

Descriptive title: Exploring the role of practical nursing wisdom in the care of patients with urinary problems at the end of life: a qualitative interview study

Concise title: Demonstrating practical wisdom in the end of life care of patients with urinary problems

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CONTRIBUTIONS

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CONFLICT OF INTEREST

The authors have no conflict of interest.

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Structured Abstract

Aims and objectives: This study examined how nurses understand urinary problems at the end of life, and identified sources of evidence upon which they base their practice through semi-structured qualitative interviews. The aim was to decide whether research or interventions (such as formulation of best practice guidelines) could improve continence care at the end of life.

Background: There is little evidence in nursing literature to indicate how nurses should manage urinary problems at the end of life. Evidence is particularly lacking regarding the insertion of indwelling urinary catheters.

Design: This was an applied qualitative interview study which used the 'guided interview' approach.

Methods: 12 participants who worked in two hospital wards and one hospice were interviewed about management of patients with urinary problems approaching the end of life. The transcribed interviews were organised using the qualitative analysis software QSR NVivo 10. Constant comparison was used to analyse the interviews.

Results: The patient and their family were a key concern of all interviewees. Participants focused on processes including: giving care, making decisions, managing uncertainty and assimilating knowledge. These processes are mediated by 'phronesis' or practical wisdom.

Conclusions: Within each of the processes (giving care, making decisions, managing uncertainty and assimilating knowledge) participants approached each patient as an individual, using experience, patient wishes, available resources, clinical knowledge, and advice from colleagues to provide care. A generalised set of guidelines on managing urinary problems at the end of life would probably not be useful.

Relevance to clinical practice: There is uncertainty about what constitutes best practice in specific areas of continence care at the end of life such as indwelling urinary catheter insertion. A careful approach is needed to ensure that the intellectual and moral knowledge that constitutes practical wisdom is shared and developed throughout teams.

Keywords: continence, palliative, end of life, qualitative, phronesis

Summary Box

What does this paper contribute to the wider global clinical community?

- Nurses display 'practical wisdom' in their practice, making use of their experience, patient wishes, available resources (including clinical guidelines and scientific evidence when available), clinical knowledge, advice from colleagues, and other sources to provide effective nursing care with respect to continence care.

- There is a lack of certainty in continence care at the end of life in areas such as urinary catheter insertion. Uncertainty must be negotiated by frequent reflection and questioning of choices made regarding continence management at the end of life, and there needs to be an awareness of the outcomes of these decisions, so that considered and appropriate choices can be made in the future.
- Due to the individualised nature of palliative care, a generalised set of guidelines on managing urinary problems at the end of life is not likely to be useful to nurses working in palliative care.

INTRODUCTION

Patients approaching the end of life frequently experience urinary difficulties, including incontinence and retention (Twycross 2003, Glare *et al.* 2011). A recent review (Farrington *et al.* 2013) found minimal research to indicate how nurses should manage this at the end of life. In addition, a local audit (Farrington *et al.* 2014) showed that nursing records do not routinely provide rationale as to why certain management strategies are adopted, such as insertion of an indwelling urinary catheter. These findings suggest that nurses rely on experiential knowledge and clinical experience rather than research-based evidence. Such sources of evidence are important in a clinical environment; however used alone they may be insufficient to ensure that nurses provide appropriate care for dying patients with urinary difficulties. It may be that informal sources of knowledge allow good care for patients with urinary problems at the end of life, but with the current available evidence it is not possible to be sure patients are being given the best care enabling them to die in comfort. Through a series of qualitative interviews with nurses, this study examines how nurses understand urinary problems at the end of life, how they make decisions regarding this, and how they articulate their practice, as well as identifying the sources of evidence upon which they base their practice. The aim was to use the data gathered to decide whether future research or interventions (such as the formulation of best practice guidelines) could improve continence care at the end of life. Existing guidelines for the management of urinary incontinence (e.g. NICE 2006, 2010) do not take into account the unique position of patients at the end of life, and may offer inappropriate advice for this patient group.

