
30
31 participants perceived UI to have a life threatening cause and this triggered help-seeking
32
33 behaviour. A study of men with lower urinary tract symptoms similarly found that a common
34
35 reason for seeking help was a wish for reassurance that they did not have prostate cancer
36
37 (Lammers et al., 2015). It can be seen from these findings that prevalent stereotypes of
38
39 ageing – such that old age is a time of frailty and poor health (Kite, Stockdale, Whitley, &
40
41 Johnson, 2005) – can have a powerful influence on how people respond to health symptoms
42
43 in later life (e.g. Leventhal & Prohaska, 1986). On the one hand, attributing symptoms such
44
45 as those related to UI to ageing itself can inhibit help-seeking, as there is no 'cure for age'
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47 (McKee & Gott, 2002). On the other hand, the salient connection between ageing and health
48
49 problems means that when new illness symptoms emerge in later life, such as those related to
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3 UI, they can be taken as indicating the presence of a serious condition and lead to help-
4
5 seeking, as our findings show.
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7

8 Embarrassment and the idea that UI is an unavoidable age-related symptom has also been
9
10 found among informal caregivers, factors found to partly explain why caregivers refrain from
11
12 supporting older people with UI in seeking help (Santini, Andersson, & Lamura, 2016). In
13
14 our study, relatives were also found to have an important role in supporting participants in
15
16 seeking health care for their UI, reflecting other research that demonstrates the significance of
17
18 a support network in influencing help-seeking behaviour (Pescosolido & Boyer, 1999). Given
19
20 that UI represent an extra burden on informal carers, affects their quality of life (Santini et al.,
21
22 2016) and makes it more difficult for carers to get used to their role (Di Rosa & Lamura,
23
24 2016), it is surprising that the influence of relatives is rarely considered in research on the
25
26 help-seeking process of older people with UI.
27
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31 *Support from health professionals*

32
33 It is surely a dispiriting finding of our study that, despite seeking help from their GP, a strong
34
35 perception from our participants was that their UI symptoms and concerns were not
36
37 considered worthy of further investigation or discussion (cf. Roin & Nord, 2015). Our study
38
39 thus reflects recent work in the UK that demonstrates a continuing lack of awareness of the
40
41 potential for treatment of UI among health professionals, resulting in older people with UI
42
43 frequently being neither assessed nor treated (Gibson & Wagg, 2014; Gibson et al., 2016).
44
45 There is thus an urgent need to raise awareness within the population and within primary care
46
47 that UI is not a normal part of the ageing process and effective treatment is available. The
48
49 potential of raising awareness of the treatable nature of UI has been illustrated in previous
50
51 research, where some older people reported that they sought help following public
52
53 information on UI (Lammers et al., 2015).
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3 However, a finding from our study not been reported elsewhere suggests an important trigger
4 for help-seeking behaviour is the confirmation of continence problems from health care
5 professionals, identified using CGA. A number of our participants described how they
6 accessed continence services as a result of receiving treatment for other medical conditions.
7
8 CGA is defined as ‘a multidimensional, interdisciplinary diagnostic process to determine the
9 medical, psychological, and functional capabilities of an older person in order to develop a
10 coordinated and integrated plan for treatment and long-term follow-up’ (Rubenstein, Stuck,
11 Siu, & Wieland, 1991, p. 8S). CGA is the key assessment method used by geriatricians
12 internationally to support the holistic assessment of older people’s needs (Rubenstein et al.,
13 1991) and is considered to be a ‘gold standard of care’ for older people (Ekdahl et al., 2015).
14 CGA has been shown to improve outcomes for older people in various settings, including
15 reduced mortality or deterioration, improved cognition, improved quality of life, reduced
16 length of stay, reduced readmission rates, reduced rates of long term care use and reduced
17 costs (Beswick et al., 2008; Ekdahl et al., 2015; Ellis, Whitehead, Robinson, O'Neill, &
18 Langhorne, 2011). From the point of view of assessment and management of continence, the
19 process of CGA has the advantage that a complete functional assessment of personal and
20 instrumental activities of daily living is part of the assessment process. Assessment of
21 functional health status in this way inevitably involves the assessment of continence, and
22 toileting issues (Ellis, Marshall, & Ritchie, 2014; Quinn, McArthur, Ellis, & Stott, 2011).
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45 46 *Strengths and limitations of the study*

