

## A qualitative approach on long-term indwelling catheter use in an outpatient setting

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THEMATIC ARTICLE

Marcelle Miranda da Silva (<https://orcid.org/0000-0003-4872-7252>)<sup>1</sup>  
Anne de Paula Tsuboi (<https://orcid.org/0000-0002-7451-2063>)<sup>1</sup>  
Thayna Silva de Assis Barros (<https://orcid.org/0000-0003-4867-1762>)<sup>1</sup>  
Audrei Castro Telles (<https://orcid.org/0000-0002-1191-5850>)<sup>1</sup>  
Nair Caroline Cavalcanti de Mendonça Bittencourt (<https://orcid.org/0000-0002-4451-6258>)<sup>1</sup>  
Annela Isabell Santos da Silva (<https://orcid.org/0000-0002-1400-5297>)<sup>1</sup>  
Cristina Rosa Soares Lavareda Baixinho (<https://orcid.org/0000-0001-7417-1732>)<sup>2</sup>  
Andreia Cátia Jorge Silva da Costa (<https://orcid.org/0000-0002-2727-4402>)<sup>2</sup>

**Abstract** *A long-term indwelling catheter may be indicated in clinical situations, such as chronic diseases of the genitourinary or neurological systems. In addition to the risks of infection, trauma, and bleeding, a catheter's permanence can affect psycho-emotional and socioeconomic dimensions. We aimed to understand how the need to use a long-term indwelling catheter affects this patient's self-perception, interrelationships, and self-care. We carried out a qualitative, descriptive study based on interviews with 17 patients, and applied thematic analysis and complex thinking. The different prognoses and expectations regarding the catheter influenced self-perception, adaptation, acceptance, or denial. The presence of a catheter, whether as a curative measure or for comfort, can affect self-image and sexuality, and generate insecurities and uncertainties, which require understanding the multidimensionality of situations that suffer interference from the personal, family, and social environment, as well as health systems' capacity to deal with it. Despite the challenges, the majority of participants reported a favorable disposition towards self-care, whether to enable catheter removal or to prevent injuries in lifelong indications.*

**Key words** *Urinary Catheterization, Cystostomy, Lower Urinary Tract Symptoms, Office Nursing, Qualitative Research*

<sup>1</sup> Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro. R. Afonso Cavalcanti 275, Cidade Nova. 20211-130 Rio de Janeiro RJ Brasil. marcellemisufri@gmail.com

<sup>2</sup> Centro de Investigação, Inovação e Desenvolvimento em Enfermagem de Lisboa (CIDNUR), Escola Superior de Enfermagem de Lisboa. Lisboa Portugal.

## Introduction

Non-communicable diseases (NCDs) that affect the genitourinary or neurological system, such as cancer, diabetes and neuropathies, as well as the consequences of some viral infections, such as HIV and HTLV, or even degenerative diseases associated with advanced age, such as dementia and care at the end of life, may indicate long-term indwelling catheter use<sup>1,2</sup>. It is defined as the passage of a catheter to the bladder through the urethra that will remain for a period of more than 28 days draining urine in a bag closed system collector<sup>1</sup>.

An indwelling catheter is a device frequently used in hospital settings, and when indicated to treat acute conditions, the best scientific evidence recommends that it be removed as soon as possible to avoid urinary tract infections, prolongation of hospitalization period, worst quality of life for patients, and to optimize health resource use<sup>1</sup>.

However, when its immediate removal is not possible, depending on the clinical indication, as in the case of people with spinal cord injury, alternatives need to be assessed. The main one refers to intermittent urethral catheterization, i.e., at necessary intervals, without the catheter remaining in the circuit between the urethra and the bladder all the time, which facilitates micro-organism entry<sup>1,3,4</sup>.

To enhance home care, patients can be trained to perform intermittent self-catheterization, when the procedure is performed by the patients themselves using a clean technique, exposing them to a lower risk of infection, promoting autonomy, and improving quality of life<sup>4,5</sup>.

