Adaptation to CIC from Introduction through Implementation: What Patients and Families Need to Know

a position document from the International Children’s Continence Society (ICCS)

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Summary

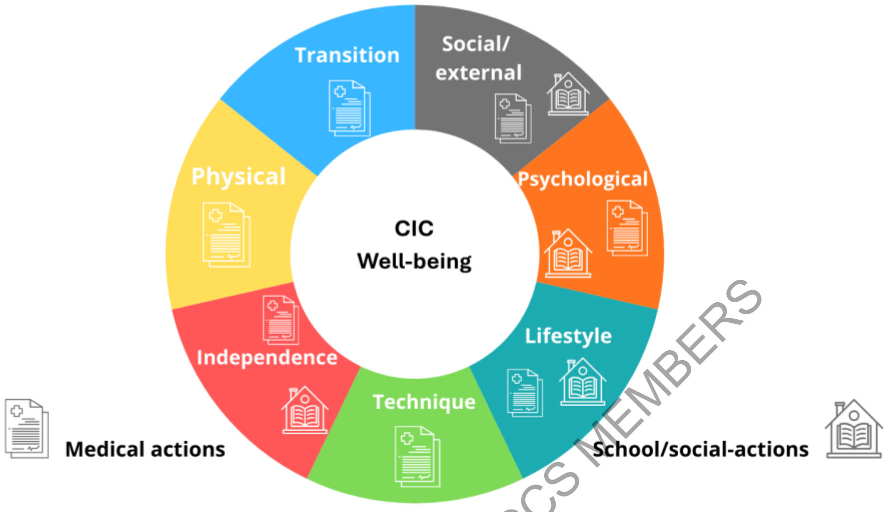
Background: Clean intermittent catheterization (CIC) plays a key role in the management of children whose neurological, anatomical, or functional conditions hinder complete or spontaneous bladder emptying. Its significance extends beyond clinical outcomes, influencing family relationships, psychosocial development, school experiences, and the child’s long-term independence.

Aim: This position paper outlines the consensus of experts from the International Children’s Continence Society (ICCS) on the broader impact of CIC on children with bladder dysfunction and their families. It offers practical recommendations for everyday life, integrating family perspectives, clinical experience, and observational insights. The paper addresses key aspects such as family dynamics, body image, self-esteem, school participation, peer relationships, and the transition to self-management and adulthood.

Methods: The content is based on evidence from the scientific literature, supplemented by expert consensus in areas where direct research evidence is limited.

Results: Central topics include optimal timing and preparation for initiating CIC, strategies to foster independence and reduce family stress, and school accommodations such as access to private facilities and flexible schedules to maintain privacy and dignity. It also highlights guidance on communication, social inclusion, and adolescent sexuality, supported through youth-focused counseling and peer networks. It provides checklists and evidence-based recommendations to help healthcare professionals, educators, and caregivers design individualized CIC plans that promote adherence, psychosocial well-being, and quality of life from childhood to adulthood.

Key words; child, clean intermittent catheterization, quality of life, adaption, learning


Holistic CIC Care Wheel

Introduction

Clean intermittent catheterization (CIC) is essential for children with bladder dysfunction due to neurologic, anatomic, or functional causes that preclude complete or spontaneous emptying. It helps preserve kidney function, reduce urinary tract infection, and manage incontinence. (1)While CIC is widely recognized for its medical benefits, e.g., improved bladder management with reduced need for diversionary surgery and continence when combined with reconstructive surgery, its broader impact on a child's daily life has been less emphasized, especially during the early stages of treatment when healthcare providers and caregivers focus primarily on their medical well-being.(2) Although its importance is well accepted, guidelines may not always fully address important aspects associated with CIC such as a child's education, social interactions, family dynamics, and psychosocial well-being.(3,4)

