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ARTICLE

Long-term Clean Intermittent Catheterization Users' Experience and Practical Barriers: A Qualitative Systematic Review and Meta-synthesis

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Abstract

Background: Clean Intermittent Catheterization (CIC) is the preferred bladder management modality among individuals afflicted with neurogenic bladder and has been deemed a safe and effective treatment. Nevertheless, extensive research reveals that adherence to CIC procedures over a prolonged period of time is less than ideal. **Aims:** This systematic review aims to collect qualitative information from CIC users to comprehend their actual experiences, assess the impact of CIC on their everyday life, and explore practical barriers to CIC use. **Methods:** Systematic searches were conducted across four databases, CINAHL, PsycINFO, PubMed, and Scopus. The author team evaluated the included articles using the Critical Appraisal Skills Programme checklist for qualitative studies. A meta-synthesis approach was employed in the analysis of the data. **Findings:** Eleven studies published in English met the inclusion criteria. The meta-synthesis findings based on third-order analysis confirmed twelve sub-themes that integrate into three higher-order themes, 'psychological experience', 'impact on daily life', and 'practical barriers'.

Keywords: clean intermittent catheterization; practical barriers; qualitative research; systematic review

1. Introduction

Clean Intermittent Catheterization (CIC) refers to inserting a catheter into the urethra under cleaning conditions to drain the urine from the bladder at intervals as needed so that achieving

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cyclical expansion and contraction of the bladder, establishing bladder reflex and training autonomous urination consequently (Campeau et al., 2020). CIC was introduced by Lapides et al. (1972) and has become a recommended intervention for individuals with incomplete bladder emptying or total urinary retention secondary to neurologic abnormalities associated with conditions such as spinal cord injury, myelodysplasia, chronic urinary retention, and multiple sclerosis. CIC is also suggested for individuals with idiopathic and non-neurogenic bladder dysfunction (Diokno, 2019).

According to the guideline of the European Association of Urology Nurses (EAUN, 2017), the CIC procedure involves using a sterile or reusable catheter with or without lubricant, practicing hand hygiene with water and soap, maintaining genital hygiene with water or a combination of water and soap, and touching the catheter without gloves. It is imperative to adhere strictly to the drinking water plan during CIC implementation and carefully time drinking water and catheterization. The interval between urinary catheterizations is determined based on residual urine volume, typically 4 to 6 hours, and the daily catheterizations do not exceed six times. It is recommended that patients or caretakers employ the CIC technique in a home setting for long-term bladder rehabilitation.

CIC procedures are generally regarded as safe, uncomplicated, and effective, while also not interfering with patients' other rehabilitation treatments (Getliffe et al., 2007). It reduces the long-term inconvenience and image damage caused by indwelling catheters, and increases social freedom and independence (Woodward et al., 2003). Amarenco et al. (2011) reported that nearly 80% of patients found CIC to be simple or easy, with little or no impact on regular daily activities. However, some studies have identified negative quality of life issues such as embarrassment, lack of confidence, and family stress (Wilde et al., 2011). Lopes et al. (2014) indicated that after three months, 92% of patients continued to adhere to CIC, but 46% of them modified specific execution techniques. While many patients show enthusiasm for learning IC, they may not continue performing it once they return home. Girotti et al. (2011) reported an implementation rate of only 58% after one year, indicating that the perceived "simplicity" may be theoretical rather than factual.

In previous review of quantitative studies, the major contributing factors to the low adherence of users were urethral trauma, repetitious urinary tract infections (UTIs), and discomfort during catheter use (Engberg et al., 2020; Prieto et al., 2021). A number of qualitative studies reported the negative fear of catheterization and urethral pain, procedural complexity, inability to achieve correct and safe gestures, and inadequate technique all influence users' adherence (Goldstine et al., 2019; van Achterberg et al., 2008). The factors that contribute to the failure of maintaining the CIC program is complicated. Although existing qualitative studies provided a better understanding of CIC users' real experiences and requirements, they varied in terms of the study population, focus, context, methods, and regional culture. Currently, there is no qualitative systematic review of CIC users' experiences studies exists.

Given the above considerations, this study aims to collect qualitative information from CIC users to comprehend their real experiences, assess the impact of CIC on daily life, and explore practical barriers to CIC adherence. This review provides theoretical information for individuals, caregivers, or the community to offer practical and effective support to CIC users.

2. METHODS

This qualitative systematic review was conducted using guidance from the Preferred Reporting Items for Systematic Reviews (PRISMA) 2020 checklist (Page et al., 2021) to establish an acceptable review structure and reduce the risk of bias, including formulating eligibility criteria, a literature search, quality appraisal, data collection and synthesis process and bias assessment.

2.1 Search strategy

The first and second authors proceeded with a systematic search on PsycINFO, CINAHL, PubMed, and Scopus databases with the following keywords: 'intermittent catheterization', 'experience', and 'barrier', 'issue', 'adherence', 'qualitative'. A query syntax along with Boolean operators was: 'intermittent catheterization' OR 'intermittent urethral catheterizations' OR 'clean intermittent catheterization' OR 'urethral self-catheterization' AND 'experience' OR 'qualitative' OR 'difficult' OR 'adherence' OR 'barrier' OR 'issue'. The search query was conducted on December, 31st 2022 (no lower date limit was applied to the bibliographic databases). Only studies in English were included. Case reports, commentaries, editorials, and grey literature were excluded. Reference lists of articles identified for potential inclusion were hand-searched for potential studies meeting the established inclusion criteria.

