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Living with an indwelling urethral catheter in a community setting: exploring triggers for unscheduled community nurse 'out of hours' visits.

Concise title: Urethral catheter community patients

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ABSTRACT

Aims and Objective: To explore the experiences of community patients living with a urethral catheter and those caring for them.

Background: Living at home with an indwelling urethral catheter often results in consequences that create a double-edged burden; firstly, on patients and their relative carers, and secondly in terms of unscheduled community nurse service 'out of hours' provision.

Design: One-to-one interviews, were conducted with patients living at home, their relative carers, qualified community nurses, augmented home carers, and health care assistant. Quantitative data in relation to frequency, duration and reason for visits were extracted from the community nurse 'out of hours' service database.

Results: Quantitative data showed that 20% of all community nurses, unscheduled 'out of hour' visits were triggered by an indwelling urethral catheter consequence. Qualitative data revealed that health and social care staff felt knowledgeable and skilled in urethral catheter management. Conversely, patients and relative carers felt poorly equipped to manage the situation when something went wrong. The majority of patients described the catheter as being a debilitating source of anxiety and pain that reduced their quality of life.

Conclusion: Urethral catheter complications are frequent and impact seriously on quality of life with informal carers also affected. Community nurses experienced frequent unscheduled visits. Patients often feel isolated as well as lacking in knowledge, skills and information on catheter management. Having better urethral catheter information resources could increase patient and relative carer confidence, encourage self-care and problem solving, as well as facilitate meaningful consistent dialogue between patients and those who provide them with help and support.

Relevance to Clinical Practice: Better patient information resources regarding urethral catheter management have potential to improve patient and relative carer quality of life and reduce service provision burden.

Summary Box:

What this paper contributes to the wider global clinical community

- The perspective of patients, their relative carer's and relevant health and social care staff relating to urethral catheterisation consequences.
- An understanding of the impact on a community nurse service in terms of unscheduled 'out of hour' visits triggered by indwelling urethral catheter consequences.
- An evidence base that supported the development of improved information resources to encourage self-care and problem solving for patients, and facilitate meaningful consistent dialogue between patients and those providing them with support.

Keywords: Continence, District Nursing, Education, Elder Care

INTRODUCTION

The introduction of the Foley indwelling flexible urethral catheter almost 80 years ago was a welcome replacement for its metal and vulcanised rubber predecessors (Feneley *et al.* 2015). However, this intervention continues to have common challenging consequences for patients including catheter associated urinary tract infection (CAUTI), encrustations, blockage (Cooper *et al.* 2016, Feneley *et al.* 2015) and incidences of urine bypassing (when urine passes between the outside of the catheter and the urethra) (Feneley *et al.* 2015, Theriault *et al.* 2012). Managing urethral catheter-related consequences creates a burden on health and social service resources, causing unnecessary attendance at accident and emergency departments and hospitalisations (Feneley *et al.* 2015). Living with an indwelling urethral catheter or with someone who has one also creates a strain in terms of managing the physical, psychological and social consequences (Darbyshire *et al.* 2016).

The study reported in this paper explored the burden of urethral catheter-related consequences through the experiences of patients living at home and those providing them with formal and informal care and support. Further, it examined the burden of urethral catheter-related consequences on the community nurse 'out of hours' service in terms of unscheduled visits over a designated two-month period in one health and social care partnership in Scotland. This paper provides insight into the significant time commitment by the community nursing service in caring for these patients, which has relevance from a national and international perspective. It also provides the evidence base for generating better patient information resources that encourages self-care and problem solving, through consistent dialogue, using a common language, between patients and those providing them with support.

BACKGROUND

A review of the literature was initially conducted to ascertain factors already known about urethral catheter-related consequences and to inform the design and focus of the present study. The search strategy utilised EBSCOhost (<https://www.ebscohost.com>) and CINAHL and Medline databases. Key words included; 'indwelling urinary catheter' and a) Management; b) 'Quality of Life' (QoL); c) 'Evidence based practice' (EBP). The search yielded 44 articles of which 21 were deemed appropriate to the study.

Multi-morbidity affects more than half of older people, often including cognitive impairment (Marengoni *et al.* 2011). Meanwhile, global population aging predictions include a significant percentage per population increase in older adults from 11.7% in 2013 to 21.1% by 2050 (United Nations Department of Economic and Social Affairs (Population Division) 2013). Concurrently, there is a trend for people with multi-morbidity and long-term conditions to live at home supported by community health and social work services as well as relative carers (Harvey & McMahon 2008, Kmietowicz 2006). If the number of people living at home with an indwelling urethral catheter increases, the incidence of urethral catheter consequences, including pain, infection (CAUTI), urine bypassing and blockage will also increase. In addition, living with an indwelling urinary catheter may impact negatively on quality of life (Wilde *et*

al. 2011). In a prospective study of 465 long-term patients living with an indwelling urethral catheter in the community, 506 emergency referrals resulting in unscheduled visits were recorded for catheter-related consequences (Kohler-Ockmore & Feneley 1996). These catheter-related consequences create a burden for patients and their families as well as health and social care services.