BACKGROUND

There is little evidence in nursing literature to indicate how nurses should manage urinary problems at the end of life. A review by Farrington *et al.* (2013) examined the evidence in textbooks and academic journals. In many textbooks, toileting problems at the end of life were only briefly mentioned, or absent from discussion (Faull *et al.* 2005, Lugton and McIntyre 2005, Kinghorn and Gaines 2007, Payne *et al.* 2008, Jevon 2009, Stevens *et al.* 2009, Becker 2010, Campbell 2012, Perrin *et al.* 2012). In both kinds of sources, information

on managing urinary problems at the end of life was not drawn from research, but from clinical opinion or case study (Flaherty 2004, Switzer 2006, Harris 2009, Kyle 2010, Baker and Ward-Smith 2011, Young and Conway 2011, Nazarko 2013). Evidence is particularly lacking regarding the insertion of indwelling urinary catheters at the end of life, and when this might be appropriate. Various authors (Fainsinger & Bruera 1991, Fainsinger *et al.* 1992, Emanuel & Librach 2007, Kyle 2010) presented their recommendations for catheter insertion at the end of life, but these were not evidence-based. Despite a lack of research on the subject, there is evidence in the literature, as well as from the authors' professional experience, to show that urinary problems can be significant at the end of life. The aim of this study was therefore to understand what occurs in practice, in order to understand how best to move forward.

METHODS

Design

This was an applied qualitative interview study which used the 'guided interview' approach. Interviews are an established method of gathering qualitative data (Silverman 2000). The purpose of interviewing is to elicit each participant's interpretation of his or her experience (Charmaz 2007). The guided interview is semi-structured, and ensures that the same general topics are addressed in each interview, but allows the interviewee to direct the conversation, ensuring that the participants' viewpoint can be elicited (Patton 2002).

Some elements of grounded theory methodology were utilised (Glaser & Strauss 1967). There was simultaneous collection of data and analysis, meaning that the on-going analysis informed subsequent interviews, enabling the questions to remain relevant. A key factor here is the emphasis on moving back and forth between data and analysis, to create novel categories and concepts (Charmaz 2007). There was no preconceived hypothesis which could bias data collection and analysis. In addition, the study used the constant comparative method, which allowed elucidation of common themes and concepts. However, this study did not fully adopt all the procedures that are consistent with grounded theory, for example it did not focus on theory generation nor engage in theoretical sampling as this was not deemed relevant to the study aims.

The study was approved by the Ethics Committee, Faculty of Health Sciences, University of Southampton. All participants provided written informed consent prior to interview. No participant identifiable data was available to anyone other than the interviewer.

Participants and Setting

Ward managers on two oncology hospital wards and a hospice were asked to identify nurses who would be willing to participate in interviews. Potential interviewees were provided with a participant information sheet, and approached by the interviewer (NF) to gauge their interest in participating. This group was selected as they have experience of caring for patients at or near the end of life. We aimed to recruit 10-15 participants. A small sample size is acceptable for this type of research design due to the rich data gained. In the event, it was felt that theoretical saturation had been reached after 12 interviews (no new data was emerging). The final 12 participants were registered nurses (all female) who worked in one of two oncology hospital wards (6 participants) or a hospice (6 participants). The majority of participants (7) were ward nurses, 3 were senior nurses and 2 were ward managers. The sample included nurses with over 20 years of nursing experience, as well as junior nurses.

Data Collection

Interviews were conducted January-April 2014. The interviews lasted between 8 minutes and 28 minutes (average 15 minutes), and took place in a quiet space on the participant's home ward (11), or in the interviewer's office (1). They were recorded using a digital recording device and transcribed verbatim. All interviews were conducted by NF.

To ensure that the questions asked were both *thematically* appropriate (relevant to the knowledge we wanted to gain from the interviews) and *dynamically* appropriate (stimulates conversation and promotes a positive interaction) (Kvale & Brinkman 2009), participants read a vignette (see **Box 1**). These were created in consultation with clinical colleagues to reflect representative patients on cancer wards and hospice units (and many participants commented that they did indeed represent 'typical' patients). Each vignette described a fictional patient with either retention ('John') or incontinence ('Anna'). The participants were prompted with questions (see interview schedule **Box 2**). As the interviews were semi-structured, the participant led the discussion; therefore not all questions were put to all participants.

Data Analyses

The transcribed interviews were checked for accuracy, and organised by the interviewer using the qualitative analysis software QSR NVivo 10. Constant comparison allowed the interviewer to analyse the conversations and trace themes that ran throughout the interviews. In this way, the actions, opinions, and concerns of nurses were identified. Analysis was conducted by NF. A sample of interviews was checked by SS for quality purposes. Efforts were made to guarantee the trustworthiness of the research, for example by actively searching for negative cases to ensure confirmability, (Lincoln and Guba 1985) and

developing early familiarity with the culture of the organisation and using established research methods to ensure credibility (Shenton 2004).