2.2 Inclusion and exclusion criteria

This is a systematic review of primary qualitative studies focusing on the experiences of clean intermittent catheterization users. The literature using the qualitative methodology was included. Mixed methods studies were included if the qualitative data was separate and clear. Studies published in non-English languages were excluded to reduce the search scope of resources and avoid translation inaccuracy. The participant's inclusion criteria were adults who performed CIC for at least 3 months after discharge and remained full or half self-catheterization ability. CIC users who have mental disorders, hearing impairment, communication disorders, and severe comorbidities were excluded. Studies that only explore the experiences of caregivers or healthcare professionals were excluded. This study context surrounded the lived experiences and practical barriers, thus any unrelated studies or insufficient data articles were excluded.

This systematic review focuses on the experiences of individuals utilizing CIC, drawing from primary qualitative studies conducted in the English language. Mixed-methods studies were considered if they presented separate and discernible qualitative data. Studies conducted in non-English languages were not included to minimize resource search scope and avoid translation errors. The inclusion criteria specified adult CIC users who had the self-catheterization ability and had been performing CIC regularly for at least three months post-discharge. Participants with mental disorders, hearing, and communication impairments, and severe comorbidities were excluded from this study. Additionally, studies that focused solely on the experiences of caregivers or healthcare professionals were excluded. Lastly, this study context surrounded the lived experience and practical barriers, thus any unrelated studies or insufficient data articles were also excluded.

2.3 Study selection

All the literature search records were exported into a single file in EndNote X9 (Clarivate Analytics). Duplicate articles were removed using the software. The first and second authors independently screened titles and abstracts according to the inclusion and exclusion criteria. Selected articles were then fully read. Disagreements on included studies were resolved through discussion until a consensus was reached, with the final author if needed.

2.4 Quality appraisal

The third and fourth authors employed the Critical Appraisal Skills Programme Qualitative Checklist (CASP-QC) (CASP, 2018) to systematically assess the trustworthiness, relevance, and results of the selected studies. The CASP-QC has 10 subcategories of analytical questions that assess study design, qualitative methodology, sampling, data collection, data analysis, and rigor, ultimately addressing whether the results are valid and helpful locally. Any conflicts among authors were resolved by the final author.

2.5 Data extraction and synthesis

The structured meta-synthesis approach involves extracting significant information from prior research, developing data-driven themes, and synthesizing these themes via a process known as reciprocal translation (Olmsted, 1989; Ring et al., 2011). In this systematic review, the first-order analysis entailed the independent examination of full-text articles by two reviewers, who identified relevant findings, comprising the author's interpretations and direct quotes from participants. These findings were then extracted into NVivo (V.11.4.3) and subject to coding. For the second-order analysis, two reviewers classified and organized the coded data into distinct categories shared across studies. The larger research team used a narrative approach to refine the lines of argument by revisiting the original papers and discussing the findings within their respective contexts. For the third-order analysis, we abstracted and reduced the identified categories to create higher-order themes. Throughout the analytical process, the research team regularly convened to facilitate ongoing discussions related to data interpretation and conceptual development.

3. RESULTS

A total of 1662 articles were yielded by the initial search for keywords and their synonyms. After removing 957 duplicated studies, 705 articles were screened for eligibility based. Upon their title and abstract, 659 articles were not directly relevant to CIC and users' experience. Thus, we obtained the full text and reread the remaining 46 articles for further review. We subsequently eliminated 35 of these due to non-conformity with the inclusion criteria (reasons listed in Figure 1), resulting in a final sample of 11 articles.

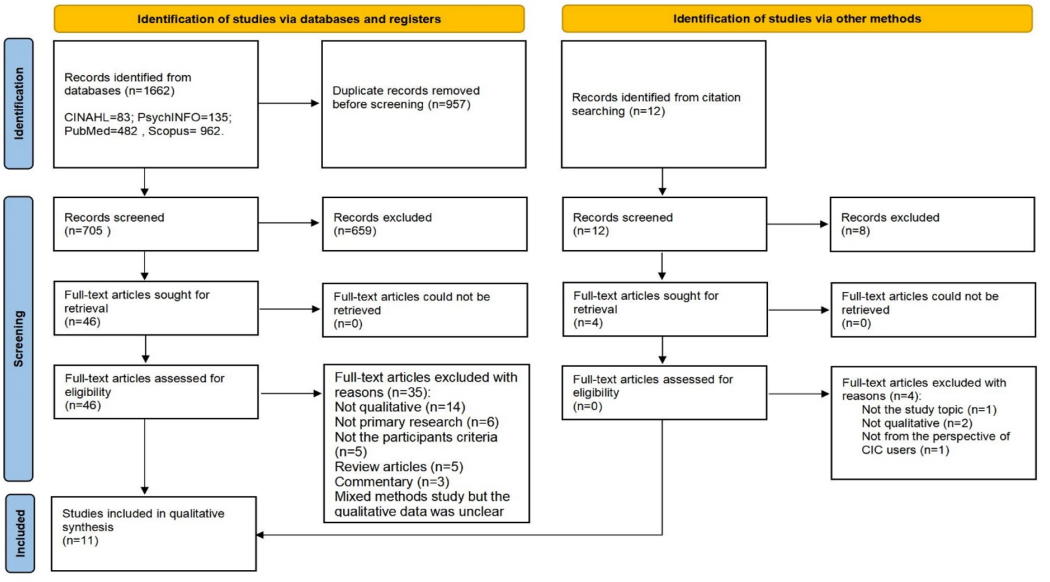
All included studies clearly stated relevant background literature, articulated purpose, and methodology description. The use of methodological triangulation (Wilde et al., 2011) and data triangulation (Goldstine et al., 2019; van Achterberg et al., 2008) enhanced the credibility and validity of the research. However, in four articles (Goldstine et al., 2019; Jaquet et al., 2009; Ramm et al., 2011; Wilde et al., 2011), there was no explanation of why the selected participants were the most appropriate for providing access to the desired

