



Managing Catheters in the Community



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Project Title: Management of indwelling urethral catheters in community settings:
Using the experiences of patients, carers, community nurses and other health and social care staff to explore issues causing out of hours calls and co-produce an education/training strategy

Keywords: Indwelling urinary catheter, community healthcare, lived experience, education and training

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1. Summary

People living with an indwelling urethral catheter often experience catheter related issues, which can be debilitating and affect their quality of life. We aimed to explore the experience of patients, carers, community nurses and other health and social care staff in relation to urethral catheter issues resulting in callouts. This study was undertaken in West Dunbartonshire, which encompasses Clydebank, Dumbarton and Alexandria localities. It was a collaboration between West Dunbartonshire Health and Social Care Partnership (HSCP) and the School of Health Nursing and Midwifery at University of the West of Scotland. District nurses recorded data relating to catheterised patients and the incidence of blocked urethral catheters. These data were collected in two localities, Clydebank and Vale of Leven/Dumbarton, over the same two months. One to one interviews, either face to face or by telephone, were carried out with health and social care staff with a role in managing urethral catheter care in the community, catheterised community living patients and relatives/carers supporting a person with a catheter. We found that the most common reasons for callouts related to urethral catheters that were bypassing or blockage. A wide variety of patient experiences were reported ranging from those who lived well in terms of catheter management to those whose quality of life was severely reduced. Healthcare staff reported feeling confident about their roles-regarding urethral catheter care, with a strong team ethic evident. However, patients and their carers reported a lack of available information about how the catheter worked, how to best manage it and what to do if something went wrong. We developed an evidenced-based educational resource focused on urethral catheters that can be used in the future to inform patients and their carers and potentially empower them to use self care strategies.

2. Background

The West Dunbartonshire Health and Social Care Partnership (HSCP) (which brings together both NHS and Local Authority responsibilities for community-based health and social care services within a single integrated structure) identified urethral catheter management issues as a major cause of out of hours callouts to the district nursing service and unnecessary admissions to hospital. Known reasons for callouts include blocked catheters and/or Catheter Associated Urinary Tract Infections (CAUTI). CAUTI is currently one of the 'harms' of the Scottish Patient Safety Indicator, which also includes falls, pressure ulcers and grade 2-4, cardiac arrest.

People with a urethral catheter (hereafter referred to as a catheter) are not a homogeneous group. They include younger people who manage their own care and lead active lives, younger people with complex needs, older people who manage their own care, and frail older people with complex needs. The symptoms of CAUTIs in older people may be ambiguous, thus it is particularly important that health and/or social care staff supporting older people with a catheter are skilled and knowledgeable. West Dunbartonshire HSCP staff managing catheter care in the community receive training, however little is known of their experiences of providing care for people with a catheter, or the experiences of patients and their relatives or carers. Anecdotal evidence suggests that people living with an indwelling catheter and their relatives/carers are reluctant to seek timely help, often resulting in a call to the out of hours district nursing service.

The project team consisted of health and social care staff within the two community teams (Clydebank and Vale of Leven/Dumbarton), and research staff from the University of the West of Scotland. The findings of this study will serve as a foundation for developing an educational and training strategy in the future.

3. Aims & Objectives

The aim was to generate an evidence based understanding of callout patterns, stakeholder experiences, and challenges associated with the management of indwelling urinary catheters in the community, and develop a shared training resource to address identified problems.

The objectives of this project were:

- To establish the incidence of callouts associated with catheter use in community living patients within West Dunbartonshire

- To establish the nature of the problems associated with catheter use based on recorded data and from the perspective of patients and carers
- To explore the experiences of people with catheters, both those managing their own care and those who are more dependent/have complex needs
- To explore the experiences of community nurses and other health professionals, social care staff and relatives/carers supporting people with catheters in the community
- To identify activities or interventions associated with positive outcomes for patients/reduction in callouts
- To utilise the data derived from 1-5 above to co-produce an education/training strategy for staff, patients, and relatives/carers
- Develop education/training resources for health and social care staff, patients and carers with people who have catheters in the community
- Use the findings of the project to underpin a bid for further funding to pilot and evaluate the training programme

4. Method & approaches

This mixed methods study took place between November 2014 and October 2015. Data were collected on callouts through collaboration with West Dunbartonshire HSCP and through face to face or telephone interviews with the participants.

Quantitative data: out of hours call out analysis

Data on callouts were recorded by the clinical staff, for people with catheters in the community within West Dunbartonshire over a two-month period. The nature of the problem was also recorded during this time period.

Qualitative data: recruitment of participants

Potential participants (patients and carers) were identified by District Nurse team leaders and given a copy of the information sheet for the study (Appendix 1, patients; Appendix 2, carers). The study was 'opt-in' and potential participants were given at least 24 hours to consider whether to participate, were provided with contact details if they wished to discuss the project in more detail, and recruited to the study through informed and signed consent (Appendix 3, patients; Appendix 4, carers).

Potential participants (health and social care staff): Frontline staff were identified by senior staff at the West Dunbartonshire HSCP and provided with information about the study (Appendix 5). The study was 'opt-in' and potential participants were given at least 24 hours to consider whether to participate, were provided with contact details if they wished to discuss the project in more detail, and recruited to the study through informed and signed consent (Appendix 6).

Participants: Target population

The target population to recruit were:

- Eight health and social care staff managing catheters in the community
- Eight catheterised community living patients
- Eight relatives/carers supporting a person with a catheter

Inclusion Criteria

- Written informed consent
- All potential participants to have an opportunity to ask questions prior to agreeing to take part in an interview. Consent to be taken by a member of the research team at UWS.
- Patients:
 - People with indwelling urinary catheters in the community
 - Age 16+
- Carers:
 - Informal carers with experience of supporting someone living with a catheter in the community within the past two years
- Health or social care staff:
 - Health and social care staff managing catheters in the community

Exclusion criteria

- Patients:
 - People with catheters aged less than 16
 - People who considered themselves too unwell to take part, or were considered too unwell to take part by the researcher
 - Communication difficulty that would have prohibited taking part in an interview. However, every effort was made to be inclusive

- Carers:
 - Informal carers who had not had experience of supporting someone living with catheters in the community within the past two years
- Health and social care staff:
 - Health and social care staff who did not manage catheters in the community

Consent

Potential participants (patients and carers): If people with a catheter/carers wished to participate they were asked to sign the consent form; the signature was witnessed by a third party. An interview was then arranged either face to face or by telephone. Face to face interviews were carried out at a place convenient to the participant and travelling expenses were covered. Permission was also sought from patients that their General Practitioner (GP) be informed of their involvement in the study.

Potential participants (health and social care staff): Staff members willing to participate were asked to sign a consent form; the signature was witnessed by a third party. An interview was arranged either face to face or by telephone at a place convenient to the participant.

All participants were recruited by the team leads from the West Dunbartonshire HSCP and were to be interviewed either at home, or by telephone by a researcher from UWS.

Ethics

The study proposal was submitted to, and consent was granted by, the West of Scotland Ethics Committee, the UWS School of Health, Nursing and Midwifery Ethics Committee, and the Research and Development Office of the Greater Glasgow and Clyde Health Board.

Data protection

The community nurses were the only group who had access to personal health data and this was as part of their job. Information gathered by university staff during the interviews was stored on password protected computers within University of the West of Scotland, and was not accessible to others. Identifiable data collected with consent was retained and used in the study.

Care of participants

The well-being of the participants was paramount. The interviewers were both cognisant of the vulnerability of all participants and were prepared to stop the interview if the interviewee requested it or if, in the opinion of the interviewer, the process was causing undue distress to the interviewee.

The interviewee was reminded that at any point they could terminate the interview without having to give a reason for doing so.

The potential benefits of this study centred on the production of additional education and training resources for patients, carers and health and social care staff, which may ultimately have benefits for people living with catheters.

Study limitations

It is acknowledged that the patient participant group included those with complex pathologies as well as having a catheter. It is also acknowledged that the staff participants included people with varying roles. It is further acknowledged that this is a snapshot of a chronic and complex situation.

5. Findings

There are four strands to the findings:

- Results of the literature review
- Quantitative findings detailing the number and nature of callouts over a two-month period
- Qualitative findings from the semi structured interviews
- A scoping of existing educational tools in catheter care management

The findings are presented in this order below.

Literature review

Keywords: Indwelling urinary catheter, management of urinary catheters in the community; quality of life and evidence based practice.

Literature Review Introduction

Urethral catheters are commonly inserted to manage urinary incontinence, relieve urinary retention, to measure urinary output in critically ill patients or as diagnostic or treatment options. This review is not concerned with the reason for the insertion of a catheter, but rather with the best practice surrounding catheter care for patients with long-term catheters, living in the community. The review is therefore particularly concerned with the prevention and management of common issues arising from catheterisation such as: catheter associated urinary tract infections (CAUTIs); blockages; leakages; encrustation; as well as the impact on the patient's social and psychological well-being. Less common problems, such as purple urine bag syndrome (Sheehan, 2014) were also considered. Of further interest are the experiences of carers, both formal and informal.

The literature review was discussed by the authors and it was agreed that a systematic approach to sourcing relevant literature was not only essential to provide a robust rationale for the project, but also for an in-depth understanding of the area of inquiry. The authors felt that as the study centred not only on issues arising from catheterisation and out of hours service provision, but also on the patient and relative/carer experiences, it was important to source literature that included evidence based practice, educational strategies and the patient perspective.

Literature Search Strategy

A biopsychosocial approach to the literature search was selected, given the nature of the topic under investigation. EBSCOhost was used to select the following databases: *AHFS Consumer Medication Information; CINAHL Plus with Full Text; Health Source: Nursing /Academic Edition; Medline; Psychology and Behavioural Sciences Collection; PsychInfo and SocIndex with Full Text.*

The search terms used were 'indwelling urinary catheter' and a) Management; b) 'Quality of Life' (QoL); c) 'Evidence based practice' (EBP). These were limited by searching for:

- Literature from the past five years
- Academic articles
- Full text only
- English language only
- Peer reviewed

The terms used were designed to give a focused result and yielded 44 relevant and informative articles. These 44 articles were screened for relevance and a total of 21 were accepted. Reasons for excluding articles included language other than English, relating only to in-patients, or referring only to short-term use of catheters.

Literature Review Findings

Of the 21 articles accepted, eleven pertained to the management of catheters: insertion, aseptic techniques, catheter changing, leg and night bags, and removal. Five articles were retained relating to QoL, and five relating to education. Some articles had content that overlapped these categories.

Catheter Management

Catheter change

Anderson (2010) reported on a study by Lawrence, Fisher and Chan (2009) in which they investigated the reasons for over frequent catheter change (over frequent referring to a more

frequent change than that recommended in the Australian and New Zealand Urological Nurses Society Inc. 2006 Guidelines). The most common reason given for frequent changes of catheter was concern regarding in-situ fluid loss from the anchoring catheter balloon. This study by Lawrence, Fisher and Chan (2009) concentrated on the loss over time of fluid from the anchoring balloon into the bladder space. Measured at intervals of 6 and 12 weekly changes, they found the amount of water removed from the anchor balloon, clearly demonstrated relative osmotic loss over time; however, the conclusion was that there was evidence for the potential to extend time between routine changes of long term indwelling urethral and suprapubic catheters.

Prevention of catheter associated urinary tract infections

Although Dailly (2011) reported on the prevention of CAUTIs in an in-patient population, there are principles and guidelines reported in this article that apply to patient care in any setting.

