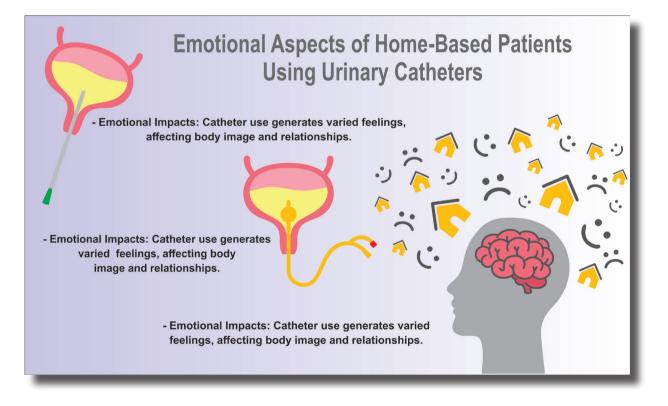


Emotional aspects of home-based patients using urinary catheters: a scoping review

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Graphic Abstract







Abstract

To identify, synthesize, and analyze the scientific knowledge produced on the emotions of home-based patients using indwelling and intermittent urinary catheters. A scoping review following the Joanna Briggs Institute's approach. The Population, Concept, and Context (P - home-based, bedridden patients; C - emotions; C - using indwelling/intermittent urinary catheter) strategy was used to formulate the guiding research question. The search was conducted from February 19 to 25, 2024, in the National Library of Medicine (PubMed/MEDLINE), Scopus, Embase, Web of Science, Scientific Electronic Library Online (SciELO), LILACS, and CINAHL with Full Text. Of the 56 articles found, 11 were included in the study for meeting the established inclusion criteria. The 11 studies identified were published over the last four decades and report positive or negative emotions related to the use of indwelling urinary catheters, such as confidence, empowerment, fear, embarrassment, pain, discomfort, aversion, depression, grief, loss, suffering, distress, limitations, changes in sexual activities, and body image. Qualified professionals knowledgeable about public policies that can better ensure a support network for these patients may have a greater impact on their care.

Keywords: Home-Based Patients. Urinary Catheters. Emotions.

INTRODUCTION

Alterations or losses in physiological functions directly impact an individual's lifestyle, routine, and perceptions. In the context of voiding dysfunctions, these are characterized by a decline or impairment in voiding function associated with anatomical, physiological, or pathological changes. One treatment alternative used for this purpose is urinary catheterization¹.

Urinary catheterization involves the insertion of a catheter through the patient's urethra, which is guided to the bladder to drain urine. Depending on its intended use, it may remain with the patient (indwelling urinary catheter), be used sporadically (relief catheter), or at intermittent intervals (intermittent urinary catheter)².

In hospital settings, urinary catheterization is performed using a sterile technique by qualified healthcare professionals³ and is generally indicated for acute treatments with a limited duration to minimize the risk of urinary tract infections^{4,5}. However, when associated with disabling conditions and chronic treatments, patients may be discharged to their homes with the catheter in place. At home, urinary catheterization can be performed with a sterile technique by qualified healthcare professionals or by patients and caregivers trained to insert the catheter. In the latter case, catheterization is usually performed intermittently and with a clean technique⁴.

Despite all precautions, the use of urinary catheters results in direct changes to the daily activities of users. The impacts on the routines of patients and their caregivers can stem from both adapting to the device and the underlying disease of the patient, which often necessitates home care^{1,6,7}. At home, the adaptation of the patient and family to urinary catheter use leads to direct changes in the patients' social, work, and sexual lives, consequently affecting their quality of life and that of their caregivers¹.

In the case of catheter use, patients report various situations. For those using intermittent urinary catheterization, the time spent performing the procedure and managing the necessary materials makes adherence to treatment challenging⁵. Among patients using an indwelling urinary catheter, perceptions arise from situations that require adaptation to a new body condition. In this modality, individuals note that the initial adjustment period for catheter use was the most difficult, and even over the years, the condition remains a source of anxiety⁷. For caregivers, accounts



indicate that assisting patients with urinary catheters creates a burden due to the required care and limitations in their own lives⁵.

