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Improving continence services for older people from the service-providers' perspective: a qualitative interview study

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Improving continence services for older people from the service-providers' perspective: a qualitative interview study

Abstract

Objective To examine in depth the views and experiences of continence service leads in England on key service and continence management characteristics that target effective treatment outcomes for older people.

Design Qualitative semi-structured interviews using purposive sample recruited across 16 continence services.

Setting Three acute and 13 primary care National Health Service Trusts in England.

Participants Sixteen continence service leads in England actively treating and managing older people with urinary incontinence (UI).

Results Participants highlighted a failure on the part of commissioners, managers and other health professionals in recognising the problem of UI and in acknowledging the importance of continence for older people. Patient assessment and continence promotion regardless of age, rather than pad provision, were identified as key issues for delivering effective treatment outcomes for older people with UI. To achieve this, the primary response by commissioners and other health professionals is to improve attitudes towards continence and older people. This, coupled with more rapid and appropriate patient referral pathways, investment in service capacity, e.g. more trained staff, and strengthened inter-service collaborations and a higher profile within medical and nurse training were specified as being important for delivering an equitable and high quality continence service.

Conclusions Improving attitudes towards continence and older people, together with strengthened inter-service collaborations, may lead to the raising of standards in continence care for older people with UI.

Article Summary

Article focus

- Urinary incontinence affects both men and women, but the quality of continence care provided is worse for patients aged 65 years and over compared to younger patients.
- To explore the views and experiences of continence service leads in England in order to identify and to gain information about the key service and continence management characteristics needed to deliver effective treatment outcomes for older people with UI.

Key messages

- Patient assessment and continence promotion regardless of age, rather than pad provision are the key issues for delivering effective treatment outcomes for older people with UI.
- Improving attitudes towards continence and older people, together with more rapid and appropriate patient referral pathways, strengthened inter-service collaborations, investment in service capacity and a higher profile of UI within medical and nurse training may lead to the raising of standards in continence care for older people with urinary incontinence.

Strengths and limitations

- This study directly asked continence service leads in England to identify key features of a high quality and efficacious continence service for older people with urinary incontinence.
- Our sampling strategy ensured a good representation of participants and the use of qualitative interviews was the optimal method for this study as it allowed participants to discuss in detail and to express openly their opinions.
- Data were only collected in England as healthcare in Wales, Scotland and Northern Ireland is devolved and has no internal market. Hence the study has a limited contribution to the debate on continence management in these areas of the UK.

INTRODUCTION

Urinary incontinence (UI) is a common condition that affects both men and women. It is estimated that in the United Kingdom (UK) approximately 1.1 million women and 400,000 men have UI [1]. The condition can have a substantial impact on the physical, psychological, social and economic well-being of the affected individual and their families [2-4], as UI symptoms are associated with significant morbidity and an increased risk of hospitalisation and admission to institutional care [5, 6]. Furthermore, negative attitudes towards older age (e.g. burden on society) and UI (e.g. distaste) are common in both society and health care, and impact on the provision of health care services [7]. Direct costs of UI to the National Health Service (NHS) are reported to be greater than those associated with chronic common illnesses, such as coronary care and cancer care, with such costs expected to rise due to the increase in the ageing population [8]. Although a higher prevalence of UI is associated with greater age [3, 9, 10], UI should not be considered a normal part of ageing as UI is a treatable condition [11]. Left untreated UI is a chronic rather than a self-limiting condition, with a propensity to worsen over time.

The latest National Audit of Continence Care [12] found that poor integration of continence services across the hospital, primary care, mental health and care home settings, resulted in disjointed care for UI patients and their carers, variable levels of adherence to National Institute for Health and Clinical Excellence (NICE) guidelines, and gaps in organisational standards and clinical care. Quality of care was found to be worse for patients aged 65 years and over compared to younger patients. Whilst audit is a tool able to measure the quality of care and services against agreed standards, it is unable to provide new knowledge in order to determine best practice. To date, the contribution made by service characteristics and the management of continence at both the service and personal levels to attain effective treatment outcomes has not been addressed. To put this into context, as part of a programme of research tackling ageing continence through theory, tools and technology (TACT^3), the qualitative study described in this paper explored the views and experiences of continence service leads in England regarding their work in order to identify and gain information about the key service and continence management characteristics needed to deliver effective treatment outcomes for older people with UI.

METHODS

Design

The study had a qualitative design, incorporating semi-structured telephone interviews, with purposive sampling of participants via a stratified sampling frame based on all former English Strategic Health Authorities (SHA).

Participants and setting

This study was targeted at continence service leads in NHS Trusts in England providing a continence service for people aged 50 years and over. A non-random sampling strategy was used to recruit a purposive maximum-variation sample of continence service leads from urban and rural NHS Trusts located within the SHAs. As far as possible when employing a qualitative design, this approach would provide the broadest representation of continence service leads from across England, ensuring that a wide range of perspectives would be present in the dataset so that the issues of continence problems could be considered from all angles prior to identifying the common themes evident in the data [13]. An information email inviting expressions of interest was sent to 40 continence service leads; four in each of the geographical areas of the SHAs. Inclusion criteria were: (1) service provided a continence service for people aged 50 years or older; (2) participants' contact time with patients > 60% of their working week so that they have valuable knowledge of working within their continence service. Twenty-six out of the 40 service leads originally approached who met our inclusion criteria agreed in principal to be interviewed. Ten potential participants withdrew from the study leaving a sample size of 16. The most common reasons for withdrawal from the study were: (1) due to Trust reorganisation potential participants did not have the time to participate in the study and; (2) loss of contact due to people leaving their post and/or not responding to follow up emails. Three participants were located in acute trusts, three participants were located in rural primary care trusts (PCT) and ten participants were located in urban PCTs.

Interviews

Data were collected by individual in-depth, semi-structured telephone interviews. A topic guide was developed by the research team from the recommendations reported in the Good Practice in Continence Services document [14], the National Service Framework (NSF) for Older People [15],

NICE guidelines [16] and the National Audit of Continence Care [12]. Topics covered included the nature of service provision and priorities, challenges in meeting these priorities, the impact of national policy on service provision, the key features of service provision, how services could be improved and how trusts could improve continence care for older people. Interviews were conducted between April 2011 and January 2012 at a time convenient for the participant. The average interview time was approximately 45 minutes. Oral consent from the participants was recorded at the beginning of the interviews and all participants were offered a hard copy of the consent form. Interview data were collected confidentially and digitally recorded within the university by a member of the research team and transcribed. During the interviews, first names only were referred to and names were not recorded in the transcriptions.

Analysis

The interview transcripts were analysed using a framework approach [17]. This is a rigorous and systematic method of qualitative analysis which combines *a priori* issues derived from key concepts in the literature and the aims of the study (deductive analysis) with categories that emerge from the data (inductive analysis) to create a thematic frame-work. Data were organised into a matrix on an Excel spread sheet with participants as rows and emerging themes as columns. Analysis followed a five stage process of familiarisation, identification of the thematic framework, indexing, charting, and mapping and interpretation [18]. Each stage was conducted by the first author and a selection of transcripts were reviewed by another member of the team (LD) to check for bias and alternative interpretation of the data. In the presentation of the results, each quote is attributed to the interviewed Continence Service Lead (CSL) by their unique identification code. The number refers to the order in which each continence service lead was interviewed.

Ethics

A favourable opinion was obtained from NHS Bradford Research Ethics Committee (Ref No.: 10/H1302/93) and research governance approval obtained from the primary care and acute trusts in each location where the continence service leads worked.

RESULTS

Six themes emerged which were particularly relevant to delivering effective treatment outcomes for older people with UI. These were: Changes in attitudes towards older people with UI; Investment in service capacity; Appropriate and rapid patient referral; Patient assessment; Continence promotion regardless of age; Continence education and specialist knowledge. Each theme is considered in detail below.

Changes in attitudes towards older people and UI

Having a negative attitude towards UI and older people was identified by all participants as a key barrier to delivering good quality treatment outcomes. The following comment typifies this:

> There's GPs [General practitioners] out there still who will say to Mrs. Jones, 'well you're 85, you've had three children, what can you expect?' The challenge is to try and persuade these staff there's things that can be done to help people and not just accept the problem. Urban PCT, CSL4.

It was felt by a number of participants that these negative attitudes towards older people with UI were reinforced by other health professionals', carers' and patients' lack of knowledge and understanding about UI, its treatment and the role of continence services in providing treatment for UI:

> If we were to ask a GP, 'What does the continence service do?' they probably wouldn't be able to tell you. Urban PCT, CSL3.
>
> We found that a lot of carers are very quick to resort to the products and we're trying to get the message across that there are many things you can do before you put someone into pads. Urban PCT, CSL5.

All of the participants agreed that to improve continence services and treatment outcomes, current prejudices towards ageing and UI need to be recognised and addressed by patients, health professionals and service commissioners. In particular, if continence care for older people is perceived to be low priority and an unimportant health need, then investment in services and the efficacy of resultant treatments may be compromised. As one participant commented:

> Commissioners of the [continence] service need to see it as important because if commissioners don't see it as important to meet the needs of older people then they're not going to commission a service if they think all it is is to provide pads, then that's all they're going to commission. Acute Trust, CSL12.

Investment in service capacity

All of the respondents highlighted a lack of service capacity as being a major challenge in delivering a quality service for older people and that investment in service capacity was required to meet the increase in service demand:

> At the moment we've actually had a 100 per cent increase in referrals from this time last year so some of the challenges are that obviously we haven't changed staffing so capacity is becoming an issue. Urban PCT, CSL10.

This increase in service demand may, in part, be a reflection of the current financial climate, with one participant reporting an increase in the number of people self-referring into their clinic in response to the expense of buying pads. Alternatively, this increase may be a manifestation of success breeding success:

> If you've got what I hope is a reasonably successful service, then more people are aware of you and more people are referred to you. Urban PCT, CSL8.

Furthermore, all participants emphasised a staff shortage within their services which impacted on the quality and availability of the service they delivered. Indeed, some participants suggested that a lack of staff was associated with their difficulties in adhering to national policy, disparity in treatment outcomes and growing waiting lists, although one participant from a rural PCT did acknowledge that local geography also impacted on referral times into their service:

> With national policy we try as best as possible to work with it. because of staffing levels it can be very difficult at times to adhere to the policies and not cut corners...and waiting lists go up [...] I don't think we're able to give the service that we should do to the elderly and it's left to the district nurses to treat where we could go out and give specific treatments, where with the district nurses it's a pad service. Urban PCT, CSL7.
>
> I have 2.5 whole time equivalent staff for half a million people...we don't have enough people...that has an impact because we've got referrals stacking up...we get over 1000 referrals a year. We do 40 sessions per month which sounds a lot, but because of the geography it isn't because we spend a lot of time travelling and there's other stuff to do. Rural PCT, CSL6.

Moreover, some of the participants explicitly felt that an investment in trained staff and an integrated continence service with other health professionals was necessary to promote continence awareness and to improve the quality of patient assessments and treatment outcomes:

> If we had a proper team we could do all the assessments and offer every patient treatment. I think you need trained continence advisors, but it would be nice to have a paediatric continence advisor and it would be nice to have a physiotherapist. Urban PCT, CSL7.