CIC is not only a medical management routine, but also a responsibility that affects the entire family. Parents may experience personal and intra-family stress related to ensuring their child follows an appropriate catheterization schedule, managing health care appointments, and advocating for accommodations at school.(5,6) Siblings may have mixed feelings, including sympathy, frustration, or even jealousy due to the extra attention required by children on CIC. Understanding family dynamics is essential to developing interventions and support systems that help caregivers balance their responsibilities while fostering a positive family and social environment. While medical guidelines for CIC focus on physical health outcomes, the psychosocial well-being of children and families is just as paramount.(7)

Children requiring CIC may experience difficulties at school due to privacy needs, scheduled bathroom breaks, and lack of awareness among teachers and peers about how CIC works. Outside of school, they may also face challenges in social interactions, including feelings of embarrassment, exclusion from peer activities, and difficulty participating in after-school activities. Stigma and misconceptions about CIC can contribute to isolation that negatively impacts their self-esteem. (8)

Drawing from family feedback, clinical practice insights, and descriptive and observational papers, healthcare professionals need to play a key role in educating families about CIC and addressing emotional concerns, while educators can help create a supportive school environment.

The goal of this ICCS policy statement is to contribute to a broader understanding of the non-medical aspects of CIC and to ensure children receive the support they need to thrive in every aspect of life. It has been developed by experts who manage children and families involved with CIC, taking into account what has been uncovered by other researchers. Increasing awareness and promoting the development of supportive practices in schools, families, and communities, will help children with CIC experience a more inclusive, confident, and fulfilling childhood and early adulthood.

This paper aims to bridge the gap between medical care and everyday life experiences by offering practical recommendations that will enhance the child's ability to participate fully in academic, social, and family activities.

Our objectives are as follows:

1. Describe adjustment to CIC: Preparation, timing, and impact on independence and family life.
2. Highlight the impact of CIC on body image and self-esteem, with strategies to mitigating this.
3. Recognize the challenges children face in school settings and identify strategies to promote inclusion.
4. Improve understanding of how patients navigate social situations, peer relationships, offering strategies for reducing stigma.
5. Understand and address the various factors that influence catheterization care, with a focus on individualized approaches as these children approach adulthood.
6. Help older adolescents and young adult navigate a path to having healthy intimate and sexual relations.
7. Provide a short and practical overview for health care professionals, teachers, and families with evidence-based recommendations to improve overall quality of life, addressing both the physical and psychosocial aspects of care.

Adjustment to CIC: Preparation, Timing, and Impact on Independence and Family Life.

A child requires catheterization to manage his/her bladder affects the entire family. Many experience fear, guilt, anxiety and denial on learning about their child's need for CIC; they need time to adjust to this new reality. (9) A thoughtful, supportive approach by the healthcare team from the moment it is considered can help them adapt more effectively. Providing comprehensive information about the condition, how the urinary tract functions, and the steps involved in the procedure as early as possible (e.g., a prenatal diagnosis of spina bifida) gives families time to prepare, easing the adjustment process. (6, 10) Having a second individual learn CIC alongside a primary caregiver or if the patient is learning self-CIC, improves comfort and confidence initiating the procedure and helps performing a CIC regimen more reliably than if only one caregiver is present. (10) It is vital the healthcare team continues providing ongoing support, to address any issues arising and offering additional educational resources as required.

Timing of Starting CIC and its Effect on Acceptance & Independence

Although the decision to start CIC depends on many factors, the child's age and developmental level can influence how easily it can be initiated. Early CIC in children at risk for upper and lower urinary tract deterioration has been shown to offset many potential disadvantages for caregivers. Nevertherless, some caregivers find catheterizing a small infant difficult, and would prefer waiting until their child is an active toddler; however this often presents other challenges. (11)

If medically appropriate, starting CIC at a younger age helps with its normalization and acceptance as the child grows and is condusive for transitioning to self-CIC when ready. (6) When transitioning to self-CIC, a child's readiness and dexterity skills are more important than their age. Caregivers and healthcare team support is paramount. (6) Timing for initiating self-CIC and fostering independence is particularly relevant during adolescence, when the focus shifts toward achieving autonomy and self-management of care.