Interestingly Dailly (2011) reported a lack of overall agreement in the literature as to the clinical criteria for a CAUTI and advocated the use of the Scottish Intercollegiate Guidelines Network (2006) recommendations, particularly when caring for older people. Dailly (2011) also reported a study where high numbers of catheter insertions were found to be inappropriate in older people in acute settings, and another study where one-third of hospital doctors were unaware their patients had catheters (also reported by Mori, 2014). Also concerning, was the highlighted confusion over whose decision it was to remove the catheter – the doctor or the nurse. This lack of clarity in the indicators for insertion or removal of catheters is reiterated by Foxley (2011) and Farrington et al (2014) in their study of catheters in end-of-life care. In contrast to these issues Dailly (2011) highlighted indicators of good practice, such as using single-use sachets of lubricant or anaesthetic gel to insert the catheter, the use of a closed system, and good hygiene practices for both carers (formal and informal) and the patient. She advocated for changing catheter drainage bags every 5-7 days, and recommended the use of monitoring forms to ensure adherence to best practice guidelines such as: Essential Steps to Safe, Clean Care: Reducing Healthcare-Associated Infections (Department of Health, 2006). Foxley (2011) reported a clinical review of a new product for measuring urine output, again in an acute setting. This new product was thought to be helpful in preventing CAUTIs by better maintenance of a closed system. Like Dailly (2011), Foxley (2011) recommended the use of guidelines (Pratt, 2007) to ensure that nurse education is embedded into clinical practice, and that effective monitoring of this practice should ensure better outcomes for the patient.

Hus, Witts and Jacobson (2012) conducted a review of the literature into the efficacy of using a vinegar solution, on a daily basis, to clean drainage bags in order to reduce CAUTIs in patients who had had a radical prostatectomy. No evidence was found that antimicrobial cleansing of drainage bags reduced either the incidence of CAUTIs or odour. One study found that washing the drainage

bags out with a mild bleach solution over a four-week period did contribute to the absence of odour. As a result of this literature review Hus, Witts and Jacobson (2012) changed the patient education on catheter care to omit daily washing of drainage bags with a vinegar solution, but retained information on good hand hygiene and washing the end of the tube with soap and water when disconnecting or connecting the drainage bag to the catheter.

At a training event for critical care nurses in America, nursing interventions to reduce CAUTIs was one of seven topics selected which could make immediate improvement to patient outcomes (Makic et al, 2011). Recommendations to use aseptic techniques and sterile equipment were acknowledged, and recent research suggesting that soap and water were more beneficial in reducing CAUTIs than antiseptic products for perineal care (this is supported by Panchisin, 2014). As in the studies above, the importance of a closed system was again stressed. Makic et al (2011) also stressed the importance of maintaining the drainage bag below the level of the bladder in order to minimise reflux into the bladder and prevent retrograde flow of urine, which is supported by Mori (2014). They further suggested that the drainage bag be emptied frequently and before moving any patient, as a means of reducing CAUTIs.

Catheter blockages

Sinclair, Hagan and Cross (2011) were one of the few studies found that examined long-term catheter care. Their focus was on examining the evidence that catheter wash-outs could prevent blockages. These three reviewers examined all randomised and quasi-randomised trials comparing bladder washout policies in any setting, for long-term (over 28 days) indwelling or suprapubic urinary catheters. The conclusion was that the trials (n= 5) were either poorly reported or of poor quality, and that there was no conclusive evidence to suggest whether or not bladder washouts were of benefit in preventing blockages.

Stickler and Feneley (2010) carried out a review over a similar time period (1980 -2009) regarding the encrustation and blockages of Foley catheters. They found strong evidence that *Proteus mirabilis* infection is the main cause of encrustation and recurrent blockages. Antibiotic therapy was recommended as soon as this was detected, although was considered ineffective for those with a history of chronic blockage and kidney stones. In this instance a regime of citrated drinks was recommended until kidney stone removal could take place.

Purple Urine Bag Syndrome

Sheehan (2014) described purple urine bag syndrome (PUBS) as “a constellation of findings”, resulting in a purple discolouration of the urine and/or drainage bag(s) occurring in patients with long-term indwelling urinary catheters. He reported incidence ranges from 8.3% to 16.7%, and listed

the risk factors as being: constipation; female gender; indwelling catheters; alkaline urine; and the presence of bacteria of containing sulphatase or phosphatase enzymes. He advised clinicians to provide reassurance to the patient and family/caregivers, while treating the co-morbid conditions and adhering to the Centres for Disease Control and Prevention Healthcare Infection Control Practices Advisory Committee recommendations for the prevention of CAUTIs.

Quality of Life

While the guidelines for the management of catheters state that there needs to be clear indicators for their insertion, Borch (2011) used a case study to demonstrate that sometimes catheterisation is the patient's choice, where it can be used to improve the patient's quality of life. In this example, the patient had a chronic inflammatory condition (interstitial cystitis) and elected to have a catheter for several years; despite having frequent urinary tract infections, she believed that this improved her quality of life by allowing her to participate in more activities and to achieve a better sleeping pattern. Although the eventual long-term solution for this patient was surgical, this case study highlights the importance of the patient's perspective. Bradway et al (2010) also found examples of where patients would have preferred an indwelling catheter over incontinence garments or bedpans in their study into continence care of obese individuals in nursing homes.

Chapple, Prinjha and Mangnall (2013) reported that understanding the patient's perspective is essential to good practice, but that there was little written about the patient's perspective of having the catheter changed. Those studies they did find reported patient experiences as being painful, anxiety-provoking and difficult. This study (Chapple, Prinjha and Mangnall, 2013) involved 36 community dwelling patients (28 had, or had had a catheter) and the interviews with these patients were transcribed and thematically analysed. Seven issues were found to be of particular importance to these study participants:

1. Having clarity about who was responsible for changing the catheter
2. Continuity of care
3. Knowledge, experience and 24-hour access to care
4. Good hygienic practices
5. Time constraints
6. Taking care to prevent leakage and protecting clothes and bedclothes
7. Listening to the patient

Underlying many of these issues was a lack of communication: between services, between healthcare professionals and between the patient and the healthcare professional. It is perhaps not surprising that patients received conflicting information from healthcare professionals, as Maeda et

al (2013) could not find an internationally agreed definition of long-term catheterisation, and that the European Guidelines (European Association of Urology Nurses, 2012) did not include recommendations for home-visiting nurses in terms of patient guidance, nor cooperation with other caregivers. Kahnen, Flanders and Magalong (2011) described a team approach to reducing incidence of CAUTIs in an acute setting, through improving communication between healthcare professionals. This involved discussions on appropriate reasons for continuing with the use of a catheter. If there was no appropriate reason, then a discontinuation order was requested at the daily meetings with the physician.

Education

Educational strategies were identified for both healthcare professionals and for people with catheters.

Maeda et al (2013) designed a study to investigate the condition of catheter users who received nursing care at home, and the status of catheter management by these nurses. Thirty nurses were asked to identify a patient with a catheter for a minimum period of six months, and then to complete a questionnaire to report interventions and difficulties encountered in providing home care. While some difficulties appear to be specific to Japan, where this study took place, there were some conclusions which would appear to be applicable internationally. These include nurses assessing the patient's or caregiver's ability to manage catheter care, better co-ordination of services and the development of a training course for nurses in catheter care at home. The study concluded that this training was necessary as there was a greater skill development needed than in acute units where catheters were more frequently used on a short-term basis.

Altun and Karakoç (2010) measured the impact of an interactive workshop for nurses, promoting best practice in the management of catheters. This pre-post-test involved 30 nurses all working in a hospital setting. The pre-intervention test scores were low, which the authors interpreted as identifying deficiencies in initial nurse training in this topic area. The post-intervention test scores showed significant improvement, however the authors observe that this in itself does not guarantee retention of knowledge and application in practice. They therefore suggested that a sustained programme of initial education, observed practice and planned updating was necessary.

Wilde et al (2013) reported on an educational self-management intervention for people with long-term catheters. These authors stated that there had been little research into self-management for this population, who learn about self-managing from "piecemeal information" from healthcare staff and "trial and error". The intervention involved three home visits from a study nurse (two visits in

the first month) to educate the participants about catheter related issues such as urine flow, using an educational booklet; to introduce self-monitoring using a urinary diary; and to choose appropriate self-management. The perceived value(s) of this intervention by the participants (n = 60) included:

- Gaining catheter related information
- Skills acquisition, and
- Feeling valued by the study nurse

Also reported were changes in behaviour and the impact on self-management: these included items such as being more aware of the position of the drainage bag; noticing urine colour; emptying the drainage bag more often; and increasing fluid intake. Ten percent of the participants reported fewer CAUTIs; two participants reported less blockages; and one participant reported “more comfort” and “less pain”.

Slater (2004) is included in this category as a short and informative article on the prevention of infection with long-term catheters. She reported that 3% of primary care service users and 13% of care home residents will have long-term catheters, and that the age range of this population spans the 20's to the 90's. It is therefore essential that healthcare professionals caring for this group of people are aware of the risks associated with long-term catheters. The most effective solution would be not to catheterise, however this is not always an option. She detailed the following strategies employed in preventing CAUTIs:

- Choosing an appropriate catheter size and material
- Inserting a catheter using an aseptic technique
- Lubricating a catheter before insertion
- Removing/changing a catheter and drainage system according to manufacturers' recommendation
- Using a closed drainage system
- Ensuring fluid intake and hydrations are maintained
- Protecting the catheter
- Preventing trauma by securing the drainage system to avoid 'pulling' on the catheter
- Education of patient, carers and health professionals on catheter care

She also provided a useful table of types of catheter, their recommended use and any important points associated with that particular type; for example, a silicon elastomer catheter is not suitable for those with a latex allergy, but may be useful in reducing encrustation.

Theriault, Ward-Smith and Soper (2012) reviewed the literature concerned with leakage, defining this as:

- Leakage accompanied with bladder spasms where occlusion of the catheter lumen or the drainage tubing has not been identified, and
- Leakage associated to occlusion of the catheter lumen or the drainage tubing

These authors also made good use of tables to summarise the literature reviewed, and continued with a conceptual approach to the cause and management of catheter leakage. They then hypothesised that one cause of catheter leakage is due to the design of the catheter, specifically catheter tip kinking, and proposed a design modification to prevent this kinking occluding the flow of urine. They concluded that healthcare professionals need to understand the mechanisms inside the bladder that result in leakage, in order to bring about clinical research to improve patient care and quality of life.

Literature Review Discussion

The literature showed a high degree of consensus over the issues associated with long-term catheters, and some consistency in strategies to prevent these. There were however several inconsistencies found particularly surrounding definitions. For example, long-term was defined as >14 days by European Association of Urology Nurses, >28 days by the Australian and New Zealand Urological Nurses Society, and >30 days by the Centres for Disease Control and Prevention Healthcare Infection Control Practices Advisory Committee. While there was agreement over many of the prevention strategies such as good hygiene, it was of note that the position of the drainage bag was mentioned only by Makic et al (2011) and Mori (2014). This advice, to ensure the drainage bag was maintained above floor level but below bladder level, was also found in the guidance from the Department of Health (2006), but not in any of the other guidance cited. This suggests that this may be information that is not regularly passed onto patients when they are being taught how to manage their catheter.

Issues surrounding communication, roles and responsibilities occurred frequently, and international differences were highlighted. Lower incidences of common problems such as CAUTIs were found where each healthcare professional was aware of their own role and responsibility, as well as the roles and responsibilities of others. The use of appropriate recording forms assisted in improving communication between healthcare professionals (Kahnen, Flanders and Magalong, 2011). It was unclear whether this improved communication benefitted the individual patient. As one patient perspective (Chapple, Prinjha and Mangnall, 2013) was for continuity of staff to ensure consistency

of care, it seems likely that improved communication between services and healthcare professionals would lead to better outcomes for the patient. It was evident from the literature that communication between the patient and the healthcare professional had to take the form of a dialogue: the patients wanted their opinions and preferences to be heard.

Education for the healthcare professional, the patient and family/caregiver was seen to be beneficial, and to lead to better outcomes; however, there was no one method of doing this that appeared more effective than any other. In the study by Wilde et al (2013), the study nurse appeared to be viewed particularly favourably by patients. This may be due to the continuity of contact or a feeling of partnership in learning how to self-manage catheter care.

