

Promoting Evidence-Based Nursing Practice: *Living with an indwelling urinary catheter*

In this newsletter we report the findings of research which aimed to understand the adult participants' perspective of living with a urinary catheter in the community. Due to embarrassment and concern with social stigma, persons with indwelling catheters often lead challenging lives. Little has been documented about how community dwelling participants experience life with a permanent urinary catheter.

What and why did we want to know?

The RDNS CNC's: Continence had identified a significant absence of literature to support practice that describes the participants' experience of adapting to a permanent, indwelling catheter. Approximately 180 RDNS adult participants live with a permanent urinary catheter so this research was deemed central to the provision of evidenced based, community nursing practice.

The research question was; *what is the adult participants' perspective of living with a urinary catheter?* The aims of the research were to; reveal the participants' perspective of living in the community with a permanent indwelling urinary catheter, raise awareness of the experiences of catheterised men and women; and to inform evidence based community nursing practice. Ethics approval was granted, informed consent was obtained from participants and names used in this paper are pseudonyms. The research was undertaken during 2002.

What did the literature say?

The literature about this subject was reviewed in a previous newsletter (Issue 2, December 2001 – see www.rdns.net.au). There was an immense amount of literature that addressed continence care and catheter care from the perspective of the health carer but there were few high quality research studies to support best practice policies particularly in the community setting, hence the motivation to undertake this research.

How did we do the research?

Participants were current or previous participants of RDNS. The experiences and issues related to life with an indwelling urinary catheter were explored through structured interviews and observation of twelve men and nine women (N=21), aged between 24 and 82 years and who had a permanently indwelling catheter (either urethral or supra pubic) for longer than six months.

The CNCs and the Senior Research Fellow conducted interviews which were prompted by pre determined questions such as: How did you feel when you first heard that you would need a catheter?, What was important to you?, Do others influence the way you think about yourself?, How do others react to the catheter?, Can you tell me a story about having a catheter that really stands out for you?, In what ways has having a catheter changed your life?, What actual changes have you experienced in regard to your sexuality?, What strategies have you used to enable you to live with a catheter?, What information has been useful or not useful to you?, What advice would you give to a friend who told you they would also need a catheter? And, Is there anything else you would like to tell me?

The entire research team undertook the process of analysis of data. We preserved, interpreted and summarised each participant's story, highlighting significant statements. We then combined the 21 stories and compiled a list of all significant statements, elucidating meaning into themes.

What did we find?

The findings revealed a trajectory about how people have learned to self manage the consequences of having a permanent catheter. The themes were:

1. Resisting the intrusion of a catheter,
2. Reckoning with the need for a catheter,
3. Being vigilant for signs of problems,
4. Reconciling between the needs of self, others and a catheter,
5. Reclaiming life,
6. The catheter as a tool for managing self
7. Taking control.

Resisting the intrusion of a catheter

Initially, for many of the participant's reluctance to have a permanent indwelling catheter reigned. Mary described her response as *'...oh how abhorrent, I can't bear it... it was a dreadful thing to contemplate... you always hope you'll get better you don't want to get worse but, well reality bites...[and then]...I just went straight ahead'*.

Neil had resisted the idea of having an indwelling catheter for almost twenty five years because it was yet another indicator that he was different to others. He recalled thinking, *'...the best word I think you can use [is] not natural. It's not right you know'*. With the benefit of hindsight, Neil says, *'I should have had it done like that from the beginning really, but I kept resisting it'*.

Initially Ron rejected the idea of a catheter, *'I wasn't at all impressed really'*. He felt desperate however that he needed to find a way to control incontinence so he had supra-pubic catheter inserted, *'...desperate as I was at that time [because I] couldn't go out anywhere, the moment you'd go somewhere you had to find where is a toilet and that sort of thing. Or you wouldn't get there and you'd get wet in the bed and all the other things associated with incontinence'*.