Family Issues Arising from a Child's Initiation of CIC

Because CIC often requires significant caregiver involvement, it often impacts family relationships and daily life. (12–14) The process of learning CIC can either strengthen caregiver-patient relationships when a caregiver is supportive and works with the child

to learn CIC or is a detriment to their relationship if caregiver(s) aren't meeting their child's needs or if there are challenges to meeting those needs (e.g., avoidance/conflict with an appropriate CIC regimen, difficulty with insertion or premature removal. (12–14)
While it has been shown many siblings aren't affected by a CIC regimen in a brother or sister and in many instances siblings are supportive, others struggle with the divided attention CIC brings 'to the table'. (12,13)
When caregivers are responsible for performing CIC, the onus of maintaining an appropriate CIC schedule can impact a spousal relationship as one caregiver is more comfortable and thus responsible for performing CIC than another. Maintaining open communication about comfort levels and delineation of roles and responsibilities, a productive and collaborative approach is achieveable. When this discussion is not forthcoming these relationship can be strained and sometimes fragmented.(13)

Recommendation:
Early, well-prepared initiation of CIC with comprehensive education, involvement of multiple caregivers, and ongoing professional support is recommended to facilitate family adjustment and promote independence, based on descriptive and observational studies.
Level of Evidence: 3 - 4
Holistic CIC Care Wheel: 🟥 🟦 🟧

Impact of CIC on body image and self-esteem, and strategies for mitigating this.

Impact upon child's self-esteem and body image

Self-esteem is how we think and feel about ourselves; it changes throughout our lives and especially when struggling with physical health particularly with CIC as it may negatively affect it.(15) Body image is a person's subjective picture or mental image of their own body. Poor body image is associated with depression, anxiety, shame and contributes to poor self-esteem. In urological conditions, poor body image may be related to urinary incontinence, the presence of an indwelling catheter or the consequences of urologic surgery. (16–18)

Understanding the impact of CIC on a child/young person's self-esteem is important, because this influences wellbeing, development, academic achievement, social relationships and overall quality of life. (19) The effects of CIC on self-esteem and body image are complex, vary between individuals and over time, and shaped by perceived positive and negative effects that CIC imparts on physical and mental health. (19)

Initiating and maintaining regular bladder drainage (CIC) is often associated with improvements in physical wellbeing and participation in daily activities, which builds confidence and enhance self-esteem and QoL. This is particularly true for those with incontinence, or UTIs as CIC often reduces incontinence and recurrent UTIs .(20–22) Even children with genital sensation performing CIC, had QoL similar to normal healthy controls. (23) Body image improvements are seen in those who had an indwelling bladder catheter who now employ CIC or have had a continent catheterisable channel created. (20,21)

Mastering CIC and following acceptable CIC routines fosters feelings of empowerment and self-sufficiency. These achievements should be celebrated by the medical team, and the patients's social support system. Once CIC has been successfully implemented longer term follow-up by caregivers and the healthcare team is required to provide physical, external/social and psychological support, to maintain adherence to the regimen. (20,24–26) This is particularly true during adolescence and young adulthood, as patients transition to adult services and may not maintain a proper CIC regimen. (27)

Psychological barriers to overcome for satisfying life

Patients require periodic review with a dedicated professionals who provide high quality teaching, continual advice, reassurance and support. (26) Ongoing positive experiences will aid adherence while negative one's risk non-adherence. Families and caregivers should have a point of contact to share concerns and to receive advice and support

Recommendation
Regular, developmentally appropriate information, skills training and ongoing psychosocial support around CIC should be offered to children and families to minimise negative effects on body image and self-esteem and to enhance independence, social participation and quality of life
Level of evidence 3
Holistic CIC Care Wheel: 🟧 ⬛ 🟦 🟥

Challenges children face in school settings and to identify strategies to promote inclusion.