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48 A few previous studies have looked into the process of help-seeking in older people with UI
49 (e.g. Horrocks et al., 2004; Lammers et al., 2015; Shaw et al., 2001; Teunissen et al., 2005),
50 and have recruited patients through primary care, many of whom had not sought help for their
51 UI. By recruiting participants from three different services settings, our participants represent
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2
3 a wider group of patients with different experiences of help-seeking. In targeting older people
4 already accessing continence services this study provides a better understanding of the
5 process of help-seeking as well as the triggers to seeking help. Unfortunately, the study
6 sample contained relatively few males and a very low representation of ethnic minorities,
7 precluding any analysis from gender or cultural perspectives. **Minority perspectives on help-**
8 **seeking behaviour regarding UI are poorly represented in research, and further studies are**
9 **needed in order to obtain a deeper understanding particularly of the role of cultural**
10 **differences.**

11
12 Through having the analysis of the interview transcripts reviewed by a second member of the
13 research team, potential bias and alternative interpretations of the data were both explored,
14 indicating that our findings have good confirmability. The transferability of our findings
15 might be thought to be limited by our study's single geographical location, but the strong
16 echoes of our key findings in previous research carried out in very different locations suggest
17 that, on the contrary, our study's transferability is good (Lincoln & Guba, 1985).

18 **Conclusions**

19
20 This study explored the views of older people with UI on the process of help-seeking and
21 provides an insight into why some older people suffer in silence despite frequently being in
22 contact with health care services. Earlier research had indicated a lack of awareness in the
23 general population and among health professionals that UI is a treatable condition and not a
24 'normal part of getting old'. It is a source of considerable disappointment that our findings
25 indicate this lack of awareness persists today. Despite raising concerns about their UI
26 symptoms with their GP, many participants described their concerns as being 'brushed aside'.
27 We propose that a holistic medical review by GPs of their older patients, such as a CGA, and
28 the routine use of screening questions by all healthcare professionals who encounter older
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people could radically alter these circumstances, such that older people’s continence problems can be better identified, assessed and treated.

For Peer Review

References

- Abrams, P., Andersson, K. E., Birdler, L., Brubaker, L., Cardozo, L., Chapple, C., . . .
Members, C. (2010). Fourth International Consultation on Incontinence
Recommendations of the International Scientific Committee: Evaluation and
Treatment of Urinary Incontinence, Pelvic Organ Prolapse, and Fecal Incontinence.
Neurourology and Urodynamics, 29(1), 213-240. doi:10.1002/nau.20870
- Aguilar-Navarro, S., Navarrete-Reyes, A. P., Grados-Chavarria, B. H., Garcia-Lara, J. M. A.,
Amieva, H., & Avila-Funes, J. A. (2012). The Severity of Urinary Incontinence
Decreases Health-Related Quality of Life among Community-Dwelling Elderly.
Journals of Gerontology Series a-Biological Sciences and Medical Sciences, 67(11),
1266-1271. doi:10.1093/gerona/gls152
- Babbie, E. (2016). *The practice of social research* (14 ed.). Boston: Cengage Learning.
- Beswick, A. D., Rees, K., Dieppe, P., Ayis, S., Goberman-Hill, R., Horwood, J., & Ebrahim,
S. (2008). Complex interventions to improve physical function and maintain
independent living in elderly people: a systematic review and meta-analysis. *Lancet*,
371(9614), 725-735. doi:10.1016/s0140-6736(08)60342-6
- Di Rosa, M., & Lamura, G. (2016). The impact of incontinence management on informal
caregivers' quality of life. *Aging Clinical and Experimental Research*, 28(1), 89-97.
doi:10.1007/s40520-015-0367-7
- Dugan, E., Roberts, C. P., Cohen, S. J., Preisser, J. S., Davis, C. C., Bland, D. R., &
Albertson, E. (2001). Why older community-dwelling adults do not discuss urinary
incontinence with their primary care physicians. *Journal of the American Geriatrics
Society*, 49(4), 462-465. doi:10.1046/j.1532-5415.2001.49094.x
- Ekdahl, A. W., Sjostrand, F., Ehrenberg, A., Oredsson, S., Stavenow, L., Wisten, A., . . .
Ivanoff, S. D. (2015). Frailty and comprehensive geriatric assessment organized as