knowledge, and recruitment discussions were lacking. Similarly, three studies did not provide information on the researchers' biases and their relationship with participants, which affected general confirmability (Cobussen-Boekhorst et al., 2016; Kelly et al., 2014; McClurg et al., 2018). One article (van Achterberg et al., 2008) stated that the study had signed informed consent with participants and supported by an institution, but did not address issues regarding confidentiality or ethical approval. The quality assessment was summarized in TABLE 1.

A total of 10 qualitative studies and 1 mixed-method study were yielded. TABLE 2 summarized the key features of the articles including the country, sampling, participants' characteristics, data collection and analysis methods, and main findings. Eleven included studies contain 191 individual participants (105 males and 86 females). One article focused on the experience and emotional responses of females, remaining 10 articles included both males and female. The time of using CIC ranged from 3 months to over 20 years.

figure 1

FIGURE 1: Flow diagram of the study selection process



The meta-synthesis findings based on third-order analysis confirmed twelve sub-themes that integrate into three higher-order themes, including psychological experience, impact on daily life, and practical barriers. TABLE 3 for information about which studies contributed to each theme and sub-theme.

3.1 Theme 1: Psychological experience

3.1.1 Fear and uncertainty

The majority of CIC users experience a certain level of fear during catheterization as the invasive procedure involving the insertion of long catheters into the body (Cobussen-Boekhorst

TABLE 1: Critical appraisal of included studies

CASP Questions										
Study	①	②	③	④	⑤	⑥	⑦	⑧	⑨	⑩
Goldstine et al. (2019)	✓	✓	✓	—	✓	✓	✓	✓	✓	✓
McClurg et al. (2018)	✓	✓	✓	✓	✓	—	✓	✓	✓	✓
Cobussen-Boekhorst et al. (2016)	✓	✓	✓	✓	✓	—	✓	✓	—	✓
Shaw et al. (2013)	✓	✓	✓	✓	—	✓	✓	✓	✓	✓
Kelly et al. (2014)	✓	✓	✓	✓	—	—	✓	✓	✓	✓
Ramm et al. (2011)	✓	✓	✓	—	—	✓	✓	✓	✓	✓
Wilde et al. (2011)	✓	✓	✓	—	✓	✓	✓	✓	✓	✓
Jaquet et al. (2009)	✓	✓	✓	—	✓	✓	✓	✓	✓	✓
Logan et al. (2008)	✓	✓	✓	✓	✓	✓	✓	—	✓	✓
van Achterberg et al. (2008)	✓	✓	✓	✓	✓	✓	✘	✓	✓	✓
Shaw et al. (2008)	✓	✓	—	✓	✓	✓	✓	✓	✓	✓

Note: ✓=yes, — = can't tell, ✘=no. ①=Was there a clear statement of the aims of the research?; ②=Is a qualitative methodology appropriate?; ③=Was the research design appropriate to address the aims of the research?; ④=Was the recruitment strategy appropriate to the aims of the research?; ⑤=Was the data collected in a way that addressed the research issue?; ⑥=Has the relationship between researcher and participants been adequately considered?; ⑦=Have ethical issues been taken into consideration?; ⑧=Was the data analysis sufficiently rigorous?; ⑨=Is there a clear statement of findings?; ⑩=How valuable is the research?

et al., 2016; Goldstine et al., 2019). With increasing proficiency in performing the procedure, users gradually developed confidence and overcame the sense of fear. However, the occurrence of complications was considered as a trigger of fear. Pain or bleeding during catheterization make users nervous during the learning process, diminish the motivation to learn and increase feel of insecurity. Cobussen-Boekhorst et al. (2016) indicated that users who have experienced pain expressed reluctance to perform CIC. In the same way, users' fear of infection resulting from repeated intubation contributes to their lack of confidence in the hygiene guarantee (Goldstine et al., 2019; van Achterberg et al., 2008). More importantly, the inability to obtain timely guidance and resolution from professionals exacerbates users' fear and concern when urinary tract symptoms occur (Cobussen-Boekhorst et al., 2016; van Achterberg et al., 2008). Recurring lower urinary tract symptoms triggered anxiety and leave users feeling uncertain about the timing and outcome of long-term treatment. (Cobussen-Boekhorst et al., 2016; Kelly et al., 2014). Individuals express apprehension regarding the potential reduction of residual normal bladder function resulting from repeated catheterization and concerns about the loss of self-reliance due to age-related motor dysfunction and unforeseeable physical accidents (Jaquet et al., 2009; van Achterberg et al., 2008).