Practicial considerations

The need for CIC in school creates many challenges for the child as he or she tries to maintain a degree of 'normalcy' during the school day; nuances in achieving this are age dependent - children who are not self-CICing need assistance from school personnel, whereas older children need time and privacy to empty their bladder while not compromising their educational experience nor extra-curricular activities. Keeping supplies in the nurse’s office, having an environment were the child or the nurse can perform the CIC cleanly and making sure the child has easy access to the nursing office are essential. Inadequate toilet facilities or challenging environments can be barriers. CIC involves more time than voiding, so bathroom absences may be prolonged which can lead to compromises in learning or time with friends. Many schools are quite amenable to helping families negotiate the needs associated with proper CIC schedules, while others seem unmindful of the requirements that CIC entails. (11,25)

Intergrating CIC at School: collaboration and practical strategies

When CIC is needed, families often have to advocate to ensure their child is supported without feeling ‘different’. Caregivers must be proactive in maintianing privacy & dignity, (22) frequently needing to arrange a CIC regimen in school, including their own attendance to perform it during the school day. Garnering support from their medical team helps educate school personnel and identify a supportive school plan.

Schools should provide private, hygienic facilities for CIC, ideally with a nurse or trained staff. When unavailable, practical plans for caregiver support must be developed to avoid disrupting learning. Availability of school nursing and care varies by region, so planning must be flexible and realistic.

Open communication between families, medical professionals and school administrators can give a young person the opportunity to voice concerns relating to peer acceptance and bullying. Schools can help by promoting empathy, facilitating peer interactions and encouraging pro-social behaviour. Staff need to be aware that disclosure of continence issues to school staff is rare and that lack of disclosure can create challenges in knowing how best to offer support. (28) Indentifying a ‘trusted’ person (e.g., school nurse, counseler or teacher) a child can go to with concerns, can go a long way in improving adaptability. (11) Above all, the child should feel comfortable in the class, with minimal attention that exposes their medical needs. A regular review of school timetables and bathroom facilities should be undertaken to maximise participation in school events. (28)

Recommendation
Schools and families should collaborate proactively with healthcare teams to ensure private, hygienic facilities, trained staff support, and flexible scheduling for CIC in school, promoting the child's privacy, dignity, inclusion, and full participation in educational and extracurricular activities without stigma or disruption
Level of Evidence: 3-4
Holistic CIC Care Wheel: ⬛ 🟦 🟧 🟥

How patients navigate social situations, peer relationships, and offer strategies for reducing stigma.

Social integration and addressing concerns about peer acceptance

The requirement to regularly catheterise can interrupt daily activities and require lifestyle modifications that interfere with participation in social activities, schooling and sporting activities, potentially impacting a young person's opportunity for positive peer interaction. (11) Peer acceptance is an important aspect of social development that influences social skills, self-esteem, academic achievement and overall wellbeing. Disclosing one's need for CIC and subsequent peer acceptance may be particularly challenging due to societal social 'norms' surrounding bodily functions which may lead to social isolation, avoidance of social activities, and/or failure to comply with the catheterisation regimen. (11,13,14,17,25,29,30) Increased attention from authoritative figures and caregivers can lead to intrusive questioning from other students resulting in resentment. (29)

Understanding how CIC affects social integration for both the young person and the caregiver is crucial. Caregivers and young people should feel comfortable discussing these challenges with their medical team so CIC schedules align with health needs and social activities.

Strategies for the child to effectively and maturely communicate their needs.