However, intermittent urethral catheterization is not an accessible therapeutic indication for all patients, as it depends on some conditions related to the availability of material resources and the physical, cognitive and psycho-emotional qualifications of patients, or their family support network. In addition to logistical and personal impediments, there are also clinical contraindications, such as in the case of urethral stenosis, increased prostate volume, risk of urinary tract injury, catheter path deviations, and bleeding<sup>4</sup>.

In some particular situations that prevent the catheter from passing through the urethra, such as severe urethral stenosis, bladder neck obstruction, bladder or urethral trauma, and even increased prostate volume, suprapubic catheterization, also called cystostomy, may be necessary, which involves inserting the catheter directly into the bladder through access through the an-

terior abdominal wall<sup>1</sup>.

For those who need to wait for some curative intervention, or as palliative care, and remain with a long-term indwelling catheter, special attention is needed to the chronicity of the situation, specific care demands, insecurities, uncertainties and risks associated with the procedure<sup>2,5</sup>.

We emphasize that many circumstances beyond patients' control can further extend the period of catheter use, such as due to hospital resources for arranging elective surgeries and availability of intensive care beds, or even unpredictability, such as the one we observed during the COVID-19 pandemic, which resulted in cancellations of appointments and elective surgeries<sup>6</sup>. The fact is that many patients, followed at the outpatient clinic, remain with an indwelling catheter for long periods<sup>2</sup>.

Nurses, during nursing consultation in the outpatient clinic or at home, are the professionals who most establish a therapeutic relationship with this patient, as they are responsible for periodic catheter changes<sup>2</sup>. These are patients with a differentiated clinicopathological profile and little addressed in published studies, which have a thematic focus, mainly on intermittent urethral catheterization and short-term indwelling catheters in hospital settings<sup>7</sup>.

Long-term indwelling catheter use involves a series of feelings and changes that affect these people's quality of life<sup>2</sup>. The presence of this catheter can undermine self-image and self-esteem, and brings consequences that disrupt self-care and the ability to cope with the problem<sup>8</sup>. And based on nurse authors' empirical experience in this context, we defined the following question: what is the patients' perception of the need to use a long-term indwelling catheter? Therefore, we aim to understand how the need to use a long-term indwelling catheter affects this patient's self-perception, interrelationships and self-care.

## Methods

This is a qualitative, descriptive study, guided by the Consolidated criteria for REporting Qualitative research (COREQ) to meet methodological rigor. It was carried out in the specialty outpatient clinic dedicated to changing indwelling catheters at a university hospital, located in the city of Rio de Janeiro, Brazil. In this outpatient clinic, nurses perform nursing consultations and change indwelling catheters, with emphasis on the profile of patients with the following medical

diagnoses: prostate cancer; benign prostatic hyperplasia; and infectious or neurological diseases that cause neurogenic bladder.

The outpatient clinic operates from Monday to Thursday, in the morning, with the work of a nurse, in addition to being a practice setting for undergraduate nursing students, under the supervision of a nurse professor. On average, five to seven patients are seen per morning; however, there are situations when care is taken outside the schedule, such as first-time patients, or due to spontaneous demands associated with complaints of discomfort, damage to collection bag circuit, obstructions, urine extravasation or bleeding.

A total of 17 patients, aged greater than or equal to 18 years, enrolled at the institution, registered in the outpatient catheter exchange program, using a long-term urethral or suprapubic/cystostomy catheter, were included. Patients hospitalized during the data collection period, with impaired cognitive capacity or who were undergoing intermittent urethral catheterization were excluded.

A semi-structured interview was carried out between November 2020 and March 2021, based on the questions: what does it mean for you to have an indwelling catheter for a long time? How do you take care of yourself with this probe? What helps and what hinders this care? What could be done to improve this care? The term “catheter” was replaced with “probe”, as this is how patients commonly recognize this device.

The interviews were carried out by the second author, who received training to apply this technique. Patients were interviewed in a private room or in an outpatient waiting room, depending on their preferences, ensuring privacy was maintained.

Before carrying out the interviews, participant sociodemographic and clinical profile was characterized. The following characteristics were considered: age, sex, type of catheter, duration of catheter use, indication for catheter use, and who they live with. When a patient did not know how to answer a question, medical records were consulted.

