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Exploring support, experiences and needs of older women and health professionals to inform a self-management package for urinary incontinence: a qualitative study

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ABSTRACT

Objectives Many women attempt to manage urinary incontinence (UI) independently with variable success while health professionals may be unaware of their needs. This study aimed to (1) understand older women's experiences of UI, their self-management strategies and support needs; (2) explore health professionals' experiences of supporting women and providing relevant services and (3) combine their experiences contribute to development of a theory-based and evidence-based self-management package for UI.

Design Qualitative semi-structured interviews were conducted with 11 older women with UI and 11 specialist health professionals. Data were analysed independently using the framework approach, then synthesised in a triangulation matrix to identify implications for content and delivery of the self-management package.

Setting Community centres, community continence clinic and urogynaecology centre of a local teaching hospital in northern England.

Participants Women aged 55 years and over who self-reported symptoms of UI and health professionals delivering UI services.

Results Three overarching themes emerged. Older women see UI as a 'fact of life' but many struggle with it: women typically considered UI as part of ageing yet expressed annoyance, distress, embarrassment and had made significant lifestyle changes. Access to information and limited high-quality professional support: health professionals provided specialist UI care and information. Yet less than half of women accessed specialist services, those who had, highly valued these services. 'Trial and error' with different self-management strategies: women had tried or were using different strategies (continence pads, pelvic floor exercises, bladder management and training, fluid management and medication), with mixed success. Health professionals provided evidence-based, personalised support and motivation.

Conclusions Findings informed the content of the self-management package that focused on providing facts, acknowledging challenges of living with/self-managing UI, sharing others' experiences, using motivational strategies and self-management tools. Delivery preferences were independent use by women or working through the package with a health professional.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ In-depth exploration of both women's and health professionals' experiences of UI, support and self-management facilitated triangulation of perspectives.

⇒ Employing a 'target population-centred' approach to intervention development driven by the views and preferences of the people the intervention serves is more likely to be acceptable and effective.

⇒ Women participants all spoke English, their views and experiences and the resultant self-management tool might not represent those who do not speak English.

INTRODUCTION

Urinary incontinence (UI), 'the complaint of involuntary loss of urine', places physical, psychosocial and economic burdens on individuals and their families.[1,2] In the UK, over 14 million people are affected by bladder control problems.[3] The prevalence is estimated as up to 40% for women over 21 years and increases with age.[4] Women with UI can experience feelings of isolation and embarrassment, making it an underreported and undertreated condition. Only a quarter of affected women seek medical help, of which, less than half receive treatment.[5] There are associations between untreated UI and generally poor quality of life, falls and fractures, and anxiety and depression, leading to increased morbidity and healthcare costs.[6–8]

Despite clinical guidance on the treatment and management of UI from international and specialty organisations,[9–11] UI remains poorly prioritised in routine healthcare practice.[12] Associated stigma, perceiving UI as inevitable, poor awareness by health professionals and low expectations of treatments may render older women silent on the topic.

Many women affected try to cope on their own with variable success.[13–17]

Self-management has been recommended for women with UI,[18] to help quality of life and increase confidence.[16 17] This refers to actions taken by individuals to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a condition.[19] However, there are gaps between women's experiences of managing UI and support provided by health professionals for self-management. Evidence suggests that women do not have sufficient knowledge or understanding of self-management principles and poor access to services,[20] while health professionals are unaware of the needs of older women and how to best support them.[18] The COVID-19 pandemic in 2020/2021 likely exacerbated these challenges by creating difficulties attending appointments in person and closure of some support services.

Our project set out to develop and evaluate a theory-informed, tailored self-management package for older women living with UI, guided by the Medical Research Council (MRC) framework for developing and evaluating complex health interventions.[21] Our systematic review[22] and feasibility trial of the package have been published.[23] We present here a qualitative study, which was carried out in parallel with the systematic review[22] during the intervention development phase. We employed a 'target population-centred' approach[24] to our intervention development whereby the intervention is based on the perspectives of the people who will use it, namely, women with UI and relevant health professionals.

Aim

The study aims were to (1) understand older women's experiences of living with UI, their self-management strategies and support needs; (2) explore health professionals' experiences of supporting women and providing services to manage UI and (3) use this combined insight to contribute to the development of a theory-base and evidence-based self-management package.

