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Adherence to Clean Intermittent Catheterization Treatment in Pediatric Patients:

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Abstract

Objectives: There are many pediatric patients who have to perform clean intermittent catheterization (CIC) for the rest of their lives but fail to do so on a daily basis. Non-adherence to CIC causes many urological complications, including UTIs, epididymitis, and decreasing renal function. The objective of this study was to identify factors that potentially promote or prevent adherence to CIC in pediatric patients. Methods: CINAHL and PubMed were searched using the keywords: urinary catheterization, clean intermittent catheterization, pediatric, adherence, and CIC. We put limits on the search for full-text articles in English that were published between 2007-2012. A total of 83 articles were found and 11 articles were kept. We included articles that focused on CIC and the quality of life for CIC patients of all ages. We excluded articles that focused on technical aspects of CIC instead of patient experience. Results: Our review suggests that there are many barriers to adherence to CIC. The nursing intervention that can have the most positive impact on CIC adherence is individualized education that addresses the named barriers. *Conclusions:* In order to improve and maintain adherence to CIC in pediatric patients, the nurse should recognize and manage potential barriers to CIC according to each patient's need. Individualized education should address all applicable barriers and include possible solutions. *Recommendations:* There were few studies done for the pediatric population and many of the studies that we found were at the qualitative, descriptive level. More research at the experimental level is necessary in order to support and test these findings.

Adherence to Clean Intermittent Catheterization Treatment in Pediatric patients:

A Comprehensive Review of Literature

Introduction

Clean intermittent catheterization (CIC), first introduced in 1972 by Lapides *et al.*, is the most commonly recommended procedure for patients who require an alternate voiding method (Kessler, Ryu & Burkhard, 2009; van Achterberg, Holleman, Cobussen-Boekhorst, Arts, & Heesakkers 2008; Wilde, Brasch, & Zhang 2011). CIC is an invasive procedure where a clean, disposable or reusable catheter is introduced into the bladder in order to empty it. The procedure can be done by the patient or caregiver and is usually preformed 4-5 times per day. CIC adherence is the focus of this literature review. "The World Health Organization defines adherence as the extent of which a person's behavior corresponds with agreed recommendations from a healthcare professional." (as cited in van Achterberg *et al.* 2008, p. 395).

To structure and develop our clinical question, we used the PICO format (Burns & Gove 2011). Our population was pediatric patients who utilize CIC. Our intervention was to promote adherence to CIC. Comparison of interventions reveals that barriers should be acknowledged and appropriate interventions based off of those barriers should be performed by nurses. Our desired outcome is adherence to CIC. Non-adherence to CIC causes many urological complications including urinary tract infections, epididymitis, and decreasing renal function (van Achterberg *et al.* 2008). These complications can be especially detrimental to pediatric patients because they can suffer lifelong effects.

RN Interview

We interviewed a pediatric charge nurse at The Children's Medical Center of Dayton. We asked her how pediatric patients are instructed to manage urinary continence. She said that they

primarily teach good hygiene in association with clean intermittent catheterization as the best strategy to manage urinary incontinence and prevent associated complications such as urinary tract infections. Children old enough to catheterize themselves are taught to do so. Otherwise, caregivers are instructed how to perform CIC on their children.

We then asked the nurse about her knowledge of current evidence based practice guiding patient teaching of management of urinary incontinence. She said that patients who don't have some sort of bladder technique tend to have recurrent UTIs. She alluded to the use of CIC as being the simplest, least invasive bladder technique. Instructional DVDs are available to patients learning CIC. She gave us the hospital's discharge teaching policy for CIC that they give to patients and their caregivers.

Methods

We used the IOWA Model of Evidence-Based Practice to direct our research. Once we idenified our topic, we formed a team and assembled relevant research and related literature according to the IOWA Model (Burns & Grove 2011). We used the databases CINAHL and PubMed using the keywords: urinary catheterization, clean intermittent catheterization, pediatric, adherence, and CIC. We narrowed our search for articles only published from 2007-2012, articles in English, and full-text articles. Our search came up with 83 articles and we also looked at related articles. We included 11 articles in our research (see Table of Studies in the Appendix). We included articles about CIC and quality of life for CIC. We included CIC articles that pertained to all ages. We excluded articles with a focus on the technical aspects of CIC, such as articles on types of catheters or the use of antibiotics with CIC because they did not focus on patient experiences. Any articles that did not address specific barriers to adherence to the procedure were also excluded.

Results

Through our review of literature we identified many barriers that could potentially prevent patient adherence and suggested that they could be overcome by individualized nursing interventions and care after acknowledgement of these barriers (Wilde *et al.* 2011). Barriers included age, environment, emotional perception of CIC, quality of life, time, physical or mental limitations, pain, and education method. The desired outcome of individualized care is a higher rate of consistent patient adherence, and as a result, diminished negative effects of urinary incontinence.