The concept of data saturation was applied; inferences began to be repeated from the 10<sup>th</sup> interview<sup>9</sup>. The interviews lasted an average of 10 minutes. Data were transcribed in full, organized in Microsoft Word®, and analyzed following the content analysis steps in the thematic modality. Thus, after transcription, the interviews were read, establishing a first contact with texts, in an

attempt to grasp the meanings that participants let shine through in their speeches<sup>10</sup>.

In the second phase, the ideas, sentences and paragraphs that identified participants' convergences and divergences in relation to the study topic were separated. In the third and final stage, statements' similarities and differences were organized and mapped, carrying out successive re-readings of texts, with the aim of outlining the main inferences and selecting the categories that answered the research question<sup>10</sup>.

All analysis steps were performed manually, with notes on the analyzed texts using pens and colored stickers to identify potential patterns and data segments. For analysis, we applied complex thinking, by Edgar Morin<sup>11-13</sup>, as it recognizes the subjective dimension of research, the complexity of the objective, and the multidimensionality of the phenomenon of interest.

Given the importance of applying a qualitative approach to understand the phenomenon investigated, the data were presented at the 11<sup>th</sup> Ibero-American Congress of Qualitative Research (CIAIQ) in the form of an abstract and a full article<sup>2</sup>.

The research project was approved by a Research Ethics Committee in November 2019. All participants signed the Informed Consent Form, and statements were identified by alphanumeric codes to guarantee anonymity.

## Results

Of the 17 patients interviewed, 14 (82%) were male and three (18%) were female. The mean age was 68 years old, with the youngest patient being 33 years old and the oldest being 88 years old. Patient concentration was in the age group between 60-69 (35%). Seven (41%) patients lived with their wives; six (35%) lived alone; and four (26%) lived with other family members (father, children or in a long-term care facility).

As for clinical characterization, six (35%) had benign prostatic hyperplasia; five (29%) had neurogenic bladder; three (18%) had urinary retention; two (12%) had prostate cancer; and one (6%) had urethral stricture. The mean time using a catheter was two years and two months, with four months being the shortest time and nine years being the longest. The majority of patients used a urethral catheter (88%), while two (12%) used a cystostomy. Interview data analysis resulted in two categories.

### Category 1: (Un)Certainty about the need to use an indwelling catheter

The perception of the need for long-term indwelling catheter use was related to quality of life and changes in self-image due to the presence of a catheter, which requires specific care and can limit activities of daily living. Associated with the unknown and, often, the unexpected, the initial period of adaptation was highlighted as the most difficult, prevailing, in some cases, even after some time, depending on the prognosis and expectations regarding the catheter and life itself.

*I've had the probe for 17 years. I had surgery for a herniated disc, and I lost movement from the waist down. I can't feel urinating or having a bowel movement. At first, it was hard, it's not part of the body, but I'm going to undergo surgery today to remove it and perform a cystostomy. It's uncomfortable because you have to tie it around your legs to hide it. I'm not ashamed, but I think there's no need for people to be watching. It's more because of people, sometimes they are having lunch, so it becomes embarrassing for people [...]* (P2).

*I've been using a catheter for nine months. I was running a marathon, I was an athlete, thank God, then my urine did not come out, and I couldn't urinate, it burned a lot, it was burning. I didn't go to the doctor, I spent about four months feeling this way. But there was a point when it was no longer possible and I went to the ECU [Emergency Care Unit – emergency service], and the relief probe was inserted, and that's when we started going after it, taking the exams. [...] the outcome was prostate cancer. I should have gone to the doctor sooner, but I was scared first. Then one day I felt a lot of pain, I went back to the ECU, showed the tests and they took me to the hospital at the same time. I went straight to the operating room, and they placed the probe in my penis. It wasn't hard to adapt, because I was anxious about getting better soon, so it was a relief [...]* (P10).

We noticed in statements many other needs, in addition to the biological one of emptying the bladder, since we are dealing with multifaceted factors, where one of the interventions to solve or alleviate it, such as catheter, contributes to affecting all dimensions of a person. However, the characteristic of approaching problems in a fragmented way in the biomedical model can neglect them. We highlighted here the issue of sexual and psycho-emotional health and pain management.