METHODS

Design

A qualitative study using semi-structured face-to-face interviews, guided by the standards for reporting qualitative research checklist.

Patient and public involvement

An advisory group was set up prior to commencing the project. Three older women with UI and one specialist nurse working in a local continence clinic formed the group. Bi-annual meetings and regular phone/email contact led by YF ensured their ongoing input into all stages of the project: reviewing sampling and recruitment strategies, interview topic guides, preliminary research findings and developing dissemination strategies. The initial draft of the self-management package (informed by the systematic review,[22] qualitative interviews and a consensus process) was co-developed with the group through frequent face-to-face meetings and phone/email discussions.

Setting and participants

The study setting was a northern UK city. We aimed to interview 10–15 women aged 55 years and over, who self-reported symptoms of UI and could communicate in English, and 8–10 health professionals delivering UI services. Exclusion criteria for the women were cognitive impaired or UI caused by neurological disease.

To recruit women, flyers were posted in the community centre of a local forum for older people. To recruit health professionals, study information was circulated by the clinical leads of a community continence clinic and urogynaecology centre of a local teaching hospital. Consecutive sampling was used for women, and maximum variation sampling was used to ensure a mix of health professions.

Women and health professionals interested in taking part either telephoned or emailed the lead researcher (YF), who then arranged a time and place for the interview.

Data collection

Face-to-face interviews were conducted in women's homes and at health professionals' workplace. Two researchers (YF and Jill Edwards) experienced in qualitative methods and health services research collected the data. Written informed consent was collected before each interview.

Interviews with women explored their specific condition and symptoms, methods and skills they use to manage their UI, experiences of coping with UI and expectations of effective self-management and desired support. Health professional interviews discussed common problems relating to UI, skills they use to support patients' self-management, their experiences of supporting patients and expectations of delivering effective self-management. Topics were informed by the findings of the systematic review[22] with advisory group input. They were expected to elicit important detail for sections of the self-management package. Interview guides ensured consistency, although the format was flexible to enable participants to generate naturalistic data on what they viewed as important. Both guides (see online supplemental files 1 and 2) were piloted, and adaptations made to improve clarity. Women's interviews lasted between 28 min and 95 min and health professionals' between 14 min and 75 min.

Data analysis

Interviews were audio-recorded and transcribed verbatim, and data were analysed using framework analysis,[25] facilitated by Microsoft Excel V.2010. Analysis was led by CJ with input from other researchers (YF, LM and AN) to ensure rigour.

Interviews from the two participant groups were first analysed independently. A thematic framework for each group was developed based on the topic guide and emergent themes from subsamples of transcripts (three women and two health professionals), then piloted with another transcript per group, before finalising. The frameworks were then applied to the interview data. Summaries of participant responses and verbatim quotes were entered. Charted data were then reviewed and interrogated to compare and contrast views, seek patterns, connections and explanations within the data; and descriptive findings were produced for both data sets. These were reviewed and refined through full team discussion, with agreement on three overarching themes. Finally, a matrix[26] was used to triangulate the key findings for each theme and their implications for the content of the self-management package. This was presented to the advisory group for their input.

RESULT

Eleven women and 11 health professionals were interviewed, after which data saturation was achieved for both groups with no new perspectives emerging.

Women aged 56–87 years (mean: 78.7 years) had experienced UI mean of 13.5 years. Most were white British, suffered stress or urge UI, were retired and had coexisting medical conditions. Over half lived alone; two were living in residential/sheltered accommodations (table 1).

Four health professionals (table 2) worked within community continence clinics and seven worked in a urogynaecology centre. All had completed specific UI training.

Three over-arching themes emerged: (1) older women see UI as challenging and a 'fact of life', (2) access to information and limited high-quality professional support and (3) 'trial and error' with different self-management strategies.

The third theme is most extensive given our focus on developing the self-management package. We present only women's accounts for theme 1, and both women's and health professionals' views on the other two themes. If only women or health professionals spoke of a specific issue, this is evident because only those data are included.

Theme 1. Older women see UI as challenging and a 'fact of life'

The women had lived with UI from 12 months to 50 years and a third for over 25 years. Symptoms had worsened for those with a lengthy experience of UI. From their accounts, it was evident that most had urge UI, a small minority had stress UI, while a few had mixed UI. Urge UI was depicted as desperately needing the toilet, often without warning. While women with stress UI, spoke of having 'an accident' after they sneeze, cough, laugh or do anything 'jerky'. Both types were unpredictable, could result in 'an accident' and happen several times a day. Furthermore, most women were waking to urinate one to three times most nights. Again this had increased in frequency over time and could result in 'an accident'.

