CONTINENCE CARE

Suprapubic Catheters—A Shared Understanding, From the Other Side Looking In

Alyson Sweeney ■ Ann Harrington ■ Didy Button

OBJECTIVE: The objective of this study was to explore the experiences of people living with a suprapubic catheter.

METHOD: This descriptive study was guided by the philosophy of Gadamerian hermeneutics. Data were gathered via indepth interviews with 6 adults living in the community who had a suprapubic catheter for long-term urinary bladder drainage. Interpretation of the data occurred via thematic analysis of the participants' stories.

RESULTS: Two distinct but interrelated themes emerged. Participants shifted, over time, from negative to positive experiences (psychologically, physically, and practically) to adjustment to life with a catheter. Participants also related that health professionals had not adequately prepared or supported them as they learned to live with a suprapubic catheter. Many of the participants' initial negative experiences were augmented by this deficiency. Issues revolved around perceptions of being psychologically unprepared, the changed body image, altered sexuality, and support needs.

CONCLUSION: The findings of this study revealed that the insertion of a suprapubic catheter brought about significant life changes for the participants. The data highlighted disparities between the needs of people who have a suprapubic catheter and health professionals' perceptions of their needs.

■ Introduction

The care of an individual with a urinary catheter is by no means a new concept for nurses, as various catheterization techniques have been documented for more than 3000 years.1,2 Urinary catheterization is often perceived by health professionals as a commonplace technical procedure.2 However, the care of the individual with a suprapubic catheter is a comparatively new phenomenon.

Suprapubic catheterization is typically classified as a minor surgical procedure that is performed under a general or local anesthetic.3 A cystostomy is formed via an incision approximately 2 cm above the pubic symphysis. A Foley catheter is inserted via the abdominal wall to facilitate bladder drainage. The predominant consensus in the literature is that catheterization should always be considered as a final alternative for the long-term management of bladder dysfunction because of the associated potential for complications.4 The most commonly experienced complications include urinary tract infection, leakage around the catheter, and encrustation and catheter blockage.3,5-7

Nevertheless, catheterization remains a valuable option for selected patients. There is a growing body of evidence indicating a decreased risk of catheter-associated complications with use of a suprapubic as compared to urethral catheters.4 In our community in Australia, suprapubic catheters have become more prevalent than indwelling urethral catheters for those requiring long-term catheterization. Consequently, we are seeing more people living with this device in our communities. However, there is limited knowledge of suprapubic catheterization from those who have one. The goal of this study is to add another dimension to the current knowledge base.

■ Related Literature

A literature search was conducted using search engines EBSCO, Proquest, and OVID. We primarily located useful articles in the CINAHL and MEDLINE databases. Key search words were suprapubic catheter, urinary catheter, suprapubic catheter—quality of life, suprapubic catheter—patient satisfaction, urinary stoma, and stoma. This literature identified a body of knowledge that was primarily
focused on physiological outcomes of suprapubic catheterization\textsuperscript{4-10} and the health professionals’ perceptions of catheter-related issues that are predominantly technical in nature.\textsuperscript{11-13} No studies were found that directly addressed patients’ perspectives of what it is like to live with a suprapubic catheter, and no qualitative studies were located.

Despite a long history of catheterization, living with an indwelling catheter presents many challenges for patients and their care providers. In addition, universal standards of nursing management of the catheterized patient are not consistent.\textsuperscript{14} The literature indicates that health care professionals are familiar with urethral urinary catheters, but less familiar with a catheterized patient’s needs, such as preparation and familiarization with the device.\textsuperscript{15,16} Complex historical issues related to the intimate nature of catheter patient care, coupled with concepts of “basic care” and “dirty work”\textsuperscript{17,18} may have contributed to the apparent lack of scholarly interest in this area.

Nevertheless, several studies were identified that provide insights into some aspects of living with an indwelling urethral catheter.\textsuperscript{15,18,19} For example, living with a urethral catheter was found to be much more than “a simple addition to a life.”\textsuperscript{20} It is clear that there is much to be learned from the lived experience. However, we believe that health care professionals cannot unquestioningly transfer their knowledge of urethral catheter patient care to those who have a suprapubic catheter.

Care of the person with an indwelling urethral catheter and a suprapubic catheter are often discussed in the literature as if they are one and the same.\textsuperscript{21,22} Clearly, this point of view is arguable in that the insertion of a suprapubic catheter involves a surgical procedure to create an ostomy. Peate\textsuperscript{23} acknowledges that body image may be affected following the insertion of this device. Health professionals may promote the suprapubic catheter because of possible advantages when compared to a urethral catheter including preservation of the bladder neck, avoidance of urethral trauma, decreased risk of urinary tract infection, and improved comfort.\textsuperscript{24,25} However, the experiences and needs of patients who undergo the permanent change to the body and its function that the creation of the suprapubic ostomy brings about are not known.

