

ORIGINAL ARTICLE

Psychosocial factors in teenagers and young adults with myelomeningocele and clean intermittent catheterization

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Abstract

Objective. The aim was to analyse the psychosocial factors of teenagers and young adults with myelomeningocele with at least 5 years' experience of clean intermittent catheterization (CIC). **Material and methods.** A qualitative interview technique with semi-structured questions was used in 22 participants aged 13–26 years (median 17) and issues addressed were information given to others, integrity, attitudes to other disabilities, friendship, partnership and sexuality. **Results.** The participants wanted to inform their peers about the disability but often did not have the courage. Ignorance of the principle of self-CIC among medical staff was confusing. Urinary incontinence after the introduction of the self-CIC regimen was not seen as a problem in comparison with other major disabilities. Half of the participants had peers that they could call a best friend. The subjects wanted more specific information regarding their own sexual function. Finding a partner and becoming a parent were strongly desired but considered problematic. **Conclusions.** The participants wished to acquire more knowledge about CIC as a bladder-emptying method from the medical staff and also to have the respect to perform self-CIC at examinations. This study did not find any negative psychosocial factors associated with CIC.

Key Words: Clean intermittent catheterization, myelomeningocele, psychosocial factors, quality of life, teenager

Introduction

Since 1971, when Lapedes reported on the first patient treated with clean intermittent catheterization (CIC), many authors have described the long-term experience of CIC [1–7]. The largest group of patients using CIC comprises patients with myelomeningocele (MMC) and congenital lesions, distinct from patients with acquired lesions, such as traumatic spinal injury. Few studies have asked patients with MMC and with experience of other bladder-emptying methods to describe their experience of living with self-CIC [8–10]. Specific challenges involved the learning of self-CIC and the practical use of the technique. Concerns were leakage and being wet, and peers finding out about their incontinence management.

This research studied patients who started CIC at school age and who were therefore able to compare their experience of long-term self-CIC with other bladder-emptying methods. Thus, this study describes how teenagers and young adults, with at least 5 years of CIC experience, reflect on self-CIC in relation to earlier bladder-emptying methods and in relation to such psychosocial factors as information to or reaction from others, integrity, attitudes towards other disabilities, friendship, partnership and sexuality.

Material and methods

All children with MMC in western Sweden were followed from birth in a special medical and

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urological programme. School-age children started to learn self-CIC during 1 or 2 weeks as inpatients. Follow-up was arranged after 3 months, and thereafter once a year. These follow-ups included medical examinations, discussions about the practical toilet problems at home and at school, and monitoring of the actual CIC procedure including hand function and body image. Between the visits there were regular telephone contacts.

In this programme, CIC for children with bladder-emptying difficulties was introduced in 1977 according to the programme of Lapedes et al. [3]. There were 102 children with MMC who started self-CIC before 1985, and who had been followed continuously from birth. Of these patients, 41 who were aged 13 years or older and had been using CIC for at least 5 years were considered eligible for semi-structured interview studies on their experience of the treatment. Because of the time-consuming nature of the study technique (about 2 weeks for tape-recording analysis of each individual), 26 individuals were sampled at random by lottery without stratification. Parental consent was obtained for teenagers younger than 18 years.

As 4 of the 26 had difficulties understanding the questions because of intellectual disabilities, 22 individuals took part in the present study, 15 females and 7 males. Their age ranged from 13 to 26 years (median 18). The age at which CIC began ranged from 6 to 15 years (median 10) and the follow-up interval to the interview ranged from 5 to 12 years (median 7).

Twelve participants were confined to wheelchairs, 3 used a wheelchair occasionally, 3 used crutches and 4 walked without support. Fourteen lived with their parents, 3 at residential schools and 3 with a partner, while 2 lived alone. Twelve attended regular schools in grades 6–12, 8 were working and 2 participants with intellectual disabilities were at special schools. Nineteen of the participants had ventricular shunt.

As a basis for the tape-recorded interview, a protocol with semi-structured questions was used. A short version of the questions is shown in Table I. The focus of this study was the individual perception of reality, not an objective description of reality. This means that it was the individuals who chose how much of their experience they would divulge.

Nineteen of the young adults were interviewed at home and 3 at the regional rehabilitation centre. The researchers were aware that parts of the interview could disturb the integrity of the patients. Had an outsider conducted the interviews, this would have risked loss of information and even a substantial

Table I. Short version of the questions used in the structured interview.

A. Information given to peers and their reactions

Who have you informed about self-catheterization?