The events associated with urinary catheterization are well documented in the literature, particularly regarding its complications, such as urinary tract infections, trauma, false passages, and others⁸. However, the psychosocial aspects related to this type of treatment remain under-researched, as studies on this topic are sparse.

Most subjects define their emotions as feelings. Contrary to common belief, feelings are one component of emotion and play a prominent role in an individual's experience^{9,10}. In this context, feelings are characterized by personal evaluation and the experience of a unique event within the individual's context. For feelings to occur, a stimulus, meanings, and the conscious perception of emotions are necessary^{11,12}. Emotions, on the other hand, are expressions of affection, with intense and specific bodily reactions in response to an unexpected, anticipated, or idealized event. Emotions encompass cognition, physical symptoms, motivation, body expression, and subjective experience, which is the feeling itself^{13,14}.

In this sense, to enhance adherence to urinary catheterization and provide comprehensive care to home care patients, it is important to understand the emotional manifestations experienced by these users due to catheter use. Therefore, this study aims to identify, synthesize, and analyze the scientific knowledge produced on the emotions of home-based patients using indwelling and intermittent urinary catheters. Understanding and describing these patients' emotions is essential to improving care practices, promoting greater adherence to treatment, and enhancing the quality of life for these users.

METHOD

This is a scoping review following the methodological approach of the Joanna Briggs Institute¹⁵ and the international guideline Preferred Reporting Items for Systematic and Meta-Analyses – Extension for Scoping Reviews (PRISMA-ScR)¹⁶. The methodology was chosen to enable a comprehensive mapping and synthesis of knowledge on the topic, identifying gaps and guiding future research.

This review was structured through the following stages: 1) formulation of the guiding question and review objective; 2) development of the search strategy; 3) database searches; 4) selection of articles based on title and abstract screening; 5) selection of scientific articles after full-text reading; 6) summarization of results; and 7) presentation and discussion of the findings.

To formulate the guiding research question and search strategy, the Population,

Concept, and Context (PCC) framework was used. Thus, we defined P - home-based, bedridden patients; C - emotions; C - using an indwelling/intermittent urinary catheter. In Population (P), "home-based, bedridden patients" refers specifically to individuals receiving home care and remaining in a continuous resting position. In Concept (C), "emotions" encompasses a range of feelings and emotional reactions to be detailed throughout the review, including aspects such as anxiety, frustration, and adaptation. In Context (C), "use of indwelling/intermittent urinary catheter" specifies patients who use this type of device either temporarily or continuously. Following this definition, the following guiding question was formulated: "What are the emotions of home-based, bedridden patients using indwelling or intermittent urinary catheters?" To ensure rigor and consistency in study selection, inclusion cri-



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teria were set for articles addressing all three elements of the PCC and answering the research question, written in English, Portuguese, or Spanish, from any period. Full-text, complete studies were prioritized to allow in-depth data analysis and greater rigor in research results. Literature reviews, expert opinions, and brochures were excluded to minimize interpretive biases. Additionally, studies without online access to the full text were disregarded, ensuring the integrity and transparency of the article selection process.

The article search was conducted from February 19 to 25, 2024, with the support of a librarian, in the following databases: National Library of Medicine (PubMed/MEDLINE), Scopus, Embase, Web of Science, Scientific Electronic Library Online (SciELO), LILACS, and CINAHL with Full Text.

For the search, health descriptors (DeCS/ MeSH), keywords, and their alternative terms were used. Specific terms reflecting the core elements of the research were selected to capture different nomenclatures and expressions found in the literature (Bedridden People, Home-Based Patients, Bed Rest, Urinary Catheters, Urinary Catheterization, Indwelling Urinary Catheter, Emotions, Manifested Emotions, Feeling), indexed in Portuguese, English, and Spanish. The boolean operators OR, AND, or NOT were also used.

The studies were organized with the help of the Mendeley[®] reference manager to facilitate categorization by keywords, containing the following information: authors, year of publication, title, publication source, and abstract. After the abstract reading stage, studies were organized into a Microsoft Excel[®] spreadsheet to allow for quick visualization and comparison of findings based on selected criteria, including title, author, year of publication, objective, methodological design, location, and result summary for a clearer understanding and visualization of findings.