Addison and Mould\textsuperscript{26} have compared the supportive services that have developed for those with other types of ostomy, finding that there are no supportive services for the patient with a suprapubic ostomy. Nursing research and knowledge development for ostomy, other than suprapubic, have developed considerably, particularly in regard to patient preparation and rehabilitation following stoma formation. While these differences are acknowledged in the literature, our literature review revealed no research focusing on the experiences of living with a suprapubic catheter.

The purpose of the study was to answer the question, “What is it like to live with a suprapubic catheter?” Gaining knowledge of the experiences of people living with a suprapubic catheter will help to determine whether current practices meet their needs and how they might be changed to better address these needs.

\section*{Methods}

This descriptive study was guided by the philosophy of Hans-Georg Gadamer. Gadamer\textsuperscript{27,28} proffers several concepts for the interpretation and understanding of dialogue. Within this framework, dialogue evolves from the participants’ constructions of reality that facilitate the development of contextually relevant insights. Knowledge gained from the literature and clinical experience is also immersed within the data generation and analysis. This study, therefore, represents a combination of the participants’ and the researchers’ location at a given time in history. Gadamer uses the metaphor \textit{fusion of horizons} to describe the emergent understanding of the life-world of the ‘other’ by the researcher, when everything that can be seen is seen by both from a particular vantage point.\textsuperscript{27,28} Given the above emphasis on dialogue, unstructured indepth interview was chosen as the method of information gathering for this study. This method enabled issues of importance to the participants to emerge from the data.

\section*{Subjects and Setting}

Participants were recruited by community nurses. They were adults living in the community with a long-term suprapubic catheter. An explanation of the study, its aims, and the recruitment process was provided by the principal investigator (AS). The nurses introduced the research to potential participants, along with a letter of introduction, information sheet, and researcher contact details. The first 6 volunteers who met the inclusion criteria and who agreed to participate comprised the study sample. This study was approved by the Flinders University Ethics Committee, and the Ethics Committee responsible for the metropolitan area of Tasmania, Australia.

\section*{Procedures}

Data were generated from each of the participant’s stories of their experiences of living with their suprapubic catheter. All aspects of the interviews were carried out by the principal investigator (AS), who is a Continence Nurse Advisor. All but one interview occurred in the participant’s home, and one occurred in a community clinic at the participant’s request. This participant also chose to have her husband with her during the interview. All other interviews were attended by the participant and the principal investigator. Participants were interviewed for approximately 1 hour. Interviews were recorded on microcassette and a verbatim text transcription of the tape recordings was created. To confirm the accuracy of the transcripts, a typed copy was returned to the participants to allow them to verify that the transcript accurately reflected what they intended to say.
Data Analysis
As with all qualitative research, the data analysis was inductive. Gadamerian hermeneutics identifies the need to recognize in the study outcome the researcher’s own voice. Data analysis began from within my horizon; I then turned my horizon to the phenomena under study (the participants’ view). Consequently, all the parts of the dialogue were investigated and challenged in relation to the researcher’s preunderstandings. A question and answer process of analysis was used to enable immersion in the data. Immersion occurred at interview, during the transcription of the text, listening to the audiotapes, and during the reading and rereading of the data. Through thematic analysis of the textual data, interpretations were reconstructed to reveal common meanings and understanding of “what it is like to live with a suprapubic catheter.”

Results
Six adults living in the community who had a long-term suprapubic catheter for urinary bladder drainage participated in the study (Table 1). One man and 5 women participated. The underlying disorders that led to suprapubic catheterization differed for each participant and included multiple sclerosis, spinal cord injury, and severe urinary incontinence. The period of catheterization varied from 3 to 72 months.

Continuum of Adjustment
Data analysis revealed that participants had moved along a continuum from initial negative experiences of living with a suprapubic catheter toward a more optimistic or positive viewpoint. This theme is a “negative to positive continuum of adjustment.” It became clear within the participants’ stories that satisfaction with their catheters occurred over time as adjustment took place. The participants described emotional, physical, and practical components of adjustment.

The relative newcomers to the device (Matt, catheterized for 3 months and Beth, 4 months) conveyed their experiences most expressively. Initial frustration was evident.