Table 1 Women participant characteristics (n=11)

Characteristic	N	%
Age (mean (SD), range) (years)	78.7 (10.6), 56–87	
Duration of UI (mean (SD), range) (years)	13.5 (15.0), 2–50	
Ethnicity		
White British	10	91
Mixed white and black Caribbean	1	10
Education		
University degree	5	45
Further (A level or equivalent)	1	9
Secondary (GCSE or equivalent)	4	36
Primary degree	1	9
Employment		
Full-time	1	10
Retired	10	91
Living arrangements		
Lives alone	6	55
Lives with husband	2	18
Lives in sheltered accommodation	2	18
No response	1	10
Receiving treatment for UI		
Yes	5	45
No	6	55
Other health conditions		
Yes	10	91
No	1	10

Percentages are rounded up so may exceed 100%.
GCSE, General Certificate of Secondary Education; UI, urinary incontinence.

Many women attributed UI to ageing, seeing it as 'a fact of life' (quote 1, table 3). Other suggested causes were health issues, for example, a throat issue that prompted coughing or medication such as taking water tablets for swollen legs. Less common attributions were having children, hormones while approaching menopause or bladder issues. Two women believed historical toilet habits were a potential cause (quote 2, table 3).

There were two contrasting views on living with UI. Most women were outwardly bothered by their UI, describing it as annoying, embarrassing, upsetting and inconvenient (quote 3, table 3). They made significant changes to their lives often giving up enjoyable activities such as going for walks, exercise classes, theatre or concerts, or modifying activities: shortening their walks, not having a drink or having a single room on holiday instead of sharing with a friend. Related to this was the significant worry about finding public toilets in time (quote 4, table 3).

A minority spoke of seeing their UI as 'part of life' (P6, stress UI) typically attributing this to being lucky and determined. They tended to say that they were not

Table 2 Health professional participant characteristics (n=11)

Characteristic	N	%
Years of working in UI service (mean (SD), range)	11.2 (8.8), 0.5–26	
Professional band		
Band 4	1	9
Band 5	2	18
Band 6	1	9
Band 7	3	27
Band 8	1	9
Medical consultant	3	27
Employment		
Part-time	9	82
Full-time	2	18
Training in UI		
Yes	11	100
No	0	0

Percentages are rounded up so may exceed 100%.
UI, urinary incontinence.

worried, had learnt to live with it and did not dwell on it too much (quote 5, table 3). Often this was because they had other issues or health conditions, for example, bereavement, a neurological condition or skin infection, that concerned them more.

There were also mixed accounts of discussing UI with others. A third of women spoke to friends and family, but not in any detail. The people they spoke to were often someone they knew who also had UI or who was seen as knowledgeable about UI, for example, a friend's daughter who was a gynaecologist. Another third of women kept it private. Indeed, two women had not discussed UI with their husbands. UI was seen as 'not a pleasant topic', 'embarrassing' and a 'British thing' not to talk about bodily functions (quote 6, table 3). Furthermore, talking about it 'doesn't make it go away' (P6, stress UI).

Finally women were typically modest in their aspirations for the UI, commenting that it was unlikely they would be cured. Instead they hoped to have better control and not to have to think or worry about having an accident on a daily basis and to find a way to live with it (quotes 7 and 8, table 3).

Theme 2. Access to information and limited high-quality professional support

Women did not appear to have sought or received much written information about UI. Comments included not knowing where to look, receiving no or limited information from their general practitioner (GP) and limited helpful advice on the internet (quote 9, table 3). Conversely health professionals working in the continence clinic and urogynaecology department alike reported providing a range of leaflets produced in-house, by local UI support groups, the NHS and British Society of Urogynaecology.

Few women had accessed professional support, with only half having consulted their GP, typically when symptoms started or worsened. Reasons included: feeling embarrassed, 'it is not life threatening' (P8, stress UI), not wanting to bother the GP, they were managing it OK and would see the GP if it got worse, perceiving there was insufficient time in an appointment to fully discuss the issues, and assuming the GP could not help (quote 10, table 3).