*There's only one part that gets in the way, which is sex, there's no way, I've always been active. I have a wife, she understands, she mocks me telling me*

*to take it off [...]. I've never had any problems, despite being 74 years old, I've always been active, and that ends up getting in the way; it's the part that gets in the way the most, and it's a necessary thing* (P17).

*I always took diazepam, and I stopped taking it and I can't sleep day or night, so I get very tired. I'm going to ask the doctor if I can start taking it again or change medication so I can rest at night, because I already have anxiety thinking that I'm going to die, I'm 75 years old* (P10).

*It will be six months since I have been using the probe. I'm not getting used to it at all, the worst part is when the penis swells, then it tightens and blood starts to come out. The probe gets in the way when I sleep, and going out on the street is also uncomfortable; it's the worst thing in my life. It had to stop hurting, because it hurts so much* (P9).

### Category 2: Reorganizing internal and external resources in search of support and resistance to catheter use

We evidenced in statements that family and social support networks, when present and strong, positively interfere with the rehabilitation or palliative care process of a person with catheter. However, the need for continued care, not only due to long-term catheter use, but due to conditions associated with this intervention, can stress these sources of resources. We also highlighted structural and housing issues that interfere with this dynamic.

*I was lucky to come here, but what makes it difficult is the distance. There are times when I came every day because of treatment and my son brought me. It's tiring, because I can't get there by bus. And I always go to the doctor here, he's a urologist, he's an oncologist [...]* (P10).

*My son brings me by car, but it's hard, because sometimes I have to come three times a week, and I live on the second floor. I have to go down stairs [...]. My son and my wife help me take care of the probe, the other children don't help me at all, they just visit and leave, saying they are disgusted [...]* (P8).

When dealing with resources, we also raise the issue of patients' own financial resources. In this case, for those who depended on diaper use and who needed to purchase them themselves, catheter use indication meant reducing this type of cost. Meanwhile, for others, the set of treatment measures, including medication use, may have been a greater burden.

*It was very easy to adapt to it [probe]. I was spending a lot of money on diapers, I couldn't con-*

trol it, I was waiting for surgery. So, it was beautiful when the urine started coming out of the probe. (P14)

[...] the medications they give are also very expensive (P9).

Despite the adversities, the majority of participants reported a favorable disposition towards self-care, whether among those who hope that one day they will no longer need the catheter or among those who are aware of the need for this device permanently. Although this type of certainty can generate emotional instability, we noticed positive attitudes in participants to prevent new injuries.

*I take care of the probe myself. I just don't walk around, making effort, and then I actually stopped. I have to spend the rest of my life with the probe. I can't do anything, so I have to take care of it as much as possible and clean it correctly (P7).*

*I've been using the probe for two years. I have prostate hyperplasia; I had been treating it for a while and it started giving me fever and infection. Because I had urinary incontinence, I started doing intermittent catheterization, and I didn't adapt [...]. I drink a lot of water to avoid infection. I take care of it myself, I take a shower, I open it, then I close it, it's been two years. The biggest difficulty is sleeping, having to sleep on one side to avoid traction on the probe. Other than that, there's no other difficulty, and I'll wait [...]. I took all my exams and I'm already considering surgery to see how it goes. At first, it was hard, to this day, it bothers me, I want to have surgery soon to get it out of here, but I've already adapted (P8).*

We highlighted that the social distancing measures due to COVID-19 had negative repercussions on family member participation in this care plan as well as prolonging uncertainties related to the outcome of solving the problem.

*I've been using the probe since August last year. I went to extract urine, and it started bleeding and I was hospitalized for eight days. I have a large prostate, and I was hospitalized there, they put me in the corona ward [coronavirus], and they didn't let me see my wife, because she is diabetic (P1).*

## Discussion

An indwelling catheter's clinical indication for these patients occurs mainly in moments of uncertainty, whether in search of a medical diagnosis through the development of signs and symptoms, as a consequence of an acute occurrence, but capable of altering the function of the biolog-

ical system involved - the genitourinary, or even due to the evolution of a disease that threatens continuity of life<sup>2</sup>.