Matt: I felt like ripping the bloody thing [catheter] off! . . . I’m still getting used of the idea . . . it’s early days yet . . . things are improving . . .

Beth also expressed an initially negative view of her catheter. However, as time progressed she too had begun to come to terms with the changes that the catheter brought about.

Beth: I’d like this damn thing out! . . . I couldn’t see how I could live with it . . . but I did it . . . you come to terms with it . . .

After 14 months of suprapubic catheterization, Louise conveyed a positive outlook that encompassed physical and emotional components of adjustment occurring over time.

Louise: It probably . . . took about three, four months . . . to become what I thought was really comfortable . . . but then again when you look back . . . perhaps another six months on from then even more comfortable . . . So . . . I feel now, physically, totally comfortable . . . emotionally totally comfortable . . .

Another participant conveyed that she had “hated” having her catheter, but the relief from pain it afforded helped her to shift more readily toward adjustment.

Claudia: . . . being free of pain to a certain extent . . . helped me to accept it . . .

Despite initial negative experiences with her catheter, Joyce considered initial problems as a past event. Her view of life with the catheter over time had also changed in a positive direction.

Joyce: . . . it seems to have settled down now . . . the catheter is [now] perhaps a convenience . . .

This last participant indicated that at some earlier stage she too had made a shift from the negative to positive experience.

Eve: I’ve gotten used to it. It is part of my life now.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Time Since Insertion</th>
<th>Reason for Catheter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matt</td>
<td>45</td>
<td>3 months</td>
<td>Neurogenic bladder related to multiple sclerosis</td>
</tr>
<tr>
<td>Beth</td>
<td>68</td>
<td>4 months</td>
<td>Urinary retention related to a spinal injury</td>
</tr>
<tr>
<td>Louise</td>
<td>56</td>
<td>14 months</td>
<td>Intractable incontinence related to cancer therapy</td>
</tr>
<tr>
<td>Eve</td>
<td>71</td>
<td>30 months</td>
<td>Failed artificial urinary sphincter</td>
</tr>
<tr>
<td>Joyce</td>
<td>75</td>
<td>36 months</td>
<td>Urinary retention related to multiple sclerosis</td>
</tr>
<tr>
<td>Claudia</td>
<td>74</td>
<td>72 months</td>
<td>Urinary retention related to spinal surgery</td>
</tr>
</tbody>
</table>
All of the participants reported a journey from initial negative experiences toward a more positive perception. The following theme addresses issues that impacted the transition time on the negative to positive continuum.

**Unpreparedness**
The most consistent theme to arise was the perception that participants had not been adequately prepared or supported by health professionals when experiencing suprapubic catheterization. They consistently relayed that they were not adequately prepared for the changes they experienced after catheter placement, reflecting a lack of understanding between patient needs and health professionals’ perception of their needs. Four distinct subthemes were identified related to the theme of “unpreparedness”: (1) psychological unpreparedness (shock), (2) the changed body image, (3) altered sexuality, and (4) support needs.

**Psychological Unpreparedness**
Three out of 6 participants expressed an initial “shock” following insertion of a suprapubic catheter. The surgical alteration in their body gave rise to the formulation of new feelings about themselves. The participants expressed overwhelming distress about their changed state of being. For example, one participant related that she had been so shocked when confronted by the perceived significant life changes imposed upon her that she thought her life was not worth living.

Beth: . . . when I first got it I cried for three days. They had to get a psychologist to me . . . I told my son I was going to commit suicide . . . . . . it was such a big shock to me . . .

Another participant described how her initial emotional response to her catheter was held back while she was a patient in the hospital. Thus this human aspect following the insertion of a suprapubic catheter remained hidden from the health profession.

Louise: I cried a lot . . . not in hospital. My husband picked me up . . . we have a shack in the mountains . . . he took me up to the shack and I waited until I was there . . . and then I just cried . . . it was a reaction to the shock . . .

A third participant relayed that the catheter became a tangible reminder of how far his disease had progressed, and that realization was distressing.

Matt: . . . so there’s a clinical side to it, and there’s the emotional side to it . . . I felt a loss . . . it really hit me . . . I burst into tears . . . I thought my god . . . its got to this stage . . . it was just like a part of me has been taken away

For each of these participants, their perception of self had been significantly and unexpectedly altered following insertion of a suprapubic catheter. Body image was a primary aspect related to the participants’ changed perceptions of self.

**Body Image**
Three of the participants related visual changes to their physical appearance, and discomfort associated with these. Aspects of this theme included both the private view and public presentations of self. To avoid adverse responses from others some participants reported avoidance of social situations, especially in the early days of adjustment as exampled below.