Patients with an indwelling urethral catheter have reported often resorting to trial and error practices or internet searches, when curious about issues such as managing their social and sex life with a catheter plus seeking information on preventing infections (Chapple *et al.* 2016, Prinjha *et al.* 2016). Roe and Brocklehurst (1987) suggested that education could improve patient acceptance of a urethral catheter, and potentially improve quality of life. The need for clear concise evidence based information for patients is well recognised (Prinjha *et al.* 2016). Godfrey (2008) suggests that nurses are in a prime position to provide such information, and patients benefit from care provided by healthcare professionals who are accepting, skilled and knowledgeable. There is, however, little known about the nurses' understanding of the information available for patients with an indwelling urethral catheter or the consistency with which it is shared.

The objective of this study was to explore the experiences of patients with catheters living at home and those providing them with formal and informal care and support. Further, the objective was to examine the urethral catheter-related consequences on a community nurse unscheduled 'out of hours' service in one health and social care partnership in Scotland.

METHODS

The study was conducted using both quantitative and qualitative approaches. The sample included patients living at home with an in-dwelling urethral catheter, their relative carers and health carers.

Design and setting

The Out of Hours District Nursing service within West Dunbartonshire manages the care of approximately 100,000 residents of both West Dunbartonshire and a small area of the adjacent health board. This area has two natural boundaries, one being

the banks of Loch Lomond and the other the River Clyde, and covers the towns of Clydebank, Dumbarton and Alexandria. In 2014, this area consisted of 1.7% of the total Scottish population. The service runs from 16:30 until 08:30 and responds to both scheduled and unscheduled visits during this period, with two teams (consisting of a registered nurse and an unregistered assistant) between 16:30 and 23:00, and two registered nurses and an untrained assistant between 23:00 and 08:30.

Sample size

The total number of people registered with the District Nursing service and living with a urethral catheter in the study area during the study period was 170. The number of staff involved in the Out of Hours District Nursing Service during the study period was 10 District Nurses and 10 Healthcare Assistants.

Participants

Quantitative data were generated from all calls to the Out of Hours District Nursing Service during the study period. Qualitative data were generated from individual interviews (n=15), either face to face at home, or by telephone. This included interviews with patients living at home (n=6), their relative carers (n=2), qualified community nurses (n=3), augmented home carers (AHC) (n=3), and a health care assistant (HCA) (n=1). All interviewed patient participants were male with an age range from 68 to 86 years (mean 70), and users of the Out of Hours District Nursing Service. The two relative carers (wife / daughter), lived with and provided patient care and support in the home. We used the Scottish Index of Multiple Deprivation (SIMD - <http://www.gov.scot/Topics/Statistics/SIMD>) to determine the level of deprivation for the patients in our study. SIMD ranks all areas (data zones) in Scotland for multiple deprivation, from 1 (most deprived) to 6,976 (least deprived) – each data zone containing 760 people. The number of West Dunbartonshire datazones in the 5% most deprived in Scotland was 8 (6.6% of all West Dunbartonshire datazones). The number of West Dunbartonshire datazones in the 15% most deprived in Scotland was 35 (25.6% of all West Dunbartonshire datazones). The most deprived datazone located in West Dunbartonshire was 83 in the overall ranking for Scotland. The least deprived datazone in West Dunbartonshire was ranked 6,317 in the overall ranking for Scotland. Therefore, the

area consisted of a wide range of levels of deprivation, and It was this population that was covered by the Out of Hours District Nursing Service, and from which we collected our quantitative and qualitative data. Regarding the qualitative study in particular, three patients were in the SIMD 1st quintile, representing the 20% most deprived data zones in Scotland, two were in the SIMD 2nd quintile, representing the 40% most deprived data zones in Scotland and one was in the 4th Quintile representing the 80% most deprived data zones in Scotland.

Data collection tools

Quantitative data were collected from the system used by District Nurses to record out of hours visits, as part of their clinical work.

Qualitative data were collected using semi-structured interviews, so that discussion, while broadly aligning to generalised themes was to some extent based on the responses of the participants (Table 1).

Data collection

Quantitative data collection occurred during May and June of 2015. Data were collected on the following factors: Date, GP practice, Type of catheter, Issue (catheter related), Outcome (catheter related), Duration of visit, Number of visits and date of planned catheter change.

Qualitative data were collected from June to September 2015. Recruitment of participants for qualitative data collection involved local community-based health and social care team leaders identifying potential participants for interview (purposive sampling). Prior to gaining signed consent, potential participants were provided with an information sheet detailing the study and the lead researcher's contact details should further information be required. Interviews lasted between 15 – 30 minutes – depending on the length of discussion.