The results were presented in tables and a descriptive report. To ensure methodological rigor, the PRISMA-ScR¹⁶ tool was applied.

RESULTS

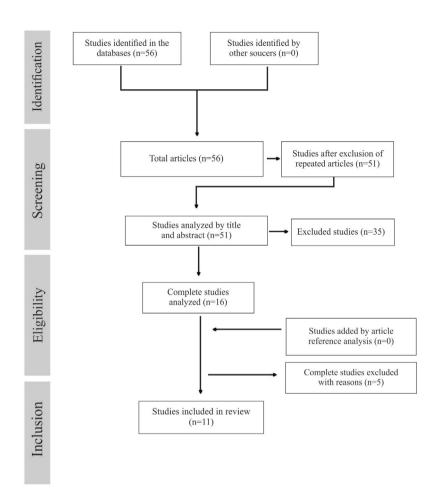
Of the 56 articles found, five were excluded using Mendeley software due to duplication across multiple databases. After a careful review of the titles and abstracts of the remaining 51 articles, 16 were selected for full-text reading.

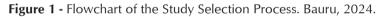
Following the selection, Gray Literature was also accessed, with no additional studies identified. After the full-text reading of the 16 selected articles, 11 were included in the study for meeting the established inclusion criteria.

The final sample for this study consisted of 11 articles. For analysis purposes, the articles were numbered from one to 11 and labeled as "Study." The selection process was conducted by three independent reviewers and is presented in Figure 1. The results are displayed in tables and a descriptive report. This review was registered on the OSF platform under DOI number 10.17605/OSF.IO/ QJRUS.









Among the 11 studies included in this sample, most were published in the last five years, in the Americas and Europe. Table 1 presents the selected studies by authorship, year of publication, and study type.

Study	Authors	Title	Year
E1	Markiewicz <i>et al</i> .	Emotional attributes, social connectivity and quality of life associated with intermittent catheterization	2020
E2	Fumincelli et al.	Quality of life of patients using intermittent urinary catheterization	2017
E3	Faleiros <i>et al</i> .	Patients With Spina Bifida and Their Caregivers' Feelings About Intermittent Bladder Catheterization in Brazil and Germany: A Correlational Study	2017
E4	Yılmaz et al.	Intermittent catheterization in patients with traumatic spinal cord injury: obstacles, worries, level of satisfaction	2014



Study	Authors	Title	Year
E5	Chapple <i>et al.</i>	How users of indwelling urinary catheters talk about sex and sexuality: a qualitative study	2014
E6	Castel-Lacanal et al.	Impact of intermitente catheterization on the quality of life of multiple sclerosis patients	2013
E7	Ramm <i>et al.</i>	A qualitative study exploring the emotional responses of female patients learning to perform clean intermittent self-catheterisation	2011
E8	Oh <i>et al</i> .	Depressive symptoms of patients using clean intermittent catheterization for neurogenic bladder secondary to spinal cord injury	2006
E9	Wilde <i>et al.</i>	Life with an Indwelling Urinary Catheter: The Dialectic of Stigma and Acceptance	2003
E10	Bakke <i>et al.</i>	Clean intermitente catheterisation-performing abilities, aversive experiences and distress	1993
E11	Roe et al.	Study of patients with indwelling catheters	1987

Table 2 presents the objectives and design of the studies, the population studied, and the sample size.

Table 2 - Selected Studies by Objectives, Study Design, Population Studied, and Sample Size. Bauru, 2024.

Study	Objective	Study design	Population	Sample size
E1	Explore the emotional aspects of adults using intermittent catheters (IC) (depression, anxiety, poor self- feelings, empowerment, independence, confidence)	Quantitative cross- sectional study	54,593 patients over 18 years old, whose first treatment method was urinary catheterization registered with the United Spinal Association	393 patients
E2	Measure and compare the quality of life of patients with neurogenic bladder using intermittent urinary catheterization in the rehabilitation process, in Brazil and Portugal	Multicenter, quantitative, cross-sectional, analytical, and correlational observational study	Patients over 18 years old with neurogenic bladder and users of intermittent urinary catheterization	222, with 170 from Brazil and 52 from Portugal
E3	Compare feelings that hinder the performance of intermittent catheterization reported by individuals with Spina Bifida (SB) and their families in two countries with different sociocultural characteristics: Brazil and Germany	Quantitative and comparative study	Patients with Spina Bifida (SB)	200, with 100 from Brazil and 100 from Germany

to be continued...