- 1
2
3 CGA-ward or CGA-consult for older adult patients in the acute care setting: A
4
5 systematic review and meta-analysis. *European Geriatric Medicine*, 6(6), 523-540.
6
7 doi:10.1016/j.eurger.2015.10.007
8
- 9
10 Ellis, G., Marshall, T., & Ritchie, C. (2014). Comprehensive geriatric assessment in the
11
12 emergency department. *Clinical Interventions in Aging*, 9, 2033-2043.
13
14 doi:10.2147/cia.s29662
15
- 16
17 Ellis, G., Whitehead, M. A., Robinson, D., O'Neill, D., & Langhorne, P. (2011).
18
19 Comprehensive geriatric assessment for older adults admitted to hospital: meta-
20
21 analysis of randomised controlled trials. *British Medical Journal*, 343.
22
23 doi:10.1136/bmj.d6553
24
- 25
26 Garcia, J. A., Crocker, J., & Wyman, J. F. (2005). Breaking the cycle of stigmatization:
27
28 Managing the stigma of incontinence in social interactions. *Journal of Wound Ostomy*
29
30 *and Continence Nursing*, 32(1), 38-52.
31
- 32
33 Gibson, W., & Wagg, A. (2014). New horizons: urinary incontinence in older people. *Age and*
34
35 *Ageing*, 43(2), 157-163. doi:10.1093/ageing/aft214
36
- 37
38 Gibson, W., Wagg, A., & Hunter, K. F. (2016). Urinary incontinence in older people. *British*
39
40 *Journal of Hospital Medicine*, 77(2), C27-C32.
41
- 42
43 Grzybowska, M. E., Wydra, D., & Smutek, J. (2015). Analysis of the usage of continence
44
45 pads and help-seeking behavior of women with stress urinary incontinence in Poland.
46
47 *Bmc Womens Health*, 15. doi:10.1186/s12905-015-0238-6
48
- 49
50 Horrocks, S., Somerset, M., Stoddart, H., & Peters, T. J. (2004). What prevents older people
51
52 from seeking treatment for urinary incontinence? A qualitative exploration of barriers
53
54 to the use of community continence services. *Family Practice*, 21(6), 689-696.
55
56
57
58
59
60

- 1
2
3 Hunskar, S., Burgio, K., Clark, A., Lapitan, M. C., Nelson, R., Sillen, U., & Thom, D.
4
5 (2005). *Epidemiology of urinary (UI) and faecal (FI) incontinence and pelvic organ*
6
7 *prolapse (POP)*.
8
- 9
10 Irwin, D. E., Kopp, Z. S., Agatep, B., Milsom, I., & Abrams, P. (2011). Worldwide
11
12 prevalence estimates of lower urinary tract symptoms, overactive bladder, urinary
13
14 incontinence and bladder outlet obstruction. *Bju International*, *108*(7), 1132-1138.
15
16 doi:10.1111/j.1464-410X.2010.09993.x
17
- 18
19 Irwin, D. E., Milsom, I., Kopp, Z., Abrams, P., & Grp, E. S. (2008). Symptom bother and
20
21 health care-seeking behavior among individuals with overactive bladder. *European*
22
23 *Urology*, *53*(5), 1029-1039. doi:10.1016/j.eururo.2008.01.027
24
- 25 John, G., Bardini, C., Combescure, C., & Dallenbach, P. (2016). Urinary Incontinence as a
26
27 Predictor of Death: A Systematic Review and Meta-Analysis. *Plos One*, *11*(7).
28
29 doi:10.1371/journal.pone.0158992
30
- 31
32 Kite, M. E., Stockdale, G. D., Whitley, B. E., & Johnson, B. T. (2005). Attitudes toward
33
34 younger and older adults: An updated meta-analytic review. *Journal of Social Issues*,
35
36 *61*(2), 241-266. doi:10.1111/j.1540-4560.2005.00404.x
37
- 38
39 Lagro-Janssen, T., Smits, A., & Van Weel, C. (1992). Urinary incontinence in women and
40
41 the effects on their lives. *Scandinavian Journal of Primary Health Care*, *10*(3), 211-
42
43 216. doi:10.3109/02813439209014063
44
- 45
46 Lammers, H. A., van Wijnhoven, R., Teunissen, T. A. M., Harmsen, S., & Lagro-Janssen, A.
47
48 L. M. (2015). Why do men suffering from LUTS seek primary medical care? A
49
50 qualitative study. *Journal of Evaluation in Clinical Practice*, *21*(5), 931-936.
51
52 doi:10.1111/jep.12407
53
- 54
55 Leventhal, E. A., & Prohaska, T. R. (1986). Age, symptom interpretation, and health
56
57 behavior. *Journal of the American Geriatrics Society*, *34*(3), 185-191.
58
59
60