Data analysis

Quantitative data were analysed to determine the number of urethral catheter-related home visits as a proportion of the total undertaken by the Out of Hours District

Nursing Service. The time required for urethral catheter-related home visits, and the reasons for these visits were also analysed.

All interviews were undertaken by qualified university researchers (Mackay, PhD [male] or Fleming, PhD [female]). Audio recordings were transcribed and managed on NVivo 10, a qualitative data software package. Thematic analysis was initially conducted independently by three researchers through a systematic process to make sense of, and create meaningful patterns from, the data (Braun & Clarke 2006). Following this comprehensive analysis, the researchers discussed the significant statements leading to agreement in the final meanings and themes, in the context of the role of the participants.

Ethical considerations

Approval for the study was granted by the West of Scotland NHS Ethics Committee (REC reference 15/WS/0016), and the Research and Development Office of the Greater Glasgow and Clyde Health Board. All participants were assured they could withdraw from the study at any time without consequence.

RESULTS

Quantitative results

Over the study period, a total of 408 'out of hours' community nursing home visits were recorded of which 82 (20%) were specifically for urethral catheter-related home visits. These 82 visits accounted for 28.5 hours of community nursing 'out of hours' time (excluding travel).

Seven urethral catheter-related triggers for 'out of hours' visits were identified (Figure 1), with the most common being urine bypassing and catheter blockage. Urine bypassing the catheter tube was the trigger for 35% (29 of 82) of visits, accounting for 9 hours 35 minutes. Catheter blockage was the trigger for 37% (30 of 82) of visits, accounting for 11 hours 20 minutes. Urine bypassing is a common symptom of catheter blockage; together these were the trigger for 72% (59 of 82) visits, accounting for 20 hours 55 minutes in terms of community nurse service investment.

Qualitative results

Four key themes were identified from analysis and interpretation of the transcripts.

Two dominant themes were evident including the 'lived experience' and 'education' with the two other themes relating to 'communication' and 'care delivery'. Each overarching theme revealed three subthemes which are presented in Figure 2.

Individual subthemes were named as each one made a significant contribution whilst sharing the same central organising concept as the key theme. Data are presented and discussed in terms themes/subthemes, and of role - patient, relative carer, and healthcare professional.

Lived experience

This theme identified as 'lived experience' was evident across all the participant groups. It was clear from the qualitative data that the lived experiences of participants had a substantial impact on the quality of their everyday lives. The subthemes emerging from the data included '*catheter related concerns*', '*learning as you go*' and '*therapeutic relationship*'.

Catheter-related concerns

Patients and relative carers: A variety of urethral catheter-related concerns were described by patients; including pain, CAUTI (sometimes accompanied with confusion), bypassing, blocking, debris, encrustation, haematuria and the catheter 'falling' or being 'pulled' out. Some patients experienced more consequences than others as a result of their multi-morbidity, level of mobility and dependency. Relative carers also reported how the adverse experiences of patients impacted on their experiences.

'since he's had it in it's been an absolute nightmare. You've no idea what we've been through' (relative carer, participant, 3)

All participants expressed their views about practical concerns related to catheter care. This included selecting the appropriate size of catheter and ensuring the necessary equipment was available in the patient's home for re-catheterisation purposes. Community nurses or a health care assistant appeared responsible for requesting a prescription for equipment.

Learning as you go

Patients and relative carers: In general, patients and their relative carers consistently reported the most common way for them to learn about living with a catheter was by *'learning as you go'*. There was consensus across all participant groups that they were given little by way of written advice in preparation for catheter care, management and maintenance. This tended to mean they often had to learn about all aspects of catheter care and management themselves through their own experiences of living with urethral catheters.

'I would have liked more advice, and I kinda blame myself for not asking'
(patient, participant, 4)

Over time, patients and relative carers also became increasingly knowledgeable and tended to adopt the terminology also used by health and social care staff. Some also reported becoming adept at recognising signs and symptoms of infection with others highlighting the dilemma of requesting antibiotics for a CAUTI versus knowing the patient risk of developing antibiotic resistance.

'this crustation was causing me a bit of bother' (patient participant, 8)

'it was bypassing' (patient, participant, 4)

'he (father) was...delirious, disorientated, so we began to recognise the signs of that and as soon as that happened we got onto the doctor' (relative carer, participant, 18)

Therapeutic relationship

Patients and relative carers: This therapeutic relationship related to how the patients, relatives/carers and health and social care staff engaged and interacted for the patient's benefit. Patients and relative carers appreciated kindness shown to them regardless of how skilled or knowledgeable the visiting health and social care staff were perceived to be. The intimate nature of catheter care left one patient embarrassed if a young health or social care worker attended.