(13,29)Young people with chronic medical conditions are constantly changing physically, psychologically and socially, which means they frequently confront questions or concerns about their body and how their medical condition affects their identity and relationships with others. Teenagers find it especially difficult to accept and discuss 'invisible' problems. (30,31)

Health care professionals should always put the young person at the centre of the consultation, give plenty of opportunity for open discussion without being judgemental, and provide as much support as possible. It is essential to encourage a young person to ask questions, convey opinions and provide the option to speak privately without their parent. (7)

Disclosing the need to self-catheterise to peers comes with a fear of social rejection. Encouraging the young person to disclose their health needs to peers or a trusted friend can lead to a sense of relief, aid adherence and social acceptance. (13,29) A supportive relationship between a young person, their caregiver(s), and family can aid communication; when a child is young, caregivers can take the lead in helping with disclosures, especially if their child is in the care of another family (e.g., when the child is spending time at a friends' home). As the child ages, caregivers and healthcare providers can offer specific language the child can use during disclosures, including deciding (in collaboration with the child and family) what information to disclose and how to phrase it. Support from a paediatric psychologist can help with communication within families and guide the young person in communicating their health needs with peers.

Social isolation and strategies for inclusivity

Providing practical information caregivers and young people can access, individual or group peer support, is important at different times in the young person's journey, and may be useful when CIC is initiated and/or at any time through their transition to independence and/or adulthood. (13) Being involved is a personal choice, as some can feel anxious and frightened by meeting others. Peer support may be offered and monitored locally or through national support groups.

Peer support can limit the adverse effects of living with a chronic condition for adolescents and can enhance social connection. (32,33) It can provide empathy and understanding, helping the family and young person realize they are not alone. Positive role models and practical information gained from lived experience help with adapting to and normalising treatments. Understanding how others have coped with treatment and re-established their routines of everyday life can be encouraging. (34,35)

Caregivers/parents may limit a young person's social involvement in activities due to fear it may negatively impact the child, thereby affecting their child's social development. (36) However, it is important for children and adolescents to promote socialization and be involved in activities that help to build secure friendships and self-esteem, as well as a strong sense of identity outside of one's medical condition. Addressing this negativity can help improve their child's socialization.

External factors can limit social activities due to lack of suitable, hygienic toileting facilities. If a caregiver is concerned a child may not perform CIC during sports practice, a clear discussion about when to perform CIC, identifying hygenic facilities to do so, may help to overcome these concerns and barriers. Medical teams can help by signposting to local or national schemes or appropriate toilet access and apps to support identifying such facilities. (26)

Recommendation
Young people and caregivers should be supported with open, youth-centred communication, guided disclosure to trusted peers, and access to peer support to reduce stigma around CIC and improve social participation, self-esteem, and adherence,
Level of evidence 3- 4
Holistic CIC Care Wheel: 🟥 🟧 ⬛

Various factors influencing catheterization care, with a focus on individualized approaches for children with CIC as they approach adulthood.

Transitioning to Self-CIC

The transition from caregiver-led CIC to self-CIC is a key developmental milestone that enables children to gain independence and take ownership of their health. When children show interest in taking on greater responsibility for CIC, a gradual, structured approach is recommended to foster their self-management abilities. (37) Readiness for this transition should be carefully assessed, taking into account the child's fine motor skills, cognitive abilities, and emotional maturity. (6,26,38) It is also essential the child understands the potential risks of incorrect technique, as improper CIC can cause long-term damage to the bladder or kidneys. Despite the importance of this transition, there is no clear consensus in the literature on the most effective teaching methods. Some children may possess the physical ability but lack confidence, intellectual capability to perform it routinely or motivation, while others may be enthusiastic yet require more time to master the technical steps required. A stepwise approach, beginning with observation, followed by guided practice, and eventually independent CIC, supports learning at the child's own pace. (39) When the child is particularly scared, teaching CIC according to an anxiety reduction program, using CBT principles and gradual exposure with small, incremental "mouse steps" effectively builds confidence and reduces fear.(40,41)