Age

Holmdahl, *et al.* (2007) found that adherence to CIC treatment decreases during adolescent years. They used studies done on chronic diseases, such as diabetes, to make suggestions for interventions. They suggested that support and motivation should be given from parents, healthcare professionals, friends, and patients in similar situations in order to improve adherence to CIC.

Environment

Availability of appropriate facilities in a patient's environment can affect CIC adherence. Two studies identified that difficulty finding public restrooms that facilitate CIC is a potential deterrent to adherence in adults (Shaw, Logan, Webber, Broome, & Samuel 2008; Wilde *et al.* 2011). Carrying extra equipment, such as pads and changes of clothing was also a necessary inconvenience. As a result, traveling became more difficult, and participants of the study were less likely to adhere to CIC while traveling. These problems could also apply to pediatric patients, specifically in a school or recreational setting. The suggested solution was education that addresses activity planning around CIC and teaches how to navigate public and private bathrooms (Wilde *et al.* 2011).

Emotional perception of CIC

Emotions related to the idea of CIC impact adherence. Fear is one such emotion that can act as a barrier (Neel 2010; van Achterberg 2008). Fear of urinary tract infections, pain, discomfort and physical harm related to CIC has shown to negatively affect adult adherence to the treatment (Shaw *et al.* 2008). Some patients perceive a negative stigma in society towards continence issues. Therefore, some people felt the need for secrecy and discretion, which lead to decreased adherence. Professional assistance was recommended to facilitate effective coping for some patients (van Achterberg *et al.* 2008).

Quality of Life

Quality of life has shown to impact adherence to CIC. When patients perceive that CIC is improving their quality of life, they are more likely to adhere to CIC treatment. In Kessler *et al.*'s (2009) study, more than 60% of the participants reported an improved quality of life because of CIC and all of them strictly adhered to CIC. One limitation of this study however, is that there was a positive selection for highly compliant patients. According to Girotti *et al.* (2011), Patients that adhere to CIC had a significantly better quality of life than those who do not adhere, based on their scores in psychological and social domains.

Time

Adult patients reported overall time involved in CIC to be a burden. CIC is often necessary before bed as well as right after waking. Bedtime and morning routines become more time consuming with CIC involved, which has implications for the time and sleep schedule for both patients and caretakers (Shaw *et al.* 2008). This article did not give recommendations on how to address the barrier of time.

Physical or mental limitations

CIC users that participated in one study experienced difficulty in mastering the skills required for the procedure. These skills included "organizational skills (sequence, organizing materials), general motor skills (how to sit, stand), fine motor skills (dexterity), and sensory skills (acting on sensory information)" (van Achterberg *et al.* 2008, p. 398). A separate article identified skill and manual dexterity as factors necessary for success with CIC (Logan *et al.* 2007). A lack of these skills may act as a barrier to complete adherence to CIC. Neither of these articles gave recommendations on how to address these barriers.

Pain

One study identified pain with catheterization as a potential barrier to adherence. The study asserts that an appropriate nursing intervention could be to provide different product options for the patient, including type and size of catheter and lubrication type. The study also suggests teaching of alternate catheterization techniques as a possible solution (Wilde *et al.* 2011).

Education Methods

Patient Therapeutic Education. One article highly recommended Patient Therapeutic Education (PTE) to improve adherence. PTE is a special kind of education aimed at teaching patients necessary skills (and their advantages) needed to manage chronic disease. However, they recognized that there are no randomized studies that demonstrate PTE's effectiveness. Therefore they were only able to make the claim that a structured education approach aimed at the patient's comprehension and performance is necessary for the patient's adherence (Le Breton *et al.* 2012).

Group Education. According to Cobussen-Boekhorst *et al.* (2010), Learning in a social environment with other children allows for decreased social discomfort. When children are taught the catheterization procedure amongst others they feel more willing to participate. Being aware that they are not the only ones that have to undergo this treatment makes them more willing to take part in skills that will help them become more capable and comfortable with CIC. However, this was a onetime study of only 7 children with no follow up, so recommendations based off of this article should be conservative.

Categories of Education. Another article highlighted three categories of teaching (psychological, physical, and service interaction) and patient's opinions about importance those categories had to adherence to CIC. For psychological education, in the patients' opinions, an informal, relaxed approach to teaching in a comfortable setting, such as the home, alleviated embarrassment about the procedure. This improved willingness to adhere to CIC. In regards to physical aspects of teaching, education that included urogenital anatomy and proper hygiene techniques improved mastery of and therefore adherence to CIC (Logan *et al.* 2007). A different study suggested that teaching of the anatomy be done prior to other CIC teaching to make patients more comfortable and prepared during education (van Achterberg *et al.* 2008). Finally, when considering service interaction during teaching, nurses' attitudes, adequate information, and effective communication strongly influenced patient's comprehension of and adherence to CIC (Logan *et al.* 2007). For Complete adherence to CIC, not only is proper education necessary, but follow-up to assess and adjust technique is also necessary (Neel *et al.* 2008).