One participant, however, highlighted the difficulties they had experienced in forming an integrated service:

> We tried to go down the route of an integrated service... [but] in terms of access to a physiotherapist we've actually had difficulty within the county of finding anyone with the skills or wanting to develop those skills. Urban PCT, CSL16.

Besides an increasing demand and a shortage of skilled staff, some participants also cited a lack of investment in clinics and equipment as being barriers to providing a quality service:

> We have a long waiting list in one particular area because there are no clinics based in that particular area. Urban PCT, CSL3.
>
> If we had the staff and the equipment we could improve services... we have a lack of equipment such as bladder scanners. Rural PCT, CSL1.

Appropriate and rapid patient referral

Paradoxically, despite participants in the PCTs reporting a high demand by patients for their continence services, several were perplexed by the lack of appropriate and timely referrals to their services from GPs and other health professionals. This was primarily attributed to GPs' lack of knowledge about continence services, and secondly to GPs and other health professionals referring patients to the wrong services**:**

> Some GPs will refer people into hospital services when really it's not necessary. Because of a good relationship the hospital services send them to us, so for the poor patient it means they've got two appointments instead of one. Urban PCT, CSL11.

Indeed, one participant noted discrepancies in referral pathways based on the patient's gender:

> It seems to be male patients go straight to secondary care and bypass primary continence services in my area. Urban PCT, CSL15.

The same participant also expressed concerns about perceived disparities in the quality of continence services provided to patients dependent on the referral pathway they had been allocated:

> For the 80 patients a month that we get there's probably 100 patients a month with continence problems who are only seen by the district nurses and they will never be seen by our service, they won't be referred to us. They will be seen and essentially, 'padded up'. They won't be investigated or given a diagnosis. So there's a very unequal service going on at the moment. Urban PCT, CSL15.

For practitioners working in the acute sector there was an added sense of frustration as patients identified with UI on the wards could not be directly referred to the outpatients' continence service on discharge, but had to be referred via their GP. Although this recommendation was included on the patients' discharge letter, it was unsure as to whether or not this was acted upon by the patients' GPs:

> The key feature is for patients being referred in the first place, because I think that's part of the problem is that they are not referred when they've seen somebody about their bladder problems or it's been picked up on the ward. It's not always seen as important. Acute Trust, CSL12.

Patient assessment

A full patient assessment including complete history taking, physical examination, review of medication, urinary analysis, bladder scan, vaginal and rectal examination if appropriate, was seen by all participants as being a key feature of quality continence care for older patients, as this provided the practitioner with the necessary information to make a differential diagnosis and to formulate an individual treatment plan for each patient:

> You need to do a proper assessment so that you can actually make a nursing differential diagnosis, refer if necessary, then make a proper treatment plan up for that individual and then follow them through. Urban PCT, CSL14.

Some participants also advocated implementing a more holistic assessment whereby patients were seen in their own home:

> We give a full holistic assessment so that we can see patients in their own home and look at their facilities, mobility and things like that, which can quite often be part of the problem that they've got, so it's more of a functional problem than anything else. Urban PCT, CSL10.

The majority of participants reported that within their continence clinics they adhered to NICE guidelines, which recommended that every patient is offered an assessment:

> I think that we are following national policy quite well within the continence service. Every patient is being offered a continence assessment by a suitably qualified member of the team. Rural PCT, CSL2.

One participant, however, stated that they were under pressure from non-clinical managers to bypass this process. Some of the participants also reported misgivings about the disparity in the quality and thoroughness of the assessments being provided by ward nurses in hospital and by district nurses to housebound patients and to nursing home residents who were unable to attend continence clinics:

> The district nurses do what we would call basic assessments for us so they would see the patients that have been referred to them, usually by the hospital if they've been discharged from secondary care, and it's just basically a pad assessment. Urban PCT, CSL10.
>
> The district nurses who go to see the patients only assess for products. They don't look at the bigger picture. Urban PCT, CSL7.

Continence promotion regardless of age

Continence promotion, rather than pad provision, was identified by all of the participants as being a central tenet of the management of older people with UI:

> Everybody should have the right to be continent so we really aim to try and get people continent whenever possible. Urban PCT, CSL14.

The majority of participants, however, reported encountering problems in achieving this outcome, with several participants citing patients' and carers' expectations of just receiving pads from the continence service as the only treatment available to them:

> People still view our service as the pad providers as much as we try and shout that we're not just about pads. Urban PCT, CSL16.
>
> The expectation seems to be an expectation of pads... it isn't any expectation that they might get better. Urban PCT, CSL15.

Two of the participants described how they were able to manage and to change patients' and carers' expectations to resolve this issue and to produce better quality treatment outcomes for the patient:

> When I hear the patient's story, that yes they were looking for pads, I will explain to them what could be going on and that we will work with them to see if we can get them better... very few people then say, 'I don't want to get better', so it depends on how you deliver it. Rural PCT, CSL6.
>
> If people's first interaction regarding continence is a positive one that gives you treatment, it's better than the first person they see saying, 'here are some pads'. We would be able to help more people and improve their symptoms rather than give them the message that you wear a pad and put up with your symptoms. Urban PCT, CSL16.

Continence education and specialist knowledge

Having a highly trained and knowledgeable workforce responsible for delivering high quality continence care was identified by the majority of participants as being an essential feature of a quality continence service for older people. Certainly all of the participants reported having at least one specialist continence nurse on their team:

> I think one of the key features [of the service] is to have a suitable trained nurse and a suitable team to implement assessment and treatment as opposed to just products. Urban PCT, CSL7.

In order to develop and improve the knowledge base and competency levels of their staff, all of the participants recognised the importance of providing and attending on-going staff training programmes, with one participant suggesting that education should be prioritised:

> Training is an integral part of the service because obviously our service is with specialist nurses who themselves access training and maintain their level of competence. Urban PCT, CSL11.

All of the participants recognised and acknowledged that district nurses and other health care professionals do not have the specialist skills and knowledge of the continence specialist nurse and felt that access to training for these professionals was essential to promote continence and to raise standards and parity in patient assessments:

> I'd like to have more time with district nurses to bring up their level of continence assessment. Urban PCT, CSL8.

A wide range of training programmes was provided by the majority of participants for anyone involved with looking after someone with continence problems. Some of the participants, however, revealed that they had experienced difficulties in delivering these programmes to their targeted audiences due to continence promotion not being recognised as a priority area by the trust and to staff shortages:

> We've asked the question whether continence assessment training could be mandatory for district nurses but the trust aren't too happy to do that at the moment. Urban Pct, CSL16.
>
> We have a training programme but the unfortunate thing is that a lot of teams are very short-staffed so being released from training is quite difficult. Urban PCT, CSL3.

DISCUSSION

The aim of this study was to explore the views and experiences of continence service leads in England in order to identify and gain information about the key service and continence management characteristics needed to deliver effective treatment outcomes for older people with UI. Foremost among the issues raised by the continence service leads was a failure on the part of commissioners, managers and other health professionals in recognising the problem of UI and acknowledging the importance of continence for older people and the impact it has on other areas of health, such as quality of life, tissue viability and falls. This was seen by all practitioners as a major barrier to effective treatment outcomes for older people with UI. Indeed, some continence service leads were highly critical of current commissioning practices which focused on purchasing pad provision rather than implementation of national guidelines, and feared that their continence services may not be recommissioned by service providers after the 2013 National Health Service (NHS) in England reorganisation.

This failure by commissioners and other health professionals in valuing the importance of continence promotion in older people may be indicative of the low status of UI and implicit ageism. Ageism, defined as a process of systematic stereotyping of, and discrimination against, people because they are old [19], is evident amongst some doctors and other health care professionals and has been shown to impact negatively on the care older patients receive [20-24]. Therefore, there needs to be a change at the top level to the ageist beliefs and attitudes about UI held by commissioners and other health professionals to one which advocates candidacy for the treatment of older people with UI by recognising that continence services provide a specialist service able to treat and potentially cure the majority of patients, including older patients, using conservative management.

This can be achieved by increasing the continence service profile and by a change in commissioning practice. By buying into a service that adheres to national guidelines with regards to patient assessment and continence promotion rather than pad provision, standards of UI care for older people can be raised, and quality of life improved. For example, results from a recent study assessing the quality of care of older ambulatory patients aged more than 75 years have shown that better quality of care for UI is associated with an improvement in UI related quality of life [25].

Investment in service capacity in terms of clinics, equipment and staff (including training) was identified as being a key factor in meeting the increasing demand for continence services by older people, as this was envisaged to reduce the gaps in local service provision and facilitate access to and availability of continence services. Despite National Guidelines there appears to be a "post code lottery" for continence services. In particular clinical leads from the rural PCTs felt that a failure by their Trusts to invest in the clinical infrastructure had a negative impact on their ability to provide a local continence service and they were concerned that access to their services was restricted in certain areas due to a lack of public transport and the long distances patients had to travel, (i.e. the distance decay effect, whereby the further away a service is the less likely it is to be used [26]). This interplay between organisational and geographical barriers as confounding factors in the ability of older people to access health services in a timely fashion is well documented as rural communities in general face poor access to health care services and may be offered a more limited range of services [27, 28]. For rural continence services this interaction between organisation and geography was amplified by staff shortages, as most staff work part time, resulting in fewer clinics being held due to the length of time spent in travelling. A better understanding of the issues surrounding rural health is therefore required by commissioners to ensure proofing of rural continence services, so as to identify and support the principles underpinning best practice.

The delivery and implementation of a full continence assessment by highly trained individuals, together with continence promotion to every patient, regardless of age, were identified by all continence service leads as two of the key features of a high quality and effective service for older people with UI. These findings are to be expected as the Good Practice in Continence Services [14] recommends that, *"All patients presenting with incontinence should be offered an initial assessment by a suitably trained professional."* Furthermore, The European Association of Urology guidelines on UI advocate that healthy older people should be offered a similar range of treatment options as younger

people and that treatment should be individualised for frail older people [29]. Moreover, NICE guidelines specify that absorbent products are not a treatment of UI but rather should be used as: a coping strategy for patients awaiting definitive treatment; an add-on to on-going therapy; and long-term management of UI only after other treatment options have been explored [16]. Our results, however, indicated a widespread feeling of frustration amongst the continence service leads at not being able to fulfil and realise all of the unmet needs for continence care services on account of patients not knowing what they want or what treatments they could have, inappropriate referrals by GPs and other health professionals and a lack of investment in service capacity, service integration and health professional education.

The quality of continence assessments delivered to domiciliary and nursing home patients by district nurses and other health professionals, as opposed to continence nurse specialists, was also deemed to be an inferior key service characteristic which contributed to the disparity in the quality of care for older people with UI. Furthermore, in certain cases, this was compounded by GPs and other health professionals referring patients into the wrong service, delaying their referrals, or in extreme cases not referring patients at all to the continence service. Several factors may be related to such behaviours, including: the short time available for GP consultations as female patients rarely present with UI as a primary complaint; GPs preferring to prescribe medications and pads due to a lack of faith in the efficacy of conservative treatment of UI; and GPs' lack of knowledge of continence services [30-33]. Moreover, there is a growing body of evidence to suggest that many GPs have limited training and skills for the treatment and assessment of UI at both undergraduate and postgraduate levels [30, 32, 33] and a substantial deficit in geriatric knowledge and training [27]. Likewise, findings from a recent nursing survey revealed gaps in nurse training and education for continence management, suggesting that nurses are not receiving sufficient support to assess and care for people with UI [34]. This apparent lack of knowledge and training needs to be addressed quickly by the promotion and endorsement of UI education in both medical and nursing curricula and by commissioners making available and supporting training opportunities for non-specialist continence nurse specialists and other health professionals.