Group-based training and interactive, play-based strategies, such as videos and child friendly materials, are valuable in preparing children for self-CIC. These methods help children better understand and accept their condition, while also strengthening the relationship with their family, and healthcare professionals. (42–44) Current evidence is limited regarding the optimal age to begin education or the most effective teaching methods, but clinical experience and research suggest self-management becomes increasingly relevant between ages eight and ten years. (45) Researchers emphasize the importance of culturally sensitive, child-centred education in fostering early independence and promoting long-term adherence. (44)

Parental, caregiver, and professional support remains essential throughout this process. Regular follow-ups and open conversations addressing barriers, such as embarrassment, fear of complications, or daily life challenges, significantly increases the likelihood of successful and confident self-CIC (26,46)

Encouraging independence not only improves adherence but also contributes to self-esteem and psychosocial development, with lasting benefits into adolescence and beyond. (14,47)

Urethral vs. Stomal Catheterization

The choice between urethral and continent catheterizable stomal access to the bladder (e.g. the Mitrofanoff procedure) depends on medical factors (dexterity, lower extremity bracing issues, etc), as well as practical, psychosocial and quality of life considerations. A continent urinary stoma is often considered when urethral catheterisation is difficult or impossible, particularly in obese, immobile or wheelchair-bound children. This approach can make hygiene easier, provide more privacy, and reduce the burden on caregivers. Studies suggest children with a stoma may experience a better QoL than those CICing via the urethra. In one study of 70 children, those with an abdominal stoma reported higher pediatric QoL scores than urethral CIC users. (48) From a psychosocial perspective, the challenges faced by children with a stoma differ significantly from those using transurethral CIC. However, a stoma may impact body image and social confidence due to its visibility and the need for ongoing stoma care, whereas transurethral CIC, although less apparent, may cause discomfort, embarrassment, or inconvenience when CIC is needed in a social setting.
Each access presents unique psychosocial stresses that must be addressed individually through tailored patient and family support.(47)

Sensate vs. Non-Sensate Bladders

Bladder sensation plays a crucial role in determining CIC routines. Children with a sensate bladder can follow a more flexible schedule based on perceived bladder fullness. In contrast, children with a non-sensate bladder, must adhere to a fixed CIC interval to prevent overdistension, infection or hydronephrosis. The latter may have to apply abdominal pressure to facilitate effective emptying. (38) Mobility status also influences the practical execution of CIC. Children who can walk usually need minimal adaptations, whereas those who are wheelchair bound or have lower extremity bracing may require accessible facilities, adaptive equipment and greater logistical support. (49)

In educational settings, individualized health plans are essential to ensure privacy, trained staff support and appropriate storage of supplies, as well as ensuring CIC routines can be performed without hindering academic or social participation (26,45)

Physical aspects

As noted in adults with spinal cord injury on CIC, dependence on caregivers, ongoing incontinence and recurrent urinary infections impact upon quality of life. (24)Ongoing incontinence has been identified as a concern in some children with spina bifida. Those who are predominantly dry were found to have greater independence and more opportunities for social interaction. (29)Urinary and especially faecal incontinence can be distressing, unpredictable and have a negative emotional effect on the child. (14)How incontinence is addressed and managed may differ based on attitudes and desires of a child and his/her caregiver(s). (29)

A number of physical considerations need to be considered as the child matures to maintain a proper CIC regimen.

- Anatomical and gender considerations: As a child ages catheter size and type may need to be changed as larger lumen catheters speed up bladder drainage, reducing the risk of incomplete emptying and UTIs. Changes in catheter type may make CIC more comfortable and discreet, as girls performing self-CIC may desire a compact catheter.
- Physical attributes: CIC management requires periodic review as a child grows and seeks to become independent. Discussions around body positioning required for catheterisation, dexterity, mental capacity and vision are keys to ensuring success. Exploring the ongoing suitability of urethral CIC in a pubertal child unable to self-catheterise, requires an ongoing dialogue between the child and his/her caregiver(s) to determine the best option for bladder access.
- Social needs: Maintaining supplies, providing low-cost catheters can be a challenge for low- and middle- income families where costs become paramount. (26,50)