Barriers to the creation of a therapeutic relationship occurred when care givers appeared to lack skill and knowledge. An example of this related to changing the catheter bag:

'I mean I hang on to this end here [catheter tubing] like grim death because I'm feart [afraid] here they're going to, you know [pull the tubing] (patient, participant, 4)

Education

This theme had a particular focus on any information resources, training and education currently available for each participant group.

Learning on the job

Patients and relative carers: Patients and relative carers reported that they acquired knowledge and developed skills themselves in terms of catheter management by problem solving as issues occurred. The internet was not reported as being used as a source of information by any patients and relative carers participants. At times, they felt the advice given to them by health and social care staff appeared superficial. For example, the patient should 'drink plenty' when 'plenty' was not quantified:

'I mean he's drinking gallons to try and keep it -- [husband interrupts] 'oh I'm drinking copious amounts of water there [wife interrupts] but it, he's still getting infections' (relative carer and patient, participants, 3 & 4)

There was evidence from patient participants that their confidence increased once their knowledge about catheter care increased. However, they reported often acquiring knowledge themselves or other routes such as approaching various companies for information about catheter-related products.

'I thought myself that the size of the catheter I was using was too small -- I found out what didn't suit me and what did suit me' (patient, participant, 15)

Healthcare professionals: '*Learning on the job*' was a recurrent theme throughout the interviews with both health and social care staff reporting that they learned from each other's experiences.

Catheter care interventions

Patients and relative carers: It was clear that information and training about catheter care and interventions was required by patient and relative carer participant groups. Some patient practices reported were potentially harmful for example, the patient who emptied his catheter bag as soon as it had any urine in it.

A small number of patients were curious about resuming sexual activity despite having an in-dwelling catheter but were unaware about this possibility 'being allowed' or any related information. Other participants reported that having to deal with catheter care consequences left them feeling socially isolated due to the embarrassment of having to change clothes or go home:

'I was bypassing, I was going out with clothes on and having to come in in the middle of the day for to change' (patient, participant, 8)

Healthcare professionals: The health care assistant and augmented home carers discussed situations that indicated a lack of patient and carer knowledge and skill:

'I can go in and they'll [patients] have elastic around their legs' (health care assistant, participant, 5)

Lack of standardised education

Patients and relative carers: There was clearly no standardised approach to how patients and relative carers were provided with educational material or relevant information about their catheter care and dealing with consequences:

'I've never seen any written information in a patient's house' (nurse, participant, 7)

Healthcare professionals: It was evident that there was a range of different approaches to education and training for nurses and health care assistant and augmented home carers. Rather than standardised catheter-related education for

qualified nurses it seemed that experiential learning, consolidating pre-registration learning and completing an optional LearnPro education module was common:

'I've also carried out the, the LearnPro, you know the eLearning package on catheterisation' (nurse, participant, 14)

'male catheterisation, -- 3 times you were to observe it being carried out by a member of staff and then you were to be observed carrying it out 3 times' (nurse, participant, 14)

The health care assistants and augmented home carers had received catheter-related education through an induction programme when new to their post. In addition, they received updates from the community nursing team. Despite this one augmented home carer was frustrated by her perceived lack of education:

'what do you do before the nurse comes out, I've not had any training' (augmented home carer, participant, 10)

Communication

It was evident that communication was a key theme across all participant groups. This was across many aspects of communication including whether the information shared between all participant groups was useful, appropriate, meaningful, timely or fragmented. The subthemes related to *'conflicting information'*, *'variations in expectations'* and *'variable transfer of care'*.

Conflicting information

Patients and relatives/carers: There was agreement from patients and relative carers about *'conflicting information'* from health care staff. This was an important factor which tended to leave patients and relative carers feeling confused and frustrated when faced with conflicting information or advice. At times this seemed to create a dilemma for them in knowing who to trust in providing them with reliable information:

'district nurses said they don't believe in that [procedure] but who's [correct?], I mean I turned round and I said well who is the top man at the job, the district nurses or Mr X [consultant]' (carer/relative, participant, 3)

Despite this tendency for '*conflicting information*', communication with the community nursing service, on the whole, tended to be a positive experience for patients and relative carers. It was, however, evident that both patients and their relative carers were confident in asking for information and could articulate their catheter-related needs:

'if I have a problem at all with the catheter all I do is phone my local health centre and they have a district nurse comes down' (patient, participant, 6)

Healthcare professionals: Likewise, there was evidence of good communication and professional trust between the nurses, health care assistants and augmented home carers:

'we very much rely on the carers [HCA and AHC] if there's a problem' (nurse, participant, 9)

Variation in expectations

Patients and relative carers: Patients and relative carers did express concern about the perceived '*variation in expectations*' in what they felt the health carers expected of them in terms of their knowledge about urethral catheter care and management. At times, the burden of responsibility this put on them was expressed coupled with a sense of vulnerability in terms of what they were expected to know:

'they're telling me (health and social work staff) that the balloon can go down - , but how am I to know that? I'm no trained to know that' (relative carer, participant, 3)

Variable transfer of care

Healthcare professionals: There was also 'variable transfer of care' in the ways information about patients with a urethral catheter were transferred between acute and community health and social work staff. The community nurse 'out of hours' service received telephone calls on an answer machine from hospital and community based nurses, health care assistants, augmented home carers, patients and relative carers. Health care assistants and augmented home carers appeared skilled in

knowing when a catheter-related consequence required assessment from the qualified nurse:

‘if the catheter’s bypassing we’ll contact the district nurse’ (augmented home carer, participant, 10)

One qualified nurse (participant 7) recalled providing unscheduled ‘out of hours’ care for a patient with a blocked catheter. During re-catheterisation *‘the patient started to haemorrhage quite badly’*. She contacted NHS24 (The Scottish emergency helpline for NHS services) and provided the relevant history; subsequently the patient was admitted to hospital. One nurse talked about a ‘catheter passport’ which was updated with each intervention; though she had not seen one being used.

Qualified nurse participants also appeared to deal with a high volume of telephone calls received in relation to urethral catheter consequences:

‘their catheter is blocked, their catheter’s maybe bypassing, a few occasions the catheter has expelled completely, - it’s maybe just a phone call to do with leg bags and overnight bags, just with a bit of concern and things like that, maybe urine’s not draining right’ (nurse, participant, 9)

Subsequent telephone discussions often involved the nurse asking practical questions such as if there is any kinking in the catheter tubing, if the leg back straps are occluding the flow of urine or if the catheter tap between the leg bag and night bag is open. Another common question included enquiring if the patient has drunk an ‘adequate amount of fluids’ (nurse, participant 9).

Care delivery

The subthemes related to ‘deciding when to phone’, ‘lack of clarity’ and ‘variation in experience’.

Deciding when to phone for help

Patients and relative carers: It was evident from the patient and relative carer groups that it was common for them to be in a dilemma when deciding to request an unscheduled community nurse visit or advice. Reasons for this dilemma varied, for

example, one relative carer perceiving a previous negative response from a community nurse, deliberately waited until 16.30 hours to telephone for help:

'he'll not let me phone my own district nurses because they've refused, so he's sitting there to after half past four... sometimes you [husband] were nearly hitting the roof [pain]' (relative carer, participant, 3)

Requesting help was often based on previous experience and fear that symptoms would worsen. One relative carer (participant, 18) telephoned to request antibiotics at the first sign of her father having a CAUTI, others delayed hoping the symptoms would resolve, for example, if they drank more fluids.

Healthcare professionals: Health care workers and augmented home carers appeared astute in judging when to ask for a qualified nursing assessment for a patient:

'for example, the colour of the urine, if there's any blood in it we'll contact the district nurse, if the catheter's bypassing we'll contact the district nurse as well' (augmented home carer, participant, 10)

Lack of clarity: who does what

Patients and relative carers: Lack of clarity appeared to occur because of the individual nature of each patient's needs, catheter-related consequences and the ability to engage patients in self-care. Meanwhile, information and advice appeared to be provided when issues occurred rather than in a preventative manner. Patients preferred talking to health or social care staff that were already familiar with their catheter-related issues; this influenced who they asked for care, advice and information.

Healthcare professionals: There was a lack of role clarity in terms of who does what in relation to catheter care and exchange of information and advice. In part this appeared to result from service delivery variation, for example the overlap in the roles of health care assistant and augmented home carers:

'you know they (some home carers) don't touch the catheter because they haven't had formal training...and they'll say to me 'that's not my job' (augmented home carer, participant, 11)

Variation in experience, skill and knowledge

There was evidence in the variation reported in experience, skills and knowledge across the participant groups.

Patients and relative carers: The patient and relative carer groups agreed that whilst verbal information and advice from health carers often made sense at the time, was then subsequently forgotten or on occasions misinterpreted by patients and relative carers. Information given to them about catheter hygiene was often described by patients and relative carers as being in superficial terms for example:

'the advice I was given was just make sure you're kept clean' (patient, participant, 15)

Patients and relative carers expressed having more confidence in some health and social care staff than others:

'some of them were coming in and they didn't know what they were doing' (patient, participant, 8)

'Other ones came in and knew what they were doing and made it less painful' (patient, participant, 15)

One participant's husband had complex catheter-related issues; at one stage of the interview she expressed a feeling of abandonment rather than empowerment:

'he [nurse] says but with catheters these are the problems that come and I'm saying well fine, I know it's the problems that come but are we just going to be left, is nobody going to help us' (relative carer, participant, 3)

Reports from each of the participant groups consistently supported the need for specific user-friendly information resources that supported the everyday aspects of those who live with an in-dwelling catheter at home.

