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**Caring for continence in stroke care settings – a qualitative study of patients’ and staff perspectives on the implementation of a new continence care intervention in a stroke ward setting.**

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## **Abstract**

**Objectives:** To investigate the dual perspectives of patients and nursing staff on the implementation of an augmented continence care intervention in a stroke ward.

**Design:** Qualitative data were elicited during semi structured interviews with stroke patients (n=15) and staff (14 nurses; 9 nursing assistants) and analysed using thematic analysis.

**Setting:** Mixed acute and rehabilitation stroke ward.

**Participants:** Stroke patients able to participate in an interview and nursing staff that experienced an enhanced continence care intervention.

**Results:** Four themes emerged from the stroke patients' interviews (a) communication about continence (b) continence care provision, (c) functional abilities and (d) personal choice and decision making in continence care. Patients' perceptions of continence care reflected the severity of their urinary incontinence. Staff described changes in (i) knowledge as a consequence of specialist training, (ii) continence interventions (including the development of nurse-led initiatives to reduce the incidence of unnecessary catheterisation amongst patients admitted to their ward) and (iii) changes in attitude towards continence from containment approaches to continence rehabilitation and (iv) the challenges of providing continence care within a stroke care context including limitations in access to continence care equipment or products and institutional attitudes towards continence.

**Conclusion:** Continence care is a complex issue involving patients, the nursing team and the wider multidisciplinary stroke rehabilitation team. The enhanced continence care intervention may facilitate a shift in nursing approaches to continence care. Patients face significant challenges in communicating about continence issues and involvement in their own continence care.

## INTRODUCTION

On admission to acute stroke settings 40-60% of patients experience urinary incontinence (1)(UI - any involuntary leakage of urine (2)) with a quarter still having UI at discharge and 15% continuing to experience problems a year after their stroke.(3, 4) Stroke-related UI is linked to greater dependence and severity of disability, poorer rehabilitation outcomes, discharge destination and even death. (3, 5-7) Where UI is poorly managed a range of secondary problems may arise including dehydration, skin breakdown and urinary tract infection. (8) The annual cost of stroke-related UI is estimated to be in the region of £743 million (with £536million in NHS costs alone). (9) Despite the impact on clinical and economic outcomes the evidence base to support continence care within supported care settings is lacking, particularly in the context of stroke related UI. (10, 11)

Continence care is a highly complex clinically embedded intervention. While some national continence care guidelines and tools are available they either focus on generic continence issues (relevant to a wide range of population groups and UI aetiologies e.g. (10, 12)) or specific to selective aspects of continence care (e.g. catheter care (13)). At local ward level the continence care context appears to vary considerably across sites with little consistency in the availability and type of continence policies, guidelines (14) and products. Support from specialist continence advisors may not always be accessible. (15) These site-specific variations in continence care may account for some of the differences in prevalence observed across sites. (11) National audit data from England highlighted that less than two thirds of patients with UI after stroke had a documented individualised continence care plan. (16) Despite best efforts there has been little change in that 'unacceptable' figure over the last decade. (15, 16)

Patients with stroke-related UI are increasingly considered to be a heterogeneous group, comprised of several subgroups with defined incontinence profiles. (11) Consequently generic tools are unlikely to address their complex needs. As with most stroke rehabilitation interventions, the exact continence care approach adopted will likely depend on the individual, their presentation, experiences and needs. (11, 16) Individual care plans based on a physical assessment and detailed history, together with details of the stroke and UI presentation are thought to offer the best hope for patient recovery. (15, 16) Continence care in hospital settings is reliant on all members of the nursing staff (10) with continence care (and in some cases assessment) often delegated to nursing assistants.(10, 17) Though staff are motivated, they have been found to be lacking in their knowledge and attitudes towards continence care. (17) Guidance to support staff in the assessment

of UI after stroke and the development of individualised continence promotion plans following stroke does not to-date exist. Ideally, stroke survivors should be involved in the development of such care plans but a better insight into the perspectives of stroke survivors' and nursing staff on continence care delivery in stroke care settings may inform this approach.

In this study completed in 2010, we developed an enhanced stroke-specific complex UI intervention and implemented it in a single stroke care setting. Our intervention sought to impact on the continence care experienced by patients, delivered by staff and supported at ward level by non-ward based specialist services. We sought to identify barriers and challenges to the implementation of the intervention and those aspects of the intervention that needed adjustment. Such insights may inform planning of clinical service delivery and our future research designs. Here we report the perspectives of patients and staff on the implementation of the complex continence care intervention.