Constant comparison involved breaking down the data into 'incidents' (Charmaz 2007). This initial coding allowed discovery of patterns and contrasts, and was followed by focused coding, where the most significant or frequent codes were used to sift through large amounts of data. Theoretical coding then involved developing relationships between the codes, and memo writing allowed a closer analysis of ideas about these codes. When memos are written, certain codes inevitably stand out and take form as theoretical categories. Memos allow the researcher to think about the processes that are occurring in the text, and help to raise focused codes to conceptual categories (Charmaz 2007).

When theoretical saturation was reached, the memos were sorted and integrated, and the meta-narrative constructed. **Figure 1** below illustrates this process with regard to ideas about the focus of care giving.

Four major themes were elicited from the data: care given, uncertainty managed, decisions made and knowledge assimilated. Examination of these allow us to draw conclusions about sources of evidence on which nurses base their practice, and introduce the concept of 'phronesis', or practical wisdom, to explain this.

RESULTS

The patient and their family were a key concern of all interviewees. The interviewees' responses were highly focused on the patient and their needs, wishes, and preferences. This concern feeds into the themes, which have been presented as processes in which the interviewees are involved: giving care, making decisions, managing uncertainty and assimilating knowledge (see **Figure 2**). These themes are detailed below, and the process by which these themes are mediated, that of practical wisdom ('phronesis') will be discussed subsequently.

Care given

'Care' here has a dual meaning, describing the activities of nursing, but also the concern or interest felt by the nurses for the patients. The two elements are inseparable in this discussion. The provision of nursing care was strongly linked with concern for the wellbeing of patients and their families. This manifested itself in discussions about 'comfort', even though the concept was not well defined (although participants were clear on what might cause a patient 'discomfort', such as being turned in bed). When asked their reasons for inserting a catheter at the end of life, 9 participants cited 'comfort'. 'Comfort' was clearly a priority for nurses.

“...because they’ve already got that kind of short prognosis, so actually once you get to that point you’re doing everything for their comfort, not necessarily to treat anything medical”
(Participant 4)

Participants emphasised the importance of consulting the patient. One mentioned acting as the patient’s “advocate” (Participant 3), and others highlighted the need to treat the patient as an individual. Another nurse talked of a patient “leading” care and having the patient “guiding you” (Participant 7). It was also extremely important for them to ensure that the patient’s wishes are respected.

Many nurses were eager to be seen to treat all patients equally. There was a consensus that treatment is based on factors like prognosis, condition and mobility, not on age or gender. When asked whether the management plan would alter if ‘Anna’ had been an elderly patient, Participant 10 responded:

“no exactly, exactly the same. I think it doesn’t, it’s regardless of age, you look at the individual as the whole, their symptoms and all of the concerns that you have, my concerns would be exactly the same, it would be fatigue, it would be her skin integrity, it would be her quality of life, it would be comfort.”

Similarly, Participant 5 stated emphatically there would be “no difference at all” in how she treated male and female patients. Several participants noted that there were inevitable differences in management options for men and women, such as bottles and condom sheaths for men where no such products are available for women. The differences between men and women were acknowledged, but participants emphasised their desire to treat all patients equally.

As well as the patient, participants sought to promote family wellbeing. Often, families were consulted as proxy decision-makers if the patient was unconscious. Participants emphasised the need for patients and families to spend quality time together at the end of life, and this was often given as a reason for inserting a catheter.

“She’s just finding it so difficult to mobilise, which will probably take all of her effort and energy, and actually I think she probably needs all of that effort and energy to spend time with her family and her loved ones really.” (Participant 10)

Overall, the theme of giving care to promote the wellbeing of patients and families was strong throughout the interviews. This was perceived as being achieved through providing ‘comfort’ for patients, having patients involved in decision making, treating all patients equally, and considering family needs.

Uncertainty managed

In discussing how they enact care of the dying patient, consensus was not reached on all points among the nurses. ‘Uncertainty’ here refers to a lack of consensus about what

constitutes best practice. Some variances appeared between hospital and hospice, for example regarding catheter-associated infections. Most participants (10 out of 12) acknowledged that catheters present an infection risk. For the hospice nurses, however, infection seemed to be more worrying. All hospice nurses talked about infection as a cause for concern. One reported that a patient had refused a catheter due to anxiety about infection risk. She was clear that infection was concerning, even for patients at the end of life.

There was also a difference between hospital and hospice regarding removal of indwelling catheters. Hospital nurses preferred to leave the catheter in, barring infection or patient request for removal. Most (5 out of 6) would leave it in situ until after death. However, 3 hospice nurses stated that this should still be reviewed at the end of life.