Three studies discovered that sentiments of fear and uncertainty were largely attributed to inadequate knowledge and insufficient proficiency in catheterization techniques, including a deficient understanding of urinary system anatomy, incapacity for complication

TABLE 2: Characterization of included studies

Reference & Study area	Aims	Sample & Time of using CIC	Data collection & Data analysis	Main findings
Goldstine et al. (2019) USA, UK, Germany, France, Netherlands	To explore IC users' perceived needs, barriers and facilitators to the successful use of IC products.	Purposive sampling M=22, F=3 Not Given	Semi-structured telephone interview Thematic analysis	Initial fear; Urinary Tract Infection; Avoiding Discomfort, Trauma, and Pain During IC; Independence; Choice; Community; Life Quality; Resilience; Acceptance
McClurg et al. (2018) UK	To describes patient experiences of both CISC and urinary tract infection and explore participant's perceptions of and attitudes towards antibiotic regimens for urinary tract infection treatment	Convenient sampling M=11, F=15 2.5-26 years	Semi-structured telephone interview Thematic analysis	Experiences of CISC and urinary tract Infection: Normalization, Perceived burden of urinary tract infection; Attitudes towards antibiotics for urinary tract infection treatment: Nonchalant, Ambivalence; Experience of low-dose prophylaxis antibiotics: Habitual behavior, Supportive accountability
Cobussen-Boekhorst et al. (2016) Netherlands	To investigate underlying barriers and facilitators for patients when dealing with IC in everyday life.	Purposive sampling M=6, F=6 ≥3 months	Semi-structured interview Thematic analysis	Information and instruction of IC; Incorporation of IC into everyday life; IC, the skills; Flexibility in the frequency of IC; Place of performing IC; Impact of IC on complaints; Influence of comorbidity; Follow-up care of the instruction procedure
Shaw et al. (2013) UK	To explore ISC users' psychological coping factors that might affect therapy adherence.	Purposive sampling M=11, F=4 Not Given	Unstructured interview Framework analysis	Normalization; Independence and control; Acceptance, avoidance and denial
Kelly et al. (2014) UK	To investigate the impact of using ISC on users' lives and to identify the key features of product design.	Purposive sampling M=8, F=8 1 to over 20 years	Semi-structured interview Framework analysis	Learning to self-catheterize; ISC product characteristics; Use of ISC outside the home; The ISC user as a health consumer; Wider issues relating to ISC use as a method of bladder management
Ramm et al. (2011) UK	To explore the lived experience and emotional responses of female patients learning to perform CISC.	Purposive sampling F=5 10 months to 10 years	Semi-structured interview Framework analysis	Grief and loss; Lack of knowledge; Negative associations and stigma; Psychological aversion and embarrassment; Nursing approaches; Coping mechanisms
Wilde et al. (2011) USA	To identify and describe CIC users' issues and concerns to address self-management needs in future research or training programme.	Internet sampling M=13, F=21 4-368 months	QUAN: Questionnaire QUAL: Semi-structured telephone interview Content analysis	Knowing the Body; Practising CIC; Limited Options in Catheters and Equipment; Inaccessible Bathrooms; Hassles; Adjustment in Making CIC a Part of Life
Jaquet et al. (2009) Denmark	To develop knowledge about how CIC users experience a disposable catheter for the rest of their life.	M=4, F=4 > 6 months	Semi-structured interview Framework analysis	Strategies; Creating rituals; Uncertainty of the unknown; What about tomorrow
Logan et al. (2008) UK	To explore the experiences of learning to carry out CISC and user views of service provision.	Purposive sampling M=8, F=7 6 months-2 years	Semi-structured interview Thematic analysis	Psychological-embarrassment and privacy; Physical difficulties encountered on learning and acquiring the skill of CISC; Service interaction: communication, information giving and attitudes
van Achterberg et al. (2008) Netherlands	To explore factors that hinder or promote adherence to CISC procedures in adults.	Stratified sampling M=14, F=6 3 months-3 years	Observation and semi-structured interview Thematic content analysis	Determinants of long-term adherence: Fears, Self-efficacy, Social interaction, Follow-up on instruction, Avoiding social interaction, Time and planning, Self-image, Intimacy and sexuality
Shaw et al. (2008) UK	To describe the experience of people carrying out CISC and the impact on their quality of life.	Purposive sampling M=8, F=7 6 months to over 2 years	Semi-structured interview Thematic analysis	Impact on quality of life: Positive impacts, Negative impacts, Physical impacts, Psychological impacts; Factors explaining variation in quality of life impacts: Reasons for carrying out CISC, Sex, Type of catheter, Frequency of carrying out CISC, Duration of CISC, Lifestyles

Note: M=Male, F=Female; IC=Intermittent Catheterization, CIC=Clean Intermittent Catheterization, CISC=Clean Intermittent Self-Catheterization.

management, and impaired decision-making skills relating to catheter selection, among others (Cobussen-Boekhorst et al., 2016; Logan et al., 2008; van Achterberg et al., 2008).