There was consensus amongst the continence service leads that there needed to be investment in the development and implementation of integrated continence services to improve service quality and the patient experience. Results from earlier research suggest that integrated

continence care in primary care improved the effectiveness of continence services and was associated with high patient satisfaction levels [35-37]. Although the National Service Framework (NSF) for Older People [15] required the establishment of integrated continence services for older people by April 2004 none of the continence service leads in this study worked in an integrated service. Indeed, findings from the latest national audit of continence care only reported four fully integrated continence services in England [12]. Therefore there is a pressing need to adopt a more dynamic approach in the provision of continence services, whereby all practice professionals are involved in the prevention, recognition, assessment and treatment of UI. By putting into effect integrated continence care services it is anticipated that this will help to meet the health care challenges of an ageing population and an increasing prevalence of treatable UI.

Strengths and limitations

This study directly asked continence service leads in England to identify key features of a high quality and efficacious continence service for older people with UI. Our sampling strategy ensured a good representation of participants from across the range of former SHAs, while the use of qualitative interviews was the optimal method for this study as it allowed participants to discuss in detail and to express openly their opinions on the key features of a successful service and how continence services for older people could be improved. While there are always limits on the extent to which one can generalise the results of qualitative research, our findings have good face validity as the main themes identified in our analyses are reflected in relevant studies [38]. Data were only collected in England as healthcare in Wales, Scotland and Northern Ireland is devolved and has no internal healthcare market, and so the study has a limited contribution to the debate on continence management in these areas of the UK.

CONCLUSION

Patient assessment and continence promotion regardless of age, rather than pad provision, were identified as key issues for delivering effective treatment outcomes for older people with UI. To achieve this, the primary response by commissioners and other health professionals should be to improve attitudes towards continence and older people. This, coupled with more rapid and appropriate patient referral pathways, investment in service capacity, (including trained staff and

facilities), strengthened inter-service collaborations and a higher profile within medical and nursing training were specified as being important for delivering an equitable and high quality continence service. Addressing quality in these identified priority areas may lead to the raising of standards in continence care for older people with UI.

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DATA SHARING

Data from this study have been deposited with the ESRC data store which can be accessed on www.data-archive.ac.uk

AUTHORS' CONTRIBUTION AO, KM, LD, MG and SGP contributed to the conception and design of the study. AO contributed to the data acquisition. AO and LD contributed to the analysis and interpretation of the data. AO wrote the manuscript and all authors contributed to the critical revision and final approval of the manuscript.

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Improving continence services for older people from the service-providers' perspective: a qualitative interview study

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Improving continence services for older people from the service-providers' perspective: a qualitative interview study

Abstract

Objective: To examine in depth the views and experiences of continence service leads in England on key service and continence management characteristics in order to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI).

Design: Qualitative semi-structured interviews using a purposive sample recruited across 16 continence services.

Setting: Three acute and 13 primary care National Health Service Trusts in England.

Participants: Sixteen continence service leads in England actively treating and managing older people with UI.

Results: In terms of barriers to a good quality service, participants highlighted a failure on the part of commissioners, managers and other health professionals in recognising the problem of UI and in acknowledging the importance of continence for older people, and prevalent negative attitudes towards continence and older people. Patient assessment and continence promotion regardless of age, rather than pad provision, were identified as important steps for a good quality service for older people with UI. More rapid and appropriate patient referral pathways, investment in service capacity, e.g. more trained staff, and strengthened inter-service collaborations and a higher profile within medical and nurse training were specified as being important facilitators for delivering an equitable and high quality continence service. There is a need, however, to consider the accounts given by our participants as perhaps serving the interests of their professional group within the context of inter-professional work.

Conclusions: Our data point to important barriers to and facilitators of a good quality service for older people with UI, from the perspective of continence service leads. Further research should address

the views of other stakeholders, and explore options for the empirical evaluation of the effectiveness of identified service facilitators.

Article Summary

Article focus

- Urinary incontinence affects both men and women, but the quality of continence care provided is worse for patients aged 65 years and over compared to younger patients.
- To explore the views and experiences of continence service leads in England to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI).

Key messages

- Patient assessment and continence promotion regardless of age, rather than pad provision are the key issues for improving continence services for older people with UI.
- Improving attitudes towards continence and older people, together with more rapid and appropriate patient referral pathways, strengthened inter-service collaborations, investment in service capacity and a higher profile of UI within medical and nurse training may lead to the raising of standards in continence care for older people with urinary incontinence.

Strengths and limitations

- This study directly asked continence service leads in England to identify key features of a high quality and efficacious continence service for older people with urinary incontinence.
- Our sampling strategy ensured a good representation of participants and the use of qualitative interviews was the optimal method for this study as it allowed participants to discuss in detail and to express openly their opinions.
- Data from other stakeholder groups in continence care was not collected.
- Data were only collected in England as healthcare in Wales, Scotland and Northern Ireland is devolved and has no internal market. .

INTRODUCTION

Urinary incontinence (UI) is a common condition that affects both men and women and is defined by the International Continence Society as, 'the complaint of any involuntary leakage of urine' [1]. Findings from an earlier epidemiological study to establish the prevalence of urinary symptoms in community-dwelling adults in Great Britain revealed that approximately 23% of women and 8.7% of men over the age of 40 years have urinary symptoms and that the prevalence and severity of symptoms increase with age [2-4]. For people with cognitive impairment or dementia living at home results from a recent systematic review reported that the prevalence of UI ranged from 1.1% in a general community population to 38% in those receiving home care services [5]. Direct costs of UI to the National Health Service (NHS) are reported to be greater than those associated with common chronic illnesses, such as coronary care and cancer care, with these costs expected to rise due to the increase in the ageing population [6].

UI can have a substantial impact on the physical, psychological, social and economic well-being of the affected individual and their families [7-9], as UI symptoms are associated with significant morbidity and an increased risk of hospitalisation and admission to institutional care [10, 11]. Furthermore, negative attitudes towards older people (e.g. burden on society) and UI (e.g. distaste) are common in both society and health care, and impact on the provision of health care services [12]. Although a higher prevalence of UI is associated with greater age [2, 3, 13-15], UI should not be considered a normal part of ageing as UI is a treatable condition [16]. According to Fonda and Abrams' "Continence Paradigm" for defining incontinence and continence management for all ages, UI can be controlled by behavioural treatments, medications or with toileting assistance or contained with pads or appliances [17]. Left untreated, however, UI is a chronic rather than a self-limiting condition, with a propensity to worsen over time.

UI usually presents and is identified in primary care settings by General Practitioners (GPs) and nurses, although the pathways to diagnostic assessment can be inconsistent with some individuals being referred directly to a variety of specialists in secondary care (e.g. physiotherapists, gynaecologists, urologists, geriatricians or specialist nurses based in secondary care) without any assessment or treatment [18]. Continence services in England are provided by GPs, Acute Trusts, private providers for the NHS, alternative providers, e.g. social enterprises and primary care

providers; with treatment being delivered in hospitals, GP surgeries, nursing and care homes, community clinics and primary care centres [18]. Generally, however, symptomatic diagnoses occur in primary care and condition-specific in secondary care.

According to the National Institute for Health and Clinical Excellence (NICE) guidelines for commissioning a urinary continence service, primary care and community teams are expected to have trained professionals able to perform initial assessment and conservative management of UI and/ or a referral pathway to a specialist continence service [19]. In addition, patients presenting with UI and symptoms indicating a more complex condition should have access to a specialist continence service that employs, amongst others, specialist continence nurse advisers (registered nurses with extensive training up to degree level in continence care and able to work as independent practitioners) and specialist physiotherapists [18]. Despite these recommendations, the latest National Audit of Continence Care [20] found that poor integration of continence services across the hospital, primary care, mental health and care home settings, resulted in disjointed care for UI patients and their carers, variable levels of adherence to NICE guidelines, and gaps in organisational standards and clinical care. Furthermore, quality of care was found to worse for patients aged 65 years and over compared to younger patients.

Whilst audit is a tool able to measure the quality of care and services against agreed standards, it is unable to provide new knowledge in order to determine best practice. To date, the contribution made by service characteristics and the management of continence at both the service and personal level to attain optimal quality of care for older people with UI has not been addressed. To put this into context, as part of a programme of research tackling ageing continence through theory, tools and technology (TACT3), the aims of the qualitative study described in this paper were to explore the views and experiences of continence service leads (specialists) in order to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI). Such knowledge may be important to the development of patient care and the design of professional education programmes and to inform service commissioners.

METHODS

Design

The study had a qualitative design, incorporating semi-structured telephone interviews, with purposive sampling of participants via a stratified sampling frame based on all former English Strategic Health Authorities (SHA).

Participants and setting

This study was targeted at senior and specialist continence nurse practitioners acting as continence service leads in NHS Trusts in England providing a continence service for community-dwelling people aged 50 years and over. We targeted the leads of specialist continence services rather than GPs or District Nurses because they are: (1) expert practitioners with extensive training in continence care and; (2) front line staff in delivering continence services.

A non-random sampling strategy was used to recruit a purposive maximum-variation sample of continence service leads from urban and rural NHS Trusts located within the SHAs. As far as possible when employing a qualitative design, this approach would provide the broadest representation of continence service leads from across England, ensuring that a wide range of perspectives would be present in the dataset so that the issues of continence problems could be considered from all angles prior to identifying the common themes evident in the data [21]. An information email inviting expressions of interest was sent to 40 continence service leads; four in each of the geographical areas of the SHAs. Inclusion criteria were: (1) service provided a continence service for people aged 50 years or older; (2) participants' contact time with patients > 60% of their working week so that they have valuable knowledge of working within their continence service. Twenty-six out of the 40 service leads originally approached who met our inclusion criteria agreed in principal to be interviewed. Ten potential participants withdrew from the study leaving a sample size of 16. The most common reasons for withdrawal from the study were: (1) due to Trust reorganisation potential participants did not have the time to participate in the study and; (2) loss of contact due to people leaving their post and/or not responding to follow up emails. Due to the time constraints for this study and the length of time required to apply for and gain NHS research governance approval, we did not replace the original ten participants who withdrew from the study. Three participants were located in acute trusts, three participants were located in rural primary care trusts (PCT) and ten participants were located in urban PCTs.

Interviews

Data were collected by individual in-depth, semi-structured telephone interviews. A topic guide was developed by the research team from the recommendations reported in the Good Practice in Continence Services document [22], the National Service Framework (NSF) for Older People [23], NICE guidelines [19] and the National Audit of Continence Care [20]. Topics covered included the nature of service provision and priorities, challenges in meeting these priorities, the impact of national policy on service provision, the key features of service provision, how services could be improved and how trusts could improve continence care for older people. Interviews were conducted between April 2011 and January 2012 at a time convenient for the participant. The average interview time was approximately 45 minutes. Oral consent from the participants was recorded at the beginning of the interviews and all participants were offered a hard copy of the consent form. Interview data were collected confidentially and digitally recorded within the university by a member of the research team and transcribed. During the interviews, first names only were referred to and names were not recorded in the transcriptions.