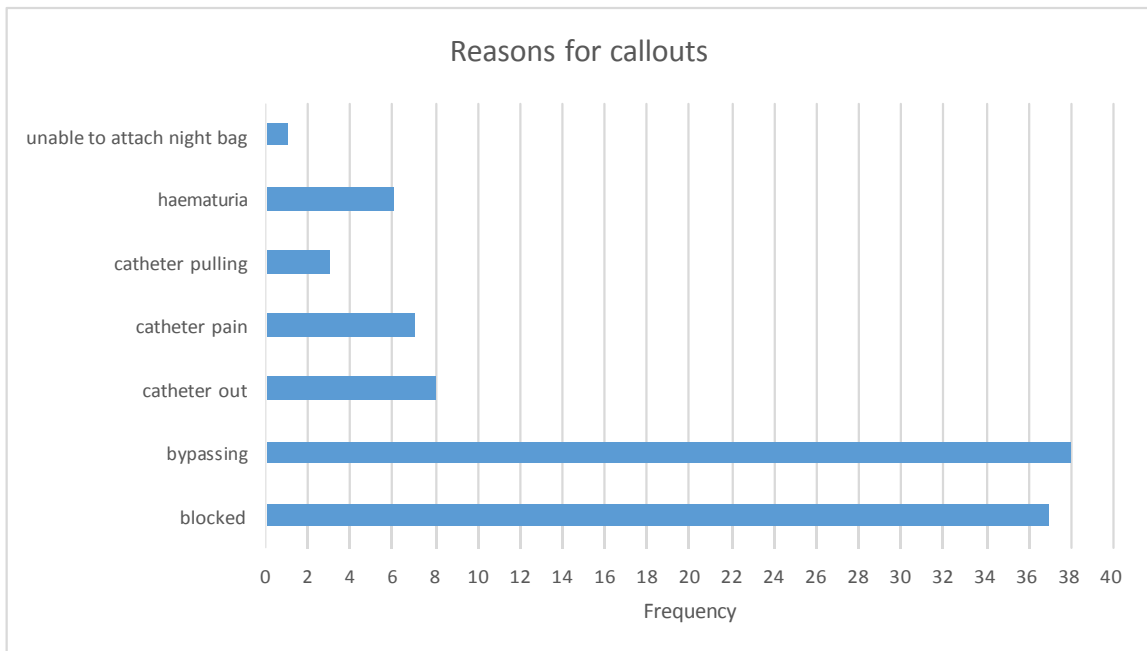
Literature Review Conclusion

It is essential that nurses and other healthcare professionals involved in caring for patients with long-term catheters use evidence-based practice in order to deliver quality care. It may be that care teams have to review this evidence locally, as in the study by Kahnen, Flanders and Magalong (2011), and agree definitions, policies and procedures. This would facilitate the continuity of care desired by patients. It is also essential that patients are provided with high quality advice and education in the management of their catheter. This has been demonstrated to increase the patient's confidence and reduce anxiety over catheter changes and in approaching services. Listening to the patient and understanding their perspective can be highly effective in improving their quality of life. For this reason, it is important that nurses have adequate resources to deliver high quality care.

Quantitative findings

Over a two-month period (May – June) in 2015 we recorded all cases in West Dunbartonshire of callouts during the evening and night that related to catheter care. Overall there were 100 recorded calls (82 for urethral and 18 for supra pubic catheters). A Summary of the reasons for the callouts is provided in Figure 1. The two most common reasons for callouts were catheter blockage (n=37) and catheter bypassing (n=38). Catheter bypassing is a common symptom of blockage and so the two taken together account for 75% of all catheter related callouts.

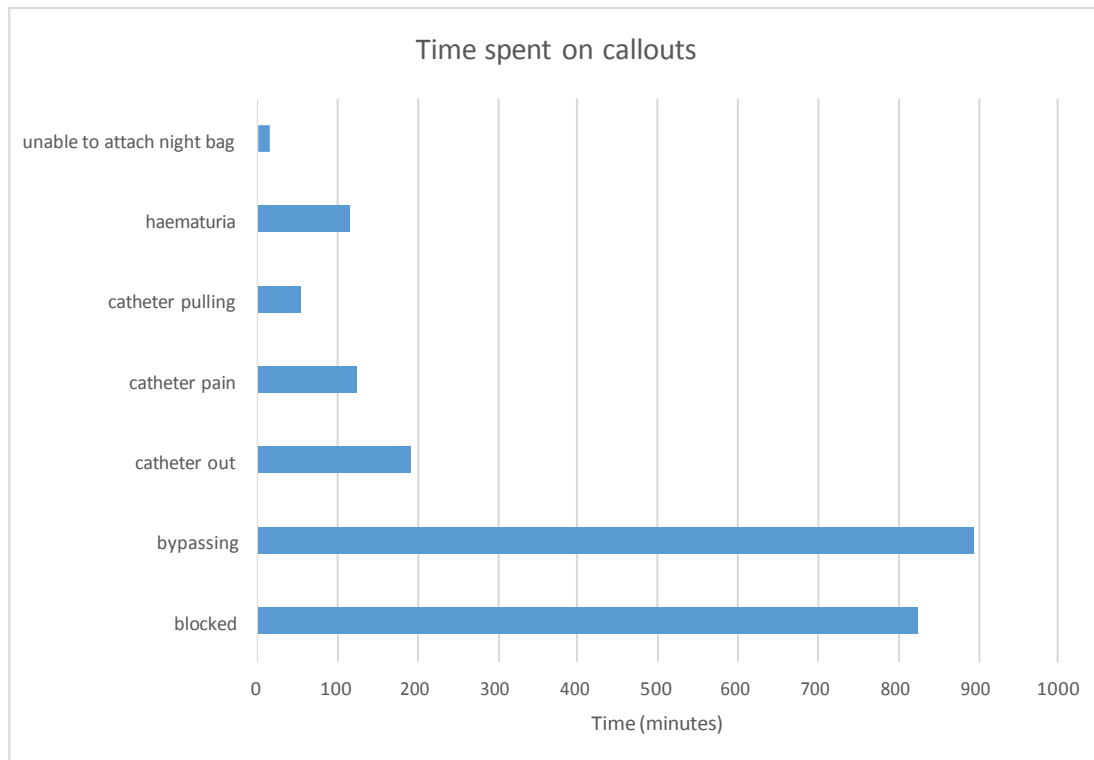
Figure 1: Reasons for callouts related to catheter care in West Dunbartonshire (May – June 2015)



The nurse contact time that was needed to support these patients was also recorded and ranged from a minimum of 10 minutes to a maximum of 120 minutes (average = 22 minutes). The total nurse contact time related to callouts for catheter care in May – June 2015 in West Dunbartonshire was 2,220 minutes. The greatest time allocation was for catheter blockage (825 minutes) and bypassing (895 minutes) (Figure 2). Taken together catheter blockage and bypassing accounted for 1,720 minutes (out of 2,220) or 77% of the total time reported for catheter related callouts.

These data demonstrate the time and resource burden placed on healthcare professionals because of callouts related to catheter care.

Figure 2: Time allocated to callouts related to catheter care in West Dunbartonshire (May – June 2015)



Qualitative Findings

A total of 15 participants were interviewed by one of two researchers:

- 6 patients (a further 2 expressed interest then withdrew)
- 2 spouse/relative carers (wife or daughter, hereafter referred to as carers)
- 3 qualified nurses
- 1 health care assistant
- 3 augmented home carers

The semi structured interview was used (Appendices 7, 8 and 9) along with a pictorial aid. The interviews lasted between 20 minutes and one hour. All interviews were audio recorded and the recordings transcribed and entered onto NVivo (version 10). Thematic analysis was conducted independently by three researchers to ensure inter-rater reliability and then discussed, with the themes and subthemes (Table 1) agreed by these researchers.

Synopsis of participant interviews

A short synopsis of the findings from each of the four participant groups is presented below. This is followed by a thematic analysis of all the participant transcripts.

Patient Interviews

Patients appear to be given advice on catheter hygiene when first catheterised but seem unaware of the range of potential issues that can occur. All patients preferred being catheterised to being incontinent. Some experienced more catheter related issues than others and some reported inconsistent expertise across health and social care providers. The patients preferred staff with whom they had a therapeutic relationship and recognised those with catheter care expertise. Catheter related pain was an issue for some patients, however none of the participants referred to pain management strategies.

Carer Interviews (spouse/daughter)

The carers demonstrated commitment to ensuring catheter care and the management of issues was addressed timeously. There was, however, a sense of learning on the job; this resulted at times in inappropriate practices for example frequently emptying the catheter bag. They discussed frustration in terms of getting help when needed whilst struggling to decide when to ask for help. Carers appeared to hope that problems would resolve as the day went on; this could result in a call to the 'out of hours' rather than the regular district nurse service.

Qualified Nurse Interviews

Nurses were regularly involved in catheter care and management of related issues. Standardised training and education for this aspect of their role did not appear mandatory, though one nurse reported completing a *learnPro* module in catheter care. Another talked about completing competencies when she was newly in her staff nurse post and of reflecting on what she had learned whilst at University. It appeared the norm to discuss management strategies for catheter related issues with the nursing team, indicating the importance of experiential learning or a 'learning on the job' approach.

Health care assistants & Augmented home carer interviews

A range of roles were undertaken by health care assistants and augmented home carers. All augmented home carers undertake extended personal care including catheter care. Mainline home carers are a lower pay grade, and while they carry out personal care they do not undertake catheter care. Some patients appeared to have up to four visits per day from a health and/or augmented home carer and in the event of catheter related issues a qualified nurse would be consulted. The

different roles and responsibilities were not clear to patients and carers and this resulted in confusion about who did what.

Thematic analysis of all the participant transcripts

Four key themes, each with three related subthemes were identified in the participant transcripts (see Table 1).

Table 1: Key themes and subthemes

Key themes and subthemes			
Lived experience	Communication	Care delivery	Education
Catheter related concerns	Inconsistent transfer of care	Deciding when to phone for help	Lack of standardised training
Learning as they go along: the patient and carer experiences	Conflicting information	Lack of clarity in terms of who does what	Learning on the job
Therapeutic relationship	Variation in patient and carer expectations	Variation in experience and knowledge	Catheter care interventions

These themes are discussed below.

Lived experience

The following discussion encompasses three subthemes identified in the lived experience theme of the data:

- Catheter related concerns
- Learning as they go along: the patient and carer experiences
- Therapeutic relationship

Quality of life with a catheter dominated the lived experience theme from the patient perspective and that of their spouse/relative carers (wife or daughter, hereafter referred to as carers).

Meanwhile for health and social care staff (health care assistants, augmented home carers and qualified nurses from the regular and 'out of hours' service) the lived experience involved task and time management orientated challenges in providing appropriate support and advice.

The participants discussed a variety of complications experienced by patients living with a catheter. These included pain, CAUTI (sometimes preceded by confusion), the catheter bypassing or blocking, debris, encrustation, haematuria and the catheter 'falling' or being 'pulled' out.

The challenges of living with or providing care and support for someone with a catheter were often discussed with a sense of inevitability and compared to the consequences that might be experienced in the absence of catheterisation, for example, urinary frequency, retention, pain and using incontinence pads:

'I just keep a night bag at the side of my bed which I plug into the catheter and that saves me trotting away to the toilet every half hour' Patient (participant, 6)

'I don't like a nurse that will come in and say to me you're bypassing, just wear a pad' Patient (participant, 8)

Practical issues discussed included debate about selecting the appropriate size of catheter, knowing how much sterile water to use to inflate the balloon and having the correct catheter related equipment in the patient's home for re-catheterisation purposes.