Such situations are intertwined by a series of factors that make them even more complex, especially when there is a lack of clarity about the therapeutic plan and difficulty in understanding health information by patients<sup>12,13</sup>. Many patients reported anxiety about waiting for the catheter to be removed and uncertainty about their current clinical condition and what to expect for its solution or palliation<sup>14,15</sup>.

The dialogue between certainty and uncertainty<sup>11</sup> can already be seen when we think about time, because we start from a definition that considers the long term to be a period longer than 28 days. However, we are not just talking about days, but rather dealing with patients who use the catheter for an average of two years and two months, a period marked by news and facts that made them maintain their dependence on this device as well as improving or worsening their self-perception, interrelationships and self-care in relation to this condition<sup>2</sup>.

In some cases, the initial plan to treat an apparently acute condition, generally in approaches to emergency services, could result in greater difficulty in accepting the catheter, not recognized as part of the body, but which, on the other hand, was the solution for that intense discomfort. Accepting or denying the catheter also reveals the fine line between the perception of what can be good or bad for oneself. The contradiction can be seen here, based mainly on logical reasoning, which in the complex view, means reaching deeper layers of reality<sup>11</sup>.

In this topic, we highlighted particularities of men's health; our unintentional sample was mostly male (82%). By nature, and self-concept of being in the world, men delay seeking medical help. Some revealed to us that this delay was due to fear of the truth, of a diagnostic confirmation that would compromise their masculinity<sup>16</sup>. When the search for help becomes inevitable, new risks may be associated, such as vulnerability to infections, inadequate coping capacity, late diagnosis, and more limited therapeutic options, such as the indication of an indwelling catheter in these cases<sup>17</sup>.

Indwelling catheter use, given its long-term prognosis, generates imbalances that require professional and family help to (re)organize life differently<sup>2,10</sup>. Participants highlighted anxiety, needs, insufficiencies, resistance and desire to remove the catheter and solve the situation<sup>18</sup>. It is

an internal desire, which may not have enough strength to cause change in the face of a larger system and which works with an unbalanced logic between little supply and a lot of demand.

It implies that, in addition to the weak representation of this desire in relation to the whole, other parts influence this outcome<sup>11</sup>, such as public hospital dynamics, with extended intervals between appointments, shortage of healthcare professionals, and difficulty in managing their resources. In addition to the person's own clinical response, which is expected to be favorable to other pharmacological and non-pharmacological interventions, and thus conditions an approach with greater technological density, as in the case of surgeries to treat prostate disorders.

Until the best approach for each case has been outlined, including palliative measures and indications for lifelong catheter use, other problems begin to gain relevance, such as advanced age, the evolution of the level of dependence on care, emotional and financial strain, and the lack of housing structure.

We highlighted that, in line with clinical indications for catheter use in our sample, 35% were older adults, with their mean age being 68 years. And in the case of older adults, speeches were equated and complacent with their life experiences, as well as the approaching death, in yet another important dialogue between life and death that needs to be valued in care for these people<sup>2,11</sup>.

However, increased life expectancy is perceived as an improvement in the population's health status, often disregarding changes in levels of morbidity, disabilities, or other indicators of older adults' health conditions<sup>19</sup>. It is essential to pay attention to older adults' particularities, which over the years suffers from increased morbidity states, resulting in multimorbidity<sup>20</sup>. This condition, associated with the physical limitations of the natural aging process, may require support for daily care with a catheter, as its presence can affect safety, increasing, for instance, the risk of falling.

Although our data were collected in the outpatient clinic, older adults' increased life expectancy and vulnerability to urinary retention, for instance, is still a latent concern, which could increase the number of older adults living in Nursing Homes, where the use of indwelling catheters with long-term indications prevails<sup>21</sup>. As an extension of the home environment, in Nursing Homes, long-term indwelling catheter use also requires daily care, often even more intensified, professionalized, and proportional to the level

of dependence of the older adult who needs this type of institutionalization.

A systematic review on the prevalence of long-term indwelling catheters in Nursing Homes pointed out that more studies need to be developed to assess the indication of this device and analyze the relevance of its clinical indication, given the negative consequences of chronic use<sup>21</sup>.