Opinions differed between participants regarding at what point the bladder is full enough to catheterise. Participant 4 stated that 500ml would be sufficient to catheterise; while Participant 9 suggested that this might not be enough to warrant catheter insertion.

Uncertainty became a clear theme as the interviews continued. Some participants readily acknowledged that they are unsure of what best practice in this area looks like.

“I don’t know if that’s best practice, to catheterise somebody purely because they’re at the end of their life, I don’t know”. (Participant 6)

One participant spoke of this decision as a “struggle”. Participants sometimes had differing ideas of the ward protocol. When asked whether inserting a catheter at the end of life was routine, one nurse stated:

“I wouldn’t put one in specifically because they are end of life care...it would just be...based on kind of their individual needs really...I don’t think it would be appropriate for it to be part of end of life care as a routine thing, but it is always considered” (Participant 1)

In contrast, another participant from the same ward stated:

“...a lot of the patients approaching the end of their days are catheterised mainly as...sort of part of the protocol...to catheterise, they’re end of life, um, have they got a catheter in? Well, if not then you know, why?” (Participant 6)

Despite working on the same ward, these nurses differed about what should be done at the end of life. The interviews showed that opinions on how to manage urinary problems at the end of life were not homogenous, although concern for patient wellbeing remained constant. The next section explores how nurses go about making decisions, and the kinds of decisions that are made.

Decisions made

Hospice nurses saw themselves as key decision-makers regarding patient care options, largely because doctors were often not present. The hospital nurses also presented themselves as influential in decision-making.

“it can come down to my judgement, I can raise it with the doctors and say ‘is a catheter appropriate in this situation...she’s in the final few days of her life, she’s constantly in a wet bed... would a catheter be more kind?’” (Participant 6)

One aspect we aimed to elicit in these interviews was the indications behind decisions to insert catheters. When asked why they would do this for a patient at the end of life, participants suggested various reasons. **Figure 3** shows the most common reasons as urinary retention, skin integrity, and comfort.

Most participants acknowledged that the needs of patients at the end of life are different from those of other patients. There were frequent implications that the nurses were more comfortable with catheterising patients at the end of life as there were fewer “long-term implications” (Participant 4). One thing that became apparent during the interviews was that there were often multiple reasons for catheterisation rather than a single indication alone. Participants talked about patients as presenting with a unique set of symptoms and issues. What came across was that decisions were based on the patient as an individual, and generally not made in a standardised fashion.

The majority of participants mentioned complications with indwelling urinary catheters, primarily infection risk, followed by discomfort. Perhaps because of this, participants also talked about alternatives to indwelling urethral urinary catheterisation. Their opinions on the different methods can be seen in **Table 2** below.

Participants also highlighted the importance of prompting and checking patients to manage toileting. A number of the hospital nurses (4 out of 6) mentioned the ‘Turnaround’ project (a tool designed to prompt checking of patients every 2 hours to reduce incidents of falls and pressure ulcers) (Thames Valley Health Knowledge Team 2014) as useful in enabling them to do this. Three participants acknowledged the need to consider underlying causes of urinary problem, such as constipation exacerbated by opiate use, in order to address these and therefore remedy the problem. Largely, however, the participants’ discussion focused on management strategies rather than treatment.

When discussing the decision to insert a catheter, two main factors were highlighted by participants. The first was patient mobility. Difficulty mobilising seemed to be a contributory factor for a catheter to be inserted.

“if they’re really struggling to get in and out of bed...and they just can’t manage it...or, you know if we physically can’t get them out anymore” (Participant 8)

The second factor is the patient’s awareness. Participants expressed thoughts that a patient should be catheterised if they are incontinent and can no longer communicate this to nurses. *“when she can’t control it at all, and she can’t tell us what’s happening, I think she should have a catheter...inserted in” (Participant 2)*

Overall, the interviews showed the nurses as key decision makers in the management of their patients' urinary difficulties, collecting and sifting through a large amount of information to make the best decision for the individual patient. The following section examines nurses' opinions on how they have learnt to manage urinary problems at the end of life.

Knowledge assimilated

All participants were asked how they had learned to manage urinary problems at the end of life. Many attributed their learning to senior colleagues in practice. The majority described a lack of formal teaching, and stated that these were skills learned on clinical placement, in practice, and through experience. Participants did not generally feel that this was a problem. None had carried out their own reading or research on the topic, although one nurse stated that practice on the ward was "certainly not evidence based" (Participant 3). Some simply accept current practice.