Analysis

The interview transcripts were analysed using Framework Analysis [24], which is an approach to qualitative data analysis developed by social policy researchers in the UK and increasingly used in health care research [26]. Framework Analysis is a pragmatic approach for applied research, developed to address specific real-world questions and with less focus on producing new theory than other approaches to qualitative data analysis, such as grounded theory [26]. In accordance with Framework Analysis, the data analysis followed a five stage process [24, 26, 27]:

1. Familiarisation: becoming familiar with and getting an overview of the richness, depth and diversity of material gathered.
2. Identification of the thematic framework: identifying key issues, concepts and themes according to which the data can be examined by combining *a priori* issues derived from key concepts in the

literature and the aims of the study (deductive analysis) with categories derived from the data (inductive analysis).

3. Indexing: a process of applying the thematic framework to the data, using codes to identify specific pieces of data that correspond with differing themes (in other qualitative analysis approaches often called 'coding').
4. Charting: creating charts with headings and subheadings drawn from the thematic framework; in this study data were organised into a chart, using Excel, with participants as rows and emerging themes as columns.
5. Mapping and interpretation: pull together key characteristics of the data, and map and interpret the data set as a whole.

Each stage of the analysis was conducted by the first author. To improve inter-rater reliability a selection of transcripts were reviewed by another member of the team (LD) to check for bias and alternative interpretation of the data. Revisiting the interview transcripts, all themes were represented within the first 12 interviews, with an indication that data saturation had been achieved as no new themes emerged from the remaining interviews [28, 29]. In the presentation of the results, each quote is sequentially numbered, and attributed to the Continence Service Lead (CSL) interviewed via an identification code, allocated in the order in which the continence service leads were interviewed.

Ethics

A favourable opinion was obtained from NHS Bradford Research Ethics Committee (Ref No.: 10/H1302/93) and research governance approval obtained from the primary care and acute trusts in each location where the continence service leads worked.

RESULTS

Sixteen continence service leads participated in the study. There were more women (n = 14) than men (n = 2). Two participants were Clinical Lead Continence Nurses, six participants were Service Leads, two participants were Continence Nurse Specialists, two participants were Service Managers, three participants were Lead Specialist Continence Nurses and one participant was a Team and Clinical Facilitator. All respondents had spent a significant part of their working lives as continence specialists (mean 9 years, range 1 to 15 years) and the time in their current post varied from 1 to 15 years, with a mean of 6 years.

From the analysis, six themes emerged that related to barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI), with an additional seventh cross-cutting theme. . These six themes were: Changes in attitudes towards older people and UI; Investment in service capacity; Appropriate and rapid patient referral; Patient assessment; Continence promotion regardless of age; Continence education and specialist knowledge; and the seventh cross-cutting theme, Allocating the blame. Each theme is considered in detail below.

Changes in attitudes towards older people and UI

Having a negative attitude towards UI and older people was identified by all participants as a key barrier to delivering good quality **care.** The following comment typifies this:

> "There's GPs [General Practitioners] out there still who will say to Mrs. Jones, 'well you're 85, you've had three children, what can you expect?' The challenge is to try and persuade these staff there're things that can be done to help people and not just accept the problem." (1) Urban PCT, CSL4.

It was felt by a number of participants that these negative attitudes towards older people with UI were reinforced by other health professionals', carers' and patients' lack of knowledge and understanding about UI, its treatment and the role of continence services in providing treatment for UI:

> "If we were to ask a GP, 'What does the continence service do?' they probably wouldn't be able to tell you." (2) Urban PCT, CSL3.
>
> "We found that a lot of carers are very quick to resort to the products and we're trying to get the message across that there are many things you can do before you put someone into pads." (3) Urban PCT, CSL5.

All of the participants agreed that to improve continence services and quality of care, current prejudices towards ageing and UI need to be recognised and addressed by patients, health professionals and service commissioners. In particular, if continence care for older people is perceived to be low priority and an unimportant health need, then investment in services and the efficacy of resultant treatments may be compromised. As one participant commented:

> "Commissioners of the [continence] service need to see it as important because if commissioners don't see it as important to meet the needs of older people then they're not going to commission a service if they think all it is is to provide pads, then that's all they're going to commission." (4) Acute Trust, CSL12.

Continence promotion regardless of age

The need to change negative attitudes towards UI and older people is closely linked with continence promotion. This, rather than pad provision, was identified by all of the participants as being a central tenet of the management of older people with UI:

> "Everybody should have the right to be continent so we really aim to try and get people continent whenever possible." (5) Urban PCT, CSL14.

The majority of participants, however, reported encountering problems in achieving this outcome, with several participants citing patients' and carers' expectations of just receiving pads from the continence service as the only treatment available to them:

> "People still view our service as the pad providers as much as we try and shout that we're not just about pads." (6) Urban PCT, CSL16.
>
> "The expectation seems to be an expectation of pads... it isn't any expectation that they might get better." (7) Urban PCT, CSL15.

Two of the participants described how they were able to manage and to change patients' and carers' expectations to resolve this issue and to produce better quality treatment outcomes for the patient:

> "When I hear the patient's story, that yes they were looking for pads, I will explain to them what could be going on and that we will work with them to see if we can get them better... very few people then say, 'I don't want to get better', so it depends on how you deliver it." (8) Rural PCT, CSL6.
>
> "If people's first interaction regarding continence is a positive one that gives you treatment, it's better than the first person they see saying, 'here are some pads'. We would be able to help more people and

improve their symptoms rather than give them the message that you wear a pad and put up with your symptoms." (9) Urban PCT, CSL16.

Investment in service capacity

All of the respondents highlighted a lack of service capacity as being a major challenge in delivering a quality service for older people and that investment in service capacity was required to meet the increase in service demand:

"At the moment we've actually had a 100 per cent increase in referrals from this time last year so some of the challenges are that obviously we haven't changed staffing so capacity is becoming an issue." (10) Urban PCT, CSL10.

This increase in service demand may, in part, be a reflection of the current financial climate, with one participant reporting an increase in the number of people self-referring into their clinic in response to the expense of buying pads. Alternatively, this increased demand for services may be a result of greater awareness and changes attitudes towards UI and continence services and/or a manifestation of success breeding success:

"If you've got what I hope is a reasonably successful service, then more people are aware of you and more people are referred to you." (11) Urban PCT, CSL8.

All participants emphasised a staff shortage within their services which impacted on the quality and availability of the service they delivered. Indeed, some participants suggested that a lack of staff was associated with their difficulties in adhering to national policy, disparity in treatment outcomes and growing waiting lists, although one participant from a rural PCT did acknowledge that local geography also impacted on referral times into their service:

"With national policy we try as best as possible to work with it. Because of staffing levels it can be very difficult at times to adhere to the policies and not cut corners...and waiting lists go up [...] I don't think we're able to give the service that we should do to the elderly and it's left to the district nurses to treat where we could go out and give specific treatments, where with the district nurses it's a pad service." (12) Urban PCT, CSL7.

"I have 2.5 whole time equivalent staff for half a million people...we don't have enough people...that has an impact because we've got referrals stacking up...we get over 1000 referrals a year. We do 40

sessions per month which sounds a lot, but because of the geography it isn't because we spend a lot of time travelling and there's other stuff to do." (13) Rural PCT, CSL6.

Moreover, some of the participants explicitly felt that an investment in trained staff and an integrated continence service with other health professionals was necessary to promote continence awareness and to improve the quality of patient assessments and treatment outcomes:

"If we had a proper team we could do all the assessments and offer every patient treatment. I think you need trained continence advisors, but it would be nice to have a paediatric continence advisor and it would be nice to have a physiotherapist." (14) Urban PCT, CSL7.

One participant, however, highlighted the difficulties they had experienced in forming an integrated service:

"We tried to go down the route of an integrated service... [but] in terms of access to a physiotherapist we've actually had difficulty within the county of finding anyone with the skills or wanting to develop those skills." (15) Urban PCT, CSL16.

Besides an increasing demand and a shortage of skilled staff, some participants also cited a lack of investment in clinics and equipment as being barriers to providing a quality service:

"We have a long waiting list in one particular area because there are no clinics based in that particular area." (16) Urban PCT, CSL3.

"If we had the staff and the equipment we could improve services... we have a lack of equipment such as bladder scanners." (17) Rural PCT, CSL1.

Appropriate and rapid patient referral

Several participants in the PCTS were perplexed by the lack of appropriate and timely referrals to their services from GPs and other health professionals. This was primarily attributed to GPs' lack of knowledge about continence services, and secondly to GPs and other health professionals referring patients to the wrong services:

"Some GPs will refer people into hospital services when really it's not necessary. Because of a good relationship the hospital services send them to us, so for the poor patient it means they've got two appointments instead of one." (18) Urban PCT, CSL11.

Indeed, one participant noted discrepancies in referral pathways based on the patient's gender:

> "It seems to be male patients go straight to secondary care and bypass primary continence services in my area." (19) Urban PCT, CSL15.

The same participant also expressed concerns about perceived disparities in the quality of continence services provided to patients dependent on the referral pathway they had been allocated:

> "For the 80 patients a month that we get there's probably 100 patients a month with continence problems who are only seen by the district nurses and they will never be seen by our service, they won't be referred to us. They will be seen and essentially, 'padded up'. They won't be investigated or given a diagnosis. So there's a very unequal service going on at the moment." (20) Urban PCT, CSL15.

For practitioners working in the acute sector there was an added sense of frustration as patients identified with UI on the wards could not be directly referred to the outpatients' continence service on discharge, but had to be referred via their GP. Although this recommendation was included on the patients' discharge letter, it was unsure as to whether or not this was acted upon by the patients' GPs:

> "The key feature is for patients being referred in the first place, because I think that's part of the problem is that they are not referred when they've seen somebody about their bladder problems or it's been picked up on the ward. It's not always seen as important." (21) Acute Trust, CSL12.

The reported lack of appropriate and timely referral to continence services may seem paradoxical to the high demands of these services by patients, as found in the previous theme. The lack of appropriate and timely referrals, however, may instead be a result of the high demand and subsequent long waiting lists.

Patient assessment

A full patient assessment including complete history taking, physical examination, review of medication, urinary analysis, bladder scan, vaginal and rectal examination if appropriate, was seen by all participants as being a key feature of quality continence care for older patients, as this provided the practitioner with the necessary information to make a differential diagnosis and to formulate an individual treatment plan for each patient:

> "You need to do a proper assessment so that you can actually make a nursing differential diagnosis, refer if necessary, then make a proper treatment plan up for that individual and then follow them through." (22) Urban PCT, CSL14.

Some participants also advocated implementing a more holistic assessment whereby patients were seen in their own home:

> "We give a full holistic assessment so that we can see patients in their own home and look at their facilities, mobility and things like that, which can quite often be part of the problem that they've got, so it's more of a functional problem than anything else." (23) Urban PCT, CSL10.

The majority of participants reported that within their continence clinics they adhered to NICE guidelines, which recommended that every patient is offered an assessment:

> "I think that we are following national policy quite well within the continence service. Every patient is being offered a continence assessment by a suitably qualified member of the team." (24) Rural PCT, CSL2.