Those who had seen their GP reported that the doctor had provided leaflets, recommended pelvic floor exercises, pads, prescribed medication and signposted to specialist services. There was a clear desire among women to access someone who could spend time discussing their condition in detail (quote 11, table 3).

Even fewer women had attended specialist services, either at the continence clinic or urogynaecology department where time to talk was available. Indeed, several health professionals observed that older women often assumed that these services were not available to them because of their age, seeing their UI as 'normal' and nothing could be done (quote 1, table 4).

Health professionals described multiple referral pathways to the continence clinic, most commonly via GPs, but also social workers, neighbourhood teams and other specialist services such as podiatry, memory and psychological (quote 2, table 4). People could also self-refer, which a healthcare assistant saw as an important option for those who reluctantly seek help from anyone (quote 3, table 4). Referrals to the urogynaecology department were from GPs or the continence clinic. Both services offered a detailed assessment, used to inform appropriate treatment typically including a self-management plan.

Women's assessment of this specialist support from both these services was very positive. The nurses at the clinics were unanimously favourably reviewed and seen as well placed to have the time and expertise to support people as 'they've heard so many people's stories' (P6, stress UI). Indeed, a medical consultant and nurse specialist both recognised the value of providing an opportunity for women to talk about their UI (quote 4, table 4).

Theme 3. 'Trial and error' with different self-management strategies

Women described using a mix of self-management strategies, with varying degrees of adherence and success. Relatedly, the consensus among health professionals was that UI self-management is challenging, and while some women are receptive and motivated to make lifestyle changes, others are not commonly linked to the misperception that nothing can be done as UI is 'normal' at their age. The professionals were using multiple strategies to motivate women: managing expectations, jointly setting realistic goals, encouraging them to take ownership, monitoring progress, providing feedback on small improvements and sharing success stories (quote 5,

Table 3 Illustrative quotes for women

No.	Quote and participant ID
1	‘It’s a bit to do with, especially as you get older. I assume that quite a few people have it really. Also, when you’re getting older there are all sorts of things, some people are losing their hair and things. I mean, which topic do you want to talk about? Or is it your knee or have you got a bunion. Sometimes you feel like an old car that the parts are dropping off.’ (P6, stress UI)
2	‘I do think it goes back to my childhood because I went to a very strict convent school where you weren't allowed to go to the toilet. So you got into the habit of holding yourself. My own theory is that that started the problem.’ (P8, stress UI)
3	‘It does make your life a misery. I feel like I could get a knife and cut it out, and finish with it, ‘cause it’s so distressing. I’m angry all the time really. I mean, I know it doesn’t do me any good, but I think, oh God, I’ve not got to go through this, I don’t want to wee again do I? And you’ve got to go.’ (P9, stress UI)
4	‘I’m usually looking around to see where there is one [public toilet]. And if I can see a disabled one, I’m in straightaway, because I do have problems with ordinary toilets being a bit low, you see? But if I can’t [find one], I’ll just take any toilet, as long as there’s a toilet.’ (P2, stress UI).
5	‘I don’t allow anything to upset me too much. I never have done. And I’ve had some very difficult times. And I believe in being positive, and there are people worse off. It doesn’t absorb every minute of the day. It’s not a worry, it’s a minor inconvenience. It’s an annoyance not a tragedy.’ (P13, urge UI)
6	‘Because it’s not the sort of thing, you say, oh by the way, I’m incontinent at times, and I quite often wet my pants.’ (P2, stress UI)
7	‘Control it, or even get rid of it, that would be brilliant would that … yeah, that, I would really love, I’m not holding my breath though.’ (P1, stress UI)
8	‘I suppose so I didn't have to consciously think about it. I was thinking when I'm with my grandsons, because it involves a lot of picking up. There’s always a bit of a worry.’ (P8, stress UI)
9	‘I never thought about trying to research online, I don’t know why, but I never did. But, apart from that, I wouldn’t even know where to turn. I don’t even know if there is any information out there.’ (P10, urge UI)
10	‘You think, if I go to my doctor I would be able to talk, but the doctor has only got 15 min, or even less than that. And everyone’s condition is so … If I can cope I cope. If I’m going to the doctors, I really am bad.’ (P2, stress UI)
11	‘I'd welcome more support, but I can't think that I could get any…some practical skills, something to support the pelvic floor. Somebody who has time to listen and perhaps give you the answer to whatever is the problem. But that is a problem finding somebody who has the time.’ (P7, urge UI)
12	‘I'm very sensitive about that [the smell] and I'm very quick to smell it on other people. It’s quite a powerful sort of smell, it’s not easy to disguise it. I try and not be in close proximity to people.’ (P8, stress UI)
13	‘That’s why I prefer to use a facecloth or a flannel or a scrunched-up hanky, because I can just wash it along with the towels and I find it … I consider it’s more economical.’ (P13, stress UI)
14	‘They didn’t make a scrap of difference.’ (P13, stress UI)
15	‘When I go to my exercise classes and everything, I'm the only one that has to go to the loo before I go home, for instance. And it’s really because I know that I won't make it home without going.’ (P3, urge UI)
16	‘And then as I say, at night, I try to go as many times as I can before I go to bed. And then I'm usually alright until the very early hours. Well, not very early hours, late hours, quarter past five, quarter past six, that time.’ (P4, urge UI)
17	‘And restricting my fluids if I'm going somewhere that I know I can't have access to a loo easily, which, you know, I don't like doing but it has to be, because otherwise I'll have an accident.’ (P3, urge UI)
18	‘And they tried me out on some tablets. But they didn’t do anything, anyway. So I thought, pft! Just leave it.’ (P12, urge UI)
19	‘Yes, I take it again, as and when, if I know I’m going to be, well, I think I’m going to be stuck for several hours without access to a toilet, then I will take a couple of pills beforehand.’ (P10, urge UI)