There appeared to be variation in the way in which equipment was sourced. One patient talked about the district nurse organising a prescription for his equipment; another talked about phoning various companies to enquire about available products. A health care assistant stated:

'I normally go in once we've had a referral and I arrange for all like stock and things like that all to go in the house as well, prescriptions and things for maintenance of the catheter' Health care assistant (participant, 5)

Meanwhile one patient with ten surplus catheters at home had no saline and was dependant on the district nurse bringing some with her:

'the last order I've got for catheters, I think I got 10' Patient (participant, 8)

The physical, psychological and social impact of living with a catheter or having a spouse/relative living with a catheter appeared on going. One patient (participant, 4) described it as a *'kinda unpleasant existence really'*. This resulted from, and appeared perpetuated by, catheter management being a focus of daily life in the home of someone with a catheter. A key problem appeared to be that patients and their carer felt they were given no written information and little by the way of advice in preparation for catheter care/management/maintenance:

'they [hospital based nurses] filled me in, aye, told me what to do, just keep it as clean as, you know. I would have liked more advice, and I kinda blame myself for not asking' Patient (participant, 4)

Patients and carers became increasingly knowledgeable over time and adopted terminology used by health and social care staff:

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

'it was bypassing' Patient (participant, 4)

'I know you were retaining' Carer (participant, 3)

Despite not having information resources to hand, some patients and carers were adept at recognising patterns in terms of complications, for example one carer participant said she knew when her father had an infection:

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

There appeared to be a dilemma in terms of the doctor prescribing antibiotics for urinary tract infections and the patient developing antibiotic resistance; this caused frustration for some patients and carers:

'He said [nurse] well a low grade antibiotic but the doctor wasn't so sure about it' Carer (participant, 18)

Having evidence based information about antibiotic use might have reduced patient and carer frustration.

Some patients experienced more problems than others:

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

'it's uncomfortable at times but other times I forget it's even there' Patient (participant, 6)

The nurse participants talked about being aware of patients who frequently experienced catheter related issues. Nurses, health care assistants and augmented home carers discussed at times being unsure what to do next in terms of solutions, for example when a catheter is bypassing. One nurse discussed an occasion when she felt she had exhausted her solutions list; this resulted in frustration for all involved:

'his wife who contacts us and our problem is there's nothing we can really do about his catheter' Nurse (participant, 9)

'I phoned them [nurses], he was bypassing and I changed him 6 times within an hour. He was absolutely soaking and I change and I phoned them and they turned round and said we're not coming out, there's no more we can do for him' Carer (participant, 3)

For some patients and carers the resultant lived experience is a wilderness of learning as they go along, fear in terms of getting an infection and going out, coupled with worries about what others will think:

'I mean if you're out in company and you know you become very self-conscious of it' Patient (participant, 6)

Some patients struggled to come to terms with having a catheter as well as with social isolation, which occurred due to fear of going out and being embarrassed if the catheter leaked or required emptying:

'getting used to the catheter I was bypassing, I was going out with clothes on and having to come in in the middle of the day for to change and you know, embarrassing as well as everything else' Patient (participant, 8)

'it's the kinda unpleasant experience having it on and obviously when the grandchildren are running about and that and you're very conscious about do you know? So it's not been a happy experience having it, it really hasn't' Patient (participant, 4)

Carers also talked of social isolation and loss of personal freedom as a result of feeling they could not leave the patient alone for any length of time. One carer discussed her exhaustion after getting up many times during the night to assist her husband who was anxious to have his catheter bag emptied as soon as it had urine in it. Both appeared unaware that frequently emptying the catheter bag could increase the risk of CAUTI. In another example a carer encouraged her husband to loop his catheter tubing (leg bag with night bag attached) through the hand that he used for his walking stick when he mobilised:

'that bag's trailing, so now what I do is I hand him up the bag and he holds it with the walking stick' Carer (participant, 3)

Her rationale was that he would not trip over the tubing; however, both appeared unaware of

potential backflow of urine causing infection. In addition, two male patient participants mentioned the impact of their catheter on potential sexual activity:

'as far as my sex life's concerned it's practically non-existent now but the treatment I'm on for my cancer it kills off my male hormones so' Patient (participant, 6)

'you can still lead an active sex life with the suprapubic whereas with this one [stops talking] ...' Patient (participant, 15)

Neither appeared to have been provided with advice in relation to catheter management strategies during sexual activity.

Regarding social participation, only one patient continued with his hobby of gardening and managed outings to the local pub by using a spigot/valve instead of a catheter bag. He appeared to have acquired information from one of the district nursing team about using this approach:

'if I'm out I don't have the bag on and I just use the toilet like anybody else only I use the catheter' Patient (participant, 6)

There was a sense across the participant groups that developing a therapeutic relationship between the patient, carer and health / social care staff was important in terms of trust and confidence:

'the girls that come down here to change my catheter, they couldn't be nicer' Patient (participant, 6)

'they'll come out, so the care has been great and they've listened to us, which is excellent' Carer (participant, 18)

Health and social care staff discussed a variety of experiences in terms of uptake and use of education resources; this is discussed in more depth later.

Communication

The following discussion encompasses three subthemes identified in the communication theme in the data:

- Inconsistent transfer of care
- Conflicting information
- Variation in patient and carer expectations

There were varying accounts of how information about patients with a catheter is transferred between nurses in the acute and community setting. There appeared to be no consistent format for transfer of information or way of ensuring the patient's catheter related history was available to the next service provider. Nurse participants said there might be a telephone call and/or a discharge letter from hospital based nurses to community nurses. Telephone calls to the district nurse regular and 'out of hours' service appeared to come from hospital based nurses, or community based health care assistants and augmented home carers as well as patients and carers. None of the health care assistants or augmented home carers discussed how they received information about a patient / client they were attending. They did, however, appear clear about which catheter related issues required a skilled assessment from the district nurse:

'if the catheter's bypassing we'll contact the district nurse as well' Augmented home carer (participant, 10)

One nurse (participant 7) recalled being called 'out of hours' to a patient with a blocked catheter, when she changed the catheter 'the patient started to haemorrhage quite badly'. In this situation she called NHS24 (The Scottish emergency helpline for NHS services) for advice; subsequently the patient was admitted to hospital. This nurse was able to provide details about the patient's catheter related history to the NHS24 nurse. One nurse talked about some patients with a catheter having a 'catheter passport'. This passport is updated with each intervention and issue the patient has had with their catheter.

When patients were transferred from hospital to home, they did not appear to be given written information about catheter care. One carer (participant 18) stated that she was not concerned about the lack of information she got about her father's discharge home:

'we were told that the carers would be in seeing to that so we didn't actually worry at that point' Carer (participant, 18)

It was evident that both patients and their carers were confident in phoning for information and help, 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)

This indicated that communication between the patient / carer and the district nursing service was a positive experience. 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 [formal] if there's a problem' Nurse (participant, 9)

Nurse participants appeared to accept as inevitable the volume of telephone calls they receive in relation to catheters:

'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)

It appeared that nurses often engage in a telephone discussion to attempt to solve the problem, for example, to ask if the patient has drunk an 'adequate amount of fluids' (nurse, participant 9), if the catheter tubing is kinked, the leg back straps are occluding the flow of urine or the catheter tap between the leg bag and night bag is open.

Patients and carers reported getting conflicting information which caused them confusion and a dilemma in knowing who to trust:

'The district nurses said they don't believe in that [procedure] but who's, 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 (participant, 3)

Patients and carers discussed positive communication during hospital appointments, however, were often aware later of information that they would have appreciated:

'he [consultant] says that I could be left with a catheter...I didn't know what a catheter was' Patient (participant, 8)

This patient wanted more 'information' though he did not tell the interviewer what would have been helpful:

'that was all the information I got...any information I got it was actually because when I went to the urology clinic' Patient (participant, 8)

The participants indicated a range of patient and carer expectations in terms of catheter care and management. One carer felt that the nurses expected her to know about her husband's catheter:

'and they're telling me that the balloon can go down and what was wrong was the balloon going down, but how am I to know that? I'm not trained to know that' Carer (participant, 3)

One patient said he would have liked more support in the form of someone to talk his catheter related concerns through with; he suggested this could be a professional or a patient with a catheter. There seemed to be locally understood demarcation between some health care assistant and augmented home carer roles. One patient said he had a mainline home carer who washed and dressed him and a health care assistant who then came in to carry out his catheter care. Health and social care staff encouraged and enabled patients and their carers to engage in fundamental catheter care including emptying the bag, checking for kinks in the tubing or that the valve was closed; some were more receptive to this than others:

'for older clients, their partners wouldn't want to touch it or [have] anything to do with it, they seem to be more nervous about it' Augmented home carer (participant, 10)

Across the participant group there was variation in expectations; these included who was responsible for what, as well as what level of self-care was reasonable. Whilst some health and social care staff felt that patients and carers could do more it was evident that reasons for disengagement included anxiety, lack of confidence and fear of doing damage:

'they said about me doing it, well to be honest, I don't feel that I'm confident enough to do that' Carer (participant, 3)

One nurse spoke of a carer going to another room while her husband was having catheter care; her reason for disengagement was not explored. Meanwhile, engagement in self-care appeared more likely in patients who were physically able and socially engaged for example patient participant 6. Patients and carers expected health and social care staff to be knowledgeable and lacked confidence in those who appeared less skilled:

'some of the younger ones that came in at night didn't know how to put the strap on or put the, the tap on' Carer (participant, 3)

They also recognised that engaging in information sharing was vital to finding appropriate solutions:

'you are the one living with it day in, day out. They don't know a thing about it until you tell them' Carer (participant, 18)

This suggests that there are various aspects to and reasons for patient and carer engagement and disengagement in catheter care.

Care delivery

The following discussion encompasses three subthemes identified in the care delivery theme of the data:

- Deciding when to phone for help
- Lack of clarity in terms of who does what
- Variation in experience and knowledge

Recognising catheter related issues was something that patients and carers became increasingly skilled in. However, they talked about a dilemma in deciding when to phone for district or out of hours nursing support and advice. The reasons for this dilemma varied, for example one carer talked about having a negative response from a regular service district nurse which resulted in her and her husband deliberately waiting until 4.30pm to call 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]' Carer (participant, 3)

This participant's husband had complex catheter related issues; at one stage of the interview she expressed a feeling of abandonment:

'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' Carer (participant, 3)

Others struggled to decide the right time to make a call because they hoped that the symptoms would resolve for example if they drank more fluids. Meantime, one carer (participant, 18) phoned her father's GP to request antibiotics at the first sign of a CAUTI. Health care workers and augmented home carers appeared to have a good understanding of when they should phone to request a district 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)

Phoning for help appeared to be based on previous experience and fear that symptoms would worsen.

As previously discussed there was a lack of 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 some overlap between health care assistant and augmented home carer responsibilities:

'They could be assisting these people [patients] to get washed and dressed in the morning but they won't, you know they 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)

Lack of clarity also appeared to occur because of the individual nature of each patient's needs, catheter related complications and ability to engage in self-care. Meanwhile, information and advice appeared to be provided when issues occurred rather than in a routine way. Verbal information and advice though making sense at the time appeared to get lost or in some cases misinterpreted; information about catheter hygiene was described by patients and carers in superficial terms for example:

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

None of the participants talked about patients having an information booklet that they could use as a resource and this is detailed in the final theme of education.

Variation in experience, skill and knowledge existed in the health and social care participants and in patients and carers. Patients and carers expressed having more confidence in some staff than others:

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

'Other ones [staff] came in and knew what they were doing and made it less painful and everything else.' Patient (participant, 15)

'the catheter isn't a problem at all and the nurses are absolutely brilliant' Patient (participant, 6)

Confidence was generated through trust in skill and knowledge as well as less tangible qualities like perceived experience; one patient was embarrassed when a young nurse attended to his catheter care. Another was cautious if health care assistants or augmented home carers appeared unskilled in changing his 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], as I said I didn't even know how it stayed in' Patient (participant, 4)

His lack of knowledge influenced his perception of risk in terms of what could go wrong. Patients and carers appreciated the kindness shown to them regardless of how skilled or otherwise they perceived the health and social care staff to be.

Education

The following discussion encompasses three subthemes identified in the education theme of the data:

- Lack of standardised training
- Learning on the job
- Catheter care interventions

The health and social care staff discussed various ways in which they had learned about catheter care and dealing with complications. It was evident that the staff tended to know which patients had complications.