3.1.2 *Shame & embarrassed*

Users, particularly young individuals or those who require assistance with catheterization, has experienced a sense of embarrassment and lacking of privacy when exposing private body parts. Embarrassing situations may arise in the following scenarios: the learning process of catheterization (Logan et al., 2008), when strangers notice the catheter (Cobussen-Boekhorst et al., 2016; Jaquet et al., 2009; Ramm et al., 2011; Shaw et al., 2008; van Achterberg et al.,

TABLE 3: Studies contributing to sub-themes

No.	Themes	Included studies
1	Psychological experience	
	Fear and uncertainty	Cobussen-Boekhorst et al. (2016); Goldstine et al. (2019); Jaquet et al. (2009); Kelly et al. (2014); Logan et al. (2008); van Achterberg et al. (2008)
	Shame & embarrassed	Cobussen-Boekhorst et al. (2016); Jaquet et al. (2009); Logan et al. (2008); Ramm et al. (2011); Shaw et al. (2008); van Achterberg et al. (2008); Wilde et al. (2011)
	Acceptance & normalization	Goldstine et al. (2019); Kelly et al. (2014); Logan et al. (2008); McClurg et al. (2018); Ramm et al. (2011); Shaw et al. (2008); van Achterberg et al. (2008); Wilde et al. (2011)
2	Impact on daily life	
	Independence	Goldstine et al. (2019); Kelly et al. (2014); Shaw et al. (2013) ; Shaw et al. (2008)
	Habitual behavior	Jaquet et al. (2009); Kelly et al. (2014); Shaw et al. (2008); van Achterberg et al. (2008); Wilde et al. (2011)
	Relationship	Jaquet et al. (2009); Shaw et al. (2008); van Achterberg et al. (2008);
	Financial burden	Cobussen-Boekhorst et al. (2016); McClurg et al. (2018); Wilde et al. (2011)
3	Practical barriers	
	The combined dysfunction	Cobussen-Boekhorst et al. (2016); van Achterberg et al. (2008)
	Catheterization outside the home site	Cobussen-Boekhorst et al. (2016); Jaquet et al. (2009); Kelly et al. (2014); Shaw et al. (2008); van Achterberg et al. (2008); Wilde et al. (2011)
	Gender difference	Logan et al. (2008); Ramm et al. (2011); Shaw et al. (2008); van Achterberg et al. (2008)
	Applicability of materials	Goldstine et al. (2019); Kelly et al. (2014); Logan et al. (2008); Shaw et al. (2008); van Achterberg et al. (2008); Wilde et al. (2011)
	Lack of health information	Cobussen-Boekhorst et al. (2016); Goldstine et al. (2019); Logan et al. (2008); Ramm et al. (2011); van Achterberg et al. (2008)

2008; Wilde et al., 2011), and when experiencing urine leakage during sexual activity (Wilde et al., 2011). Despite the fact that catheterization is a daily necessity, users quite perceive a societal stigma associated with urinary issues (Cobussen-Boekhorst et al., 2016; Ramm et al., 2011; van Achterberg et al., 2008), which leads to a heightened sense of confidentiality and caution when catheterization was required outside of the home environment (Ramm et al., 2011). In some cases, CIC was viewed as abnormal and further pointed out their circumstances, rather than mitigating dilemma.

3.1.3 Acceptance & normalization

Over time, users tend to experience a decrease in both psychological and technical difficulties associated with catheterization. While a small percentage of individuals may adapt to CIC immediately, many require a longer period to accept this practice as a part of their daily

routine (Logan et al., 2008; Ramm et al., 2011; Shaw et al., 2008; Wilde et al., 2011).

Medical professionals played a crucial role in promoting the initial acceptance and education of CIC (van Achterberg et al., 2008). Through the initial education, users were able to reflect on their experiences with disease or injury and came to the realization that they must make adjustments in their health management, work participation, and interpersonal relationships (van Achterberg et al., 2008). After comparing negative experiences associated with other forms of bladder emptying, CIC was usually considered as a necessary skill to master.

Users maintained a positive attitude towards CIC, leading them to pay closer attention to physical changes and seek out personalized health information (Goldstine et al., 2019; Kelly et al., 2014; Ramm et al., 2011; Shaw et al., 2008; van Achterberg et al., 2008; Wilde et al., 2011). Gradually, users begin to experience the benefits of coexisting with CIC, such as a reduction in symptoms associated with frequent urination and urgency, fewer restrictions on daily activities, and normalization of the practice (McClurg et al., 2018; Shaw et al., 2013). Moreover, engaging in fulfilling activities such as work, family, and hobbies enhanced physiological resilience (Goldstine et al., 2019; Kelly et al., 2014).