One participant, however, stated that they were under pressure from non-clinical managers to bypass this process. Some of the participants also reported misgivings about the disparity in the quality and thoroughness of the assessments being provided by ward nurses in hospital and by district nurses to housebound patients and to nursing home residents who were unable to attend continence clinics:

> "The district nurses do what we would call basic assessments for us so they would see the patients that have been referred to them, usually by the hospital if they've been discharged from secondary care, and it's just basically a pad assessment." (25) Urban PCT, CSL10.
>
> "The district nurses who go to see the patients only assess for products. They don't look at the bigger picture." (26) Urban PCT, CSL7.

Continence education and specialist knowledge

Having a highly trained and knowledgeable workforce responsible for delivering high quality continence care was identified by the majority of participants as being an essential feature of a quality continence service for older people. Certainly all of the participants reported having at least one specialist continence nurse on their team:

> "I think one of the key features [of the service] is to have a suitable trained nurse and a suitable team to implement assessment and treatment as opposed to just products." (27) Urban PCT, CSL7.

In order to develop and improve the knowledge base and competency levels of their staff, all of the participants recognised the importance of providing and attending on-going staff training programmes, with one participant suggesting that education should be prioritised:

> "Training is an integral part of the service because obviously our service is with specialist nurses who themselves access training and maintain their level of competence." (28) Urban PCT, CSL11.

All of the participants recognised and acknowledged that district nurses and other health care professionals do not have the specialist skills and knowledge of the continence specialist nurse and felt that access to training for these professionals was essential to promote continence and to raise standards and parity in patient assessments:

> "I'd like to have more time with district nurses to bring up their level of continence assessment." (29) Urban PCT, CSL8.

A wide range of training programmes was provided by the majority of participants for anyone involved with looking after someone with continence problems. Some of the participants, however, revealed that they had experienced difficulties in delivering these programmes to their targeted audiences due to continence promotion not being recognised as a priority area by the trust and to staff shortages:

> "We've asked the question whether continence assessment training could be mandatory for district nurses but the trust aren't too happy to do that at the moment. (30) Urban PCT, CSL16.
> We have a training programme but the unfortunate thing is that a lot of teams are very short-staffed so being released from training is quite difficult." (31) Urban PCT, CSL3.

Allocating the blame

In addition to the six themes identified above, a seventh, cross-cutting theme emerged from the analysis indicative of participants' tendency to see the blame for many of the barriers to a good quality service as lying with other health professionals. Embedded within the quotations provided above is a consistent apportioning of responsibility to, for example: GPs (quotes (1), (2), (18), (19)); commissioners (4); and district nurses ((12), (20), (25), (26)). When other health professionals are not

identified as the main barrier to a good quality service, family carers and/or patients themselves are seen as part of the problem (quotes (3), (5), (6)). One can question, therefore, the veracity of the service leads' perspective, which may be informed, as per the tenets of attribution theory [30] by a self-serving bias in which the cause of problems is externalised, rather than acknowledging that the potential causes of poor service outcomes may be partly due to one's own behaviour (or in this current context, a group-serving bias might be operating in order to defend the credibility of one's own professional group [31]). Where specific groups of individuals are not pinpointed as creating problems, the issue of a lack of investment in capacity, training, infrastructure, etc., is presented as a further 'external' causative factors (investment in service capacity theme). With regard to facilitating positive developments within the service, there is some evidence within the data to suggest our participants see a role for themselves for positively influencing service development (e.g., quotes (29),(30), (31)), although even here such developments are frustrated by external actors; and there is no indication of, for example, creative solutions for working with low resources. The continence service leads identify their positive impact on individual patient expectations (quote (8)), but notwithstanding that one participant saw it as a 'challenge […] to try and persuade these staff there are things that can be done to help people and not just accept the problem.' (quote (1)), there is little evidence that the continence service leads saw themselves as responsible for advocating for a change of culture and practice around attitudes to older people and continence problems within the health service. This, despite their expressed perception that such is required.

DISCUSSION

The aim of this study was to explore the views and experiences of continence service leads in England in order to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI). Foremost among the issues raised by the continence service leads was a failure on the part of commissioners, managers and other health professionals in recognising the problem of UI and acknowledging the importance of continence for older people and the impact it has on other areas of health, such as quality of life, tissue viability and falls **[32].** Indeed some continence service leads

were highly critical of current commissioning practices which focused on purchasing pad provision rather than implementation of national guidelines, and feared that their continence services may not be recommissioned by their Clinical Commissioning Group after the 2013 National Health Service (NHS) in England reorganisation.

All participants posited that a positive attitude towards ageing and UI was a key factor in providing a good quality continence service and that a change in the current attitudes of commissioners and other health professionals towards UI and ageing was a key factor in improving continence services for older people with UI. This perceived failure by commissioners and other health professionals in valuing the importance of continence promotion in older people may be indicative of both the low status of UI and implicit ageism. Ageism, defined as a process of systematic stereotyping of, and discrimination against, people because they are old [33], is evident amongst some doctors and other health care professionals and has been shown to impact negatively on the care older patients receive [34-38]. Taken at face value, our findings would indicate a need for change at the top level to ageist beliefs and attitudes about UI held by commissioners and other health professionals, to a standpoint that advocates candidacy for the treatment of older people with UI.

There was consensus amongst the continence service leads that there needed to be investment in the development and implementation of integrated continence services to improve service quality and the patient experience. Results from earlier research suggest that integrated continence care in primary care improved the effectiveness of continence services and was associated with high patient satisfaction levels [39-42]. Although the National Service Framework (NSF) for Older People [14] required the establishment of integrated continence services for older people by April 2004 none of the continence service leads in this study worked in an integrated service. Indeed, findings from the latest national audit of continence care only reported four fully integrated continence services in England [20]. There would appear, therefore, to be a pressing need to adopt a more dynamic approach in the provision of continence services, whereby all practice professionals are involved in the prevention, recognition, assessment and treatment of UI

A lack of investment in service capacity was identified by our participants as being a key factor in failing to meet the increasing demand for continence services by older people. There may be

some reservation in accepting the notion that a barrier to a good quality service is merely the provision of further resources, and certainly such an interpretation needs to be challenged given that there is little research evidence of a simple relationship between investment and quality services. However, our participants did not advocate a blanket increase in investment, rather investment targeted at certain perceived needs, such as in the need for more clinics, specialised equipment and staff (including staff training). Of interest is the fact that such resources were envisaged to reduce the gaps in local service provision and facilitate access to and availability of continence services. Despite National Guidelines there appears to be a "post code lottery" for continence services. In particular clinical leads from the rural PCTs felt that a failure by their Trusts to invest in clinical infrastructure had a negative impact on their ability to provide a local continence service, exacerbated by the lack of public transport and the long distances patients had to travel [43]. This interplay between organisational and geographical barriers to older people accessing health services in rural communities is well documented. [43, 44]. For rural continence services this interaction between organisation and geography was amplified by staff shortages, as most staff work part time, resulting in fewer clinics being held due to the length of time spent in travelling. A better understanding of the issues surrounding rural health would seem to be required by commissioners to ensure proofing of rural continence services, so as to identify and support the principles underpinning best practice.

The delivery and implementation of a full continence assessment by highly trained individuals, together with continence promotion to every patient, regardless of age, were identified by all continence service leads as two of the key features of a high quality and effective service for older people with UI. The European Association of Urology guidelines on UI advocate that healthy older people should be offered a similar range of treatment options as younger people and that treatment should be individualised for frail older people [45]. Moreover, NICE guidelines specify that absorbent products are not a treatment of UI but rather should be used as: a coping strategy for patients awaiting definitive treatment; an add-on to on-going therapy; and long-term management of UI only after other treatment options have been explored [19]. Our results, however, indicated a widespread feeling of frustration amongst the continence service leads at not being able to fulfil and realise all of the unmet needs for continence care services on account of patients not knowing what they want or what treatments they could have, inappropriate referrals by GPs and other health professionals and a lack of investment in service capacity, service integration and health professional education. The

quality of continence assessments delivered to domiciliary and nursing home patients by district nurses and other health professionals, as opposed to continence nurse specialists, was also deemed to be an inferior key service characteristic which contributed to the disparity in the quality of care for older people with UI. Furthermore, in certain cases, this was compounded by GPs and other health professionals referring patients into the wrong service, delaying their referrals, or in extreme cases not referring patients at all to the continence service.

At one level, the participants' identification of other health professionals as being 'part of the problem' with regard to the failure to deliver a high quality continence care service is borne out by evidence. For example, research indicates that GPs prefer to prescribe medications and pads due to a lack of faith in the efficacy of conservative treatment of U, and have a lack of knowledge of continence services [47-50]. Moreover, many GPs receive limited training and skills for the treatment and assessment of UI at both undergraduate and postgraduate levels [47, 49, 50] and have a substantial deficit in geriatric knowledge and training [47]. Likewise, findings from a recent nursing survey revealed gaps in nurse training and education for continence management, suggesting that nurses are not receiving sufficient support to assess and care for people with UI [51].

However, it is necessary to consider this 'pointing of the finger' as potentially due to other factors. Earlier we considered the self-serving bias for negative events to be attributed to external causes, but our findings could also be related to research on intergroup relations, which in general suggests that successful collaboration around a common purpose should lead to positive intergroup interactions, and less stringent group boundaries, whereas collaboration carried out under strained circumstances, and with less clarity around a common purpose, results in stronger in-group identification and more negative out-group perceptions [52]. Placed within the context of inter-professional working, it could be argued that status issues (e.g., medical versus nursing power within the National Health Service) might foster conditions whereby GPs refer directly to other medical services in acute hospitals; or that finite resources create the conditions for territorial disputes between 'specialist' continence service leads and 'generalist' health professionals such as GPs and district nurses [53, 54].

Nevertheless, if the level of frustration expressed by the continence service leads with the failing of fellow health professionals (and by extension the health service itself) reflects actual shortcomings, then one might understand why there seems within this group an apparent lack of

initiative to effect real and significant improvements in service quality. If perceived control over the quality of their service is low, and this perception is enduring, then one might hypothesise the manifestation of a state of hopelessness whereby, no matter what one does, the anticipation is always of a negative outcome [55].

Strengths and limitations

This study only presents views on continence services from one perspective, that of service leads, and it is entirely true that this perspective may not in all respects correspond with the perspectives of, for example, GPs or commissioners. While comparison across different stakeholders would have been welcome, space restrictions would have precluded a detailed analysis of the perspective of a single stakeholder group as provided in this study. Further research is required to establish the perspectives of other stakeholder groups on the barriers to, and facilitators of, a quality continence care service. While there are always limits on the extent to which one can generalise the results of qualitative research, our findings have good face validity as the main themes identified in our analyses are reflected in relevant studies [56]. Our sampling strategy ensured a good representation of participants from across the range of former SHAs, while the use of qualitative interviews was the optimal method for this study as it allowed participants to discuss in detail and to express openly their opinions on the barriers to a successful service and how continence services for older people could be improved. Data were only collected in England as healthcare in Wales, Scotland and Northern Ireland is devolved and has no internal healthcare market, and so the study has a limited contribution to the debate on continence management in these areas of the UK.