The catheter passport was mentioned, but did not appear to be in use:

'we've just been forwarded something recently...a catheter passport I think it was called' Nurse (participant, 7)

Patients preferred it if a member of health or social care staff were already familiar with their catheter related issues:

'if a new doctor or anybody comes in here [home] he [husband] feels uncomfortable because he feels he's got to start [telling catheter history] from the beginning' Carer (participant, 3)

There appeared to be no standardised catheter related training or education requirement for qualified nurses; rather it seemed that experiential learning with colleagues whilst on the job was

popular, reflecting on what they had learned pre-registration was common, and completing for example a learnPro education module optional:

'whilst I attended university we had significant amount of skills lab training to perform a female urethral catheterisation, I don't feel that at the university we were trained in how to deal with problems as such, you know, if it becomes blocked or if it starts to bypass' Nurse (participant, 14)

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

'male catheterisation, it was your competencies, so you were just kinda shown that, I think it was 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)

When asked about catheter related training for staff, one of the 'out of hours' nurses stated that the nature of the work involved unplanned care:

'all our catheter sort of contact is all unplanned things going wrong basically' Nurse (participant, 7)

When pressed, participant 7 said she thought there had been some training:

'let me think, the catheter management team, I'm sure they did training, like training sessions with the day staff but obviously because I'm no longer day shift I don't really get to attend that any more' Nurse (participant, 7)

Learning on the job was a recurrent theme with staff saying they talk to each other and learned from each other's experiences of catheter care. One health care assistant stated:

'they [the team] kinda keep us up to date with the research and we all talk as a team about different things' Health care assistant (participant, 5)

'I think very often I go with the experience I have had and obviously, if anything comes in, updated information, it's usually disseminated amongst us' Nurse (participant, 9)

The catheter related training and education requirements of health care assistants and augmented home carers appeared to be similarly hard to define:

'my induction was 13 years ago and I can't quite remember what kind of training we had back then' Augmented home carer (participant, 11)

'a couple of years ago we, we had a talk with one of the district nurses about catheter care' Augmented home carer (participant, 11)

'our [manager] is quite good, she kinda keeps up to date with a lot of kinda catheter and likes of research and that, so i.e. we changed a lot of the bladder lavage stuff' Health care assistant (participant, 5)

'To be honest I never had any training at all' Augmented home carer (participant, 12)

All home carers receive the appropriate level of training for their remit through induction, supplemented by additional training as required, often provided by district nursing colleagues. A safe system at work has been developed for catheter care, and augmented carers have been fully briefed.

In the case of catheter complications one augmented home carer appeared frustrated by her lack of training, especially when she wanted to alleviate the patient's discomfort:

'but it's like what do you do before the nurse comes out, I've not had any training, is there anything you can do until the nurse can come out' Augmented home carer (participant, 10)

There was evidence that nurses felt apprehensive about some aspects of clinical decision making in relation to catheter care for example, when the patient had haematuria. Apprehension appeared to be linked to lack of experience. Some patients appeared to have been admitted to hospital when the attending nurse was concerned about what was happening or might happen. Other challenging catheter care issues were resolved in the patient's home:

'I attempted a second bladder irrigation which actually disturbed the clots which drew out with the wash and his catheter actually unblocked with no, no further bleeding' Nurse (participant, 14)

'the patient started to haemorrhage quite badly so that had never happened to me before so was quite shocked really having to deal with that because I was quite, I was like oh my goodness, so we had to phone for NHS24' Nurse (participant, 14)

As previously discussed patients and carers appeared to acquire knowledge and skill in terms of

catheter care by problem solving as issues arose; at times the advice they received appeared superficial. For example, advice that a patient with a catheter should 'drink plenty' was frequently mentioned by the participants, although 'plenty' was not quantified:

'I mean he's drinking gallons to try and keep it... [interrupted by husband] 'oh I'm drinking copious amounts of water there [interrupted by wife] but it, he's still getting infections' Carer and Patient (participant, 4)

One patient discussed how he gained confidence and knowledge:

'I thought myself that the size of the catheter I was using was too small and I says could you upgrade it, we went from a 14 catheter up to a 16 now for a while...I was starting to get control of things, and as I gradually got on I found out what didn't suit me and what did suit me' Patient (participant, 15)

Some patient practices were potentially harmful for example, the patient who emptied his catheter bag as soon as it had urine in it. Health care assistants 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 round their legs' health care assistant (participant, 5)

None of the patient or carer participants spoke about using the internet to search for information; rather they appeared dependant on the health and social care staff that they came into contact with for advice. There appeared to be a gap in terms of written catheter related information in the patient's home coupled with evidence that calls to the district nurse service often resulted in advice to check for example if the catheter tubing was kinked. One patient when asked if he had been given catheter related information said:

'to be honest...I didn't have much advice about how to use it or what to do. I just woke up with that there [catheter] and just accepted it' Patient (participant 4)

Another patient felt he received adequate information:

'you get enough, they give you enough information' Patient (participant, 15)

One carer felt unprepared for the catheter related issues her husband experienced:

'I didn't even know it got changed every 12 weeks...didn't realise he was going to have all these problems. I mean and the infections...a couple of months back he

[husband] came in and said "look at my bag" and it was full of blood...I'm trying to act dead brave cause I don't want to upset him' Carer (participant, 3)

Nurses, meantime, appeared to give verbal information and advice rather than written:

'I don't think there is any information given out' Nurse (participant, 9)
'once they're home [patients] the district nurses doing the day shift will go out and just ask them how they're getting on...I've never seen any written information in a patient's house' Nurse (participant, 7)

Nurses appeared aware of a catheter related information and advice gap. One nurse said she thought patients should be given more information prior to hospital discharge:

'I don't know how well explained sometimes it is before they [patients] leave the hospital and I don't know how well, how much they are shown of the care of the catheter before they leave hospital...some of them are quite happy with things and some of them aren't and I think possibly if, if they were taught maybe more or discussed more before they left hospital it might help' Nurse (participant, 9)

The absence of written information for patients was also noted by one health care assistant, who appeared aware of an information gap:

'it would be nice to have information that I could leave for patients' Health care assistant (participant, 5)

There was a wide range of catheter care interventions discussed by the participants some of these highlighted training and education needs. For nurses these needs included what to do in the case of haematuria, how long to persevere when trying to unblock a catheter, when to use bladder lavage, and how to manage a patient's pain:

'She [nurse] worked on him for 45 minutes trying to get that catheter sorted and he was in agony, he was hitting the roof and it ended up she had to end up taking it out and putting a new one in. She says, now if that had been flushed earlier' Carer (participant, 3)

One health care assistant said she would try a bladder lavage to alleviate a patient's pain in the event of his catheter being blocked:

'I can go in to do the bladder lavage...sometimes you get a lot of pressure and it [lavage fluid] won't go in at all and the patients maybe in a bit of pain or retention or something' Health care assistant (participant, 5)

It appeared that a blocked catheter, urinary retention and a catheter coming out unintentionally were common occurrences:

'catheters are blocked or bypassing or have fallen out' Nurse (participant, 7)

'if the patient is retaining usually we just have to change the catheter' Nurse (participant, 7)

Health and social care staff all indicated they had a role in offering psychological support and fundamental problem solving prompts:

'you know, throughout the night, early hours in the morning, they're very apologetic but they, they just panic, you know, because they don't have a lot of information' Nurse (participant, 9)

Pain appeared a recurring problem and was discussed by patients and carers as occurring in the event of 'crustation', blockage, infection, and when a catheter was being changed. None of the patients discussed taking analgesia or using pain management strategies.

Feedback from the project team

Following the opportunity to scrutinise the quantitative and qualitative findings from this study, a meeting was held with the project team. The feedback from the project team included perceived negativity in the report, in particular in relation to health and social care education and training. The team highlighted that the education and training as discussed in the qualitative data did not reflect current practice (see roles and responsibilities of staff below). This is possibly due to the interviewers being from a university, which may have led participants to think that they were being asked about *formal accredited* education rather than *practice based* training.

The project team felt that some of the patient and carer narratives were negative and this may have been due to the type of participants attracted to take part, that is those with a story to tell. Thus mainly patients and carers with complex needs were possibly attracted to participate. In addition, only one side of a story gets told, as is the nature of qualitative interviews. There was a degree of contradiction in the interviews which meant that some negative comments were counterbalanced by later positive comments about care received.

Following the feedback meeting, some amendments were made to the report which was fed back to, and agreed, by the steering group.

Roles and responsibilities of staff

Nursing staff

The registered nurses have in-house training for male catheterisation and suprapubic catheterisation, which is delivered by band 6 or team leaders. Nurses are also expected to complete the learnPro module.

The nurses are observed (minimum three times) by the Band 6 trainer to assess for competence in male catheterisation and suprapubic catheter care. There are also simulation training techniques for Male catheterisation if this is thought to be useful to the practitioner. In addition, the nurses receive guidance notes on the procedures.

Nurses are expected to be able to troubleshoot problems for males and females with urinary and suprapubic catheter problems. They are expected to have covered this in their nurse training during their practice placements. Nurses will not be delegated male catheterisation or suprapubic re-catheterisation until deemed competent by trainer and are advised not to proceed if unsure or if problem arises. All staff have telephone back up from the team and can refer the patient to another team member if required. The team encourages reflective practice and team meetings allow for time to talk about any problems (and solutions) that have arisen that the rest of the team can learn from.

Health care assistants deliver much of the essential day to day care associated with catheter care and registered nurses are accountable for ensuring that the delegation of tasks is appropriate and staff are competent in delivering the care safely.

Health care assistants

The training provided in West Dunbartonshire for health care assistants (HCAs) in catheter care is delivered by registered nursing staff working directly with the HCA. This enables the HCA to observe procedures prior to carrying out tasks under direct supervision until deemed competent by a registered nurse.

Competency Framework for HCA catheter care

Tasks observed/supervised

- Hand Hygiene – regular updates in-house training

- What is a catheter and purpose?
- Awareness of catheter products on formulary
- Catheter hygiene
- Empty catheter bag or valve
- Change catheter bag or valve
- Administer a catheter instillation and have awareness of appropriate solution which is determined by pH reading
- Obtain catheter specimen and undertake urinalysis
- Maintain appropriate drainage bag position
- Recognise common associated catheter complications ie bypassing, blocked
- Awareness of symptoms associated with urinary tract infection
- Accurate record keeping

Awareness sessions and updates are delivered to all staff in-house as new products become available and to refresh staff on best practice in relation to catheter care.

Existing educational tools in catheter care management

A scoping exercise on the available training was undertaken the results of which are summarised in Tables 2 and 3.

Table 2: Formal training for health care workers

<p>1.Greater Glasgow and Clyde Community Nursing guidelines: urethral catheterisation and supra-pubic re catheterisation for adult patients</p>	<p>On NHS staff net: approved by Clinical Governance committee October 2014</p>	<ul style="list-style-type: none"> • Nurses should be competent in catheterisation • Nurses should be aware of current guidelines including NICE and SIGN • Staff education/learning should be done through personal study • Wherever possible patients and carers should be independent in the ongoing management of the catheter • Information and advice should be given on hygiene, fluid intake, prevention of constipation and correct use of drainage system' • There is a troubleshooting guide within these guidelines (NICE No.3 and SIGN No.4), with advice on drainage, blocking, infection, bypassing and pain • Guidelines (NICE No.3 and SIGN No.4) state that patients and carers must be provided with a 24-hour contact number to the district nursing service • All education given to patients and carers must be documented
<p>2.NHS Greater Glasgow and Clyde Urology Formulary 2015/2017</p>	<p>Produced by Therapeutics Short Life Working Group Aug 2014</p>	<p>Points of interest</p> <ul style="list-style-type: none"> • Patients and carers should be given the opportunity to make informed choices when selecting a product to order • Some of the product prescribing detail contradicts the guidance given in the above guideline (NICE No.3 and SIGN No.4). Supra-pubic catheter should be changed 6-8 weekly; the prescribing guidelines state change every 3 months
<p>3. NICE- Quality Standard Urinary Catheters Infection Prevention and control</p>	<p>NICE, www.nice.org.uk Produced April 2014</p>	<p>This concentrates of preventing infection for indwelling catheters; for example, position catheter bag below the bladder, bag should not be in contact with the floor, bag emptied frequently, and hygiene</p>
<p>4. SIGN Management of urinary incontinence in primary care</p>	<p>SIGN Guideline 79</p>	<p>Withdrawn Feb 2015 as out of date</p>
<p>5. NES via learn pro Catheter- best practice online training programme</p>	<p>By NES is learn pro web site. Part of CPD, not mandatory</p>	<p>Is again on the prevention of infection with urinary catheters</p> <ul style="list-style-type: none"> • Has one module section on catheter care and maintenance. This is focused on catheter infection prevention and CA-UTI bundles • The CA-UTI bundle is paperwork that help the nurse ensure that when the catheter is inserted the risks of infection are limited and problems highlighted. It is used at the time of catheter change • This module is very hospital based. It outlines hospital based care rather than living with the catheter at home

No tool was found for nurses to use to provide education to patients and carers other than what should be covered in the guidelines. For paid carers within West Dunbartonshire this education was given by the district nurses to the council employed carers.