- 1
2
3 Li, Y., Cai, X., Glance, L. G., & Mukamel, D. B. (2007). Gender differences in Healthcare-
4 Seeking Behavior for urinary incontinence and the impact of socioeconomic status - A
5 study of the medicare managed care population. *Medical Care*, 45(11), 1116-1122.
6
7
8
9
10 Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, California: SAGE.
11
12 McKee, K. J., & Gott, M. (2002). Shame and the ageing body. In P. Gilbert & J. Miles (Eds.),
13 *Body shame: Conceptualisation, research and treatment* (pp. 75-89). London:
14 Routledge.
15
16
17
18 Office for National Statistics. (2016). Population Estimates for UK, England and Wales,
19 Scotland and Northern Ireland. Retrieved 25th August 2016
20 [https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/pop](https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalescotlandandnorthernireland)
21 [ulationestimates/datasets/populationestimatesforukenglandandwalescotlandandnorthe](https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalescotlandandnorthernireland)
22 [rnireland](https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalescotlandandnorthernireland)
23
24
25
26
27
28
29 Orrell, A., McKee, K. J., Dahlberg, L., Gilhooly, M., & Parker, S. (2013). Improving
30 continence services for older people from the service-providers' perspective: a
31 qualitative interview study. *BMJ Open*, 2013;3:e002926. doi:10.1136/bmjopen-
32 2013-002926.
33
34
35
36
37
38 Pescosolido, B. A., & Boyer, C. A. (1999). How do people come to Use mental health
39 services? Current knowledge and changing perspectives. In A. V. Horwitz & T. L.
40 Scheid (Eds.), *A handbook for the study of mental health: Social contexts, theories and*
41 *systems* (pp. 392-411). New York: Cambridge University Press.
42
43
44
45
46
47 Peters, T. J., Horrocks, S., Stoddart, H., & Somerset, M. (2004). Factors associated with
48 variations in older people's use of community-based continence services. *Health &*
49 *Social Care in the Community*, 12(1), 53-62. doi:10.1111/j.1365-2524.2004.00468.x
50
51
52
53
54 Quinn, T. J., McArthur, K., Ellis, G., & Stott, D. J. (2011). Functional assessment in older
55 people. *British Medical Journal*, 343. doi:10.1136/bmj.d4681
56
57
58
59
60