3.2 Theme 2: Impact on daily life

3.2.1 Independence

For most users, CIC was perceived as meeting their physiological needs for urination and ultimately enhancing their ability to live independently. Compared to indwelling or suprapubic catheterization, CIC offers greater independence, and ease of use (Goldstine et al., 2019; Kelly et al., 2014; Shaw et al., 2013; Shaw et al., 2008). Maintaining physical independence was important for users as it fostered better control over their lives, allowing them to live independently without relying on others (Shaw et al., 2013).

3.2.2 Habitual behavior

A standard CIC needs to be accompanied by a regular drinking schedule. However, to avoid the need for catheterization in unfamiliar or inappropriate environments, users tend to actively reduce their fluid intake to reduce the frequency of catheterization, such as avoiding drinking before bedtime or before leaving their homes (Shaw et al., 2008; Wilde et al., 2011). Besides, users may limit travel time or control the duration of the trips according to catheter frequency (Jaquet et al., 2009; Kelly et al., 2014; van Achterberg et al., 2008). Predominately, users pay closer attention to their bodies, exploring their anatomies, devising drinking water plans, and learning to observe the color and smell of urine and precursors to catheterization needs (Wilde et al., 2011).

3.2.3 Relationship

At home site, users performed on-limits about their CIC needs to family carers (Jaquet et al., 2009; Shaw et al., 2008). However, for some younger users, there may be a tendency to avoid CIC in front of a partner or potential partner, which may lead to one or more skips of catheterization during dating or intimate contact (van Achterberg et al., 2008). Male users may be more likely to conceal their thoughts on this matter even from intimate

partners (Jaquet et al., 2009). When outside the home environment, males generally choose to hide the existence of the catheter and avoid discussing their condition because of the incomprehension from strangers or colleagues (Jaquet et al., 2009; Shaw et al., 2008).

3.2.4 Financial burden

The cost of catheters may be prohibitively high for users without relevant insurance, constituting only a portion of the overall financial burden borne by most individuals with disabilities (Wilde et al., 2011). Conversely, those with good insurance coverage may not be significantly impacted by the cost of medical expenses (Cobussen-Boekhorst et al., 2016; Wilde et al., 2011). Despite society's provision of employment opportunities, the available jobs may not sufficiently meet the needs of individuals. With the caveat that young and middle-aged men may experience a heavier economic burden because of reduced job opportunities and income (McClurg et al., 2018). To mitigate the expenses associated with catheterization, some users may opt for reusable catheters such as red latex rubber catheters that can be boiled and disinfected for reuse (Wilde et al., 2011).

3.3 Theme 3: Practical Barriers

3.3.1 The combined dysfunction

van Achterberg et al. (2008) asserted that successful catheterization requires the mastery of various skills, such as organizational ability in terms of selecting materials and following a proper sequence of steps, general physical ability (e.g., sitting, standing), fine motor ability (e.g., flexibility), and sensory ability (e.g., responding to physical sensations). Patients with neurogenic bladder generally faced additional challenges due to the comorbidities, including motor hand dysfunction, sensory dysfunction of the lower urinary tract system, and visual impairment. The comorbidities hinder independent completion of catheterization and require caregiver involvement, which reduced the feasibility and initiative for CIC.

Moreover, the success of catheterization relies on intact cognitive functions, such as attention, memory, understanding, and orientation (van Achterberg et al., 2008). The procedure and the associated steps increase the cognitive load required. Additionally, Cobussen-Boekhorst et al. (2016) reported that the preparation process can be challenging, involving environmental selection, hand washing, catheter preparation, cleaning, and other preparatory steps.

3.3.2 Catheterization outside the home site

From the point of CIC users, public toilets were observably characterized by limited space, insufficient lighting, inappropriate toilet positioning, inadequate privacy, and poor sanitation conditions, which may discourage users from catheterization in such settings and prompted them to void before leaving the residences (Cobussen-Boekhorst et al., 2016; Jaquet et al., 2009; Kelly et al., 2014; Shaw et al., 2008; van Achterberg et al., 2008; Wilde et al., 2011). Additionally, the conspicuous nature of catheterization devices may attract unwanted attention from strangers, further complicating the situation (Jaquet et al., 2009; Shaw et al., 2008; van Achterberg et al., 2008.

3.3.3 Gender difference

Females generally encountered more significant difficulties when performing urinary catheterization due to their inconspicuous anatomy and poor vision, which can make locating the urethra challenging, resulting in intubation failure, catheter waste, and considerable shoulder and neck pain (Logan et al., 2008; Ramm et al., 2011; Shaw et al., 2008; van Achterberg et al., 2008). The procedure usually requires women to use a mirror or receive assistance. By contrast, males face challenges associated with their anatomical structure and managing lengthy catheters. As a result of their longer urethra, male users were susceptible to muscle spasms during intubation and may experience urethral strictures or dysuria, which can cause notable pain during catheterization (Logan et al., 2008; Shaw et al., 2008; van Achterberg et al., 2008).