Table 3: Information for patients and their unpaid carers

<p>Leaflet- Living with an Indwelling Catheter</p> <p>Spoke with hospital and they had out this leaflet to patients with a new catheter. I have never seen this</p> <p>Also spoke with Continence team in Clydebank who also had this leaflet for patients</p>	<p>Produced by Fittleworth (company in providing stoma and continence supplies)</p>	<p>Headings</p> <ul style="list-style-type: none"> • The urinary catheter • Catheter comfort • The Drainage system • Night bags • catheter valves • Hygiene • Diet • Fluid intake • sexual activity • travel advice plane, car, rail and sea • bypassing • discomfort • pain • dark, offensive urine • blockage
<p>Leaflet – ‘At home with your catheter’ available from the Urology clinic This leaflet also handed to patients and carers with catheter</p>	<p>Produced by medical illustrations</p>	<p>Via phone this contains pictures of where catheter goes, what you should drink, eat...</p>
<p>Online resource SPHERE bladder and bowel service www.nhsggc.org.uk/services/continence</p>		
<p>Online resource NHS CHOICES- living with a urinary catheter www.nhs.uk</p>	<p>Section on looking after your catheter</p>	<p>This leads the reader to the BAUS website for leaflet on management of urinary catheters</p>
<p>Online resource BAUS British association of urological surgeons Baus.org.uk</p>	<p>Management of a urethral catheter leaflet Frequently asked questions Published July 2014</p>	<p>Headings</p> <ul style="list-style-type: none"> • what is a catheter • the catheter • the leg bag for day • leg bag support • gstrap • the night drainagebag • bladder spasms • leakage • blood or debris in urine • blockage • catheter falling out • urine infection
<p>Online resource Healthtalk.org</p>	<p>Living with a urinary catheter</p>	<p>Lots of sub sections on living with an indwelling catheter with info and then lots of different experiences from patients, formal and informal carers and health care professionals This website contains mostly videos from experiences. It appears to cover most issues</p>

6. Discussion

We undertook a study of the experiences of healthcare professionals, carers and people living with a catheter in order to determine the nature of the lived experience and to develop education/training resources designed to impact positively on the experiences of patients. The study focused not on patients alone because this approach would have been incomplete.

Here we present our progress against the project objectives.

What is the incidence and nature of callouts associated with indwelling urinary catheter use in community living patients within West Dunbartonshire?

Our review of the literature could not find any detailed information on the incidence of callouts related to problems with catheters. However, infection, bypassing and blockage were frequently mentioned in the literature as problems experienced by patients. In our study callouts related to catheter issues were assessed retrospectively through an analysis of records in West Dunbartonshire over a two-month period during 2015. While the reasons for callouts varied there was a clear trend towards catheter bypassing and blockage being the main issues experienced by patients (accounting together for 75% of callouts). Interviews with patients, carers and healthcare professionals provided detail that the figures above could not. The experiences of patients differed markedly with some experiencing few issues while others were frequently impacted by debilitating issues (such as bypassing or blockage). There was a view expressed by some patients that these issues were inevitable yet better than having to worry about urinary retention or incontinence. While we were heartened on more than one occasion by the positive attitudes of the people we interviewed, we as a community of carers must focus on helping people lead a better life where their health means that a catheter is a requirement.

Our data support the view that the main issues experienced by patients relate to catheter blockage (bypassing is a common symptom of this). The nature and reasons for blockage are not well understood but we do know that bacteria play a role, perhaps by changing the pH of the urine and allowing crystalline materials to coat the inside of the catheter (Stickler and Feneley, 2010). Bladder irrigation is commonly recommended to reduce the incidence of catheter blockage yet the quality of evidence supporting its efficacy is weak (Sinclair, Hagan and Cross, 2011). We are currently updating the Cochrane Review on catheter washout solutions and our main recommendation is that there is a lack of good quality peer-reviewed scientific articles in this area. Therefore, we plan to seek funding to undertake a randomised control trial to assess the efficacy of catheter washout solutions.

What were the experiences of people with indwelling urinary catheters both those managing their own care and those who are more dependent/have complex needs?

Living with a catheter is tolerated because the alternatives are not feasible, yet catheter care appears problematic and complications seem inevitable. Across the participant groups there was evidence of knowledge and skill being a positive support mechanism for patients and carers. An important aspect of physical and psychological support for patients and carers was knowing that they could phone someone for advice at any time of the night or day. It was clear that patients thought positively about the care that they received and also clear that healthcare professionals valued the caring role that they undertook. However, patients had little knowledge about what issues and complications could occur after the catheter had become part of their daily lives. Patients often learned about catheter care through experience with the help of healthcare professionals. There was a clear evidence-based argument for an education resource for patients that would provide them with information on why they needed the catheter, how their catheter worked, and what issues and complications they may experience. Empowering patients with information would allow them to take more control of their own care, which would benefit the patients as well as those who cared for them. We aimed to interview eight carers yet only managed two. We approached many carers but they were reluctant to become involved. While the reasons for this are currently unclear, it may be that they were concerned that they were doing something wrong: perhaps they felt unclear about their role, or perhaps they were unwilling to discuss personal issues about their loved-one. Providing carers with education about catheters may help them to better understand the experiences of the person with the catheter, promote discussion through common language and empower them to become more actively involved in their care.

We concluded based on our findings gained both through an extensive review of available education/training resources, the results of the interviews and through peer group discussion that there was a need for education resources for patients and their carers in order to promote self management in catheter care. We presented our views to Angie Henney during a meeting at the Vale of Leven Health Centre and agreed that a strategy focusing on patients and their carers was appropriate.

What were the experiences of community nurses and other health professionals, social care staff and relatives/carers supporting people with indwelling catheters in the community?

Health professionals worked closely together and none of the interviewees felt unable to cope with situations related to catheter care. However, some of the patients had complex health requirements and nurses, health care assistants and augmented home carers discussed at times being unsure what to do next in terms of solutions.

An important aspect of the professional support for health care assistants and augmented home cares was provided by the qualified nurses. Similarly, qualified nurses valued and trusted the referrals made to them by health care assistants and augmented home carers. All of the healthcare professionals interviewed felt comfortable in their level of knowledge and expertise and were able to undertake their duties of care in a confident manner. Yet when the staff were interviewed they, on occasion, did not provide much detail about the education/training that they received. This apparent contradiction requires explanation. Healthcare staff may have felt that they were being asked about 'formal education', lectures and tutorials for example and this view may have been reinforced because the interviewer was a teacher (lecturer). A review of the training resources utilised by healthcare professionals both within their work locality and the wider healthcare community showed that there was a variety of resources available. Healthcare staff made extensive use of online resources and experiential learning, which is appropriate considering that many of the skills required were very practical and best learned through example and peer support.

The communication between the patient, their carer and healthcare workers was a positive experience and there was evidence of good communication, with staff working together in a trusting way. The nurse participants talked about being aware of patients who frequently experienced catheter related issues, which was also evidenced in the callout data that was collected during the study.

What activities or interventions were associated with positive outcomes for patients/reduction in call-outs?

One of the main issues with catheters is the potential for infection (CAUTI). While it is generally accepted that most if not all people with a catheter will have bacteria present in their urine, it is not clear whether this represents a classic infection or rather colonisation. The symptoms of CAUTI in the elderly are not as clear as in younger people and here there is a role for carers and healthcare professionals in recognising when an infection has occurred. Over time carers may learn to recognise

the symptoms and we found one example of this in our study where the carer of an elderly individual recognised presentation of delirium and disorientation as signs of CAUTI.

The presence of this indwelling device is a route for bacteria to enter the usually sterile urinary tract. The most common treatment for CAUTIs is an antibiotic (Stickler and Feneley, 2010). Prophylactic antibiotics (to reduce the risk of infection) may be indicated in some cases but there is the long term risk of antibiotic resistance developing and there seems to be evidence of a disconnect between different areas of healthcare on when such treatment should be given. This may be indicative of the professional pressures that doctors are under regarding reducing the use of antibiotics as part of the drive towards better antibiotic stewardship. However, patients may not appreciate the importance of antibiotic stewardship and wonder why they are not being offered a treatment that would give them relief from chronic infection. It is telling that these infections which are so common in people with catheters are seen as almost inevitable and without a truly effective regime for prevention. This is not a criticism of the healthcare service but it does raise the question of whether it is the design of the catheter itself which is at fault; a design which we have now been using relatively unchanged for 80 years. It is best to try to prevent these infections in the first place through the principles of infection control. Good practices such as using single-use sachets of lubricant or anaesthetic gel to insert the catheter, the use of a closed system, and good hygiene practices for both carers (formal and informal) and the patient all help to reduce the risk of infection. Each time a catheter is changed there is a heightened risk of infection and therefore catheter changes should be kept as infrequent as possible (Dailly, 2011). When to change the catheter is very much unique to the patient's personal circumstances and experiences. For those patients who experience issues of CAUTI and/or blockage then changing the catheter on a more frequent basis may help to reduce the incidence of complications and lead to a better quality of life. Therefore, the role of the healthcare professionals is central to the person-centred care that is unique to each patient.

What education/training would best support patients, carers and health professionals?

We undertook a review of the available resources for the education/training of patients, carers and healthcare professionals relating specifically to catheter care. We found that there was a robust education/training regime in place for healthcare staff: as outlined in the sections entitled "Roles and responsibilities of staff" and "Existing educational tools in catheter care management". None of the healthcare professionals interviewed stated that they felt unable to undertake their duties of care because of a lack of education. In contrast patients and carers were clearer in stating that they had little knowledge of the issues that may occur after the catheter had been inserted. There was also a

lack of understanding around general catheter care and maintenance from the patient and carer perspective, with one patient emptying the catheter bag as soon as there was some urine in it. Such practice may increase the likelihood of infection because each time the bag is disconnected there is the risk of contamination. We focused therefore on the patients and their carers and endeavoured to develop an educational tool to support them.

Development of an education/training resources for patients, and carers with people who have indwelling catheters in the community

We worked to produce a patient/carer focused educational resource that would support people living with a catheter in the community. The content of this resource was informed by the data that we collected during this study and through evidence from the literature about catheter care.

We decided to develop a patient leaflet that focused on describing what the catheter is and how it works, how to maintain the catheter, what issues may occur and what to do about them, and finally, who to contact when there are questions or concerns. It is hoped that this leaflet will help empower patients to take more control of their own care and ultimately lead to a better quality of life.

The patient/carer leaflet was developed through a series of working group meetings attended by NHS and UWS colleagues. We reviewed the data gained from the interviews and the published literature and determined the key themes that needed to be addressed. The main themes regarding catheter care and maintenance were around how to position the catheter, when to empty the leg bag, dealing with the night bag, diet and fluid intake. We focused heavily on the issues reported during callouts related to catheter care (See the Findings section). A draft of the patient/carer leaflet is provided in Appendix 10 of this report. The draft patient/carer leaflet was reviewed by the steering group and then also reviewed by NHS Medical Illustration (NHS Greater Glasgow and Clyde). It has not escaped the authors' attention that this new resource would be of benefit nationally.

It is envisaged that we will evaluate this new resource but this will require further funding (see section – Next steps). Following a successful evaluation, the leaflet will be made operational within West Dunbartonshire HSCP. The leaflet will be given to all patients who are due to have a catheter, or those patients coming out of acute care with one newly inserted. We will undertake information sessions for healthcare staff so that we can introduce this new resource. We will also communicate with general practice to ensure that they are also aware of the new resource and to make sure that it is made as widely available as possible. We will also approach patient support groups to ensure the widest possible coverage.