Transition to adulthood and adult medical care

Transition into adulthood for young people is complex and has added complexity in those with additional long-term health needs. Transition should be seen as a process rather than as an event and transition to adult services should be planned for, as early as possible. The young person needs to have adequate understanding of their condition and the skills required to manage their healthcare needs. Support is needed to help them navigate adult health systems whilst integrating CIC into their lives to minimise social/vocational disruption. (13)

Recommendation
Individualized, stepwise transition to self-CIC should be implemented based on readiness assessments of motor skills, cognition, and emotional maturity, with tailored strategies for urethral vs. stomal access, sensate/non-sensate bladders, mobility, and planned handover to adult services to promote independence, adherence, and quality of life.
Level of evidence 3-4
Holistic CIC Care Wheel: 🟨 ⬛ 🟩 🟥 🟦

Navigating healthy intimate and sexual relationships for older adolescents and young adults.

Addressing concerns about sexuality & intimate relationships

As individuals reach older adolescence and young adulthood, intimacy and sexuality become important aspects of their lives; unfortunately, this is also an area frequently overlooked and one that has been underresearched. It is known CIC can impact one's confidence regarding intimacy, which in turn adversely affects forming relationships and/or in some instances, increases the possibility someone on CIC would delay or even avoid a scheduled emptying when anticipating an intimate encounter. (26) Individuals might experience distress around disclosing their CIC needs to intimate partners, as they fear a partner would prefer a platonic friendship over an intimate relationship. Other individuals may feel CIC impacts their ability to be spontaneous with intimacy. (13)

Counseling and educating adolescents by health care providers

Investigations have noted a lack of education and comfort with discussions surrounding sexual health and intimacy by urologists; this is particularly true for some pediatric urologists who primarily focus on children (13,17,26,51) From a provider perspective, lack of formal training, comfort, and adequate time for discussing sexual issues, all serve as challenges or barriers to having these practical conversations with their older patients. (51) Maturing individuals currently rely on pediatricians, school nurses, and caregivers, for basic sexual health education but these individuals are less equipped to provide accurate, comprehensive and specific sexual health information to patients with complex urological conditions compared to urologists who have more intimate knowledge of an individual's anatomy and physiology. (52) While caregivers are identified as playing "an important role as their children's primary sexuality educators," their knowledge and comfort regarding this topic may also vary; they in turn, rely on the urologist to provide expert guidance. (52) Urologists who are eager to learn to provide competent sexual health care, can practice these skills and facilitate consistent discussions about sexual health and intimacy as a child grows and matures. With increasing provider comfort and open discussion about sexual health and intimacy from an early age (teaching children anatomically correct terminology for genitalia), patients and caregivers may be more receptive to these discussions, which helps to reduce stigma surrounding the topics of sexuality and intimacy (52,53)

Achieving a level confidence fosters a healthy sexual relationship

Many individuals who perform CIC have expressed anxiety about disclosing their CIC needs when in an intimate relationship. However, as a patient receives factual information, has time to absorb it and relates their concerns, their self-confidence of what they need to do when becoming intimate with someone, increases. They will feel more comfortable about disclosing their medical needs earlier in a relationship (13) This helps to reduce the potential 'stigma' of CIC a person may feel; that leads to increased openness about the topic with an individual's inner circle (e.g., friends, caregivers, urology providers, inimate partners). Sexual health and CIC, is a topic that becomes just one of many natural conversations an individual has with friends and intimate partners as they mature into adulthood.

Recommendation
Healthcare providers should proactively offer age-appropriate, comprehensive sexual health education and counseling to adolescents and young adults performing CIC, addressing disclosure concerns, intimacy spontaneity, and stigma reduction to build confidence and foster healthy relationships
Level of evidence 4
Holistic CIC Care Wheel: 🟨 🟥 🟦 🟧 🟩

Practical overview

These checklists offer healthcare professionals, teachers, and families actionable guidance for managing CIC in children, addressing both challenges to mitigate and strengthen one’s approach to preserving a healthy life style.