CONCLUSION

From the perspective of continence service leads, patient assessment and continence promotion regardless of age, rather than pad provision, were identified as facilitators of the delivery of a high quality service for older people with UI, embedded within a change of attitudes to older people and UI among commissioners and other health professionals. More rapid and appropriate patient referral pathways, investment in service capacity, (including trained staff and facilities), strengthened inter-service collaborations and a higher profile for UI within medical and nursing training were specified as

being important for delivering an equitable and high quality continence service. Further research is required to determine whether change within these identified priority areas may lead to the raising of standards in continence care for older people with UI. There should, however, be concern that, overwhelmingly, the participants in our study identified problems in the delivery of a good quality continence care service as located within the behaviours and attitudes of other health professionals, the health service in general, or even family carers or patients themselves. While potentially a true reflection of the situation, there is also an alternative interpretation that the pervasiveness of this blame allocation is at least partly due to our participants being members of a perceived low-status group within the NHS, who are treating a group of patients also perceived to be low-status – an issue highlighted by the participants themselves. Addressing this latter situation, while challenging, might be regarded as of foremost importance: not just in terms of its direct impact on improving service quality as suggested by our participants, but also in terms of its potential indirect impact in reducing inter-professional blame-allocation and empowering specialist continence nurses to effect meaningful change for themselves.

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Improving continence services for older people from the service-providers' perspective: a qualitative interview study

Abstract

Objective: To examine in depth the views and experiences of continence service leads in England on key service and continence management characteristics **in order to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI).**

Design: Qualitative semi-structured interviews using a purposive sample recruited across 16 continence services.

Setting: Three acute and 13 primary care National Health Service Trusts in England.

Participants: Sixteen continence service leads in England actively treating and managing older people with UI.

Results: In terms of barriers to a good quality service, participants highlighted a failure on the part of commissioners, managers and other health professionals in recognising the problem of UI and in acknowledging the importance of continence for older people, and prevalent negative attitudes towards continence and older people. Patient assessment and continence promotion regardless of age, rather than pad provision, were identified as important steps for **a good quality service** for older people with UI. More rapid and appropriate patient referral pathways, investment in service capacity, e.g. more trained staff, and strengthened inter-service collaborations and a higher profile within medical and nurse training were specified as being important facilitators for delivering an equitable and high quality continence service. There is a need, however, to consider the accounts given by our participants as perhaps serving the interests of their professional group within the context of inter-professional work.

Conclusions: Our data point to important barriers to and facilitators of a good quality service for older people with UI, from the perspective of continence service leads. Further research

should address the views of other stakeholders, and explore options for the empirical evaluation of the effectiveness of identified service facilitators.

Article Summary

Article focus

- Urinary incontinence affects both men and women, but the quality of continence care provided is worse for patients aged 65 years and over compared to younger patients.
- To explore the views and experiences of continence service leads in England **to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI).**

Key messages

- Patient assessment and continence promotion regardless of age, rather than pad provision are the key issues for **improving continence services** for older people with UI.
- Improving attitudes towards continence and older people, together with more rapid and appropriate patient referral pathways, strengthened inter-service collaborations, investment in service capacity and a higher profile of UI within medical and nurse training may lead to the raising of standards in continence care for older people with urinary incontinence.

Strengths and limitations

- This study directly asked continence service leads in England to identify key features of a high quality and efficacious continence service for older people with urinary incontinence.
- Our sampling strategy ensured a good representation of participants and the use of qualitative interviews was the optimal method for this study as it allowed participants to discuss in detail and to express openly their opinions.
- Data from other stakeholder groups in continence care was not collected.
- Data were only collected in England as healthcare in Wales, Scotland and Northern Ireland is devolved and has no internal market. .

INTRODUCTION

Urinary incontinence (UI) is a common condition that affects both men and women **and is defined by the International Continence Society as, 'the complaint of any involuntary leakage of urine' [1]. Findings from an earlier epidemiological study to establish the prevalence of urinary symptoms in community-dwelling adults in Great Britain revealed that approximately 23% of women and 8.7% of men over the age of 40 years have urinary symptoms and that the prevalence and severity of symptoms increase with age [2-4]. For people with cognitive impairment or dementia living at home results from a recent systematic review reported that the prevalence of UI ranged from 1.1% in a general community population to 38% in those receiving home care services [5].** Direct costs of UI to the National Health Service (NHS) are reported to be greater than those associated with common chronic illnesses, such as coronary care and cancer care, with these costs expected to rise due to the increase in the ageing population **[6].**

UI can have a substantial impact on the physical, psychological, social and economic well-being of the affected individual and their families **[7-9],** as UI symptoms are associated with significant morbidity and an increased risk of hospitalisation and admission to institutional care **[10, 11].** Furthermore, negative attitudes towards older people (e.g. burden on society) and UI (e.g. distaste) are common in both society and health care, and impact on the provision of health care services **[12].** Although a higher prevalence of UI is associated with greater age **[2, 3, 13-15],** UI should not be considered a normal part of ageing as UI is a treatable condition **[16]. According to Fonda and Abrams' "Continence Paradigm" for defining incontinence and continence management for all ages, UI can be controlled by behavioural treatments, medications or with toileting assistance or contained with pads or appliances [17].** Left untreated, however, UI is a chronic rather than a self-limiting condition, with a propensity to worsen over time.

UI usually presents and is identified in primary care settings by General Practitioners (GPs) and nurses, although the pathways to diagnostic assessment can be inconsistent with some individuals being referred directly to a variety of specialists in secondary care (e.g. physiotherapists, gynaecologists, urologists, geriatricians or specialist nurses based in secondary care) without any assessment or treatment [18]. Continence services in England are provided by GPs, Acute Trusts, private providers for the NHS, alternative providers, e.g.

social enterprises and primary care providers; with treatment being delivered in hospitals, GP surgeries, nursing and care homes, community clinics and primary care centres [18]. Generally, however, symptomatic diagnoses occur in primary care and condition-specific in secondary care.

According to the National Institute for Health and Clinical Excellence (NICE) guidelines for commissioning a urinary continence service, primary care and community teams are expected to have trained professionals able to perform initial assessment and conservative management of UI and/ or a referral pathway to a specialist continence service [19]. In addition, patients presenting with UI and symptoms indicating a more complex condition should have access to a specialist continence service that employs, amongst others, specialist continence nurse advisers (registered nurses with extensive training up to degree level in continence care and able to work as independent practitioners) and specialist physiotherapists [18]. Despite these recommendations, the latest National Audit of Continence Care **[20]** found that poor integration of continence services across the hospital, primary care, mental health and care home settings, resulted in disjointed care for UI patients and their carers, variable levels of adherence to NICE guidelines, and gaps in organisational standards and clinical care. Furthermore, quality of care was found to worse for patients aged 65 years and over compared to younger patients.

Whilst audit is a tool able to measure the quality of care and services against agreed standards, it is unable to provide new knowledge in order to determine best practice. To date, the contribution made by service characteristics and the management of continence at both the service and personal level to attain **optimal quality of care for older people with UI** has not been addressed. To put this into context, as part of a programme of research tackling ageing continence through theory, tools and technology (**TACT3**), the **aims of the** qualitative study described in this paper **were to explore the views and experiences of continence service leads (specialists) in order to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI). Such knowledge may be important to the development of patient care and the design of professional education programmes and to inform service commissioners.**

METHODS

Design

The study had a qualitative design, incorporating semi-structured telephone interviews, with purposive sampling of participants via a stratified sampling frame based on all former English Strategic Health Authorities (SHA).

Participants and setting

This study was targeted at **senior and specialist continence nurse practitioners acting as continence service leads** in NHS Trusts in England providing a continence service for community-dwelling people aged 50 years and over. **We targeted the leads of specialist continence services rather than GPs or District Nurses because they are: (1) expert practitioners with extensive training in continence care and; (2) front line staff in delivering continence services.**

A non-random sampling strategy was used to recruit a purposive maximum-variation sample of continence service leads from urban and rural NHS Trusts located within the SHAs. As far as possible when employing a qualitative design, this approach would provide the broadest representation of continence service leads from across England, ensuring that a wide range of perspectives would be present in the dataset so that the issues of continence problems could be considered from all angles prior to identifying the common themes evident in the data **[21]**. An information email inviting expressions of interest was sent to 40 continence service leads; four in each of the geographical areas of the SHAs. Inclusion criteria were: (1) service provided a continence service for people aged 50 years or older; (2) participants' contact time with patients > 60% of their working week so that they have valuable knowledge of working within their continence service. Twenty-six out of the 40 service leads originally approached who met our inclusion criteria agreed in principal to be interviewed. Ten potential participants withdrew from the study leaving a sample size of 16. The most common reasons for withdrawal from the study were: (1) due to Trust reorganisation potential participants did not have the time to participate in the study and; (2) loss of contact due to people leaving their post and/or not responding to follow up emails. **Due to the time constraints for this study and the length of time required to apply for and gain NHS research governance**

approval, we did not replace the original ten participants who withdrew from the study. Three participants were located in acute trusts, three participants were located in rural primary care trusts (PCT) and ten participants were located in urban PCTs.

Interviews

Data were collected by individual in-depth, semi-structured telephone interviews. A topic guide was developed by the research team from the recommendations reported in the Good Practice in Continence Services document [**22**], the National Service Framework (NSF) for Older People [**23**], NICE guidelines **[19]** and the National Audit of Continence Care [**20**]. Topics covered included the nature of service provision and priorities, challenges in meeting these priorities, the impact of national policy on service provision, the key features of service provision, how services could be improved and how trusts could improve continence care for older people. Interviews were conducted between April 2011 and January 2012 at a time convenient for the participant. The average interview time was approximately 45 minutes. Oral consent from the participants was recorded at the beginning of the interviews and all participants were offered a hard copy of the consent form. Interview data were collected confidentially and digitally recorded within the university by a member of the research team and transcribed. During the interviews, first names only were referred to and names were not recorded in the transcriptions.

Analysis

The interview transcripts were analysed using **Framework Analysis [24], which is an approach to qualitative data analysis developed by social policy researchers in the UK and increasingly used in health care research [26]. Framework Analysis is a pragmatic approach for applied research, developed to address specific real-world questions and with less focus on producing new theory than other approaches to qualitative data analysis, such as grounded theory [26]. In accordance with Framework Analysis, the data analysis** followed a five stage process **[24, 26, 27]:**

1. **Familiarisation: becoming familiar with and getting an overview of the richness, depth and diversity of material gathered.**
2. **Identification of the thematic framework: identifying key issues, concepts and themes according to which the data can be examined by combining *a priori* issues derived from key concepts in the literature and the aims of the study (deductive analysis) with categories derived from the data (inductive analysis).**
3. **Indexing: a process of applying the thematic framework to the data, using codes to identify specific pieces of data that correspond with differing themes (in other qualitative analysis approaches often called 'coding').**
4. **Charting: creating charts with headings and subheadings drawn from the thematic framework; in this study data were organised into a chart, using Excel, with participants as rows and emerging themes as columns.**
5. **Mapping and interpretation: pull together key characteristics of the data, and map and interpret the data set as a whole.**

Each stage **of the analysis** was conducted by the first author. **To improve inter-rater reliability** a selection of transcripts were reviewed by another member of the team (LD) to check for bias and alternative interpretation of the data. **Revisiting the interview transcripts, all themes were represented within the first 12 interviews, with an indication that data saturation had been achieved as no new themes emerged from the remaining interviews [28, 29].** In the presentation of the results, each quote is sequentially numbered, and attributed to the Continence Service Lead (CSL) interviewed via an identification code, allocated in the order in which the continence service leads were interviewed.