Challenges successes and lessons learned

We developed a close working relationship through undertaking this project. UWS researchers gained a clearer understanding of the day-to-day experiences of healthcare workers and in turn healthcare workers gained a better understanding of the research process. However, this project was challenging at times.

We were delayed initially by the time taken to achieve ethics and research and development approval. In future we would allow more time for this.

We found that it was difficult to recruit participants to the study. This is well recognised as an issue in research but perhaps the difficult subject of urinary issues (incontinence for example) meant that patients and carers were more reluctant to become involved. We had originally aimed to recruit eight each of patients, carers and healthcare professionals. In the end we recruited six patients, two others were initially interested but did not ultimately take part. We recruited two carers even though we contacted multiple candidates. We recruited seven healthcare professionals, with one further individual initially showing interest but ultimately withdrawing. If further time were available, we would probably have been able to recruit more and if we were to repeat this study would probably extend the recruitment period.

The immediate impact of this project as a whole:

- A better understanding of the frequency and reasons for catheter related callouts
- An appreciation of the lived experience of people who have a catheter including the issues encountered
- A better understanding of the gaps in the knowledge of patients and carers relating to catheter maintenance and issues
- An appreciation that patient/carer education must be improved
- A pilot patient/carer education plan centred around an information leaflet that can be given to all patients with a catheter

We are indebted to the Queen's Nursing Institute Scotland for the support that they provided to us. We are indebted to all of the people who gave up their valuable time to be interviewed for this project. We are especially indebted to the patients who invited us into their homes and spoke frankly about their experiences.

7. Conclusion

1. Bypassing and blockage are the most common reasons for callouts related to catheters in West Dunbartonshire.
2. Every patient's catheter journey was unique to them. Some people experiencing few problems (such as bypassing or blockage) while others were frequently impacted by such debilitating issues.
3. Health professionals worked closely together. None of the interviewees felt unable to cope with situations but did voice that they were sometimes unsure of the best course of action when helping patients with complex needs.
4. Good infection control practices were considered effective at reducing the risk of infection. Antibiotics were prescribed for infection when it did occur yet there were differences in professional opinion centred around when such intervention was required.
5. There were a number of education and training resources available for healthcare professionals both locally and nationally. However little written information was available for patients and their carers about how the catheter worked, how it should be maintained, and what may go wrong.
6. We developed an evidence-based patient/carers education resource targeted at the issues highlighted through our research.

8. Dissemination

We plan to host a one-day event at the new Vale of Leven Health Centre and invite NHS and Social Care colleagues, patients and their carers in early 2016. This event was scheduled to occur before the end of 2015 but has been delayed because of NHS commitments in December. The one-day event will highlight the findings of the study, including an unveiling of the patient information leaflet and the reasons why we believe, through evidence-based research, that this resource is needed. In addition, a short summary of the project findings will be sent to each of the people who participated in the study through giving their time to be interviewed.

A copy of the final report for the study will be sent to key managerial personnel within the Health and Social Care Partnership in West Dunbartonshire to ensure that the findings are sited by those with overall responsibility for the care of people living with a catheter. We will also disseminate a summary of the findings to all of the GP practices in the geographical area of the study so that general practice is informed of our findings.

We will prepare a paper for publication of our findings and initially target the Journal of Community Nursing, as it is the most read by community nurses. In addition, we plan to submit a conference paper to the Royal College of Nursing Continence Care Conference during 2016.

A summary of the findings will also be communicated through the University of the West of Scotland's social media outlets including Twitter.

9. Next steps

We have brought together a team of healthcare professionals and academics with a shared and determined focus on the support of people living with a catheter. It is crucial that this team continues to build upon the solid grounding provided by support from the Queen's Nursing Institute Scotland. We have prepared an action plan for how we progress this work, which is detailed below.

Pilot of the new patient/carer information leaflet

We plan to seek further funding during 2016 to support a pilot study focused on determining the efficacy of the catheter patient/carer information leaflet.

Updating the international guidelines on catheter washout solutions

We are currently updating the Cochrane Review on catheter washout solutions (Washout policies in long-term indwelling urinary catheterisation in adults; <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD004012.pub4/full>). The evidence base around catheter washout solutions is weak. The updated Cochrane Review will, we hope, provide an updated evidence base for the generation of guideline documents but also highlight the real need for more research around policies for the administration of washout solutions as part of catheter care.

Widening the research team

We are pleased to note that since the beginning of our QNIS-funded project our team has increased in number to include additional NHS and UWS colleagues. We have also developed links with colleagues at University of Stirling (Dr Ashley Shepherd) and Glasgow Caledonian University (Professor Suzanne Hagan). Dr Shepherd and Prof. Hagan bring extensive experience in nursing, qualitative research methods and systematic review.

Towards a large scale study on catheter care

We are in the early stages in planning for a large scale, multicenter randomised control trial on catheter washout solutions. This is an important next step that draws together our work to-date (funded by QNIS) with our work on the Cochrane Review for catheter washout solutions.

We have developed robust short, medium and long-term plan to ensure that the legacy of our QNIS-funded project on catheter care is maintained and so provides the best value for money to QNIS as well as contributes in a positive way to people living with these devices and for those caring for them (both professionally and personally).

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11. Financial report – a brief summary of how the money was spent on a separate page

Item	Funding received	Funding spent
University staff time	£4,028	£4,028
NHS Senior Nurse time	£3,000	£3,000
NHS/UWS joint half day event	£850	£0*
Interview transcription	£1,800	£373.80
Travel expenses	£300	£0*

* The joint half day event is due to happen in January / February 2016 so we request that we reserve funds to cover the costs of this. We will send QNIS an estimated running budget for this in January.

Appendix 1: Patient information sheet



MANAGEMENT OF INDWELLING URETHRAL CATHETERS IN COMMUNITY SETTINGS

Information Sheet

(Patient)

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with family, friends, and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document, and a member of the research team would be pleased to discuss the project with you.

Who is doing the research?

The research will be carried out by staff from the University of the West of Scotland who are working in collaboration with West Dunbartonshire Community Health and Care Partnership.

What is the research about?

We are interested in the experiences and perceptions of people who are living in the community with a urinary catheter. The information provided by the project will be used to develop education/training resources for health and social care staff working with patients who have indwelling catheters in the community, and their carers.

Why have I been invited to take part in the project?

You have been invited to take part in this research because you have been living in the community with a urinary catheter. We hope to speak to eight people.

What would taking part in the study involve?

If you decide to take part in the study you will be asked to take part in an interview. A member of the research team from the University of the West of Scotland will contact you to arrange a time that is suitable to visit you in your home or another place of your choice and ask about your experience. If preferred the interview may be conducted by telephone. Interviews should last around 30 minutes. You can have someone with you at the interview (such as a carer or friend) if that would make you feel more comfortable. Prior to the interview, if you have time, you would be asked to think of, and perhaps write a few lines about, a time when you felt that you were managing your catheter very well, and also a time when you found it more difficult. During the interview you will be asked about your experiences of living with an indwelling catheter in the community, and to discuss the incidents that you thought of in preparation for the interview. In order to facilitate note-taking, we would like to record interviews and would seek your permission for this at the time. If during the interviews information is disclosed that is a cause for concern the researcher may have to disclose confidential information to the appropriate body.

As well as speaking to you, we would like to speak to any relatives and/or carers who provided you with additional support, to ask their views. If you do decide to take part, we will ask you if you have a relative or friend who helps you, and if so, if it would be possible to ask if they would be willing to take part in the research, for example by passing on an information sheet inviting them to join the study.

If you decide to take part, we would like to let your GP know that you are taking part in a study, and will seek your permission to send him/her a letter.

What are the benefits or disadvantages in taking part?

There would be no direct benefit to you from taking part in the research. However, analysis of the information gathered from interviews will be used to develop an education/training strategy for health and social care staff, patients, and carers which will be developed in collaboration with volunteers from these three groups. If you would like to be involved in this stage of the project, please speak to a member of the research team who will provide you with further information.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Participation is entirely voluntary and you will be free to withdraw at any time without giving a reason, and withdrawal would have no impact on your continuing care. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Should you wish to withdraw from the study at any time, you are at liberty to do so.

What will happen to information collected in the study?

All information collected during the course of the research will be kept strictly confidential. No individual will be able to be identified in the study report or any other publication. All information collected during the course of the research will be kept strictly confidential. No individual will be able to be identified in the study report or any other publication. However, should you disclose any information during the interview which suggests that you or anyone connected to you is at risk, we

would discuss this with you, and with your permission refer you to an appropriate source of support. We may wish to use some quotations verbatim to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings from the project will also be presented at conferences and written for publication. We may wish to use some quotations verbatim to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings from the project will also be presented at conferences and written for publication.

Further information about this research study:

Members of the research team will be pleased to answer any question you may have and can be contacted at:

Contact	Telephone	Email
Val McIver	01389 817024	Val.mciver@ggc.scot.nhs.uk
William Mackay	07828669984	w.mackay@uws.ac.uk

Thank you for reading this information sheet.

Appendix 2: Carer information sheet



MANAGEMENT OF INDWELLING URETHRAL CATHETERS

IN COMMUNITY SETTINGS

INFORMATION SHEET

(Relative or Carer)

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with friends and relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document. A member of the research team would be pleased to discuss the project with you, either by visiting you or by telephone.

Who is doing the research?

The research will be carried out by staff from the University of the West of Scotland who are working in collaboration with West Dunbartonshire Community Health and Care Partnership.

What is the research about?

We are interested in the experiences and perceptions of people who have supported a relative or friend who is living in the community with a urinary catheter. The information provided by the project will be used to develop education/training resources for health and social care staff working with patients who have indwelling catheters in the community, and their carers.

Why have I been invited to take part in the project?

You have been invited to take part in this research because you support someone who has a urinary catheter. We hope to speak to up to eight families.

What would taking part in the study involve?

If you decide to take part in the study you will be invited to take part in an interview. A member of the research team from the University of the West of Scotland will contact you to arrange a time that is suitable to visit you in your home or another place of your choice, or if you prefer a telephone interview could be arranged. Interviews should last no longer than 30 minutes. Prior to the interview, if you have time, we would like you to think of, and perhaps write a few lines about, a time when you felt well prepared to support your relative or friend who had an indwelling catheter, and also a time when you found it more difficult. During the interview you will be asked about your experiences of supporting someone with an indwelling catheter in the community, and to discuss the incidents that you thought of in preparation for the interview. In order to facilitate note-taking, we would like to record interviews and would seek your permission at the time. If during the interviews information is disclosed that is a cause for concern the researcher may have to disclose confidential information to the appropriate body.

What are the benefits or disadvantages in taking part?

There would be no direct benefit to you from taking part in the research. However, analysis of the information gathered from interviews will be used to develop an education/training strategy for health and social care staff, patients, and carers which will be developed in collaboration with volunteers from these three groups. If you would like to be involved in this stage of the project, please speak to a member of the research team who will provide you with further information.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Participation is entirely voluntary and you will be free to withdraw at any time without giving a reason, and withdrawal would have no impact on your relative or friend's continuing care. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Should you wish to withdraw from the study at any time, you are at liberty to do so.

What will happen to information collected in the study?

All information collected during the course of the research will be kept strictly confidential. No individual will be able to be identified in the study report or any other publication. However, should you disclose any information during the interview which suggests that you or anyone connected to you is at risk, we would discuss this with you, and with your permission refer you to an appropriate source of support. We may wish to use some quotations verbatim to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings from the project will also be presented at conferences and written for publication.

What should I do now?

If you decide that you would be happy to take part in the research by speaking to a member of the research team, please complete the attached slip and return it using the pre-paid envelope provided, or contact the research team by telephone or email, contact details are included below. A

member of the research team will then contact you to arrange a suitable time to speak with you, either face to face, or by telephone.

Further information about this research study:

Members of the research team will be pleased to answer any question you may have and can be contacted at:

Contact	Telephone	Email
Val McIver	01389 817024	Val.mciver@ggc.scot.nhs.uk
William Mackay	07828669984	w.mackay@uws.ac.uk

Thank you for reading this information sheet.