Although, in part of daily care, long-term indwelling catheter indication may reveal an intrinsic ease in the midst of daily tasks when compared to periodic changing of diapers and hygiene care, from the perspective of the whole inherent to health resource management and its complications, especially in older adults, a long-term indwelling catheter can represent increased costs and a worse quality of life<sup>21</sup>.

Thus, assessing the real need for a catheter or whether it can be removed or even replaced by alternatives aligned with patients' needs and preferences, although there is no evidence whether the difference between urethral or suprapubic catheters invariably reflects different needs, implies the logic of person-centered care, which still does not happen in many contexts that orient their practices towards disease-centered care<sup>11,21</sup>.

This logic of health systems, based on the biomedical model and centered on the hospital, was further disturbed by the COVID-19 pandemic. In addition to having resulted in measures that changed the therapeutic plans for these patients, due to the postponement of consultations, exams and elective surgeries, it caused even more uncertainty and contradictions.

As the majority are older adults, with chronic illnesses or those that affect immunity, the contradiction between the need to leave the house, expose oneself to COVID-19 and, in a certain way, having to periodically change the catheter in the hospital could intensify feelings of insecurity and fear, in addition to isolation, especially during hospitalizations<sup>22,23</sup>. Without a doubt, patients using long-term indwelling catheters were also affected by the stress of this pandemic, due to change in daily routine, adaptation to a new scenario, and community, family and work distance<sup>22</sup>.

The difficulties expressed by participants in relation to managing pain care and other psycho-emotional needs highlighted the need for emotional care and caregiver/family member training to ensure continuity of care and support the use of effective coping strategies that allow for coping with the disease, managing emotional

support and the feelings aroused by care provision<sup>23</sup>.

In some situations, the need to use a long-term indwelling catheter is associated with a recent illness, which implies the transition to the role of caregiver so that the self-care and health needs of people with complex clinical situations are guaranteed.

Hence, data lead us to a discussion about palliative care, going against the health model that is still fragmented and incapable of relating the whole and the parts, whether within the scope of the care network itself, the social context and the individuality of the people assisted<sup>11</sup>. In the field of individuality, we see parallel situations in reports, which go beyond the presence of a catheter, realities that cause pain, shame, embarrassment and limitations in activities of daily living. Multidimensionality, considered from the philosophical perspective of palliative care and often forgotten in the Cartesian and hegemonic biomedical model, is a complex phenomenon that, like a tissue, is made up of different but inseparable elements<sup>11</sup>.

Carelessness related to the different dimensions that involve patients in the health-disease process constitutes the “cultural challenge”<sup>13</sup>, where there is a separation between humanistic culture and scientific culture; the latter still separates the areas of knowledge, also strengthening the “civic challenge”<sup>13</sup>, where, in the face of the weakening of a global perception, each person tends to be responsible for only one part, one specialty, generating losses for everyone involved.

## Final considerations

Our data revealed that changes caused by the presence of a long-term indwelling catheter, added to the uncertainties regarding the clinical condition, the capacity to provide services and their adjustments as a result of COVID-19, reflect the self-perception of dependence on the catheter to perform the biological function of emptying the bladder and relieving discomfort, but also on its physical presence altering self-image, self-esteem and social interrelations.

The different prognoses and expectations regarding the catheter influence this self-perception as well as the ability to cope and adapt to the catheter for its acceptance or denial. However, despite the limitations caused by the catheter, patients reported a favorable disposition towards self-care, whether to enable its withdrawal as early as possible, or to prevent problems in lifelong indications.

We highlighted as limitations of this study the application of only one data collection technique, as we consider that triangulation with observation, for instance, could enrich the understanding of the phenomenon, safeguarding the qualitative approach, fundamental to achieving objective and respect for the subjectivity of the topic. We also considered the need to include family members/caregivers and expand to other settings.

## Collaborations

MM Silva: study design, data analysis and interpretation of results, article writing and critical review, approval of the final version to be published. AP Tsuboi: study design, data collection, data analysis and interpretation of results, article writing and critical review, approval of the final version to be published. TSA Barros, AC Telles, NCCM Bittencourt, AIS Silva, CRSL Baixinho and ACJS Costa: data analysis and interpretation of results, article writing and critical review, approval of the final version to be published.

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