## **METHODS**

Following approval from the Scotland A Research Ethics Committee and NHS R&D, using a mixed methods approach, we evaluated the implementation of a complex clinically embedded UI intervention within a mixed acute/rehabilitation stroke ward in a Scottish hospital over a four month period. This paper reports on data from the interviews only. Our enhanced programme of care included staff training (accessible to all members of the stroke multidisciplinary team), access to a continence assessment tool, protocol of care, improved links to continence care experts, continence assessment equipment (e.g. bladder scanner) and products. In this way we expected patients would receive an augmented continence care service (individualised continence care plans based on detailed assessment of patients' continence status). (18) All patients admitted to the ward within one month of a primary diagnosis of stroke received continence care that was subject to components of our enhanced continence care programme, even those with severe communication and cognitive deficits.

### **Recruitment and Consent to interviews**

Only those participants with capacity to consent and who were considered communicatively able to participate in a semi-structured interview were approached to participate in interviews. Patients with cognitive impairments were excluded from interviews as this data collection process meant that their participation in interview was not appropriate. Given the likely heterogeneity within the sample we anticipated interviewing between 12 and 20 participants to achieve data saturation. (19) All registered nurses and nursing assistants were approached for interview. All participants (both

patients and staff) were informed, provided consent and recruited to participate in the study and data collection procedures.

### **Data Collection**

One member of the research team conducted all the face-to-face semi structured interviews (KJ). Interviews were conducted with the nurses and nursing assistants at the end of the four month intervention implementation period and with patients on their discharge from the ward. Interviews were digitally recorded and field notes were taken. All interviews were orthographically transcribed, transferred to word documents and analysed manually guided by the Framework approach to data analysis. (20)

The interview schedules were piloted, reviewed and refined after the first and second interviews. Further reviews took place alongside data from subsequent interviews to ensure the schedule continued to support the elicitation of important data. The interviews focussed on patients' views of their continence care (including their perception of its patient centeredness) and the degree to which care met their individual needs. Each member of staff was asked to discuss their perceptions of the enhanced program of care, the staff training, perceived changes in clinical practice and in attitudes towards continence issues, how the tools were implemented and their ease of use and functionality. The interview schedules are available in Appendix 1. To contextualise the sample we report the patient demographic data (age, gender, length of hospital stay), other stroke data including the modified Rankin Scale (22) (as recommended by the European Stroke Organisation Outcomes Working Group<sup>5</sup> (21)) and continence symptoms using the ICIQ and the Urogenital Distress Inventory (UDI-6) (23) on admission to the study.

### **Data Analysis**

Drawing on the Framework Approach to data analysis (20) an initial familiarisation of all the patient and staff data was undertaken –through repeated listening to all recordings and reading of all the transcripts . An initial thematic framework for the interview data was then systematically developed based primarily inductively on the data with some a priori codes based on the research questions by one of the research team (KJ). Interview transcripts and emerging themes were reviewed and discussed with other members of the research team (CB and MB) until a final thematic framework was developed and applied across the dataset. To explore patterns in the data we charted all the data around the thematic framework and then

utilised this charting to search for patterns to map and interpret the data. In this manner we also undertook relevant comparisons such as comparing data from patients who were continent or incontinent and between registered nurses and nursing assistants.

## **RESULTS**

Of the 30 patient participants admitted to the ward with a diagnosis of stroke and recruited to the study, 15 were able to participate in an interview. Of the 33 members of nursing staff employed on the ward, 23 (70%) were available to participate in interviews. The remaining members of staff were unavailable for interview (due to being on leave secondment or sick, maternity or holiday leave arrangements).

### **Patients admitted with stroke**

The 15 patients interviewed had a mean age of 70 years (SD 14.33; range 37-88) and a mean length of hospital stay of 13 days (SD 10; Range 3-38). Ten were considered to be moderate-severely impaired on a disability scale (Modified Rankin Scale (mRS) 3-5) while five were admitted with slight or no disability (mRS 0-2). Based on available imaging data the patients had a new infarct (n=9) or haemorrhage (n=3), an extension to an old lesion (n=2). Lesions were located in the mid cerebral (n=3), frontal lobe (n=3), lateral ventricle (n=2), posterior parietal (n=1) basal ganglia (n=1), lacunar (n=1) or parieto-occipital region (n=1). A specific site was not described in 3 cases. All patients were admitted via local A&E or the emergency admissions ward. Additional demographic and clinical data are presented in Table 1.