Recommendations

The literature presents many barriers to CIC adherence and few solutions. However, one nursing intervention that proved to be very effective in multiple studies is individualized,

thorough patient education. Individualized teaching that addresses the named barriers and possible ways to overcome them can increase the rate of adherence among pediatric patients (Wilde *et al.* 2011). Adequate information about CIC, along with effective training, support, and motivation gives patients encouragement to adhere with the treatment. However, poor information and instruction undermines confidence, co-operation and adherence (Holmdahl et al. 2007; Logan *et al.* 2007). We think that more comprehensive individualized education of CIC should be incorporated into the policies of healthcare facilities. However, further research is needed. We found few studies on CIC education in the pediatric population, and most of the studies we found were descriptive. There need to be studies conducted at the quasi-experimental and experimental levels on this area in order to improve and support the findings and move farther down the IOWA model to promote quality care for pediatric patients who utilize CIC (Burns & Grove 2011).

Author/ Year/ Country	Aim/ Purpose/ Question	Method/ Level of Evidence/ Sample Size	Findings
Cobussen- Boekhorst, H.J., et al. (2010). Netherlands	To teach children to perform clean intermitt ent self-catheterization	Descriptive study, Level VI (n=7)	Group interactions and a multidisciplinary approach seems to be of great help in learning CISC for selected children.
Girotti, M.E., et al. (2011) Brazil	To determine adherence rate and variables associate with patients' adherence to Clean Intermittent Self Catheterization	Corhort study, Level VI, (n=60)	Patients in CISC program present a reasonable adherence after one year. Women, neurogenic voiding dysfunction and patients under 40 years old were significantly more adherents. The psychological and social relationship status seems to positively interfere on adherence.
Holmdahl, G., et al. (2007) Sweden	To identify the main problems and complications associated with self- CIC in a group of adolescents with no overt neurological problems	Descriptive study, Level VI, (n=24)	One of the main problems associated with CIC during adolescence is poor compliance with the treatment. Epididymitis and recurrent urinary tract infections were seen more frequently in connection with poor CIC routines.

Appendix: Table of Studies

Kessler, T.M., Ryu, G., Burkhard, F.C. (2009). Switzerland	To assess patients' perception of clean intermittent self- catheterization for voiding dysfunction	Descriptive study, Level VI, (n=92)	The majority of patients considered CISC to be an easy and painless procedure which did not interfere with daily activities. Quality of life improved in more than 60% of the patients. CISC does not appear to be a burden for the patient and, from a patient's perspective, can be recommended.
Le Breton, F., et al. (2012). France	To review the literature and to clarify the recommendations for therapeutic education programs for intermittent self- catheterization	Literature review	Teaching self- catheterization is now well known; nevertheless, the effectiveness of CISC educational therapeutic programs remains to be demonstrated.
Logan, K., Shaw, C., Webber, I., Samuel, S., & Broome, L. (2007). United Kingdom	To explore the experiences of learning to carry out clean intermittent self-catheterization and user views of service provision.	Qualitative grounded theory framework, Level VI, (n=15)	Development of a policy supporting evidence- based care and a consistent teaching program is highly recommended for use where this treatment is regularly employed.

Neel, K. (2010) Canada	To review the feasibility and late outcomes of patients with normal urethral sensation who began CIC.	Cohort Study, Level VI, (n=52)	Patients who are compliant with the CIC demonstrated a better chance of avoiding subsequent surgical intervention for the management of a noncompliant bladder.
Neel, KF., et al. (2008) Kingdom of Saudi Arabia	To determine the applicability, acceptance, and compliance of the option of clean intermittent catheterization CIC when needed by patients in Saudi Arabia	Cohort study, Level VI, (n=280)	Clean intermittent catheterization is an appropriate method of treatment for our group of patients. They showed excellent acceptance of and compliance with the procedure, however, we suggest that for complete success, proper education, teaching, and follow-up should be conducted.
Shaw, C., Logan, K., Webber, I., Broome, L., & Samuel, S. (2008) United Kingdom	To describe the experience of people carrying out clean intermittent self-catheterization and the impact on their quality of life.	Qualitative study, Level VI, (n=15)	The model has the potential to help professionals to identify the factors likely to influence response to clean intermittent self- catheterization, and could be used as a tool to help identify those who may have difficulty complying with the treatment or to aid advice-giving on situations that may cause difficulties.

van Achterberg, et al. (2008) Netherlands	To explore factors that hinder or promote adherence to clean intermittent self-catheterization (CISC) procedures in adults.	Descriptive Study, Level VI, study 1 (n=10), study 2 (n=20)	Determinants of adherence relate to knowledge, complexity of the procedure, misconceptions, fears, shame, motivation and quality and continuity of professional care and in younger patients, availability of materials, physical impairments and
Wilde, M. H., Brasch, J., & Yi, Z. (2011) United States	To identify and describe issues of intermittent urinary catheter users for future self- management research and/or training programs	Qualitative Descriptive study, Level VI, (n=34)	resistance to a sickness role. The lack of acceptable bathrooms can interfere with being able to go to work, travel or be with friends and family. All using intermittent catheterization should have adequate insurance coverage when this is needed.

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