UI, urinary incontinence.

table 4). A good relationship with women was seen as critical to success. The continence clinic team tried to provide continuity and ensure that women saw the same professional each time. Two nurses who had UI themselves shared this to demonstrate that they knew how it felt (quote 6, table 4).

Using continence pads

Continence pads were the most common self-management tool. One continence clinic nurse, estimated that this accounted for 90% of her work, while another commented that 80% of clinic patients were using pads. All but one of the women were using pads, with varied motives. Some wore a pad ‘just to be on the safe side’ (P1, stress UI),

Table 4 Illustrative quotes for health professionals

No.	Quote and participant ID
1	'Some of the older ladies have put up with the symptoms for a lot longer and not wanted to…they've found it embarrassing or they've thought it's just something that you had to put up with age.' (HP8, clinical nurse specialist, urogynaecology department)
2	'We can accept, basically, any referral.' (HP2, nurse, continence clinic)
3	'It is an embarrassing situation, and a lot of people don't want to go to another person and have to admit to it, and then ask them to refer. So we do fiercely defend our self-referral policy. There's very few services where you can self-refer, but continence is one.' (HP3, healthcare assistant, continence clinic)
4	'But they do feel that they get a lot off their chest when they come and speak to us. And, you know, they are always pleased to hear that they're not the only ones who suffer with it and it's not unusual. Some of the appointments are like a counselling kind of appointment where they're so upset and fed up.' (HP8, nurse specialist, urogynaecology department)
5	'I think that you are passionate about what you're doing and you're willing to work with them to a common goal, which I can identify is the problem, and if you do x, y and z on my advice, we can aim to achieve, and if we're struggling there's always somewhere else I can go. And you find that because it is such a personal thing, then they're quite relieved and they will join you on the journey, I don't find many people who haven't done what I've asked.' (HP1, nurse, continence clinic)
6	'I'll tell my patients, yeah, I've been incontinent, I know what it feels like. Because then, it will alter the dynamics quite often. You choose your patient, you know, not with all of them. But with some of them where I think that's going to give me what I need, so that I can work with them, then yeah, I'll tell them.' (HP3, healthcare assistant, continence clinic)
7	'I mean we know that 40 per cent of women have got incorrect pelvic floor technique. So, that's quite a lot of women that are doing pelvic floor exercises wrong.' (HP5, physiotherapist, urogynaecology department)
8	'Some of them, they don't want to stop drinking a caffeinated tea because they've drunk that all their life and they don't want to change their habits.' (HP5, physiotherapist, urogynaecology department)

usually when going out or at night. For others, the pad was more of a necessity to 'stop the embarrassment of wetting my knickers' (P2, stress UI).