"I've just kind of gone along with this is what we do" (Participant 1)

Others imply that they use intuition, or a "sixth sense" (Participant 5). Some also consider personal or family experiences they themselves have undergone. They seem to take these information sources and then use their own judgement.

"So yeah so it would literally just be what people, what people said, maybe watching various people and deciding for myself what's the best, what's the best approach, I guess" (Participant 4)

There is also acknowledgement that the nurse cannot be prepared for every eventuality: *"sometimes you have to sort of make it up as you go along as well, based on individual patients and what they want as well"* (Participant 12)

The question 'how did you learn about how to manage urinary problems/incontinence?' revealed a variety of information sources utilised by nurses. The following section draws together the themes explored in this paper and discusses how nurses negotiate expectations, demands, and experiences to care for patients at the end of life using the core concept of 'phronesis'.

DISCUSSION

At the heart of the nurses' narrative were a focus on the patient and family, concern for the patient's wellbeing, and a desire to respect the patient's wishes, even though there was variance in the care enacted, and uncertainty about best practice. Both hospital and hospice nurses saw themselves as influential in making key decisions about managing continence at the end of life.

Practical wisdom and its role in nursing

All of the themes are influenced by the idea of 'phronesis' or practical wisdom, which mediates these processes. Phronesis, also termed 'clinical wisdom' (Haggerty & Grace 2008), 'practical knowledge' (Eraut 2000) or 'professional craft knowledge' (Titchen 2000) can be defined as:

'the virtue that enables a person to know how to act not because of some formulaic response to a given situation or set of circumstances but because of the development of a particular set of personal characteristics or virtues' (Sellman 2009, p.85).

The term describes the idea that an effective practitioner relies not only on rules, policies and evidence, but also on intellectual and moral knowledge. We argue that in a situation where a solid evidence base is absent (as with the management of urinary problems at the end of life), nurses must rely on this form of knowledge. In these interviews, nurses showed that they assimilated knowledge from various sources, and weighed these up before making a decision, for example whether or not an indwelling urinary catheter was required. Their learning was highly experiential, based more on practice experience than classroom learning, which resonates here with the 'practical' element of phronesis.

It has been suggested that 'research-based nursing' should be replaced with the concept of phronesis (Flaming 2001). However, the two are not mutually exclusive, but points on a spectrum. As Flaming suggests, a 'phronetic' nurse will be able to utilise the findings of research (where it exists) and then assess how to use the findings appropriately in a given situation. This is an aspect of phronesis not displayed in this study, as no participants spoke of employing research findings or evidence gained from reading in their practice (perhaps due to the lack of research-based evidence in this subject area). Nonetheless, this notion of phronesis is useful in helping nurses to move away from the idea that intuition, the idea of knowing something with no inference or reason, governs their practice. Holding this view of nursing knowledge must devalue it. What we think of as 'intuition' is in fact a complex collection of attributes, including expertise, experience and knowledge, but also other factors such as personality, environment, and the nurse-client relationship (McCutcheon & Pincombe 2001, Green 2012). A phronetic nurse is one who can negotiate the uncertainty, contradictions and differences displayed in this study, to make decisions based on the best interests of the individual patient, ultimately using their practical wisdom to inform their clinical judgement.

Negotiating uncertainty is necessary where research-based evidence is absent. For example, where there is no formal consensus regarding how full a patient's bladder should be before a catheter is inserted, the nurse must be able to use their judgement. Other studies have found uncertainty among clinicians regarding how much urine should be in the bladder before catheterisation (Murphy 2014). This does not mean, however, that nurses are acting blindly and independently of their colleagues. To illustrate, we can compare the indications

for catheter insertion at the end of life given here with the indications given by the Royal College of Nursing (RCN 2012). The significant overlap suggests that despite the lack of research-based evidence, nurses are practising in a coherent and justifiable manner.

The nurses interviewed for this study had high expectations of themselves.

Participant 2 indicated that nurses should be able to anticipate what will happen to a patient at the end of life, and therefore insert a catheter before the last stages of life, when doing so may cause discomfort. It is notoriously difficult to diagnose dying (Gibbons 2009), and nurses must use the various resources at their disposal, including past experience and their concern for the patient (their practical wisdom) to determine this.