Most were continent at the time of interview, though many were admitted with UI problems (n= 10) or were catheterised (subsequent to the stroke but prior to admission to the stroke ward n=2). In seven cases some mixed continence issues pre-existed the stroke (Table 1). These pre-existing continence issues had not resulted in any previous bladder training or surgical intervention. The interview participants experienced no significant change in their feelings of distress overall caused by the symptoms of the UI between admission and discharge as measured on the Urogenital Distress Inventory (UDI-6) (23) (mean change UDI-6 score 0.2, SD 0.97; 95% CI 0.2,0.6; t=1.2, p=0.3). A total of 9 individuals reported being moderately to greatly bothered by their urinary incontinence. Patients were asked to describe their recent continence care management and describe how important they thought their continence needs were to the healthcare team. Four overarching themes emerged from the patients' data (a) challenges in communicating about continence, (b)

mixed perceptions of continence care, (c) mobility versus continence status and (d) inconsistent patient involvement in decision making.

***(a) Challenges in communicating about continence***

Communication about continence (verbal or written) between patients and nursing staff was lacking. Patients described very different experiences of communication about continence. Issues related to (i) initiating conversations about continence care (by staff and by patients) and (ii) a lack of continence information provision and exchange. Each patient quotation is indexed as P followed by the study identification number, male/female (M/F) and continence profile (e.g. continent, mixed incontinence, urge).

*(i) Initiating continence conversations*

In some cases patients with UI following their stroke did not perceive their UI as stroke related. As a result some patients refrained from informing staff about episodes of UI. Others did not inform staff because they were embarrassed, were unsure as to how staff could have assisted or perceived a disinterest amongst staff in UI related issues.

*I didn't really....no...too embarrassed...it [UI] was enough to wet my trousers but I didn't think it was worth mentioning* *P18: M:Continent*

Others placed the responsibility of initiating such conversations with nursing staff. Although there were opportunities for a discussion relating to continence, a lack of prompting from nursing staff led to the patients masking their continence problems for fear of further interventions or prolonged hospital stays. In other cases obvious UI appeared to elicit no comment from staff.

*Well if I told them then I don't know what they would do.....but I didn't....the bed ridden ones they'll have catheters of course....but for someone in my state of health I don't think that would be necessary...you know....having a catheter....* *P18: M:Continent*

*No....they haven't said anything about it.....I was wet through the night I came in and they just changed the bed and everything and said nothing* *P23:F:Urge & Nocturia*



In some cases patients' communication in relation to continence issues was influenced by the perception of continence as of lower priority than other aspects of recovery. One patient in particular related this to the invisibility of his particular continence problem.

*...I think if I hadn't said anything to them [nursing staff] that they wouldn't have known at all.....well they can see that you need help to walk or to move your arms but they can't see this [continence problems]*

*P24:M:Acute retention*

Other patients described being open to discussions relating to their continence needs but they lacked opportunities to do so.

*I just said 'I'm still having trouble with my waterworks'. But you know, they [nursing staff] weren't at all interested.*

*P13:F:Mixed*

In one case in particular a patient was able to compare their recent experience of care and discussions around continence issues to a previous hospital admission. She was able to reflect upon the realisation that UI was a common occurrence following stroke which seemed to help her discussing the issue.

*....Last time I was in hospital it [UI] wasn't mentioned and this time because I was so worried it really helped me because people were trying to make sure I could get to a toilet.....It wasn't difficult to talk about...I didn't feel like someone with two heads...I know now that it happens to a lot of people not just me....*

*P13:F:Mixed*

#### (ii) Information Provision and Exchange

In evaluating the implementation of our complex UI intervention we explored patients' perceptions of the study screening and assessment process. Many patients were unaware of any continence screening or assessment at any point during their stay on the ward.

*I don't think they have asked any questions about it, to be perfectly honest about it*

*P9:M:Freq & Urge*

About half (n=7) were aware of their continence being screened or assessed and described provision of continence information (verbal and written). Though some participants clearly recalled being

involved in a continence assessment or a continence intervention, patients at times lacked adequate information to allow an understanding of the reason for a subsequent intervention.

*I: Why were you asked to fill in a urine chart?*

*P: I don't know....I really don't know...it wasn't really explained to me ...to see how I was getting along I think*

*P8:M:Continent*

*I just know that the catheter was in and that was it*

*P12:F:Urge*

*No real reason has been given as to why I could need pelvic floor exercises. I put it down to weakness due to my old age. I'm 88 for goodness sake!*

*P11:F:Urge*

*I have been told about trying to hold the toilet for so many hours. Sometimes I don't know when I need the toilet so go anyway and I was not, that this was not the best thing to do but I have forgotten why.*

*P13:F:Mixed*

Patients who were referred to a continence specialist or on discharge to a district nurse (n=3) described information provision and an awareness of screening and assessment procedures.