Overall pads were perceived as effective although several women mentioned discomfort due to skin soreness, pad movement and being bulky and rough. This prompted some to restrict their use or, deliberately wear 'tight pants', tights or trousers to prevent pads movement. A common concern was embarrassment associated with the pads smelling, being visible and not having anywhere to immediately change and dispose of a soiled pad when away from home (quote 12, table 3).

The continence clinic team perceived that some women used pads because they were an easier option than other self-management strategies. While pads were available from the clinic for as long as the women needed them, there was a clear view that pads would not be given to people who only attend to access free pads or 'who just cannot be bothered to do self-management' (HP3, advisor, continence clinic). Indeed, only two women accessed pads free of charge, at the clinic. The rest bought them, often recommended by their GP or on TV adverts. Half did not see cost as an issue, because money was not a concern, they did not need to buy many or they perceived them to be cheap. However, three women were affected by the cost, seeing them as 'quite expensive' (P3, urge UI), particularly if buying them on a regular basis or when needing the larger, specialist ones. Strategies to save cost were putting toilet paper on top of the pad or using a scrunched-up hanky (quote 13, table 3).

Understanding the correct type/size of pad to use as well as how to wear it was seen as important by a physiotherapist and consultant. Two women concurred that it would be useful to have this information, explained clearly, and in large writing on packaging.

Pelvic floor exercises

No women were currently doing pelvic floor exercises on a regular basis, although some had previously performed them when their stress UI had first started or during worsening symptoms. Multiple barriers to performing these exercises were reported, often linked to a lack of understanding; for example, uncertainty about technique, perceived lack of muscle strength or finding the exercises too tiring. Other barriers were forgetting and not having time. Women reported variable success and effectiveness of the exercises, further affecting motivation (quote 14, table 3).

These reasons were all familiar to health professionals (quote 7, table 4). All were teaching pelvic floor exercises to women with stress UI, believing them to be effective for most women when performed correctly over time. However, they recognised the challenge of staying motivated when improvement might take 3 months.

Bladder management and training

Two-thirds of women were using their own strategies to manage their bladder and UI, including going to the toilet before leaving home, before going into meetings/concerts and going as many times as possible in the evening to try to stay dry (quotes 15 and 16, table 3).

Other approaches were to only go when your bladder feels full or to go every 2 hours 'like they do with patients in care homes' (P6. stress UI).

Several health professionals were advising women with urge UI to train their bladder (ie, allow it to fill up before going to the toilet) and to complete a fluid chart. The physiotherapist described following the guideline of 6 weeks of bladder retraining prior to considering using medication. The healthcare assistant explained high variability regarding success dependant on how long women has had a particular habit. She considered a reduction in the number of times someone goes, from 12 to 11 times a day, as important progress.

Managing fluid intake

Two-thirds of women had changed their drinking habits to try to manage their UI. Strategies mentioned were drinking less or no caffeine, particularly coffee, drinking less or nothing after 18:00 and not drinking before going out to a new place (quote 17, table 3).

Health professionals provided verbal and written advice on fluid intake: to drink 1.5–2 litres a day, drink water, reduce/avoid caffeine, fizzy drinks and alcohol and avoid drinking 1–2 hours before bed if leaking at night. Conversely, sometimes the advice was to drink more fluids to change the urine consistency and avoid infections. Fluid management was seen by health professionals as effective. Indeed, most women who had tried this confirmed that these changes had worked. A physiotherapist commented that some women find it difficult to break long-established drinking habits (quote 8, table 4).

Taking medication

Medication (anticholinergics and antimuscarinics) was seen as an option by the health professionals for patients with urge UI, when self-management had not worked. Half the women had been prescribed medication (eg, oxybutanin, solifenacin, mirabegron, etc), usually by their GP. The key barrier to adherence, identified by several women and health professionals, was 'pretty horrible' (P7, urge UI) side effects, for example, dry mouth, tight chest, blurred vision, bad indigestion, constipation and headaches. To try to address this, women attending the continence clinic would be prescribed a low dose, spray or patch, which might be less effective but has fewer side effects.

There were mixed views among women on the effectiveness of the medication, ranging from completely ineffective to highly successful (quotes 18 and 19, table 3). The nurses in the continence clinic acknowledged that medication works for some patients and not others.