Without exception, all the nurses interviewed were concerned with the comfort and wellbeing of the patient and family. They were highly empathetic, putting themselves in the position of a patient lying on a wet bed (Participant 2) or an uncomfortable bedpan (Participant 4). The concept of phronesis has an ethical or moral component (James *et al.* 2008), which is being displayed here. The phronetic practitioner is motivated to some extent by altruistic emotions to pursue the wellbeing of others (Sellman 2009). The strong presence of themes such as comfort, consulting the patient and adhering to their wishes that emerged during interviews displayed the ethical component of nursing practice for these nurses. Even though the concept of 'comfort' was poorly defined (see also Morse *et al.* 1994, Seifert 2002), nurses were clear that this was an essential part of their clinical responsibility.

Despite elements of standardisation, the experiences of each nurse during their training and career pathway are distinct to each individual. When combined with an individual personality and motivation, this creates a nurse who has their own perspective on how things should be done. This outlook is influenced by elements such as ward culture, and local and national policy, but when these elements are unclear or absent, the experiences and perspectives (making up the practical wisdom) of the individual nurse will come to the fore in determining actions. This may account for the variations and uncertainty seen in this study; the individual phronesis of each nurse creates a unique, non-standardised perspective. Combined with the variability between patients at the end of life, and the fluctuations that occur day to day, this may mean that standardising how patients with urinary problems at the end of life are cared for is not only impossible, but also undesirable. Indeed, Titchen (2000) suggests that professional craft knowledge is 'invisible', in that it is tacit, embedded in clinical practice, and difficult to articulate, and as such cannot be made 'formal, explicit, general and objective'. The core theme of these interviews was the wellbeing of patients and their families, and the nurses interviewed used their practical wisdom to enhance this, despite a lack of evidence-based guidance. We agree with the assessment of Greenhalgh *et al.* (2014) who cautioned that over-reliance on evidence-based algorithms prevents the development of nuanced clinical expertise (which draws on elements such as

practical experience, tolerance of uncertainty, and ethical judgement) and ultimately, loses sight of the patient as a complex individual. We also support the arguments made by Rycroft-Malone et al (2004) that a wide range of sources of evidence must be utilised in order to offer high-quality patient-centred care. Research, along with clinical experience, patient experiences and preferences, and the local environment, is one source of evidence.

This study was limited as it took into account the opinions of only 12 nurses, and focused only on one trust. For pragmatic reasons, it only took into account the opinions of nurses, and not healthcare assistants who often catheterise and manage catheters. Nonetheless, the rich data provided by the qualitative methods used provided a useful insight into the management of urinary problems for patients at the end of life.

CONCLUSION

The nurses interviewed displayed many elements of phronesis or practical wisdom. In giving care, they were motivated by a deep concern for the wellbeing of patients and their families. They were aware of their role as decision-makers, and were explicit in weighing up various kinds of information from a variety of sources in order to assimilate knowledge and make decisions in the best interests of their patients. They were able to acknowledge their limitations, including the lack of certainty about best practice. Lack of formal teaching on the management of urinary problems at the end of life, in addition to lack of personal investigation on the part of nurses, is by no means ideal, but is probably symptomatic of the lack of attention that this area has been given in nursing literature to date. Overall, the participants' accounts show that they aim to approach each patient on an individual basis. They use knowledge from previous occasions, but they treat each patient's situation as unique. They then use their own experience, the patient's wishes, the available resources, clinical knowledge, advice from colleagues, and a raft of other sources to provide nursing care. It is therefore difficult to imagine that a generalised, prescribed set of guidelines or instructions as to how to manage urinary problems at the end of life would be of use to nurses working in palliative care settings. We therefore suggest that future research focuses on improving the options available to nurses who are helping patients manage urinary difficulties at or near the end of life, including investigation of new products and devices.

RELEVANCE TO CLINICAL PRACTICE

This study has shown that a set of guidelines or instructions for nurses on how to manage patients with urinary difficulties at the end of life is not likely to be useful in practice, as nurses who look after patients at the end of life are confident in utilising their practical wisdom in caring for patients as individuals, focusing strongly on their overall comfort and wellbeing. However, this study has brought to light a lack of certainty about

what constitutes best practice in enacting specific areas of continence care at the end of life such as indwelling urinary catheter insertion. This is an area of practice which lacks a solid evidence-base. In such a situation, a careful approach is needed to ensure that the intellectual and moral knowledge that constitutes practical wisdom in individual practice is shared and developed within nursing teams, so that all staff and patients can benefit. Nurses, and those in supervisory roles such as clinical educators, therefore need to adopt a different approach to decision-making in continence care at the end of life. Uncertainty must be negotiated by frequent reflection and questioning of choices made regarding continence management at the end of life, and there needs to be an awareness of the outcomes of these decisions, so that considered and appropriate choices can be made in the future.