Reckoning with the need for a catheter

Many participants had come to the decision to have a catheter after having experiences with incontinence. Sometimes the humiliation or threat of public incontinence was a prime motivator to try a catheter. Greg reflected on his experiences of being publicly incontinent:

'[I felt] sort of emotional and you feel really, you know like a second class person. It was really embarrassing. I would attend quite a few meetings. This sort of thing would happen quite a few times. So I thought in the end that the supra-pubic might be the answer over these things'.

Spiros felt that the catheter restored some reliability back into his life. Reg was determined to get on with life, and happily wears shorts in the summer with the leg bag tube on show, *'I thought bugger, why not live my life, I'm gonna go out...they stare but they don't stare much'*.

For some participants, the need to have a urinary catheter was an unwelcome indication that their disease was progressing. Sue had MS and had been introduced to the idea of having a urinary catheter during a period of hospitalisation when she had made a conscious decision that this would be the better option for both her and her partner who was also her full-time carer, *'a catheter gives me freedom, is more convenient, has made life easier'*.

Robert had quadriplegia following a motor vehicle accident and placed the early days of needing a urinary catheter in context: *'Once they put me in the spinal ward section I was being fed through my stomach, I had the neck thing for breathing, I couldn't breathe at all I was a Christopher Reeve for a while. I had traction after the operation to bolt the bone together. So really I didn't know much about what was happening for 2 or 3 months. Where I was peeing from didn't worry me... [it] wasn't a major concern'*.

Being vigilant for signs of problems

The most identified concern for participants was the risk of infection. Infection disrupted their lives from the routine they had established. Sue experienced regular infections and said; *'it is mainly a nuisance with the likelihood of the catheter being expelled.'* Neil stated that what was important was *'just keeping infection free'*. Ann also experienced problems with thrush and infections, but remained philosophical about the recent change from a urethral to a supra-pubic catheter:

'...it means I can clean myself a lot better...I still get infections and when they're bad, they're bad but this way is such a better way for a change, a better way for me.'

Hygiene was important to Ian as, *'about every four months have to go on antibiotics. I have a problem with infection'*. For Warwick with quadriplegia, a blockage of his catheter when he was alone was his overwhelming fear:

'That blockage is a real fear. I wouldn't care if the house burnt down but if the bloody catheter blocks up, I am in real trouble... you get a thumping in the back of your head again, obviously a vein that has been under pressure.. a very, very strong pain. If you have it while you are getting your gear out and you have to wait 5 or 10 minutes, then it just gets worse and worse. It goes with your heartbeat, thump. It is a pain not like a throb it is a real pain.'

Reconciling between the needs of self, others and a catheter

The impact of a catheter when connecting and maintaining relationships was often at the forefront of people's concerns. Many participants perceived that a supra-pubic catheter would be more acceptable to others because it was not positioned in the genitalia. Mary was not participating in a sexual relationship, but since changing from a urethral catheter to a supra pubic catheter, *'I feel much better I must admit because it's not down there.'* This was because *'I didn't like being tampered with down there'*.

It was important to Joyce that her catheter bag did not show, *'the last thing you need is for your catheter bag to fall out so that people can see it and things like that'*. The way others had reacted to the sight of her catheter bag had left an impression on Joyce, *'...my brother and sister in law were just embarrassed when they saw the catheter bag hanging out below my trousers or something like that, they really didn't accept it as such'*.

For Neil the suprapubic catheter had simplified the opportunity for sexual relationships, because previously Neil needed to prepare himself by manually expressing urine from his bladder and restricting fluids for one to two hours prior to sex. The supra pubic catheter has however, *'made it easier than anything from what I had before'*. Having previously had an active sex life, Roger and his wife accepted it to be in the past, *'...since I've had the prostate operation I've had no sex life'*. While Roger said that, *'just as well he had an understanding wife'*, he later commented *'...she thinks I don't love her any more...I've lost all feelings you know'*.