Ethics

A favourable opinion was obtained from NHS Bradford Research Ethics Committee (Ref No.: 10/H1302/93) and research governance approval obtained from the primary care and acute trusts in each location where the continence service leads worked.

RESULTS

Sixteen continence service leads participated in the study. There were more women (n = 14) than men (n = 2). Two participants were Clinical Lead Continence Nurses, six participants were Service Leads, two participants were Continence Nurse Specialists, two participants were Service Managers, three participants were Lead Specialist Continence Nurses and one participant was a Team and Clinical Facilitator. All respondents had spent a significant part of their working lives as continence specialists (mean 9 years, range 1 to 15 years) and the time in their current post varied from 1 to 15 years, with a mean of 6 years.

From the analysis, six themes emerged that related to barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary incontinence (UI), with an additional seventh cross-cutting theme. . These six themes were: Changes in attitudes towards older people **and** UI; Investment in service capacity; Appropriate and rapid patient referral; Patient assessment; Continence promotion regardless of age; Continence education and specialist knowledge; **and the seventh cross-cutting theme, Allocating the blame.** Each theme is considered in detail below.

Changes in attitudes towards older people and UI

Having a negative attitude towards UI and older people was identified by all participants as a key barrier to delivering good quality **care.** The following comment typifies this:

> "There's GPs [General Practitioners] out there still who will say to Mrs. Jones, 'well you're 85, you've had three children, what can you expect?' The challenge is to try and persuade these staff there're things that can be done to help people and not just accept the problem." (1) Urban PCT, CSL4.

It was felt by a number of participants that these negative attitudes towards older people with UI were reinforced by other health professionals', carers' and patients' lack of knowledge and understanding about UI, its treatment and the role of continence services in providing treatment for UI:

> "If we were to ask a GP, 'What does the continence service do?' they probably wouldn't be able to tell you." (2) Urban PCT, CSL3.

> "We found that a lot of carers are very quick to resort to the products and we're trying to get the message across that there are many things you can do before you put someone into pads." (3) Urban PCT, CSL5.

All of the participants agreed that to improve continence services and **quality of care**, current prejudices towards ageing and UI need to be recognised and addressed by patients, health professionals and service commissioners. In particular, if continence care for older people is perceived to be low priority and an unimportant health need, then investment in services and the efficacy of resultant treatments may be compromised. As one participant commented:

> "Commissioners of the [continence] service need to see it as important because if commissioners don't see it as important to meet the needs of older people then they're not going to commission a service if they think all it is is to provide pads, then that's all they're going to commission." (4) Acute Trust, CSL12.

Continence promotion regardless of age

The need to change negative attitudes towards UI and older people is closely linked with continence promotion. This, rather than pad provision, was identified by all of the participants as being a central tenet of the management of older people with UI:

> "Everybody should have the right to be continent so we really aim to try and get people continent whenever possible." (5) Urban PCT, CSL14.

The majority of participants, however, reported encountering problems in achieving this outcome, with several participants citing patients' and carers' expectations of just receiving pads from the continence service as the only treatment available to them:

> "People still view our service as the pad providers as much as we try and shout that we're not just about pads." (6) Urban PCT, CSL16.
>
> "The expectation seems to be an expectation of pads... it isn't any expectation that they might get better." (7) Urban PCT, CSL15.

Two of the participants described how they were able to manage and to change patients' and carers' expectations to resolve this issue and to produce better quality treatment outcomes for the patient:

"When I hear the patient's story, that yes they were looking for pads, I will explain to them what could be going on and that we will work with them to see if we can get them better... very few people then say, 'I don't want to get better', so it depends on how you deliver it." (8) Rural PCT, CSL6.

"If people's first interaction regarding continence is a positive one that gives you treatment, it's better than the first person they see saying, 'here are some pads'. We would be able to help more people and improve their symptoms rather than give them the message that you wear a pad and put up with your symptoms." (9) Urban PCT, CSL16.

Investment in service capacity

All of the respondents highlighted a lack of service capacity as being a major challenge in delivering a quality service for older people and that investment in service capacity was required to meet the increase in service demand:

"At the moment we've actually had a 100 per cent increase in referrals from this time last year so some of the challenges are that obviously we haven't changed staffing so capacity is becoming an issue." (10) Urban PCT, CSL10.

This increase in service demand may, in part, be a reflection of the current financial climate, with one participant reporting an increase in the number of people self-referring into their clinic in response to the expense of buying pads. Alternatively, this **increased demand for services may be a result of greater awareness and changes attitudes towards UI and continence services and/or** a manifestation of success breeding success:

"If you've got what I hope is a reasonably successful service, then more people are aware of you and more people are referred to you." (11) Urban PCT, CSL8.

All participants emphasised a staff shortage within their services which impacted on the quality and availability of the service they delivered. Indeed, some participants suggested that a lack of staff was associated with their difficulties in adhering to national policy, disparity in treatment outcomes and growing waiting lists, although one participant from a rural PCT did acknowledge that local geography also impacted on referral times into their service:

"With national policy we try as best as possible to work with it. Because of staffing levels it can be very difficult at times to adhere to the policies and not cut corners...and waiting lists go up [...] I don't think we're able to give the service that we should do to the elderly and it's left to the district nurses to treat

where we could go out and give specific treatments, where with the district nurses it's a pad service." (12) Urban PCT, CSL7.

"I have 2.5 whole time equivalent staff for half a million people...we don't have enough people...that has an impact because we've got referrals stacking up...we get over 1000 referrals a year. We do 40 sessions per month which sounds a lot, but because of the geography it isn't because we spend a lot of time travelling and there's other stuff to do." (13) Rural PCT, CSL6.

Moreover, some of the participants explicitly felt that an investment in trained staff and an integrated continence service with other health professionals was necessary to promote continence awareness and to improve the quality of patient assessments and treatment outcomes:

"If we had a proper team we could do all the assessments and offer every patient treatment. I think you need trained continence advisors, but it would be nice to have a paediatric continence advisor and it would be nice to have a physiotherapist." (14) Urban PCT, CSL7.

One participant, however, highlighted the difficulties they had experienced in forming an integrated service:

"We tried to go down the route of an integrated service... [but] in terms of access to a physiotherapist we've actually had difficulty within the county of finding anyone with the skills or wanting to develop those skills." (15) Urban PCT, CSL16.

Besides an increasing demand and a shortage of skilled staff, some participants also cited a lack of investment in clinics and equipment as being barriers to providing a quality service:

"We have a long waiting list in one particular area because there are no clinics based in that particular area." (16) Urban PCT, CSL3.

"If we had the staff and the equipment we could improve services... we have a lack of equipment such as bladder scanners." (17) Rural PCT, CSL1.

Appropriate and rapid patient referral

Several participants in the PCTS were perplexed by the lack of appropriate and timely referrals to their services from GPs and other health professionals. This was primarily attributed to GPs' lack of knowledge about continence services, and secondly to GPs and other health professionals referring patients to the wrong services**:**

> "Some GPs will refer people into hospital services when really it's not necessary. Because of a good relationship the hospital services send them to us, so for the poor patient it means they've got two appointments instead of one." (18) Urban PCT, CSL11.

Indeed, one participant noted discrepancies in referral pathways based on the patient's gender:

> "It seems to be male patients go straight to secondary care and bypass primary continence services in my area." (19) Urban PCT, CSL15.

The same participant also expressed concerns about perceived disparities in the quality of continence services provided to patients dependent on the referral pathway they had been allocated:

> "For the 80 patients a month that we get there's probably 100 patients a month with continence problems who are only seen by the district nurses and they will never be seen by our service, they won't be referred to us. They will be seen and essentially, 'padded up'. They won't be investigated or given a diagnosis. So there's a very unequal service going on at the moment." (20) Urban PCT, CSL15.

For practitioners working in the acute sector there was an added sense of frustration as patients identified with UI on the wards could not be directly referred to the outpatients' continence service on discharge, but had to be referred via their GP. Although this recommendation was included on the patients' discharge letter, it was unsure as to whether or not this was acted upon by the patients' GPs:

> "The key feature is for patients being referred in the first place, because I think that's part of the problem is that they are not referred when they've seen somebody about their bladder problems or it's been picked up on the ward. It's not always seen as important." (21) Acute Trust, CSL12.

The reported lack of appropriate and timely referral to continence services may seem paradoxical to the high demands of these services by patients, as found in the previous theme. The lack of appropriate and timely referrals, however, may instead be a result of the high demand and subsequent long waiting lists.

Patient assessment

A full patient assessment including complete history taking, physical examination, review of medication, urinary analysis, bladder scan, vaginal and rectal examination if appropriate, was seen by all participants as being a key feature of quality continence care for older patients, as this provided the

practitioner with the necessary information to make a differential diagnosis and to formulate an individual treatment plan for each patient:

> "You need to do a proper assessment so that you can actually make a nursing differential diagnosis, refer if necessary, then make a proper treatment plan up for that individual and then follow them through." (22) Urban PCT, CSL14.

Some participants also advocated implementing a more holistic assessment whereby patients were seen in their own home:

> "We give a full holistic assessment so that we can see patients in their own home and look at their facilities, mobility and things like that, which can quite often be part of the problem that they've got, so it's more of a functional problem than anything else." (23) Urban PCT, CSL10.

The majority of participants reported that within their continence clinics they adhered to NICE guidelines, which recommended that every patient is offered an assessment:

> "I think that we are following national policy quite well within the continence service. Every patient is being offered a continence assessment by a suitably qualified member of the team." (24) Rural PCT, CSL2.

One participant, however, stated that they were under pressure from non-clinical managers to bypass this process. Some of the participants also reported misgivings about the disparity in the quality and thoroughness of the assessments being provided by ward nurses in hospital and by district nurses to housebound patients and to nursing home residents who were unable to attend continence clinics:

> "The district nurses do what we would call basic assessments for us so they would see the patients that have been referred to them, usually by the hospital if they've been discharged from secondary care, and it's just basically a pad assessment." (25) Urban PCT, CSL10.
>
> "The district nurses who go to see the patients only assess for products. They don't look at the bigger picture." (26) Urban PCT, CSL7.

Continence education and specialist knowledge

Having a highly trained and knowledgeable workforce responsible for delivering high quality continence care was identified by the majority of participants as being an essential feature of a quality

continence service for older people. Certainly all of the participants reported having at least one specialist continence nurse on their team:

> "I think one of the key features [of the service] is to have a suitable trained nurse and a suitable team to implement assessment and treatment as opposed to just products." (27) Urban PCT, CSL7.

In order to develop and improve the knowledge base and competency levels of their staff, all of the participants recognised the importance of providing and attending on-going staff training programmes, with one participant suggesting that education should be prioritised:

> "Training is an integral part of the service because obviously our service is with specialist nurses who themselves access training and maintain their level of competence." (28) Urban PCT, CSL11.