- 1
2
3 Robinson, D., Pearce, K. F., Preisser, J. S., Dugan, E., Suggs, P. K., & Cohen, S. J. (1998).
4
5 Relationship between patient reports of urinary incontinence symptoms and quality of
6
7 life measures. *Obstetrics and Gynecology*, *91*(2), 224-228. doi:10.1016/s0029-
8
9 7844(97)00627-3
10
- 11 Roin, A., & Nord, C. (2015). Urine incontinence in women aged sixty to sixty-five:
12
13 negotiating meaning and responsibility. *Scandinavian Journal of Caring Sciences*,
14
15 *29*(4), 625-632. doi:10.1111/scs.12190
16
17
- 18 Rubenstein, L. Z., Stuck, A. E., Siu, A. L., & Wieland, D. (1991). Impacts of geriatric
19
20 evaluation and management programs on defined outcomes: Overview of the
21
22 evidence. *Journal of the American Geriatrics Society*, *39*(9 PART 2), 8S-16S.
23
24
- 25 Santini, S., Andersson, G., & Lamura, G. (2016). Impact of incontinence on the quality of life
26
27 of caregivers of older persons with incontinence: A qualitative study in four European
28
29 countries. *Archives of Gerontology and Geriatrics*, *63*, 92-101.
30
31 doi:10.1016/j.archger.2015.10.013
32
33
- 34 Shaw, C., Das Gupta, R., Williams, K. S., Assassa, R. P., & McGrother, C. (2006). A survey
35
36 of help-seeking and treatment provision in women with stress urinary incontinence.
37
38 *Bju International*, *97*(4), 752-757. doi:10.1111/j.1464-410X.2006.06071.x
39
40
- 41 Shaw, C., Tansey, R., Jackson, C., Hyde, C., & Allan, R. (2001). Barriers to help seeking in
42
43 people with urinary symptoms. *Family Practice*, *18*(1), 48-52.
44
45 doi:10.1093/fampra/18.1.48
46
47
- 48 Simeonova, Z., Milsom, I., Kullendorff, A. M., Molander, U., & Bengtsson, C. (1999). The
49
50 prevalence of urinary incontinence and its influence on the quality of life in women
51
52 from an urban Swedish population. *Acta Obstetricia Et Gynecologica Scandinavica*,
53
54 *78*(6), 546-551. doi:10.1034/j.1600-0412.1999.780613.x
55
56
57
58
59
60

- 1
2
3 Teunissen, D., & Lagro-Janssen, T. (2004). Urinary incontinence in community dwelling
4
5 elderly: are there sex differences in help-seeking behaviour? *Scandinavian Journal of*
6
7 *Primary Health Care*, 22(4), 209-216. doi:10.1080/02813430410006666
8
9
10 Teunissen, D., van Weel, C., & Lagro-Janssen, T. (2005). Urinary incontinence in older
11
12 people living in the community: examining help-seeker behaviour. *British Journal of*
13
14 *General Practice*, 55(519), 776-782.
15
16 Wagg, A. (2013). Urinary incontinence in older people: An overview. *Medicine*, 41(1), 20-23.
17
18 doi:10.1016/j.mpmed.2012.10.015
19
20
21 Wagg, A., Harari, D., Husk, J., Lowe, D., & Lourtie, J. (2010). *National audit for continence*
22
23 *care*. London: Healthcare Quality and Improvement Partnership & Royal College of
24
25 Physicians.
26
27
28 Xu, D. J., Wang, X. J., Li, J. J., & Wang, K. F. (2015). The mediating effect of 'bothersome'
29
30 urinary incontinence on help-seeking intentions among community-dwelling women.
31
32 *Journal of Advanced Nursing*, 71(2), 315-325. doi:10.1111/jan.12514
33
34
35
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Table 1. Participant characteristics

	Service A (<i>n</i> =18)	Service B (<i>n</i> =22)	Service C (<i>n</i> =10)
Gender, <i>n</i>			
Female	16	17	10
Male	2	5	0
Mean age (SD)	70.06 (9.69)	68.36 (7.44)	63.70 (10.07)
Ethnicity, <i>n</i>			
White British	18	22	9
White Asian	0	0	1
Highest level of formal education, <i>n</i> (%)*			
Left full time education at or < age 16	11 (78.6)	15 (68.2)	7 (77.8)
Left full time education at or < age 18	2 (14.3)	0 (0.0)	0 (0.0)
College diploma	1 (7.1)	4 (18.2)	1 (11.1)
University degree	0 (0.0)	3 (13.6)	1 (11.1)
Occupational status, <i>n</i> (%)			
Employed full time	0 (0.0)	1 (4.8)	0 (0.0)
Employed part time	0 (0.0)	2 (9.5)	2 (25.0)
Retired	14 (93.6)	17 (81.0)	5 (62.5)
Unemployed	1 (6.7)	1 (4.8)	1 (12.5)
Full or part time study	0 (0.0)	0 (0.0)	0 (0.0)