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TABLES AND FIGURES (GIFs)

Box 1. Interview vignettes: participants were asked to read about either ‘John’ or ‘Anna’ to prompt discussion within the interview

John

John is a 78-year old man, admitted to the ward with anaemia and worsening breathlessness. He also has pain from bony metastases, and doctors have prescribed long acting morphine sulphate tablets, as well as Oramorph for breakthrough pain. Due to pain and breathlessness, John finds it difficult to get to the toilet to urinate without assistance, and has been using bottles by his bed. However, three days after admission, the nurse looking after John notices he has not passed urine all shift. She decides to do a bladder scan, and finds that John has 500mls of urine in his bladder. She discusses this with the doctor, and they decide to catheterise. John agrees, the catheter is inserted, and 500mls of fluid is drained immediately. The catheter continues to drain well, however over the next few days John’s condition deteriorates and he passes away two weeks after admission with his family present.

Anna

Anna is a 36-year old woman, admitted to the ward with end-stage ovarian cancer. She has ascites which have been drained regularly. Due to the ascites and general weakness, Anna has difficulty mobilising to the toilet. She requires nursing assistance to use commodes, and occasionally bedpans. At night, she has incontinence pads as she is worried about wetting the bed before she can get to the commode. Over the next few days, Anna gradually deteriorates and finds it more difficult to use the commode. The nurse looking after Anna supplies her with pads during the day as well as at night, to help Anna feel more comfortable. Anna passes away two weeks later with her family present.

Box 2. Interview schedule: examples of questions and prompts

Please read the scenario (either John or Anna).

Having read the description, what are your thoughts on this situation?

Prompt: what are your roles and responsibilities here?

Prompt: would you have done the same if you were the nurse?

What would be different if the patient were:

- male/female:
- younger/older:
- had a problem with retention/incontinence?

Prompt: how would you manage the patient’s urinary problems in this case?

For what reasons would you catheterise a patient at the end of life?

Prompt: tell me more about patients who have catheters at the end of life.

How did you learn about how to manage urinary problems/ incontinence?

Prompt: do you mainly learn from colleagues/ previous jobs/ literature?

Is there anything else you would like to mention that we haven’t discussed?

Figure 1. An illustration of the process of analysis using constant comparison


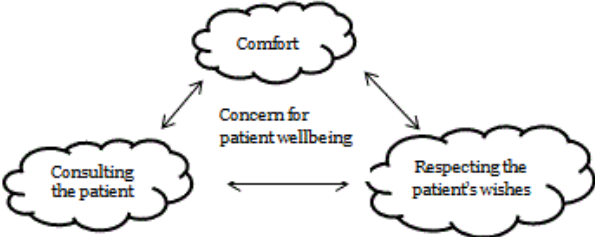
Initial Coding	<p>Identification of potentially meaningful 'incidents'. Regarding 'patient comfort':</p> <p>"...to protect the patient and help them feel more comfortable..."</p> <p>"...my responsibility would just be to ensure that John's very comfortable..."</p> <p>"...he is end of life, so you would try to keep him as comfortable as possible..."</p>
Focused Coding	<p>Using frequent codes to sift through the data:</p> 
Theoretical Coding	<p>Looking for relationships between codes:</p> 
Memo Writing	<p>Exploring the theme of patient wellbeing:</p> <p>Nurses see patient comfort as high priority in terms of management of patients at the end of life – see it as their responsibility. How do they go about ensuring this? They ask the patient what they want, and do their best to carry out patient wishes. Interviewees are keen to be seen as treating patients equally rather than based on gender/age. Talk about importance of helping patients spend time with family and friends.</p>
Theoretical saturation	<p>No new data emerging, sampling ends.</p>
Memo Sorting and Integrating	<p>Patient and family wellbeing emerges as focus of care given.</p>

Figure 2. Illustrating the themes and processes elicited from the qualitative interviews.