3.3.4 Applicability of materials

The choice of materials used in catheterization is a significant concern. Kelly et al. (2014) suggest that catheters should strike a balance between stiffness and flexibility, while pre-lubricated or hydrophilic-coated catheters were thought to provide good lubrication with minimal destructive effects during intubation. However, such slippery catheters may increase technical difficulties for users with impaired flexibility due to conditions such as arthritis or multiple sclerosis (Logan et al., 2008; Wilde et al., 2011). Users with physical disabilities may require less common materials, but their options are limited by the availability and types of materials purchased by institutions or regions (van Achterberg et al., 2008). They prefer small disposable brand packaging due to its convenience and ease of concealment (Cobussen-Boekhorst et al., 2016; Kelly et al., 2014; Shaw et al., 2008). However, this type of packaging is not suitable for all users, and some believe the catheter included in the kit is unsuitable and expensive (Wilde et al., 2011).

3.3.5 Lack of health information

The acquisition of health-related knowledge of CIC was essential for enhancing self-confidence and coexistence with long-term catheterization (Logan et al., 2008). The timing of information provision, decision-making processes, and educational guidance concerning catheterization were crucial factors in facilitating adaptation to this new role, and early intervention was recommended (van Achterberg et al., 2008). However, existing research revealed that healthcare workers' delivery of health information may be insufficient to meet users' needs. Ramm et al. (2011) reported that users receive routine rather than personalized care during the learning process. While Logan et al. (2008) asserted that nursing presentations were inadequate and personalized instruction was necessary.

Additionally, users have expressed a need for timely advice and assistance regarding bleeding, pain, and infection (Cobussen-Boekhorst et al., 2016; Goldstine et al., 2019; van Achterberg et al., 2008). In the context of daily life, regular knowledge acquisition was necessary to prevent forgetting details about catheterization procedures. Goldstine et al. (2019) reported a lack of knowledge and professional advice on appropriate catheter materials, indicating that there remains a gap between healthcare workers' medical support and users' actual needs.

4. DISCUSSION

This systematic review illustrated that as the recovery period progresses, individuals who performed CIC experience personal difficulties and growth in their role as CIC users. The lack of CIC operation skills and confidence, the privacy exposure, lower urinary tract symptoms, and uncertainty about the treatment period give rise to many fears, embarrassment, anxiety, and uncertainty. The emergence of complications and embarrassing moments intensifies negative emotional experiences, resulting in withdrawal and denial. However, with the gradual proficiency of operation skills and continuous self-adjustment and adaptation, individuals can explore a beneficial life, facilitate psychological resilience, and gradually adapt to changes in life. The CIC population exhibits multiple psychological experiences. Families, healthcare professionals, and society should take note of their emotional changes, understand the difficulties associated with self-performing CIC, and provide comprehensive multi-strategy support.

4.1 Partner support

The results of integration synthesis indicate that individuals who receive CIC inevitably adjust their personal lives. The presence of urinary catheters alters patients' intimate and social relationships (Fumincelli et al., 2017). With family caregivers being the preferred complaint partners for CIC users regarding their illness, they play a crucial role in helping users establish new living habits and intimate relationships (Culha et al., 2021). A strong family resilience can assist patients in acquiring new strength and social resources during times of hardship and aid them in overcoming adversity (Engkasan et al., 2014). The support and encouragement of family caregivers are vital for enhancing the recovery confidence of CIC individuals. As the disease progresses, the sensitivity of independent operations may decline, necessitating caregiver assistance with urinary catheterization. Therefore, it is recommended that caregivers learn the necessary urinary catheterization methods, develop a drinking water plan, keep a urination diary, and receive bladder function training simultaneously with the CIC individuals to understand the emotional and behavioral changes caused by diseases and CIC (Barken et al., 2022). Moreover, it is recommended to establish mutual aid social groups where users can communicate and interact with peers to obtain peer support, thus accessing a platform for discussion and communication (Ngai et al., 2009).

4.2 Healthcare support

The results of integration synthesis indicate that the provision of timely and convenient professional medical care support is unequivocally the most prominent source of security for users. Notably, healthcare professionals advocate the initial acceptance of CIC, and knowledge acquisition and compliance display a positive correlation over extended periods of rehabilitation. For this reason, healthcare support should extend to long-term self-management following discharge, which places greater responsibility on community care (Vaidyanathan et al., 2001). It is advisable to establish health promotion groups with regular knowledge training to facilitate continuous access to health information. Additionally, 24-hour online services or internet services may work out any emergency complications arising from catheterization, such as UTIs, bleeding, or pain (Wilde et al., 2016). Given that

most neurogenic bladder patients exhibit limb dysfunction, which hinders the independent performance of procedures (Joshi et al., 2022; Sekido et al., 2021), Emphasis on comorbidity rehabilitation during long-term urinary catheterization is essential to increase confidence in CIC normalcy (Di Pierdomenico et al., 2014).