Triangulating women's and health professionals' views to inform the content and delivery of the self-management package

Table 5 summarises the key findings for each theme for women and health professionals, with the implications for, and final content of, the self-management package (full table in online supplemental file 3). Both groups focused on providing facts, acknowledging the challenges of living with/self-managing UI, sharing others' experiences and providing motivational and self-management strategies. Women and health professionals had mixed views on how they would prefer to use a self-management package. Some saw it as a tool for women to use independently, while others believed it should be used with health professional support.

DISCUSSION

This qualitative study offers valuable insight into women's lived experience of UI, their self-management challenges and needs for support, alongside health professionals' perspectives on providing this support. Together with a systematic review,[22] these findings informed the content and delivery of a theory and evidence-based self-management package for UI.

Similar to previous studies,[27 28] most women interviewed considered UI to be normal at their age and still a stigma reported in this study attached to UI and embarrassment about disclosing UI. Reasons include childbirth, the ageing process and lack of knowledge, which were not only reported among people living with UI but also caregivers who experienced the extra burden and affected the quality of life in previous studies.[29] Women in this study described their symptoms as upsetting, embarrassing and inconvenient, leading to changes in their behaviours and routines. This prevented many women from talking to peers or family members and seeking support. However, our study found that all women expressed a strong desire to access specialist services to facilitate detailed discussion about their condition. Women's lack of awareness of referral pathways often led to poor access to specialist services. This underlines the importance of health professionals using a proactive approach when consulting and assessing patients and the need for training on handling sensitive topics. Some regions of the UK support NHS self-referral services, although these are patchy and are not consistent in their processes. Publicising these services through public campaigns may increase patients' self-referral and promote knowledge of local resources and health services.

This study explored a range of self-management strategies and participants reported varied outcomes from these strategies. With limited access to existing services, women were familiar with the concepts of some self-management strategies provided by health professionals, including pelvic floor muscle training, bladder training and control fluid intake that are recommended by guidance.[30 31] However, no participants consistently performed these activities with barriers reported, including forgetting, lack of time or limited progress. Instead, in line with other studies,[32] women commonly used continence pads without rigorous evidence.[11 33] This suggests low level of motivation to self-manage UI and the potential psychological dependence on pads developed in women with

Table 5 Triangulating women's and health professionals' views to inform the content and delivery of the self-management package

No.	Theme	Women's views	Health professionals' views	Implications for content	Final content
1	Older women see UI as a fact of life	Many attributed UI to their age, seeing it as a 'fact of life'. They had modest aspirations to have better control of UI and worry less, rather than hoping to be rid of it		Provide facts on causes of UI, educate that UI is not a fact of life for older women and that it treatable and potentially curable	Stage 1: recognition and awareness Stage 3: understanding the cause
		Most were upset and bothered by their UI and were making significant changes to their lives. Clear concern about finding public toilets when out		Acknowledge the physical, social and emotional challenges of living with UI, share other women's experiences, educate on public toilet resources	Stage 1: recognition and awareness Stage 4: learning to manage your UI
		Two-thirds did not discuss UI with anyone, keeping it private		Acknowledge that talking about UI can be difficult, share other women's reasons for not discussing it with friends and family	Stage 1: recognition and awareness
2	Access to information and high-quality professional support is limited	Most had not accessed information about UI	Were providing women with written UI resources	Provide guidance on where women can access good information on UI	Stage 6: how can you find out more?
		Very few were accessing professional support. Even less had accessed specialist support. Those who had were very positive about it	Older women may not think services are available to them because nothing can be done. Multiple referral pathways available	Encourage women to seek professional support (that the UI can be treated) and provide guidance on how to access services	Stage 2: getting the support you need Stage 6: local healthcare support that may help you
3	Trial and error with different self-management strategies	All had tried/were using different self-management strategies with varying success	Self-management is hard, some do better than other. Employing multiple strategies to motivate women. Good relationship seen as critical to success	Educate on the important of self-management. Acknowledge the challenges of self-management. Advice on self-management including developing a self-management plan	Stage 4: learning to manage your UI Stage 5: developing a self-management plan—managing expectations and thinking positively
		All were routinely using continence pads, usually buying them. 3 women were bothered by this cost. Seen as effective but uncomfortable and associated with worry. 2 women wanted guidance on correct type and size	Continence pads used by most patients in the continence clinic. Some noted that some women use pads as easier than other self-management strategies. 2 women mentioned that it is important for women to use the correct type and size	Educate that pads are not a treatment for UI. Advise on their correct use, the different sizes and where available for free	Stage 4: learning to manage your UI
		None were routinely doing pelvic floor exercises. Key barriers were poor understanding, concerns about getting up/urinating and not seeing them as effective	All were teaching pelvic floor exercises for stress UI, considered them effective for most women were done correctly over time, acknowledging the challenge for women to remain motivated	Educate on the value of pelvic floor exercises and how to do them. Acknowledge the challenge of staying motivated when improvement takes time. Share other women's experiences	Stage 4: learning to manage your UI—pelvic floor muscle exercises