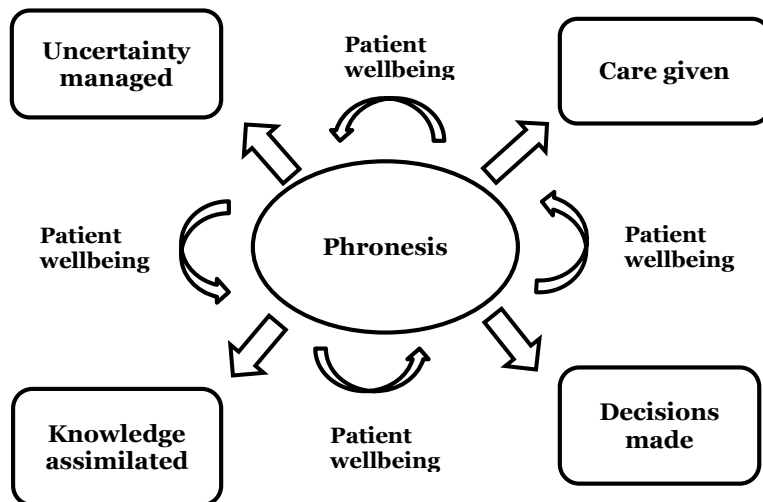


Figure 3 Indications given for catheter insertion at the end of life.

* Incontinence not associated with skin integrity was given as an indication for catheter insertion on three occasions. The specific reasons are as follows:

- 1) Patient may find incontinence distressing
- 2) Patient might find incontinence uncomfortable
- 3) Family may be distressed by incontinence

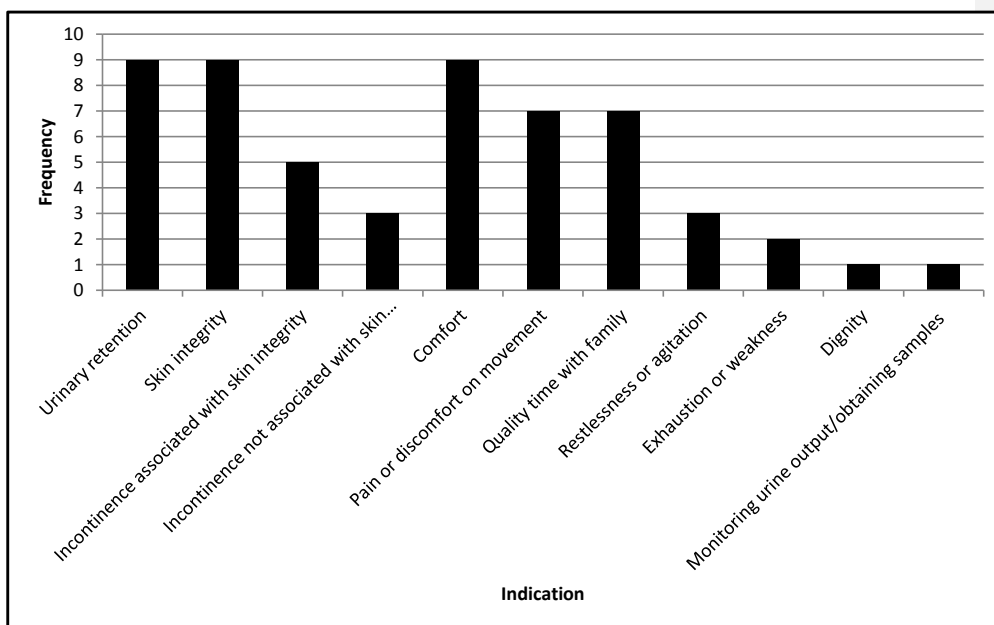


Table 2. Participants' opinions on the advantages and disadvantages of alternatives to indwelling urethral catheterisation.

	Advantages	Disadvantages
Condom sheaths	<ul style="list-style-type: none"> • Less invasive than catheter (less infection risk) • Good option where a catheter cannot be passed (e.g. prostate problems) 	<ul style="list-style-type: none"> • Not for women • Can leak • Can be sore • Confused patients can pull them off
Pads	<ul style="list-style-type: none"> • Good short-term solution for incontinence 	<ul style="list-style-type: none"> • Contraindicated if patient on pressure-relieving mattress • Can be uncomfortable • Problems with skin integrity
Bottles	<ul style="list-style-type: none"> • Can be used independently (can promote dignity) 	<ul style="list-style-type: none"> • Not useful for women
Commode	<ul style="list-style-type: none"> • Promotes independence 	<ul style="list-style-type: none"> • Not useful for patients with poor mobility
Bedpan		<ul style="list-style-type: none"> • Can be uncomfortable • Can leak • Cannot use independently
Intermittent catheterisation (IC)	<ul style="list-style-type: none"> • Potentially useful for retention 	<ul style="list-style-type: none"> • Issues of training, time and resources on the ward • Self-catheterisation only for patients with good dexterity
Suprapubic catheterisation	<ul style="list-style-type: none"> • Useful where catheter cannot be passed via urethra 	<ul style="list-style-type: none"> • Unsuitable for insertion at end of life