Reclaiming life

Ann had a positive attitude to having the catheter inserted because she had been constantly wet, wetting the bed and unable to go out by herself, *'I would never enjoy myself because I would be wet most of the time. Like I used to go to the football and by half time I'd be soaked. But I would stay because my friends were there'*.

Ron is happy with the catheter, *'the quality of life has just been improved...well it's a lot more than I expected put that way, it really is.'* Ron is very pleased with getting his freedom back.

The decision has enabled Ann to be independent; *'I just find the fact that I can do it [empty bladder] whenever I like, and I can drink as much as I like, and the good things outweigh the bad...I've learned a lot of things about myself and how I handle situations. I used to call mum and dad all the time but I haven't done that for years...I finally go*

to the realisation that if I want to live independently I have to do everything independently.'

The catheter as a tool for managing self

The catheter was perceived to be a tool for self managing, enabling some order in life as opposed to the disorder and turmoil created by incontinence. Neil was enthusiastic about the significance the catheter had made to his life:

'I haven't had the problem of weeing myself so much...where as before you know this is huge, you're talking about 10 times a week. You have to go and change and have a shower, and especially when you are ready to go out and dressed in your best clothes and just getting into the car, oops...you know'.

The need to create order in his life was evident. Ron, having lived with a long term illness has learnt to reconcile with the notion of constant change, *'It just goes on...life goes on. At least now I can at least go somewhere...you've got about 4 hours before your bag is really full'*. The catheter had become a routine in Ron's life, *'the main concern was here to just get a better life and which it has done'*. The care of the catheter has been entwined into ordinary life. Ron describes the care of the catheter in line with other mundane ritualistic activities in his daily life, *'Well, like, it's just this, it's like, um getting dressed, putting a pair of socks on or anything like that, we change the bag every ten days or whatever which they recommend.'*

Taking control

Albert, an 80-year-old engineer, described self-management of his catheter as being a *'damn nuisance'*. Managing other illnesses and conditions took precedence. By comparison, the catheter was a *'secondary thing'*. He described catheter management as elementary. *'I can always tell whether there is muck in the bladder'*. He engineers his self-management as shown by the details he gives about bags and maintaining good hygiene, valves and piping. Regarding his catheter, *'I put up with it'*. He made an effort to appear *'normal'* by wearing clothing over the leg bag. Moreover, he chose not to disclose to others than he has a catheter, *'I don't tell anybody that I've got a catheter'*. He is also accepting, *'you have to accept the loss of sex life, and you have to accept loss of various activities'*.

Carl was proud that he has learned how to live with a catheter.

He described his understanding in mechanical terms using words like: caps, valves and pipes. Carl had formed clear ideas about what was and what was not hygienic. Learning to manage has meant *'getting into the habit'*. In making decisions about the type of drainage bag he indicated control over his management.

Jane had MS and diabetes but appeared to be taking control made implicit by her actions. She sought from the GP an intervention for *'wetting the bed all the time. The fact that I've now got a catheter and that makes me feel a lot safer'*. A blocked catheter was Jane's major concern about catheter management. *'I am worried that the muck inside the bladder, the sediment or whatever you call it that is going to block when I'm out'*.

What can we learn from this research?

During the initial stages of learning to live with a catheter, participants were reliant on managing their condition in partnership with health care professionals. It is suggested that support from nurses at crucial stages of the trajectory can help to improve health, quality of life and reduce incapacity. Together with the client, the nurse can look at ways that living with a catheter impacts on daily life and the client's response to that impact. The emphasis could be on ways people can take greater control over their condition on a day-to-day basis. The most desirable outcome of interventions is that participants can take responsibility for their own management.

Self-management is more than providing education for clients or giving them relevant information. Working with people,

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nurses can develop client confidence and encourage clients to use their own skills, information and professional services to take effective control. Locating where clients are situated in the management of self and working alongside our clients may assist nurses in facilitating self-determination. And should self-determination not be the goal of all our nursing interventions?

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