### ***(b) Mixed perceptions of continence care***

Within the interviews we explored the patients' experiences of the type of care provided in relation to their continence. Patients' responses varied and the variations seemed to reflect the severity of the continence problems – those with mild problems tended to praise their care whereas patients with more severe UI did not. Some recalled good continence care which was given a high level of importance by staff and which they were satisfied with.

*The nurses were really very helpful....they were really kind .....they actually moved me to a bed space nearest the toilet...they always asked if I could manage myself and I could press a buzzer when I wanted to go and they would come and get me*

*P13 F: Mixed*

In contrast others were unaware of any care or described limitations to their continence care. Patients described their perceptions of the degree of importance nursing staff afforded to

continence care issues which varied from 'very important' (P12 F:Urge and P18 M:Continent) and 'an important issue' (P10 F:Continent) to some less positive perceptions.

*They don't find it [continence] important so they don't bother* P24: M:Acute Retention

*I was just left to it.* P11:F:Urge

Other patients were uncertain how important continence care was to staff. At times, they made the assumption that this aspect of care had been considered by staff despite having no evidence or recollection of this. In contrast however, some patients felt that improvements could have been made to continence care.

*I had to look after myself.....my own toilet things and that doesn't feel right....*

*... there could have been more care* P23 F:Urge & Nocturia

### **(c) Mobility versus continence status**

A number of patients recalled being questioned about using the toilet but their descriptions suggested staff were focused on the patient's mobility and ability to access a toilet rather than the ability to pass urine once there.

*... the nurse knew I could get to the toilet myself so it probably didn't come into the equation.....the nurse just asked if I was able to get up myself and are you able to stand...and was I steady on my feet and then said 'Right then, you'll be able to go to the toilet yourself.'*

P10 F:Continent

### **(d) Inconsistent involvement in decision making**

Patients were asked whether they were given a choice and able to make their own decisions about their continence care. Patients described decision making led by themselves, or by staff, while others again described joint decisions. Most expressed satisfaction with the decisions made. Two patients however described encountering difficulties when they tried to become involved in, or to direct their own continence management.

*I had to fight for that [catheter] and I knew what was happening...I had had a prostate problem before and I knew that something wasn't right because I couldn't pee properly but I told the nurse and she did nothing...I kept telling her but I think she thought I was being clever or something....she wasn't interested...I think she thought I was a nuisance or was telling her her job or something...but it wasn't till I demanded to see a doctor that she decided to do something about it....I hadn't pee'd all day and was damned uncomfortable...*

*P24:M:Acute retention*

For some patients, continence care choices were based on degree of physical independence. While one patient was happy with using a bottle while physically immobile, the degree to which this approach (which accommodated his mobility problems) was suited to or adequate for his continence needs did not seem to be considered. Other participants experienced some involvement in continence care choices while others had little or no involvement.

*They asked if I preferred to use a bedpan or a commode. I said 'I would rather go to the loo if possible'. They said that was fine...*

*P13:F:Mixed*

*I had to stay in bed and when I was using the bottle in bed I couldn't go properly. It felt like I wasn't finishing properly.*

*P8:M:Continent*

## **Nursing Staff**

We conducted interviews with 14 nurses and 9 nursing assistants at the end of the study. Each member of nursing staff was asked to discuss their perceptions of the study intervention, in particular, their training, whether they perceived any changes in clinical practice and in attitudes towards continence issues, how the UI screening, assessment and management tools were implemented and their opinion on their ease of use and functionality. Nurses described in particular (a) changes in their continence knowledge as a result of the training (b) a transitioning in their approach to continence care (c) changes in their attitude to continence care and (d) contextual changes to support optimum continence care.

### ***(a) Changes in Continence Knowledge & Training***

All registered nurses within the ward described receiving a basic level of continence education during their student training and most were engaged in completing their stroke core competencies. In some cases this also involved the continence sections of the Stroke Training and Awareness

Resources.(24) Continence product company representatives were reported as responsible for providing some registered nurses with continence product information and another member of staff within the hospital was responsible for teaching use of the bladder scanner. Only two registered nurses described attending a continence course following their student training. The nursing assistants had no formal continence training. They talked about being given 'in ward' information and relied upon the registered nurses to provide support and training (particularly towards their vocational awards). Many nurses and nursing assistants suggested their knowledge of continence management was limited and the ward culture tended to focus on containment (pads or catheters) and two hourly toileting, without any in-depth continence assessment.