Beth: I am shutting myself off because I feel embarrassed with this [catheter]

It became apparent that some of the participants had adjusted to the body change to varying degrees. For others, as below, total acceptance may never be achieved.

Louise: I don’t like the look of it still . . . and when I say that it’s not that I’m distressed by it . . . but I’m not comfortable. I’m the one who is not comfortable.

In addition to changes in body image, participants also experienced a perceived alteration to sexuality.

**Altered Sexuality**
Two of the participants expressed altered perceptions of themselves as sexual beings following insertion of their suprapubic catheters. One participant, who did not have a partner at the time of his interview, no longer viewed himself as a sexual being and could not see how anybody else would. This unforeseen perspective of having his catheter created considerable sadness.

Matt: . . . there’s ways and means of . . . still having a sexual relationship, but . . . I’ve totally wiped it completely . . . your partner would have to be really understanding . . . you can see the catheter . . . you can’t get away from it . . . its there . . . its not nice to look at, so I have resigned myself to . . . well that part of my life is over . . .

However, this extract from another participant illustrates that this aspect of people’s experience could also improve over time.

Louise: . . . so there was another sense of grief about what I thought might be another loss of freedom, that enjoyment . . . but I am pleased to say that, that hasn’t been so. It was just again a matter of time . . . of letting my body settle and possibly getting my head around it as well . . .
Having a supportive partner emerged as an important component that helped participants resume sexual expression.

**Support Needs**

Analysis of the data revealed the important role that support from others played in enabling participants to adjust to living with a suprapubic catheter. Accessing support had been difficult for 2 of the participants who did not feel they had anyone to call on. One participant stated an awareness that the community nurses were available to help with his concerns. However, he had avoided contacting them as he had felt that his issues were too personal.

Matt: I don’t ring them . . . haven’t sort of contacted them very often ‘cause I feel it’s such a private thing . . .

Similarly another participant relayed that she did not have anybody close to her with whom she felt comfortable discussing private bodily functions of elimination. Consequently she persevered with her experiences of adjustment alone.

Beth: . . . and I’ve no daughters . . . so I didn’t really have anybody who I could really talk to, about it . . . I mean you can’t talk to boys. I definitely couldn’t talk to my sons about it, I couldn’t so of course I’ll often try to lock it all in . . .

Other participants had spoken of their appreciation of supportive spouses, family members, friends, and work colleagues.

Joyce: Well now the youngest one [grandchild] who is five . . . he’s noticed that I’ve got this belly bag . . . he felt the belly bag on my tummy and then he gets a bit of fluid in it, he plays the drums [laughter]. I never say anything about it because . . . I just want them to accept it as part of me.

It had become clear from the participants’ stories that support through acceptance from others was integral to adjustment to life with their suprapubic catheters. These meaningful insights into the experiences of living with a suprapubic catheter highlight some aspects of adjustment that included psychological preparation, body image, altered sexuality, and support needs.

**Discussion**

The 2 major and interrelated themes to arise from the data were the negative to positive continuum of adjustment and not being prepared for indwelling suprapubic catheterization. It is possible that if participants been better prepared and supported by health professionals for suprapubic catheterization many of their earlier negative experiences may have been prevented. They may have begun at a better position on the continuum of adjustment and the transition time on the continuum may have been reduced. Participants also conveyed an expectation, based on the health care information provided to them, that insertion of their suprapubc catheter was an uncomplicated or basic procedure. While it was true that the surgical procedure is relatively minor, the experiences prompted by its insertion were neither simple nor straightforward.

**Adjustment Over Time**

Time as a factor of adjustment to a suprapubic catheter is consistent with adjustment to other types of catheterization or stoma creation. Piwonka and Merino reported a powerful correlation between time lapsed since surgery and adaptation to a colostomy. The first postoperative year was the cut-off point for the ostomy patient. Similarly Roe and Brocklehurst found that people who had a urethral catheter took approximately 12 months to adjust.

*Adaptation or transition* are terms that have been used to describe how people incorporate the consequences of their illness into their lives. Self-management, bringing about order in one’s life, has been identified as a key element of adaptation. Self-management refers to the activities that people undertake to create order, discipline, and control in their lives. It is likely that patients will benefit from an understanding that it can take considerable time to adjust to life with a suprapubic catheter. This understanding would help to facilitate realistic rehabilitation expectations. It is imperative that members of the health profession are aware of this reality. Had the participants been aware of the positive and potentially negative aspects of living with a suprapubic catheter, they may have moved more easily toward an optimal level of adjustment.