DISCUSSION

The majority of patients claimed that urethral catheter management was often a debilitating source of anxiety and pain that reduced their quality of life. Only one patient reported experiencing minimal problems. All patients and their relative / carers also felt poorly equipped to manage catheter care when something went wrong. Health and social care staff perceived themselves to be knowledgeable and skilled in urethral catheter management. While we hoped to recruit women and men with urethral catheters to the study, only men were recruited. We therefore recommend that future studies focus on women with urethral catheters.

There was consensus in the study that a urethral catheter is a necessary and tolerated intervention with the consequences outweighing the challenges of incontinence or urine retention. Yet this population of urinary catheter users is often forgotten by wider society because the issues they experience on a regular and recurrent basis are not visible, are not directly life-threatening, and are not discussed. Older people, who often experience a range of co-morbidities may become marginalised from society as a result of feeling conscious of urinary catheter-related issues. Living with or providing care and support for someone with a urethral catheter is a complex experience. The consequences of a urethral catheter often trigger unscheduled community nurse 'out of hour' visits. These visits create a burden in terms of service provision. Meanwhile the trigger for the visit creates a burden on the patients and their relative carers.

Blockage and bypassing (usually a sign of blockage) were frequently reported as problems experienced by patients (Figure 1), though not infection as recorded in previously published studies (Getliffe 1994, Kohler-Ockmore & Feneley 1996). While not usually life-threatening in themselves, these issues of blockage and bypassing impact greatly on the quality of life of people living with a urethral catheter. The fact that this phenomenon impacts on so many people usually in later life is something that requires urgent attention. The nature and reasons for blockage are not well understood. However, bacteria play a role, perhaps by the changing of the pH of the urine, thus allowing crystalline materials to coat the inside of the catheter (Stickler 2014).

Across all participant groups there was evidence that knowledge and skills were a positive support mechanism for patients and relative carers coupled with the option to contact the community nurse service for advice. An important aspect of the professional support for HCAs and AHCs was provided by the qualified nurses. Similarly, qualified nurses valued and trusted the referrals made to them by HCAs and AHCs. All health and social care participants felt comfortable in their level of knowledge and expertise and claimed they were able to undertake their duties of care in a confident manner.

Patients, however, appeared to lack insight into the possible consequences of a urethral catheter and often learned through experience with the help of healthcare professionals. Positive interactions between patients and healthcare professionals are central to the care of the patient with a urethral catheter (De Jaeger 2011). Patients wish to be in control of their lives and this includes their catheter (De Jaeger 2011). However, this means they need to have educational support before and after the catheter is first inserted so that problem solving and self-care can be promoted.

Education prior to the insertion of the urethral catheter may not always be possible, however, patients need to be involved in the management of their own catheter care (Wilde & Brasch 2008), to improve their quality of life and those around them (Kralik *et al.* 2007). The findings of this study mirrored those of (Prinjha *et al.* 2016) in emphasising the need for generating better patient information resources that encourages self-care and problem solving, as well as facilitating meaningful consistent dialogue between patients and those providing them with support.

CONCLUSION

Urethral catheter-related issues and complications are frequent and impact seriously on the quality of life of the individuals. Common complications impact wider, with carers also affected, and healthcare professionals impacted by frequent, costly unscheduled community nurse visits.

Self-care and problem solving strategies need to be nurtured and supported with better and more comprehensive and person-centred information resources for patients and carers. Such resources would also facilitate ongoing and meaningful dialogue between patients and those who provide them with support. In turn, this

could improve quality of life and reduce the volume of 'out of hours' visits from the community nursing service to provide unscheduled care.

This work provides further evidence that better patient information resources regarding urethral catheter management have potential to improve patient and relative carer quality of life and reduce service provision burden.

REFERENCES

- Braun V & Clarke V (2006): Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**, 77-101.
- Chapple A, Prinjha S, Feneley R & Ziebland S (2016): Drawing on Accounts of Long-Term Urinary Catheter Use: Design for the "Seemingly Mundane". *Qualitative Health Research* **26**, 154-163.
- Cooper F, Alexander C, Sinha S & Omar M (2016): Policies for replacing long-term indwelling urinary catheters in adults. *Cochrane Database of Systematic Reviews*.
- Darbyshire D, Rowbotham D, Grayson S, Taylor J & Shackley D (2016): Surveying patients about their experience with a urinary catheter. *International Journal of Urological Nursing* **10**, 14-20.
- De Jaeger M (2011): Exploring urinary catheters: the perspectives of patients and nurses. *British Journal of Nursing* **20**, 400-408.
- Feneley RCL, Hopley IB & Wells PNT (2015): Urinary catheters: history, current status, adverse events and research agenda. *Journal of Medical Engineering & Technology* **39**, 459-470.
- Getliffe KA (1994): The characteristics and management of patients with recurrent blockage of long-term urinary catheters. *Journal of Advanced Nursing* **20**, 140 - 149.
- Godfrey H (2008): Living with a long-term urinary catheter: older people's experiences. *Journal of Advanced Nursing* **62**, 180 - 190.
- Harvey S & McMahon L (2008) Shifting the balance of health care to local settings: The SeeSaw report. King's Fund, London.
- Kmietowicz Z (2006): UK government to shift NHS power to community health care. *BMJ* **332**, 253.
- Kohler-Ockmore J & Feneley RCL (1996): Long-term catheterization of the bladder: prevalence and morbidity. *British Journal of Urology* **77**, 347 - 351.
- Kralik D, Seymour L, Eastwood S & Koch T (2007): Managing the self: living with an indwelling urinary catheter. *Journal of clinical nursing* **16**, 177-185.

- Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, Meinow B & Fratiglioni L (2011): Aging with multimorbidity: A systematic review of the literature. *Ageing Research Reviews* **10**, 430-439.
- Prinjha S, Chapple A, Feneley R & Mangnall J (2016): Exploring the information needs of people living with a long-term indwelling urinary catheter: a qualitative study. *Journal of Advanced Nursing* **72**, 1335-1346.
- Roe BH & Brocklehurst JC (1987): Study of patients with indwelling catheters. **12**, 713 - 718.
- Stickler DJ (2014): Clinical complications of urinary catheters caused by crystalline biofilms: something needs to be done. *Journal of Internal Medicine* **276**, 120-129.
- Theriault R, Ward-Smith P & Soper C (2012): Leakage associated with urinary catheter usage: A design challenge. *Urologic Nursing* **32**, 307-312.
- United Nations, Department of Economic and Social Affairs, Population Division (2013): World Population Ageing 2013. ST/ESA/SER.A/348.
- Wilde MH & Brasch J (2008): An intervention to teach self-monitoring of urine flow in long-term catheter users. *International Journal of Urological Nursing* **2**, 62-71 10p.
- Wilde MH, Brasch J & Zhang Y (2011): A qualitative descriptive study of self-management issues in people with long-term intermittent urinary catheters. *Journal of Advanced Nursing* **67**, 1254-1263.

Patient questions

Can you tell me a bit about what was happening before you were given an indwelling urinary catheter?

At the time that you first had the catheter inserted, what health and social care staff supported you? How long ago was this?

Can you remember what sort of advice you were given? Who provided you with information?

Now that you have had your catheter for a while can you tell me how you feel about living with a catheter?

Can you think of a time when you felt that you were really managing your catheter well, for example once you got used to managing it yourself and began to feel more confident?

What was it that made you feel better?

Can you think of a time when you were having difficulty with your catheter?

Can you tell me a bit more about the staff that support you?

Can you tell me about your experience of contacting the 'Out Of Hours' service?

Relative Carer questions

Can you tell me a bit about what was happening before your relative was given an indwelling urinary catheter?

At the time that the catheter was inserted, what health and social care staff supported you and your relative? How long ago was this?

Can you remember what sort of advice you were given? Who provided you with information?

Now that you have been supporting your relative with their catheter for a while can you tell me how you feel about your role?

Can you think of a time when you felt that you were really managing to support your relative to manage their catheter well, for example once you got used to providing support and began to feel more confident?

What was it that made you feel better?

Can you think of a time when you were having difficulty supporting your relative to manage their catheter?

Can you tell me a bit more about the staff that support you?

Can you tell me about your experience of contacting the 'Out Of Hours' service?

Healthcare professional questions

Can you tell me what your role is?

How long have you been in this post?

How much contact do you have with patients living with an indwelling urinary catheter in the community?

What is the general nature of this contact?

How many people? How often? Do they normally have relatives supporting them? If so what contact do you have with the relatives?

Are you involved in providing out of hours care?

Can you think of a time when you felt that you were really managing to support someone living in the community to manage their catheter well?

What was it that made you feel that you were managing well?

Can you think of a time when you were having difficulty supporting someone to manage their catheter?

Can you tell me about your experience of providing 'Out Of Hours' support?

Can you tell me about the education and training that you have undertaken relating to supporting people with catheters in the community?

Do you think the education training that you have undertaken is adequate, and do you feel that you are well equipped to deal with all types of difficulties?

What sort of information and advice is provided for patients and their relatives?

Who gives them the information?

Do you think that education and training relating to the management of catheters in the community could be improved?

If so in what way?