Consistent with our findings, it was indicated by some literature that the quality and depth of the training provided by healthcare workers need to be improved (Diokno, 2019; Gray et al., 2019). The effectiveness of imparting health information to the users is contingent upon the nurse's interpersonal style and teaching skills (Gray et al., 2019). A conducive setting for formal and unhurried teaching that inspires trust between nurse and patient, together with a well-suited private setting, can alleviate the sense of embarrassment during the instruction (Soifer et al., 2009). The multi-strategy comprehensive teaching methods are recommended to enhance acceptance of the information, such as pamphlets, charts, and audio explanations (Bauer et al., 2023). Additionally, different educational approaches ought to be employed according to the abilities of each patient. For instance, female users with poor vision may require instruction on locating the urinary opening using a mirror or applying greater pressure on the genitalia. Regarding patients with cognitive impairment, Vahter et al. (2009) suggest that mastering CISC skills are feasible even among those with mild to moderate cognitive impairment but highlight the importance of increased time for communication and repeated confirmation of learning efficacy. In conclusion, the provision of regular training and unceasing support for healthcare staff is crucial.

4.3 Toilet facilities improvement

The research findings indicate that some CIC users exhibit reduced participation in social activities due to concerns about the availability of appropriate public toilets at the designated activity site. This issue stems from two factors: sub-optimal hygiene levels in public toilets and inadequate spatial planning for catheterization, as reported in previous literature (Joshi et al., 2022) These findings highlight the need for government to prioritize efforts toward constructing accessible public toilets equipped with clean operating tables, faucets, hand sanitizers, bright lighting, and dedicated spaces suitable for catheterization disinfection procedures.

4.4 Catheter support

The utilization of unsuitable catheter materials may result in pain, bleeding, and urinary tract infection, thereby instilling fear in users. Under the premise of achieving adequate urinary drainage, a minimum luminal catheter is recommended to minimize the stimulation of the urethral wall (Davis et al., 2018). Normally, with F10-14 for male and F12-16 for female. Although several studies have reported a low risk of infection associated with the use of disposable sterile hydrophilic coated catheters, which effectively alleviate pain as well (Plata et al., 2023). The Best Practice Report of Catheter Use from the Canadian Urological Association (Campeau et al., 2020) indicated that various catheter coatings and physical modifications have been developed to prevent biofilm production, bacteriuria, and UTI, no intervention has been conclusively proven efficacious in clinical studies. This conclusion was reached in one meta-analysis of 23 trials as well (Prieto et al., 2021). Which is knew, there

are over 40 different catheters available from various manufacturers, differing in product characteristics such as accessibility, independent insertion, and urinary tract infection risk, which may impact user preference and satisfaction (Kelly et al., 2014). The adaptation of catheterization materials to meet the needs of diverse users is a challenge for manufacturers, agents, and users.

4.5 Financial support

Due to the long treatment cycle, the financial burden of families constantly increases (Berendsen et al., 2021), the tendency and support of national policies will greatly reduce the burden of families, such as incorporating intermittent catheterization supplies under medical insurance coverage, thereby reducing out-of-pocket expenses. Instituting specialized healthcare subsidies for specific diseases is suggested. Consistently, formulating relevant policies to broaden the employment channels for CIC users may greatly reduce the financial burden and increase the personal sense of value.

Strength and Limitation

This is the first systematic review that utilizes qualitative methods to examine the experiences of individuals using clean intermittent catheterization (CIC). All reviewed papers are sourced from six developed countries, lending this review the potential to contribute to the perspective of long-term CIC users within these regions while also highlighting region-specific issues surrounding the practice. Four of the authors have possessed extensive experience guiding and administering CIC in general wards and has provided continuous care to CIC users via telephone. Consequently, the profound familiarity with the CIC enhances the sensitivity of the data analysis. Furthermore, screening, critical appraisal, and data extraction were completed by two reviewers independently.

Several limitations of this review need to be acknowledged. Firstly, due to the study period spanning over 11 years (2008–2019), the absence of recent qualitative research may cause the findings to lag the actual CIC users' situation. Additionally, only English language studies were included, potentially resulting in overlooked insights and knowledge presented from non-English sources. Lastly, case reports, commentaries, editorials, and grey literature were excluded from consideration, possibly leading to missed opportunities to gather valuable non-peered reviewed information.

Conclusion

This systematic review presents a comprehensive portrayal of the psychological experience of fear and uncertainty, shame and embarrassment, acceptance, and normalization that individuals undergoing CIC. Additionally, this study investigates the impact of CIC usage on various facets of life including independence, habitual behavior, relationship, and financial burden. Furthermore, it highlights the practical challenges encountered by users in adhering to CIC procedures in daily life, including comorbidities, inappropriate toilet facilities, difficulty accessing appropriate catheters, and lack of sufficient knowledge and skills. The qualitative inquiry summarized herein provides valuable insight into these processes and

suggests viable support pathways for families, healthcare providers, and society at large, seeking to foster long-term adherence to CIC treatment regimens.

Contribution of the paper

What is already known:

• CIC has gained appraisal worldwide and is especially recommended in the treatment of urinary and overflow incontinence.

• CIC procedures are technically considered simple, safe, and have positive effects.

• The benefits to the health of CIC are dependent on adherence to the treatment.

What this paper adds:

• It described the long-term experience of CIC users and explored the practical barriers when dealing with CIC in everyday life

• It gave suggestions of possible support directions for families, healthcare, and society wanting to promote long-term adherence among users.

• It provides a foundation for further research in this field.

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Declaration of competing interest

The authors declare that there is no competing interest.

Note

Mengfen ZHAO & Beitao GONG contributed equally to this work and should be considered co-first authors.

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