...continution table 2

Study	Objective	Study design	Population	Sample size
E4	Examine the obstacles faced by patients with traumatic spinal cord injury (SCI) in performing IC, as well as their concerns and satisfaction level	Quantitative descriptive study	Patients with traumatic spinal cord injury who had been performing IC for at least 3 months	269 patients
E5	Explore individuals' perceptions of how indwelling urinary catheterization can affect body image, sex, and sexuality	Qualitative study	Individuals using indwelling urinary catheters	36 patients
E6	Prospectively assess the impact of IC on the quality of life of patients affected by Multiple Sclerosis (MS)	Quantitative and prospective study	Patients affected by Multiple Sclerosis (MS)	23 patients
E7	Report the experiences and emotions of female patients performing clean intermittent self- catheterization (CISC)	Qualitative phenomenological study	Intentional sample of adult female patients performing CISC	5 patients
E8	Evaluate depression symptoms in patients with spinal cord injury who use clean intermittent catheterization	Prospective quantitative cross-sectional study	Patients with spinal cord injury from private home care agencies	102 patients
E9	Describe and interpret the experiences of users with indwelling urinary catheters	Qualitative phenomenological study	Patients registered in a CIC program, over 16 years old	14 patients
E10	Identify the opinions and feelings of patients regarding clean intermittent catheterization (CIC)	Quantitative study	Home-based patients using indwelling urinary catheterization, over 50 years old	407 patients
E11	Investigate patients' understanding and knowledge of the location and function of their catheter, their acceptance, associated problems, social implications, and subsequent management	Mixed study (quantitative and qualitative)	54,593 patients over 18 years old, whose first treatment method was urinary catheterization registered with the United Spinal Association	36 patients

Table 3 presents the studies according to their main results and conclusions.

Table 3 - Selected Studies by Main Results and Conclusions. Bauru, 202	Table	3 - Selected	Studies by	v Main Results	and Conclusions.	Bauru, 2024
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Study	Main Results and Conclusions	
E1	Dependence on others to perform IC significantly influences patients' emotional aspects: the more independent they are, the more positive feelings they report, such as feeling confident and empowered, particularly for women compared to men. Regarding negative feelings such as depression, anxiety, and feeling bad about themselves due to IC use, there was no significant influence.	
E2	Patients' quality of life (QoL) can be determined by the improvement of urinary symptoms, independence, self-confidence, social relationships, access to work activities, and social integration.	

to be continued...



...continuation table 3

Study	Main Results and Conclusions
E3	Family support and encouragement for patients with SB to participate in rehabilitation programs reduce fear and insecurity for both patients and family members in performing intermittent urinary catheterization, leading to autonomy, improved social relationships, and the ability to face difficulties.
E4	Concerns that patients had when starting Intermittent Catheterization (IC) included fear of lifelong dependence, accidental injury, embarrassment, infection, bleeding, pain, and difficulties in personal hygiene. Reported obstacles included insufficient hand function (for men), while women struggled with proper seating. However, patients preferred IC over indwelling catheterization, which improved their quality of life.
E5	Some individuals stated that sex was not a significant part of their lives due to age, illness, or the catheter. Others mentioned how catheter use and their disability affected their sexual self-esteem, feelings of masculinity or femininity, and how catheter use caused pain, discomfort, or unexpected symptoms during sex. Many noted a lack of information on the subject and stated that healthcare professionals are reluctant to discuss sexuality. For a minority, the catheter was not a significant issue in relation to sex.
E6	The use of Intermittent Catheterization (IC) impacted items measured by the Qualiveen (COSTA P) instrument (general quality of life associated with limitations, fears, feelings). No differences were found in overall quality of life when measured by the SF-36.
E7	Loss of normal bladder function can be a devastating event, triggering emotional responses associated with pain, loss, embarrassment, and aversion. Psychological distress is not inevitable and varies greatly among individuals.
E8	Results show that patients with neurogenic bladder secondary to spinal cord injuries experience higher levels of depression compared to the general population. Additionally, findings suggest that depression is closely related to gender and the patient's ability to perform self-catheterization.
E9	Living with a urinary catheter involved a dialectical balance between recognizing the catheter as "a part of me" and feeling alienation and vulnerability when experienced as a stigma.
E10	Aversion and distress were more commonly reported by younger patients, females, and patients with non-neurogenic bladders. Patients' physical disabilities and previous experience duration with CIC did not appear to influence feelings of aversion toward catheter use.
E11	Discomfort, fear, and concerns about how catheter use might affect the body, the embarrassment of the urine bag being seen, having to empty it, or potential catheter leakage were the most perceived feelings.