Appendix 3: Patient consent form



MANAGEMENT OF INDWELLING URETHRAL CATHETERS

IN COMMUNITY SETTINGS

PATIENT CONSENT FORM

Participant ID:.....

Date:.....

Principal Researcher: Val McIver

Please initial

1. I confirm that I have read and understand the information sheet dated 01 April 2015 for the above research study.	
2. I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
3. I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
4. I am happy for the interview to be recorded and transcribed, and for verbatim quotations to be used in reports with the understanding that they will be anonymised.	
5. I understand that the researcher may have to disclose confidential information to the appropriate body if it is a cause for concern.	
6. I agree to my GP being informed of my involvement in this study.	
7. I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Witness

Date

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)

Appendix 4: Carer consent form



MANAGEMENT OF INDWELLING URETHRAL CATHETERS

IN COMMUNITY SETTINGS

RELATIVE OR CARER CONSENT FORM

Participant ID:.....

Date:.....

Principal Researcher: Val McIver

Please initial

8. I confirm that I have read and understand the information sheet dated 01 April 2015 for the above research study.	
9. I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
10. I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
11. I am happy for the interview to be recorded and transcribed, and for verbatim quotations to be used in reports with the understanding that they will be anonymised.	
12. I understand that the researcher may have to disclose confidential information to the appropriate body if it is a cause for concern.	
13. I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Witness

Date

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)

Appendix 5: Staff information sheet



MANAGEMENT OF INDWELLING URETHRAL CATHETERS

IN COMMUNITY SETTINGS

(Staff Information Sheet)

We would like to invite you to take part in a research study. This information sheet provides information about the study and what would be involved if you decide to take part. Before you decide we would like you to understand why the research is being carried out and what it would involve for you. Take time to think it over, discuss it with friends and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information, contact details are included at the end of this document.

Who is doing the research?

The research will be carried out by staff from the University of the West of Scotland, who are working in collaboration with West Dunbartonshire Community Health and Care Partnership.

What is the research about?

Within the West Dunbartonshire Community Health and Care Partnership (HSCP) urinary catheter management is a major cause of unplanned call-outs and unnecessary admissions to hospital. The main reason for call-outs is due to blocked catheters, however data collected by GPs and District Nurses are not linked, nor are data relating to outcomes for patient, therefore the true health burden related to blocked catheters is unknown.

Community healthcare presents a distinct set of challenges for professionals. The diversity of community provision, in terms of facilities, services offered and staffing mix, make audit of recurring reasons for call outs more difficult to monitor. However, anecdotal evidence from staff from the West Dunbartonshire HSCP has identified that many callouts are specifically related to blocked catheters and thus close monitoring of this problem is indicated, with a view to implementing strategies to prevent blockages.

Why have I been invited to take part in the project?

You have been invited to take part in this research because you are a health or social care professional who has provided care to someone who has a urinary catheter and is being cared for in the community.

What would taking part in the study involve?

If you decide to take part in the study you will be asked to take part in an interview. A member of the research team from the University of the West of Scotland will contact you to arrange a time that is suitable to meet you at a place that suits you, if preferred the interview may be conducted by telephone. Prior to the interview you would be asked to think about a time when you felt well prepared to manage someone with an indwelling urinary catheter in the community, and another time when you felt less well prepared. During the interview you will be asked about your experiences as a member of staff supporting someone with an indwelling catheter in the community, and discuss the incidents that you thought of in preparation for the interview. Interviews should last around 15 minutes. In order to facilitate note-taking, we would like to record interviews and would seek your permission for this at the time. If during the interviews information is disclosed that is a cause for concern the researcher may have to disclose confidential information to the appropriate body.

What are the benefits or disadvantages in taking part?

There would be no direct benefit to you from taking part in the research. The information provided by the project will be used to develop education/training resources for health and social care staff working with patients who have indwelling catheters in the community, and their carers.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Participation is entirely voluntary and you will be free to withdraw at any time without giving a reason; withdrawal would have no impact on your position at work. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Should you wish to withdraw from the study at any time, you are at liberty to do so.

What will happen to information collected in the study?

All information collected during the course of the research will be kept strictly confidential. No individual will be able to be identified in the study report or any other publication. We may wish to use some quotations verbatim to illustrate specific points. Any information used in this way will be anonymised. Audio recordings will be destroyed once they have been transcribed. All participants will be provided with a copy of the final report. The findings from the project will also be presented at conferences and written for publication.

Further information about this research study:

Members of the research team will be pleased to answer any question you may have and can be contacted at:

Contact	Telephone	Email
Val McIver	01389 817024	Val.mciver@ggc.scot.nhs.uk
William Mackay	07828669984	w.mackay@uws.ac.uk

Thank you for reading this information sheet.

Appendix 6: Staff consent form



MANAGEMENT OF INDWELLING URETHRAL CATHETERS

IN COMMUNITY SETTINGS

STAFF CONSENT FORM

Participant ID:.....

Date:.....

Principal Researcher: Val McIver

Please initial

14. I confirm that I have read and understand the information sheet dated 01 April 2015 for the above research.	
15. I have had the opportunity to think about the information, ask questions, and have them answered satisfactorily.	
16. I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason.	
17. I am happy for interview to be recorded and transcribed, and for verbatim quotations to be used in reports with the understanding that every effort will be made to anonymise them.	
18. I understand that the researcher may have to disclose confidential information to the appropriate body if it is a cause for concern.	
19. I agree to take part in the above research.	

Name of Participant

Date

Signature

Date

Name of Witness

Signature

Name of Person taking consent

Date

Signature

When completed, 1 for participant: 1 researcher site file (original)

Appendix 7: Patient semi-structured interview schedules

PATIENT INTERVIEW SCHEDULE

The following schedule will be a guide only. Extensive experience of interviewing older people, and people with chronic conditions, indicates that following a set schedule does not always work. We will be exploring experiences that will vary between participants and believe that they need to tell their story in their own way, in the order that suits them. We have developed a visual prompt which has been found useful to give participants an idea of where they are in the interview.

Thank you for taking the time to take part in this study. The aim of the study is to explore the experiences and perceptions of people who are living in the community with a urinary catheter. The information provided by the project will be used to develop education/training resources for health and social care staff working with patients who have indwelling catheters in the community, and their carers. If you look at this sheet, it shows, with pictures, the topics that I would like to cover.

You are I are at the right hand side, this is the interview, and the topics are from left to right – so initially I would like to ask you a bit about your life before you had the catheter. I would also like to know a bit about what happened when you first had the catheter inserted. We would like to know about the information and advice that you were given at the time, as well as information and advice that you have received since. We are interested in the things that you find difficult and the things that you feel that you manage well, and the support that you receive. You don't have to answer any questions that you don't want to, and if you feel tired please let me know, we can take a rest for a short while, or stop altogether.

As discussed when we completed the consent form I would like to record the interview and will put the recorder here between us.

- ◆ 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?
 - Prompts: written, verbal, film etc
 - What did you find most useful at the time?

- ◆ Now that you have had your catheter for a while can you tell me how you feel about living with a catheter?
 - For example, does living with a catheter restrict you in the things that you would like to do?

Critical incidents

You will remember that after you indicated that you would be happy to take part in an interview we asked you to think of, and perhaps write a few lines about a time when you felt that you were managing your catheter very well, and also a time when you found it more difficult.

If participants have written a bit on the form, you can talk through it, otherwise take the following approach:

- ◆ ‘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?
 - For example you were in pain, or felt that something had gone wrong?
 - Can you tell me what happened, was anyone else with you? What did you do? Is there anything that you think would prevent something like that happening again?

In the critical incidents participants will probably have mentioned health and social care staff that support them, follow up on this:

- ◆ Can you tell me a bit more about the staff that support you?
 - Prompts: How often do you see them? What do different people do to support you? How do you feel about the support that you receive?

Participants may also have reported an incident involving out of hours service. If not ask if they have used it.

- ◆ Can you tell me about your experience of contacting the ‘Out Of Hours’ service?
 - How often have you had to do this? What prompted you to call them, what led up to this? What happened? Was the response what was expected, did you find it useful?

Appendix 8: Carer semi-structured interview schedules

RELATIVE/CARER INTERVIEW SCHEDULE

The following schedule will be a guide only. We will be exploring experiences that will vary between participants and believe that they need to tell their story in their own way, in the order that suits them. We have developed a visual prompt which has been found useful to give participants an idea of where they are in the interview.

Thank you for taking the time to take part in this study. The aim of the study is to explore the experiences and perceptions of people who are living in the community with a urinary catheter, and their relatives or carers. The information provided by the project will be used to develop education/training resources for health and social care staff working with patients who have indwelling catheters in the community, and their carers. If you look at this sheet, it shows, with pictures, the topics that I would like to cover.

You are I are at the right hand side, this is the interview, and the topics are from left to right – so initially I would like to ask you a bit about the time before your relative had the catheter. I would also like to know a bit about what happened when they first had the catheter inserted. We would like to know about the information and advice that you were given at the time, as well as information and advice that you have received since. We are interested in the things that you find difficult and the things that you feel that you manage well, and the support that you receive. You don't have to answer any questions that you don't want to.

As discussed when we completed the consent form I would like to record the interview and will put the recorder here between us.

-
- ◆ 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?
 - Prompts: written, verbal, film etc
 - Was any of the advice designed specifically for informal carers?
 - What did you find most useful at the time?

- ◆ Now that you have been supporting your relative with their catheter for a while can you tell me how you feel about your role?
 - For example, does supporting your relative to manage their catheter restrict you in the things that you would like to do?

Critical incidents

You will remember that after you indicated that you would be happy to take part in an interview we asked you to think of, and perhaps write a few lines about a time when you felt that you were managing to support your relative with their catheter very well, and also a time when you found it more difficult.

If participants have written a bit on the form, you can talk through it, otherwise take the following approach:

- ◆ ‘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?
 - For example were they in pain, or did you feel that something had gone wrong?
 - Can you tell me what happened, was anyone else with you? What did you do? Is there anything that you think would prevent something like that happening again?

In the critical incidents participants will probably have mentioned health and social care staff that support them, follow up on this:

- ◆ Can you tell me a bit more about the staff that support you?
 - Prompts: How often do you see them? What do different people do to support you? How do you feel about the support that you receive?

Participants may also have reported an incident involving out of hours service. If not ask if they have used it.

- ◆ Can you tell me about your experience of contacting the ‘Out Of Hours’ service?
 - How often have you had to do this? What prompted you to call them, what led up to this? What happened? Was the response what was expected, did you find it useful?

Appendix 9: Staff semi-structured interview schedules

STAFF INTERVIEW SCHEDULE

The following schedule will be a guide only. We will be exploring experiences that will vary between participants depending on their role and experience.

Thank you for taking the time to take part in this study. The aim of the study is to explore the experiences and perceptions of staff who work with people who are living in the community with a urinary catheter, the individuals themselves, and their relatives or carers. The information provided by the project will be used to develop education/training resources for health and social care staff.

As discussed when we completed the consent form I would like to record the interview and will put the recorder here between us.

- ◆ 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?

Critical incidents

You will remember that after you indicated that you would be happy to take part in an interview we asked you to think of, and perhaps write a few lines about a time when you felt that you were managing to support a person living with a catheter in the community very well, and also a time when you found it more difficult.

If participants have written a bit on the form, you can talk through it, otherwise take the following approach:

- ◆ '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?
 - For example were they in pain? Was their catheter blocked?
 - Can you tell me what happened, was anyone else with you? What did you do? Is there anything that you think would prevent something like that happening again?

If participant involved in the provision of out of hours care explore this further:

- ◆ Can you tell me about your experience of providing 'Out Of Hours' support?
 - How often have you had to do this? What usually prompts people to call this service, what type of problems lead up to this? What do you do?

- ◆ 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? 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?
 - Prompts: written, verbal, film etc
 - Was any of the advice designed specifically for informal carers?
 - What did you find most useful at the time?
- ◆ 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?

Appendix 10: Draft patient information sheet

A PDF copy of the draft patient/carer leaflet has been provided as a separate PDF file.