Table 1 describes strategies targeting negative factors like incontinence, pain, and social isolation, while Table 2 focuses on maintaining positive aspects of CIC for independence, acceptance, and transition to adulthood.

Table 1: Checklist for addressing any negative aspects of CIC from both a medical and school /social perspective.

Physical	Medical perspective	School- Social perspective
Urinary incontinence	Review of medical management of bladder function	Adequate storage of supplies and provide facilities to allow changing and disposal of pads
Bowel management	Review medical management of bowel emptying	Adequate storage of supplies and provide facilities to allow changing and disposal of pads
Urine infections	Review of proper catheter technique	Discuss importance of a clean environment
Pain	Review of catheter type, lubricant, anaesthetic gels	
Difficulties catheterising (pain, bleeding, time, inability to easily insert)	Review of technique, catheter size. Medical review for cause of difficulties	
Psychological/Social		

Misconceptions	Address concerns by providing developmentally appropriate education Empower patients ‘to ask’	Share education with schools; create & review specific educational &health plans
Anxiety, fear	Psychological support to address fears	
Social isolation	Listen to young person’s concerns Psychological support to aid communication	Promote social connections Regularly review timetable
Social/external factors	Provide a framework for enlightening others	Obtain support from administrative people
Suitable environment	Signposting: Local/national access schemes Apps to find suitable toilets	Suitable toileting facilities Private storage of supplies
Supplies of catheters	Access to supplies Address costs associated with supplies	Have discreet storage facilities
Communication between primary and secondary care	Establish shared care plans, direct advice lines, and multidisciplinary meetings for coordinated CIC oversight	Include school in care communications via designated contacts and joint planning for seamless support
Communication with care givers/school	Facilitate interprofessional discussions with families and schools to address peer concerns	Promote empathy and pro-social behavior; designate a trusted contact for bullying/acceptance issues

Table 2. Checklist for maintaining the positive aspects of CIC from medical and school /social perspective.

Aspect	**Medical** perspective	**School**- social perspective
Growth	Monitor height/weight charts and nutritional status during routine CIC reviews	

Physical disabilities	Assess mobility aids and adapt CIC technique for physical limitations	Provide accessible toileting facilities and assist with positioning if needed
Carer/Patient-centred goals	Co-develop personalized CIC plans with family input focusing on autonomy	Support patient-led goals through individualized education plans (IEPs)
Type of CIC	Review urethral vs stomal catheterisation options based on patient situation, feedback and complications	Ensure storage and access match CIC type
Psychosocial: Acceptance	Provide counseling on body image and 'normalization' of CIC	Foster peer education sessions to reduce stigma and promote acceptance
Psychosocial: Independence	Train self-catheterization techniques early	Allow private, unsupervised toileting time to build confidence
Psychosocial: Lifestyle	Advise on travel kits and infection prevention for activities	Integrate CIC needs into extracurricular participation policies
Transition to adulthood	Plan handover to adult services with skill reinforcement	Collaborate on vocational training and post-school support networks

Conclusion

These recommendations from the ICCS are meant as a guide for patients, caregivers and providers to use when navigating the social impact of CIC. The implications of CIC management beyond the specific medical improvements it achieves, has been a topic that has not been currently well researched, but one that clearly requires more attention from the medical community. Patients need to be instructed, CIC is not something that sets them apart from others but is rather a means of maintaining a healthy urinary tract when there are impediments to normal function. Caregivers need to be educated so they can help guide their child as they grow and mature into meaningful members of society. Educators have to be aware of how they can facilitate those students who require additional aids for a healthy urinary tract to provide the environment that fosters and not hinders learning and socialization. And, finally health care providers need to be a resource of knowledge and accessible to meeting the needs of adolescents, young adults and their families.

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