Table 4 below presents the positive and negative feelings mentioned in the studies by type of urinary catheter, intermittent and/or indwelling.



Feelings	Intermittent	Indwelling
Positivos		
Confidence	E1, E2, E3	-
Independence	E1, E2, E8	-
Empowerment	E1, E3	
Negative		
Fear	E4, E6, E3	E11
Embarrassment	E4, E7	E11
Pain	E4, E7	E5
Aversion	E7, E10	-
Discomfort	-	E5, E11
Depression	E4, E8	-
Grief	E7	-
Loss	E7	-
Emotional suffering	E7	-

-

E10

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-

E6

Table 4 - Feelings Mentioned in Studies by Type of Urinary Catheter, Intermittent and/or Indwelling. Bauru,

DISCUSSION

Decreased sexual self-esteem

Distress

Shame

Alienation

Limitations

Concern about body image

To restore voiding function when bladder function is abnormal, patients often require external devices such as intermittent or indwelling urinary catheterization, which can represent an inconvenience in their lives.

The use of a urinary catheter affects motor, sensory, and autonomic functions, as well as, emphatically, the biopsychosocial aspects of patients, altering their basic human needs and impacting their quality of life⁴. Catheter use involves a combination of technologies and emotions that lead to changes in the patient's daily activities and varying degrees of dependence on family members and professionals for the necessary care to maintain the catheter at home. The results shown in Figure 1 demonstrate that although studies have addressed this topic since the 1990s, the last 10 years have seen an increase in research on this subject, especially in European and American countries.

F5

-

E11

E9

-

E11

In this study, as shown in Table 1, it was observed that the study of emotions provoked by catheter use has been a concern for other researchers across various contexts and among diverse groups of patients using intermittent or indwelling catheters. Intermittent catheters, currently available in different technologies, are generally associated with patients attending rehabilitation programs, contributing to more effective treatment processes and improved quality of life⁴. Indwelling catheters, on the other hand, due to their permanence, infection risk, and the limitations they impose on the patient, are associated with less effective programs and



more traditional technology².

The studies analyzed in this research used various methods for their investigations and were conducted on distinct and consistent populations and samples (young and adult patients) with different underlying pathologies. Often, these patients were registered in supply programs of public and private institutions and/or in databases of organizations and associations dedicated to assisting patients using urinary catheters, such as the United Spinal Association¹⁷ and the Spina Bifida and Hydrocephalus Association in Dortmund, Germany (ASBH)¹⁸, among others, as shown in Table 2. Centers and programs dedicated to scientific development, professional training, and the treatment of patients using urinary catheterization generally maintain a relevant database for analysis, reflecting higher-quality care based on strong evidence and technological updates, which directly supports the patient in this new phase of life, provides support to professionals, and advances science.

When faced with a health problem, returning home and incorporating the use of a urinary catheter into daily life evokes emotions in patients¹¹. Such emotions can generate positive or less positive aspects depending on the idealization of the treatment, fear, guilt, changes in autonomy, and the value attributed to performing the procedure¹². In this sense, it is essential to monitor the patient throughout the treatment. At home, this support should include the patient's formal or informal caregivers, providing assistance in adjusting to this new reality. However, in Brazil, such support is not always provided by most healthcare services; interventions and guidance are often limited to the hospitalization period, when the diagnosis and initiation of treatment occur^{4,19}.