(i) New and Old Continence knowledge

All but one member of staff described the training sessions in positive terms such as 'very informative' (e.g. S6;RN or NA indicating *Staff Id; registered nurse or nursing assistant*), 'in-depth' (S8:RN) and 'excellent' (S4;RN). One experienced member of staff was dismissive of the training component describing it as 'nonsense'. Referring to their own considerable nursing experience, the nurse felt the information within the training session was irrelevant.

*"I mean I've been here for 20 odd years. I've done professional studies on incontinence so to me it wasn't really relevant."* S21:RN

In contrast however, responses from other members of staff described the acquisition of new knowledge gained or the renewal of knowledge gained in the past. One member of staff (S15:NA) felt the session presented a lot of information to acquire in one session.

*"We all felt that we learned something as well as other bits being a really good refresher."* S16:RN

*"It was just really interesting. And being pretty new on the ward you know it really helped me. I think they should teach you that when you first start. It would be more helpful than trying to learn it all when you're here at work...it would have really helped me to know about them [fluid volume charts] before coming to the ward."* S18:NA

*"I think everybody enjoyed it and came back to the ward with the feeling that we understood a wee bit better"* S12:NA

The staff welcomed the availability of the training to the wider multidisciplinary team (S16:RN), the comprehensive inclusion of all nursing staff from the ward (S3:RN) and the off-ward location of the training (S3:RN). There was a clear sense of the impact of the training extending beyond the session.

(ii) Continence knowledge into practice

The nursing staff referred to many examples of the application of their newly acquired knowledge including the identification and assessment of continence problems and how this might inform a UI intervention. A small group (n=5) felt there had been no change to their practice.

*Yes, straight away I started look at patients differently and trying to watch them more closely, you know, checking to see if they were going to the toilet and whether they were going too often or looking worried about going.* S18:NA

*I suppose we do deal with incontinence but there was quite a lot that made you think about why they are incontinent and what we could do about their incontinence* S4:RN

Others described improved interpretation of fluid volume charts which had regularly been used in the ward to measure fluid intake and urinary output prior to the study. Staff described using the fluid volume charts to review the pattern (including frequency) of voiding, to identify the need to void and the impact of different fluid intake (drinks) on voiding. An improved knowledge of different urinary incontinence profiles and a greater insight into the use of fluid volume charts was perceived by staff as having informed their understanding of patients' needs which in turn informed their continence care plans.

*I would actually say that whereas before we didn't look at them [fluid volume charts] in great detail I would say now we do. To see when they are passing the most urine. Whereas before we didn't do that we just totalled it up to see what they were passing. Like what their intake and output was.*

S6:NA

*...Just being more aware of patterns of individual patients you know. What type of incontinence they have. Whether its urge or stress or mixed and actually making a plan and letting the rest of the team know that the patient is on this toileting regime...And discussing it with the patient obviously and then saying 'Every two or three hours'.* S22:NA

Use of the fluid volume charts however was variable and charts were often incomplete. Staff did report alternative ways of capturing accurate information on fluid output by for example, involving family members in recording the intake during visiting time or asking individuals (those with cognitive capacity) to complete their own chart. These approaches were described as useful, time saving and more accurate. Staff were also able to highlight a number of limitations including the high number of bank nurses employed on the ward during the course of the study (who had not participated in the training). In addition, staff felt it would have been better had all patients in the mixed ward (not just limited to those with a diagnosis of stroke) received their continence care based on the same approach.

### **(b) Transitioning to a culture of enhanced continence care**

Many staff described the translation of their new knowledge into practical continence interventions. Staff described improved insight into UI from the patient's point of view, tailoring the approach to continence care for that individual and discussing the plans with the patient.

*Taking their needs on instead of routinely catheterising them* S2:RN

*...she [patient] was buzzing every 15 minutes to half an hour needing the toilet and it was only dribs and drabs. So we spoke to her and asked her about going on to [the study assessment followed by bladder retraining]. ...now she's going every two hours and sometimes two and a half hours.* S1:NA

*... and when a young patient thought she would be incontinent and that was it, I explained about the different types of incontinence and she felt a lot better and she got her confidence back.* S6: NA

#### Functional and environmental adjustments

Changes described by staff also included providing advice to patients on toileting positions and changing the patient's environment in order to facilitate continence through easier access to toileting facilities.