Table 1: Questions asked of patients, carers and healthcare professionals during semi-structured interviews

Figure 1: Triggers for an unscheduled, 'out of hours' community nurse visit, and associated community nurse time

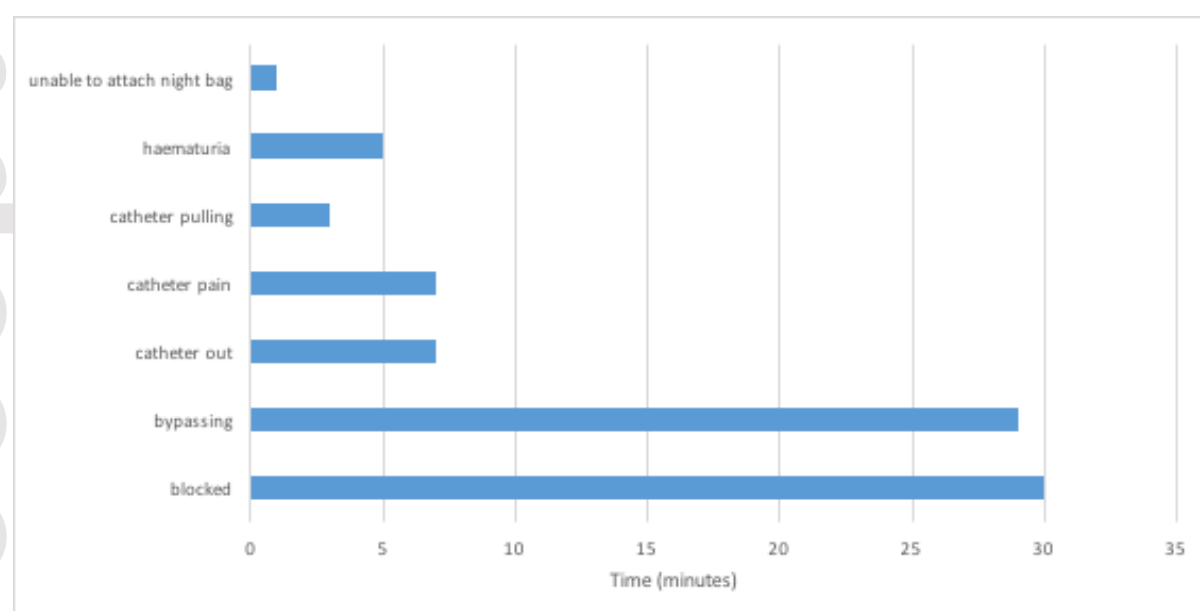
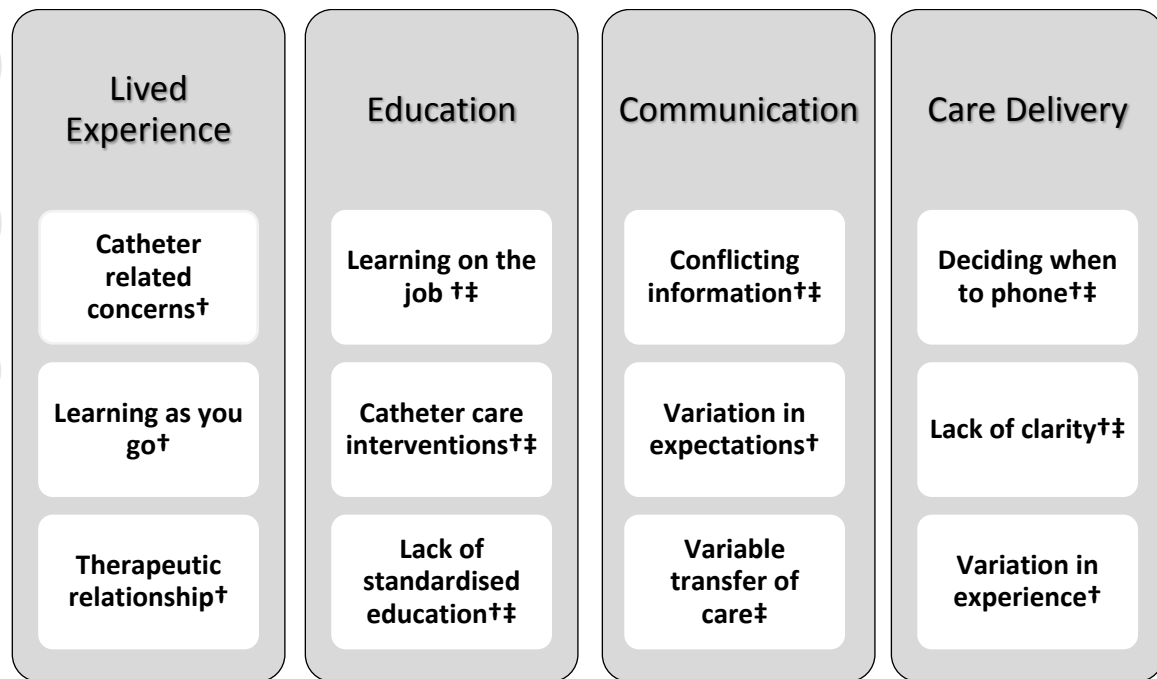


Figure 2: Key themes and subthemes



[†] Patients and relative carers, [‡] Healthcare professionals.