All of the participants recognised and acknowledged that district nurses and other health care professionals do not have the specialist skills and knowledge of the continence specialist nurse and felt that access to training for these professionals was essential to promote continence and to raise standards and parity in patient assessments:

> "I'd like to have more time with district nurses to bring up their level of continence assessment." (29) Urban PCT, CSL8.

A wide range of training programmes was provided by the majority of participants for anyone involved with looking after someone with continence problems. Some of the participants, however, revealed that they had experienced difficulties in delivering these programmes to their targeted audiences due to continence promotion not being recognised as a priority area by the trust and to staff shortages:

> "We've asked the question whether continence assessment training could be mandatory for district nurses but the trust aren't too happy to do that at the moment. (30) Urban PCT, CSL16.
> We have a training programme but the unfortunate thing is that a lot of teams are very short-staffed so being released from training is quite difficult." (31) Urban PCT, CSL3.

Allocating the blame

In addition to the six themes identified above, a seventh, cross-cutting theme emerged from the analysis indicative of participants' tendency to see the blame for many of the barriers to a good quality service as lying with other health professionals. Embedded within the quotations

provided above is a consistent apportioning of responsibility to, for example: GPs (quotes (1), (2), (18), (19)); commissioners (4); and district nurses ((12), (20), (25), (26)). When other health professionals are not identified as the main barrier to a good quality service, family carers and/or patients themselves are seen as part of the problem (quotes (3), (5), (6)). One can question, therefore, the veracity of the service leads' perspective, which may be informed, as per the tenets of attribution theory [30] by a self-serving bias in which the cause of problems is externalised, rather than acknowledging that the potential causes of poor service outcomes may be partly due to one's own behaviour (or in this current context, a group-serving bias might be operating in order to defend the credibility of one's own professional group [31]). Where specific groups of individuals are not pinpointed as creating problems, the issue of a lack of investment in capacity, training, infrastructure, etc., is presented as a further 'external' causative factors (investment in service capacity theme). With regard to facilitating positive developments within the service, there is some evidence within the data to suggest our participants see a role for themselves for positively influencing service development (e.g., quotes (29),(30), (31)), although even here such developments are frustrated by external actors; and there is no indication of, for example, creative solutions for working with low resources. The continence service leads identify their positive impact on individual patient expectations (quote (8)), but notwithstanding that one participant saw it as a 'challenge […] to try and persuade these staff there are things that can be done to help people and not just accept the problem.' (quote (1)), there is little evidence that the continence service leads saw themselves as responsible for advocating for a change of culture and practice around attitudes to older people and continence problems within the health service. This, despite their expressed perception that such is required.

DISCUSSION

The aim of this study was to explore the views and experiences of continence service leads in England in order **to identify and improve our understanding of barriers to a good quality service and potential facilitators to develop and improve services for older people with urinary**

incontinence (UI). Foremost among the issues raised by the continence service leads was a failure on the part of commissioners, managers and other health professionals in recognising the problem of UI and acknowledging the importance of continence for older people and the impact it has on other areas of health, such as quality of life, tissue viability and falls **[32].** Indeed some continence service leads were highly critical of current commissioning practices which focused on purchasing pad provision rather than implementation of national guidelines, and feared that their continence services may not be recommissioned by their Clinical Commissioning Group after the 2013 National Health Service (NHS) in England reorganisation.

All participants posited that a positive attitude towards ageing and UI was a key factor in providing a good quality continence service and that a change in the current attitudes of commissioners and other health professionals towards UI and ageing was a key factor in improving continence services for older people with UI. This **perceived** failure by commissioners and other health professionals in valuing the importance of continence promotion in older people may be indicative of both the low status of UI and implicit ageism. Ageism, defined as a process of systematic stereotyping of, and discrimination against, people because they are old **[33]**, is evident amongst some doctors and other health care professionals and has been shown to impact negatively on the care older patients receive **[34-38].** Taken at face value, our findings would indicate a need for change at the top level to ageist beliefs and attitudes about UI held by commissioners and other health professionals, to a standpoint that advocates candidacy for the treatment of older people with UI.

There was consensus amongst the continence service leads that there needed to be investment in the development and implementation of integrated continence services to improve service quality and the patient experience. Results from earlier research suggest that integrated continence care in primary care improved the effectiveness of continence services and was associated with high patient satisfaction levels **[39-42]**. Although the National Service Framework (NSF) for Older People [14] required the establishment of integrated continence services for older people by April 2004 none of the continence service leads in this study worked in an integrated service. Indeed, findings from the latest national audit of continence care only reported four fully integrated continence services in England **[20].** There would appear, therefore, to be a pressing need

to adopt a more dynamic approach in the provision of continence services, whereby all practice professionals are involved in the prevention, recognition, assessment and treatment of UI

A lack of investment in service capacity was identified **by our participants** as being a key factor in failing to meet the increasing demand for continence services by older people. There may be some reservation in accepting the notion that a barrier to a good quality service is merely the provision of further resources, and certainly such an interpretation needs to be challenged given that there is little research evidence of a simple relationship between investment and quality services. However, our participants did not advocate a blanket increase in investment, rather investment targeted at certain perceived needs, such as in the need for more clinics, specialised equipment and staff (including staff training). Of interest is the fact that such resources were envisaged to reduce the gaps in local service provision and facilitate access to and availability of continence services. Despite National Guidelines there appears to be a "post code lottery" for continence services. In particular clinical leads from the rural PCTs felt that a failure by their Trusts to invest in clinical infrastructure had a negative impact on their ability to provide a local continence service, exacerbated by the lack of public transport and the long distances patients had to travel [**43**]. This interplay between organisational and geographical barriers to older people accessing health services in rural communities is well documented. **[43, 44].** For rural continence services this interaction between organisation and geography was amplified by staff shortages, as most staff work part time, resulting in fewer clinics being held due to the length of time spent in travelling. A better understanding of the issues surrounding rural health would seem to be required by commissioners to ensure proofing of rural continence services, so as to identify and support the principles underpinning best practice.

The delivery and implementation of a full continence assessment by highly trained individuals, together with continence promotion to every patient, regardless of age, were identified by all continence service leads as two of the key features of a high quality and effective service for older people with UI. The European Association of Urology guidelines on UI advocate that healthy older people should be offered a similar range of treatment options as younger people and that treatment should be individualised for frail older people **[45]**. Moreover, NICE guidelines specify that absorbent products are not a treatment of UI but rather should be used as: a coping strategy for patients awaiting definitive treatment; an add-on to on-going therapy; and long-term management of UI only

after other treatment options have been explored [19]. Our results, however, indicated a widespread feeling of frustration amongst the continence service leads at not being able to fulfil and realise all of the unmet needs for continence care services on account of patients not knowing what they want or what treatments they could have, inappropriate referrals by GPs and other health professionals and a lack of investment in service capacity, service integration and health professional education. The quality of continence assessments delivered to domiciliary and nursing home patients by district nurses and other health professionals, as opposed to continence nurse specialists, was also deemed to be an inferior key service characteristic which contributed to the disparity in the quality of care for older people with UI. Furthermore, in certain cases, this was compounded by GPs and other health professionals referring patients into the wrong service, delaying their referrals, or in extreme cases not referring patients at all to the continence service.

At one level, the participants' identification of other health professionals as being 'part of the problem' with regard to the failure to deliver a high quality continence care service is borne out by evidence. For example, research indicates that GPs prefer to prescribe medications and pads due to a lack of faith in the efficacy of conservative treatment of U, and have a lack of knowledge of continence services [**47-50**]. Moreover, many GPs receive limited training and skills for the treatment and assessment of UI at both undergraduate and postgraduate levels [**47, 49, 50**] and have a substantial deficit in geriatric knowledge and training [**47**]. Likewise, findings from a recent nursing survey revealed gaps in nurse training and education for continence management, suggesting that nurses are not receiving sufficient support to assess and care for people with UI [**51**].

However, it is necessary to consider this 'pointing of the finger' as potentially due to other factors. Earlier we considered the self-serving bias for negative events to be attributed to external causes, but our findings could also be related to research on intergroup relations, which in general suggests that successful collaboration around a common purpose should lead to positive intergroup interactions, and less stringent group boundaries, whereas collaboration carried out under strained circumstances, and with less clarity around a common purpose, results in stronger in-group identification and more negative out-group perceptions [52]. Placed within the context of inter-professional working, it could be argued that status issues (e.g., medical versus nursing power within the National Health Service) might foster conditions whereby GPs refer directly to other medical services in acute

hospitals; or that finite resources create the conditions for territorial disputes between 'specialist' continence service leads and 'generalist' health professionals such as GPs and district nurses [53, 54].

Nevertheless, if the level of frustration expressed by the continence service leads with the failing of fellow health professionals (and by extension the health service itself) reflects actual shortcomings, then one might understand why there seems within this group an apparent lack of initiative to effect real and significant improvements in service quality. If perceived control over the quality of their service is low, and this perception is enduring, then one might hypothesise the manifestation of a state of hopelessness whereby, no matter what one does, the anticipation is always of a negative outcome [55].

Strengths and limitations

This study only presents views on continence services from one perspective, that of service leads, and it is entirely true that this perspective may not in all respects correspond with the perspectives of, for example, GPs or commissioners. While comparison across different stakeholders would have been welcome, space restrictions would have precluded a detailed analysis of the perspective of a single stakeholder group as provided in this study. Further research is required to establish the perspectives of other stakeholder groups on the barriers to, and facilitators of, a quality continence care service. While there are always limits on the extent to which one can generalise the results of qualitative research, our findings have good face validity as the main themes identified in our analyses are reflected in relevant studies [**56**]. Our sampling strategy ensured a good representation of participants from across the range of former SHAs, while the use of qualitative interviews was the optimal method for this study as it allowed participants to discuss in detail and to express openly their opinions on the barriers to a successful service and how continence services for older people could be improved. Data were only collected in England as healthcare in Wales, Scotland and Northern Ireland is devolved and has no internal healthcare market, and so the study has a limited contribution to the debate on continence management in these areas of the UK.

CONCLUSION

From the perspective of continence service leads, patient assessment and continence promotion regardless of age, rather than pad provision, were identified as facilitators of the delivery of a **high quality service** for older people with UI, embedded within a change of attitudes to older people and UI among commissioners and other health professionals. More rapid and appropriate patient referral pathways, investment in service capacity, (including trained staff and facilities), strengthened inter-service collaborations and a higher profile for UI within medical and nursing training were specified as being important for delivering an equitable and high quality continence service. Further research is required to determine whether change within these identified priority areas may lead to the raising of standards in continence care for older people with UI. **There should, however, be concern that, overwhelmingly, the participants in our study identified problems in the delivery of a good quality continence care service as located within the behaviours and attitudes of other health professionals, the health service in general, or even family carers or patients themselves. While potentially a true reflection of the situation, there is also an alternative interpretation that the pervasiveness of this blame allocation is at least partly due to our participants being members of a perceived low-status group within the NHS, who are treating a group of patients also perceived to be low-status – an issue highlighted by the participants themselves. Addressing this latter situation, while challenging, might be regarded as of foremost importance: not just in terms of its direct impact on improving service quality as suggested by our participants, but also in terms of its potential indirect impact in reducing inter-professional blame-allocation and empowering specialist continence nurses to effect meaningful change for themselves.**

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