*...how you said about incomplete bladder emptying ....I found that was very useful just to make sure that patients were emptying their bladder and you could say to them to sit forward that wee bit...to lean forward... and it did make a difference and I have used that since....* S23:RN

*I think staff are thinking more about “well so and so, they are starting to mobilise but they are too far away from the toilet so rather than you know having an accident, they know they need to go, but by the time they get there it’s too late”. So it’s “Let’s reconfigure this room. Let’s get their bed next to the toilet”*

S3:RN

### Confidence in Continence Care

Change in staff knowledge about and attitudes toward continence care was also reported to have impacted upon their confidence in identifying continence problems, planning interventions, providing continence care for their patients and supporting these care decisions with explanations. Improved levels of confidence amongst the staff were perceived to have had positive benefits for patients too.

*I think the training gave me the confidence to look closely at their toileting and that ...we had a lady in who was a bit confused and I dipped her urine and let the staff nurse know the results. The lady couldn’t really tell me about if it was sore when she wee’d or anything but she seemed to be going to the toilet more often. So, em, I got a urine chart so that we could try to look at how often she was actually going and how much she was drinking. I wouldn’t have done this before the training session.*

S18:NA

*I think the training gave us the confidence to speak to patients a wee bit more like openly, and, no, it was more than that. It was you know, having more knowledge, that makes you more confident doesn’t it? I’ve heard a few of the girls talking to patients about their toileting regime and it’s like you don’t have to feel guilty about telling them to try not to go to the toilet every 10 minutes. ...*

S16:RN

*I think it made you think more about when putting a catheter in....definitely made you think why you were putting it in and....you know....was it necessary.....and we are probably taking catheters out a lot quicker now.*

S19:RN

*I think it has improved the untrained [nursing assistants] even more because they’ll come to you and tell you about the continence, like the pad was dry or they’re just not getting there (to the toilet) or whatever.*

S2:RN

### **(c) Changed Staff Attitudes towards Continence**



Many staff felt that the attitudes to continence care on the ward had changed as a result of the study with a resulting increase in its prioritisation on the ward. Some members of staff that described no change on the ward explained their response reflected the lack of change in attitude amongst some members of staff *'the odd few who are just going to cause you problems'* (S19:RN) while others would always have been supportive of continence care (S23:RN).

*I think the whole thing [INSPIRE study] identified and highlighted how important continence is and has probably pushed it up their scale. I think if you look right back at to score continence out of 10 it would maybe be 3 or 4 but I think it's maybe up, at a higher number anyway. So that it's got a better priority so I think the fact that it's done that obviously has to benefit the patient* S8:RN

*I think it helped us to think about their problems more and really try to make sure we didn't leave continence problems until they were just about ready to go home...* S16:RN

(i) 'Getting Continence Back'

Staff also described a shift in approach from containment towards management of continence problems. The issue of UI was now perceived as an acceptable rehabilitation topic that could be openly discussed.

*... the past, yes, they [nursing assistants] came to me to say "So and so's complaining of pain" or "There appears to be an infection and they may need an antibiotic". But now they may be more aware of the importance of trying to get some sort of continence back to patients.* S8:RN

*I'm trying to think about what we used to do before. It was pad and pants and that would be it. They would be offered a urinal and if they could transfer to go to the bathroom then they would go.* S6: NA

*When we were doing this [complex intervention] anyway, there was more discussion on the ward. It's raised the fact that continence is a problem and that it can be managed individually to each patient instead of just always number 6 pad and pants.* S2:RN

(ii) Continence: a rehabilitation team responsibility

All AHP members of the stroke multidisciplinary team participated in that continence training component of our intervention. Some nursing staff felt it had changed AHPs' practice. Others did not

agree. This seemed to be related to individual AHPs, whether they would toilet a patient independently or seek ward support for that activity.

*I don't think there has been a huge change. Everybody seems to think it's our job [nursing] so they leave the toileting and that to us. It's a shame because sometimes patients don't understand what's happening. Like when they go to physio and end up being brought back to the ward wet because the physios won't take them to the toilet.* S12: NA

*They are actually changing patients and all that now, on the shifts that I've been on anyway. Whereas they never used to before the training.* S15: NA

#### **(d) Contextual changes to support optimum continence care**

##### **(i) Nursing Team**

Nursing staff anticipated challenges in maintaining their new prioritised approach to continence care when faced with service issues such as nursing staff shortages and the high level of clinical need on the stroke ward. In addition, shared continence care between nursing staff and nursing assistants raised some issues. Much of the data required for completion of the assessment tool (nature of the problem) and some of the interventions (fluid balance chart, containment products) were seen by the nursing team to be most accessible to the nursing assistants. Both nurses and nursing assistants on the ward highlighted the benefits of nursing assistants completing the tools with data they routinely collected. The nursing assistants were also recognised as those most aware of the volume and frequency of patients' UI. Supportive working relationships between the two groups could be further strengthened and developed.