Continued

Table 5 Continued

No.	Theme	Women's views	Health professionals' views	Implications for content	Final content
4	Self-management strategies	Two thirds were using bladder training strategies. No one commented on how well this was working	Several advised women with urge UI to train their bladder, while acknowledging effectiveness can be affected by how long poor toilet habits have been in place	Educate on the value of bladder training for urge UI and how to do it. Provide a bladder diary and recommend to use it	Stage 4: learning to manage your UI—bladder training Stage 5: developing a self-management plan
		Two-thirds had changed their drinking habits and found this to be effective	Fluid management strategies used with women and seen as effective, especially for urge UI	Educate on the importance of balancing fluid intake and provide guidance. Provide a fluid intake diary and recommend to use it	Stage 4: learning to manage your UI—lifestyle changes Stage 5: developing a self-management plan
		Half had been prescribed medication with mixed views on effectiveness. Key barriers to adherence were side effects	Medication seen as an option for UI when other strategies not worked, while acknowledging the side effects and that does not work for everyone	Explain reason for UI medication, acknowledge side effects	
5	Delivery preferences	Mixed views. Some favoured reading it before meeting with a health professional so they are prepared with questions. Others preferred to go through it first time with a health professional for personalised support	Mixed views. Some (especially those in the urogynaecology department) wanted to go through it with their patients to ensure understanding. Others said if the package was good enough it could be used independently with support as needed		

UI, urinary incontinence.

UI[34] despite the cost and discomfort. There is a need to develop and maintain motivation in conjunction with self-management with optimal interventions, which may require empowerment approaches underpinned by motivational interviewing, concordance skills and cognitive behavioural therapy from health professionals.[35]

Guided by the MRC framework for developing and evaluating complex interventions,[36] the identified challenges and needs for self-management of UI in this study together with the systematic review published[22] formed the content of a self-management package for UI in older women that was proven to be feasible and acceptable.[23] Given there are only a few self-management programmes developed either focusing on a single type of UI[37] or a specific self-management strategy, for example, pelvic floor muscle training,[38] this study provided an evidence base, from both women and health professionals' perspectives, of the development of multifaceted self-management intervention that factored in awareness building, description of self-management behaviours and promotion of confidence and motivation in older women.

The key strength of this study was including both women and health professionals, facilitating systematic triangulation of views and experiences of both user groups to inform the development of the self-management package. This 'target population-centred' approach[24] to intervention development using the views of the people who will be using the SM package should increase the likelihood of acceptability and feasibility. A limitation is that we recruited women from local voluntary organisations who could converse in English. We did not purposively sample on ethnicity, and only have one participant from a black, Asian and minority ethnic background. It is uncertain if participants' accounts would be different to women recruited in other ways, with a different ethnic background or those who do not speak English. However, we achieved data saturation, captured a good diversity of views that were consistent with the existing literature.[27 28 32] This, and the rigour of the study design and conduct, give us confidence in our findings and generalisability (as a qualitative concept)[25] to other older women living with UI.

CONCLUSION

Older women do not actively seek early help for their UI and UI management. Barriers to self-management of UI identified include relying on pads, lack of instruction and guidance, lack of motivation and poor adherence. These factors are important to be taken into account and addressed in developing future evidence-based intervention aiming to raise awareness, improve self-management behaviour and build confidence and motivation in older women with UI. The self-management package for UI that was developed from this work has since been evaluated in a feasibility trial with 50 women living with UI.[23] The package was highly acceptable and showed a positive trend in reducing the UI severity, symptoms and anxiety. Women further reported higher subjective improvement and self-efficacy. The next step would be to support the implementation of this package in routine practice.

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