Table 1. Participant characteristics (continued)

	Service A (<i>n</i> =18)	Service B (<i>n</i> =22)	Service C (<i>n</i> =10)
Quality of life in last four weeks, <i>n</i> (%)			
Very poor	0 (0.0)	0 (0.0)	1 (11.1)
Poor	1 (6.7)	3 (14.3)	1 (11.1)
Fair	9 (60.0)	10 (47.6)	6 (66.7)
Good	4 (26.7)	7 (33.3)	0 (0.0)
Excellent	1 (6.7)	1 (4.8)	1 (11.1)
Frequency of leaking urine over past four weeks, <i>n</i> (%)			
Never	0 (0.0)	0 (0.0)	2 (22.2)
About once a week or less often	2 (13.3)	4 (18.2)	0 (0.0)
Two or three times a week	3 (20.0)	1 (4.5)	1 (11.1)
About once a week	3 (20.0)	1 (4.5)	1 (11.1)
Several times a day	6 (40.0)	14 (63.6)	5 (55.6)
All the time	1 (6.7)	2 (9.1)	0 (0.0)
Amount of urine leaked over past four weeks, <i>n</i> (%)			
None	0 (0.0)	1 (4.5)	2 (22.2)
A small amount	5 (33.3)	7 (31.8)	3 (33.3)
A moderate amount	9 (60.0)	12 (54.5)	2 (22.2)
A large amount	1 (6.7)	2 (9.1)	2 (22.2)
How much leaking urine interferes with everyday life, Median (IQR =1-3)**	6.0 (3.0-8.0)	6.5 (3.8-7.3)	7.0 (1.5-8.5)
*Numbers may not add up to <i>n</i> due to missing data.			
**Scored on a scale of 0 to 10, where 0 = not at all and 10 = a great deal.			

Table 2. Main themes and illustrative quotes

Main themes	Sub-themes	Illustrative quotes
1. Being brushed aside		“I felt that he [GP] didn’t really want to know, you know just do your pelvic floor exercises and that was it. He didn’t say anything else and I just felt utterly defeated.” [Interview 44, Female 52, Service B]
2. Putting up with it	2.1 Embarrassment and shame	“It was embarrassment so I thought I’d put up with it quite a long time before I went to see the doctor.” [Interview 10, Female 58, Service B]
	2.2 Keeping on top of it	“I tried to sort it out myself...I was in denial erm going from thick pads to Tena pants, the thicker ones, thinking that maybe it was a temporary thing and I’d be able to sort it out” [Interview 37, Female 59, Service A]
	2.3 I’m just getting old	“I just felt it was normal every day, an age thing you know, something that I’d got to tolerate and put up with.” [Interview 22, Female 61, Service B]
	2.4 Nothing they can do.	“I’ve never sought medical advice.... I didn’t know they could do anything.” [Interview 3, Female 77, Service A]

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Table 2. Main themes and illustrative quotes (continued)

Main themes	Sub-themes	Illustrative quotes
3. Something has to be done	3.1 Everyone knows	“I’ve been in Morrisons in [...] and I’ve sneezed or something and I was wet right down It actually ran into my shoes.... and that made me decide God you’ve got to do something about this.” [Interview 43, Female 66, Service C]
	3.2 Make me go	“I had a word with my mother, she said you’ll have to have summat done about that...go to hospital and summat done.” [Interview 7, Female 88, Service A]
	3.3 This is serious	“I thought I’m going to have to ask for help...as I thought I’d got some sort of cancer.” [Interview 10, Female 58, Service B]
	3.4 Are you having any problems?	“I didn’t actually put myself forward....they sent me an appointment (clinic for the elderly) and I just went to see him.... he asked me different things and well he was asking me if I had any trouble with incontinence.” [Interview 3, Female 77, Service A]