*I wouldn't mind doing it [detailing continence information on assessment forms] but the staff nurses would have a problem with nursing assistants doing that...that would be the barrier...that a [nursing assistant] shouldn't be completing forms like that...that's more for trained nurses to do... S6:NA*

##### **(ii) Stroke Rehabilitation Team**

Nursing staff felt that continence care continued to be perceived as a nursing issue rather than a responsibility shared by the multidisciplinary stroke rehabilitation team (MDT). This perception reflected the degree to which individual members of the team considered continence care within their patient contacts and at team level to what extent continence issues were considered within the

team meetings. While patients' continence status was established within MDT meetings, continence care goals were not discussed.

*... and when you go to the meeting the question is "Is Mrs so and so continent or incontinent?" and then "Is that faeces or urine?"...and that's it....end of! And even when they get to point of discharge there's never a ... "Are they incontinent or continent?"...it's... "Can they transfer?" and if they can transfer they obviously have some mobility so "Let's discharge them"...*

S8:RN

(iii) Hospital Service

Some changes experienced by patients occurred as a result of an intervention component at a level beyond the ward setting. Staff initially only had access to one size of a continence pad which often did not fit patients well. As a consequence of the study, staff were able to order more than one size of pad from the ward procurement list. In a similar (but unforeseen) development, the nursing staff became aware of the high number of patients being admitted to their ward via admission wards with catheters inserted while in these locations. Taking a proactive approach the ward nursing staff discussed continence care with their colleagues from these settings. Staff described how this had reduced the number of catheterised patients being admitted to the ward from these settings.

*... speaking with A&E and the Ward 5 [emergency admission ward] staff they sometimes, because they [patient] were a stroke routinely catheterised. But... we said "Don't catheterise - we'll try other ways to manage their incontinence".*

S2:RN

*Not as many patients are coming from A&E and Ward 5 with catheters in situ. That's the difference I've seen.*

S6:NA

## DISCUSSION

### *Summary of findings*

Patients' perceptions of continence care varied but appeared to reflect the severity of their continence problems. Despite our intervention (and in stark contrast to nursing staff perceptions), patients described a lack of communication about continence issues and few opportunities to engage in discussion about the topic or plans for their own continence care. Some patients described situations where nursing staff appeared to evaluate continence status with reference to the patients' mobility and functional abilities rather than continence itself.

In contrast our training, screening and assessment components were perceived by the nursing staff to have had a positive impact on their identification, diagnosis and management of UI and general confidence in relation to continence care. Staff described a shift from containment to continence 'rehabilitation' based on individualised assessment and management which was very encouraging. Yet the patients' observations which were collected during the course of the study indicate that there is still much improvement to be made in communicating with and engaging patients in this aspect of care.

Our qualitative data highlighted (through the nursing staff description) the challenging multilayered contexts (nursing team, stroke rehabilitation team, hospital service) within which continence care is delivered on a daily basis. In our study changes to patients' continence care reflected intervention components initiated at other 'levels' of care; alterations to catheter policies in admission departments and wards, expansion of procurement lists and improved referral procedures. Some aspects of the wider context did not alter – our attempts to secure a ward specific bladder scanner failed and the resource was still shared with other hospital wards. Consequently future continence care interventions for stroke care settings should consider these broader contextually related issues which are likely to impact on the successful delivery of any continence intervention but which merely reflect the realities of delivering continence care in a 'real' clinical setting.

### *Strengths*

A qualitative approach to this implementation study has enhanced our understanding of the impact of our intervention both in terms of anticipated and unanticipated interactions between components of the intervention itself and between intervention components and the context within which it operated. Other contextual issues related to the operationalisation of continence care by a nursing team (registered nurses and nursing assistants), operating within a multidisciplinary stroke rehabilitation team and stroke ward, which in turn exists within a hospital setting were highlighted. Continence care interventions rarely occur in isolation and in the context of a stroke rehabilitation setting requires consideration of how the continence care will function within the wider service context. In addition, it is also likely that these interactions will vary across different teams, wards and hospitals and continence intervention development should consider and anticipate them and be flexible enough to accommodate them when required.