In this review, as shown in Table 3, most studies focused on users of intermittent urinary catheterization. Among this population, positive emotions related to independence^{4,17,20}, confidence^{4,17,20}, and empowerment^{17,18} were identified, while negative emotions included fear^{19,21,22}, embarrassment^{22,23}, pain^{22,23}, aversion^{23,24}, depression^{22,25}, grief, loss, suffering²³, distress²⁵, and limitations²¹.

Regarding patients using indwelling urinary catheters, the analyzed studies refer only to negative emotions, identified by fear, embarrassment, shame, concern about body image²⁴, pain²⁶, discomfort^{24,26}, decreased self-esteem²⁶ and social withdrawal²⁷.

An indwelling urinary catheter used indefinitely is a prosthesis for which patient and caregiver education is essential. Patients using indwelling catheters feel that these devices (urinary catheter, collection bag) alter their body image. They experience negative emotions due to having a collection bag attached to their body, which may also be accompanied by leaks, urine odor, affecting their interpersonal relationships, and causing feelings of fear, pain, embarrassment, social withdrawal, aversion, shame, and discomfort. Additionally, they often depend on others (professionals) to change the devices^{24,27}.

Regarding relationships and sexual issues, when patients are not in a relationship and use an indwelling catheter, they tend to experience more positive feelings, as they do not have to worry about partners. However, in general, all indicate a negative impact of indwelling catheter use on sexual life, due to partner complaints of discomfort and pain during sexual activity, further highlighting the lack of preparedness among healthcare professionals in addressing this topic²⁶.

When patients receive the news that they will need to perform intermittent urinary catheterization, they often express feelings of grief and loss. However, after receiving guidance and training, they feel more capable, confident, empowered, and autonomous, positively impacting their social reintegration and quality of life. This reduces obstacles and the consequences of improper catheter management, such as urinary infections, urethral trauma, and others^{23,28}.

Regarding catheter management and patient training, the literature widely emphasizes the use of appropriate supplies, such as correctly sized catheters, lubricated or hydrophilic catheters, adequate amounts of lubricant, and proper handling of the catheter⁴. Thus, it is up to professionals to know the technique so they can recognize, support, minimize, and address emotions like pain, discomfort, isolation due to embarrassment, odors, and rejection^{22-24,26-28}.

Patients prefer intermittent catheterization over indwelling catheterization, and in this regard, the positive emotional impacts are more pronounced with the use of hydrophilic and pre-lubricated catheters, as these promote independence, greater acceptance, and proper device management by



reducing iatrogenic complications²².

Intermittent catheter users who feel dependent, more restricted, and isolated tend to experience negative emotions with low self-esteem, often accompanied by depression, shame, and embarrassment, which are more commonly observed in adults due to associations with sexuality, changes in social interactions, work life, relationships, loss of capacity to independently perform daily activities, among others^{18,20,21,23,24,26}. When these emotions are associated with patients' restriction to the home, the care involving intermittent and/or indwelling urinary catheters calls for a deeper analysis of this scenario, particularly regarding dependency on healthcare professionals and caregivers. Professionals generally involved in home care programs and caregivers, often overwhelmed by the burden of care and a range of unexplored emotions, should be a focus of new research on this topic.

CONCLUSION

The use of intermittent or indwelling urinary catheters is a significant event in the lives of many patients, eliciting positive or negative emotions such as confidence, empowerment, fear, embarrassment, pain, discomfort, aversion, depression, grief, loss, suffering, distress, limitations, changes in sexual activity, and body image. These outcomes can be better addressed when interpreted by qualified professionals knowledgeable about public policies that can ensure a stronger support network for these patients.

Although this study has limitations related to the number of available and analyzed pieces of evidence and is restricted to certain databases, the studies reviewed show that this topic has been increasingly discussed over the past four decades, with a stronger emphasis on intermittent catheterization, possibly due to advancements in treatment and the prioritization of this catheter type. Thus, investing in improved care, with better supplies, greater use of evidence, and better-prepared professionals, is essential to better support intermittent and indwelling catheter users and their caregivers.

Based on the findings, future studies on this topic may address the training of professionals beyond technical skills, focusing on providing qualified psychosocial support to catheter users and their families. Additionally, the gaps in the literature regarding the psychosocial consequences of catheterization, particularly concerning interpersonal relationships and body image, could be further explored.

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