**Preparation Needs and Shock**

Participants related inadequate preparation and support from health care professionals. The simplicity of the surgical procedure did not match of the level of preoperative preparation and support that patients required. Results of this study also suggest that health professionals either inadequately prepared patients or believed that people implicitly understood all that needed to be known about their suprapubic catheter. Some participants also blamed themselves for not having found out more. As a result, patients may return to their communities with misconceptions or a lack of knowledge that hinders adjustment to a suprapubic catheter.

Some participants relayed that they had concealed their initial outward emotional responses from health professionals. Away from the hospital setting they reported feeling overwhelmed by emotion. They also conveyed that no health professional had inquired about their first impressions. Therefore their feelings may have been inadvertently negated.

**Body Image**

The participants’ shock reaction was largely in response to their changed appearance. Their perception of self, in relation to their body image, had been altered by
catheterization. Schilder defined body image as “the picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves.”

Perceptions of distorted body image are not surprising. The participants now had an abdominal wound, the stoma, with a permanent device protruding from it. Further, the catheter is 20 Fr and 40 cm in length. It tends to sit awkwardly at a 45° angle from the lower abdomen and drains into a urine collection device that is anchored to the body.

Rumsey and associates noted that psychosocial issues associated with disfigurement are not directly proportional to the severity of the condition. Consequently, people who have a relatively minor disfigurement are often overlooked as being at risk for psychological distress. This oversight is linked to a biomedical bias towards the assumption that people who are the most severely disfigured are at greatest risk. However, the location of the catheter is only one aspect of sexual intimacy. Health professionals cannot assume that people who have a suprapubic catheter have no, or fewer, problems with sexuality.

Support
Support relates to the role of others such as a spouse, family, friends, or colleagues during the process of rehabilitation. Acceptance of the changed body by others was perceived as beneficial to adjustment to life with a catheter. However, the location of the catheter is only one aspect of sexual intimacy. Health professionals cannot assume that people who have a suprapubic catheter have no, or fewer, problems with sexuality.

Sexuality
Some participants reported difficulties with sexual expression and impaired perception of sexual self since the insertion of their suprapubic catheters. The literature proposes that sexual intercourse may be easier for those who have a suprapubic catheter compared to a urethral catheter. However, the location of the catheter is only one aspect of sexual intimacy. Health professionals cannot assume that people who have a suprapubic catheter have no, or fewer, problems with sexuality.

Implications for Nursing Practice
Knowledge about the experiences of people who have a suprapubic catheter should be disseminated to nurses. Patients scheduled to have a suprapubic catheter should be provided with comprehensive preoperative information to prepare them for life with a suprapubic catheter. This information should be provided by a health professional with an understanding of the issues associated with long-term suprapubic catheterization. Preparation includes familiarization with the catheter, its placement, and drainage equipment. Preoperative counseling should also address altered body image and sexuality. The patient should be informed that adjustment to the changes can take considerable time.

The private nature of having a suprapubic catheter can limit the amount of social support that a person is offered. Therefore patients may perceive few opportunities to share information and concerns with interested others. Nevertheless, the value of interacting with supportive people was identified by participants as exerting a positive impact on adjustment to a suprapubic catheter. Therefore, the development of a supportive network, such as meetings or a patient support group, literature, newsletters, websites, and chat rooms or discussion forums, has the potential to bridge this gap and enhance patients’ adjustment to life with a suprapublic catheter.

Summary
This study revealed that the insertion of a suprapubic catheter brought about significant and often unanticipated life changes for the participants. The changed body and its function gave rise to new feelings, and adjustment to the changes took considerable time. To positively influence a patient’s adjustment to their suprapubic catheters, comprehensive preparation and support from health professionals for the transition are required.

KEY POINTS

- Having a suprapubic catheter can bring about significant life changes for the individual—psychologically and physically impacting body image, sexuality, and support needs.

- People who are to have a suprapubic catheter require comprehensive preoperative preparation and coordinated ongoing professional support when they return to their communities.
The role of significant others in providing support to the suprapubically catheterized patient needs to be recognized and supported where indicated by the patient.

Formal and informal information sharing opportunities need to be created for those whose lives are affected by suprapubic catheterization.

ACKNOWLEDGMENTS

This manuscript reports on a study carried out by a Master of Nursing candidate in the School of Nursing and Midwifery, Flinders University. The authors wish to thank the patients within the community health services for their contribution to this study.

References