Some of our findings support recent work in relation to catheters in acute stroke care. Lack of policy, assessment and documentation has been observed (14, 25) together with a lack of communication with patients and their families in relation to catheterisation. (25)

### *Limitations*

As with most implementation studies our investigation of the implementation of a complex intervention at ward level was based in a single stroke ward on a small number of people who had experienced a stroke. We were unable to interview some patients, specifically those who were unable to participate in interview because they had severe communication or cognitive impairments, a subgroup of patients often most in need of nurse-led continence care. Amongst those patients interviewed, the nature of their stroke, related impairments and their continence status varied considerably. Some of this variation is likely to reflect a number of factors including differences in continence care knowledge, attitudes and skills between individual members of staff and in turn care delivered to individual patients. Similarly, some patients, particularly in the early stages of stroke recovery, may have been unable to recall (or participate in) specific continence interventions or conversations about continence, though others were able to describe specific continence related interactions and experiences. Based on the data generated within our patient interviews we did not feel that we had reached data saturation but because of the study's funding limitations we were unable to further extend our recruitment period.

Our staff data reflect the views of a small number of registered nurses and nursing assistants from a single stroke ward. Data saturation was reached. In contrast, our approach to data, seeking this qualitative data from both patients and nursing staff, provided us with the very important opportunity of capturing essential information about facilitating or perhaps augmenting the implementation of this complex intervention.

A recent case study evaluation of a systematic voiding programme for patients with stroke related UI had similar findings to our own. (26) Staff in that study initially described a 'containment' approach to continence care. As with our own research, the researchers found it was possible to shift that perception of continence 'containment' through the implementation of a comprehensive complex intervention with nursing staff on the ward to a more rehabilitative approach to continence care. Their investigation also highlighted the limited consideration of continence care issues amongst the wider stroke rehabilitation multidisciplinary team. As with our study, continence related issues were considered in the context of possible impacts on discharge arrangements but interestingly continence was also considered when it was perceived it might limit engagement in other rehabilitation activities. (26)

Additional research studies which aim to identify, describe and demonstrate the effectiveness of interventions for continence care after stroke are urgently required. However, in developing such interventions complex packages of care are likely to be required involving individualised care plans, based on personalised assessment and comprehensive screening of admissions to the stroke ward and facilitated through excellent communication skills at staff level and the good communication strategies within the ward, amongst the stroke rehabilitation team and beyond. Staff training appears to be a core component in facilitating a shift from containment approaches to enhanced rehabilitation approaches to continence care. Consideration of contextual factors within the nursing team, the stroke rehabilitation ward and the hospital setting are also essential to ensuring the implementation of any intervention in the stroke care setting.

## **CONCLUSIONS**

Continence care is a complex issue involving patients and all members of the nursing team. The wider multidisciplinary stroke rehabilitation team also has a role to play in continence care, though it is limited at present. Enhanced continence care intervention may facilitate a shift in containment approaches to continence rehabilitation approaches. Patients face significant challenges in continence communication and involvement in their own continence care.

### **Clinical Messages (50 words)**

- Continence care after stroke is a complex multifaceted intervention
- Stroke survivors experiencing continence problems should have the opportunity to participate in continence assessment and individualised care planning
- Staff appear to benefit from specific specialist training on continence assessment and care
- Continence care is a multidisciplinary team concern

### **Competing interests**

None

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**Table 1 Stroke Patient Demographics and Clinical Characteristics**

<b>Feature</b>	<b>Frequency n = 15</b>	<b>Percentage %</b>
<b>Gender</b>		
Male	5	33
Female	10	66
<b>Communication difficulties</b>		
Mild	2	13
Moderate	8	53
Severe	1	7
None	4	27
<b>Continence profile pre-stroke</b>		
Stress incontinence	2	13
Urge incontinence	4	27
Urgency but continent	2	13
Mixed incontinence	1	7
Nocturia	1	7
Urinary tract infection history	2	13
Acute retention history (enlarged prostate)	1	7
<b>Continence profile on admission</b>		
Functional problems leading to UI	8	53
Urge incontinence	4	27
Mixed incontinence	3	20
Stress incontinence	1	7
Nocturia.	4	27
Catheterised	2	13
<b>Frequency of UI leakage (ICIQ)</b>		
Never	3	20
About one a week or less often	5	33
Two or three times a week	3	20
Several times a day	1	7
All the time	1	7
(Catheterised)	(2)	(13)
<b>Volume of UI leakage (ICIQ)</b>		
None (continent)	3	20
A small amount	5	33
A moderate amount	2	13
A large amount	3	20
(Catheterised)	(2)	(13)