How old were you when you started to inform people about self-catheterization yourself?

Was there anyone else who had informed your friends or classmates about self-catheterization?

What were the reactions to the information?

B. Aspects of integrity

Tell me about your experiences when another person intends to catheterize you.

If you need help with self-catheterization, from whom do you want the help?

C. Attitudes to other disabilities

Can you compare different types of disabilities?

The individuals were given 8 cards with examples of different disabilities (urinary leakage, faecal leakage, cannot walk, cannot have a baby, cannot see, cannot talk, cannot hear, cannot move arms and legs) and were asked to sort them into 2 groups (mild and severe)

D. Attitudes toward friends, relationships and aspects of sexuality

Do you find it easy or difficult to make friends?

What is the reason?

Have you had any sex education and what is your opinion about the information?

If yes, how old were you when you received this education?

Do you meet with a boy- or girlfriend regularly?

Have you thought of having children of your own?

Do you believe that you can become a partner?

Do you have erections and/or ejaculations?

number of dropouts. Therefore, the urotherapist was chosen to carry out the tape-recorded interviews.

To avoid possible bias, transcripts of the tapes were typed word by word by an independent secretary. They were then listened to twice and analysed by the urotherapist together with an independent psychologist (AM), specializing in physical and mental disorders. All answers were categorized inductively in relation to the researchers' perception of their meaning. This means that all answers from the individuals were registered, analysed and put together into categories. In those cases where quantifications could be done in a meaningful way, results are presented as numbers. Consequently, some parts of the results are presented as categorized answers to the interviews (qualitatively), and some as numbers in tables (quantitatively).

Results

All 22 participants were enthusiastic about the interview, which was completed without problems. The total interview time ranged between 2 and 3 hours per subject. Table II presents some examples of answers to the questions.

Table II. Examples of responses to questions in the structured interview.

A. Information given to peers and their reactions
 Female, 17 years old: My grandmother knows everything. She can help me with CIC. She thinks CIC is a great invention.
 Male, 14 years old: No, our relatives have not been given any information about CIC, since they would never understand it anyway.
 Male, 14 years old: Relatives and peers know about CIC but they don't tell others. However, if they gossip about my CIC I take my catheter and hit their legs so it hurts. Thereafter, they know.

B. Aspects of integrity
 Female, 20 years old: I will do it myself when necessary and I make a point of it. At first they protested, but now they have learned, at least at some clinics. There is no reason for them to poke about my bladder with their bugs.
 Male, 19 years old: I have never been asked if I could insert the catheter myself. They have just kind of done it and I have not said anything.
 Male, 24 years old: I have been through too many examinations, so if someone else comes to catheterize me, I just say: "Get on with it!" Often they do have a reason and I am used to it.

C. Attitudes to other disabilities
 Female, 15 years old: To me, not having control of bowel function is a very mild disability and the same is true for urine incontinence, because I know what can be done about it.
 Female, 20 years old: Paralyzed legs are not a very severe disability, since I can "walk with my wheelchair" anyway.

D. Attitudes toward friends, relationships and aspects of sexuality
 Female, 23 years old: No, I do not have many mates. I think it is linked to my childhood when I could not run with the others. The old mates are gone. At work there is not anyone in the same age. My former home help is one of the few friends I have.
 Male, 20 years old: I have a girlfriend with similar disability and in the same age. We met at the centre for disabilities. Our families don't know about our relationship but she visited me on my birthday party and I liked it. We know about our problems related to our disability. Even though she uses a wheelchair we can manage.
 Female, 24 years old: I met him at the information course for disabilities. No one thought that the relationship would succeed. In the beginning we mailed each other and it was a hard time. After three years we were engaged and after another three years we married. It was a magnificent feeling that another person outside the family could love me. Late in the relationship we had sexual activities but we always used condoms, we wanted to be truly safe. Since I started taking contraceptive pills I have become more urinary incontinent.

A. Information given to other people and their reactions (Table III)

The 22 participants stated a wide range of opinions and experiences about information given to other people, and their reactions were expressed. The participants' best friends were informed privately and thoroughly and the information was given in confidence. Before puberty, classmates were even allowed to be present during the CIC in 14 cases.

Some individuals of school age gave the first information themselves about their self-CIC and disability to selected classmates. During the early years of school, it was most common that the mother

Table III. Information given to peers and their reactions (n = 22).

	n
By whom the information was given	
The individual	17
Mothers, teachers, nurses	5
Age (years) at which the information was given by the individual	
7-9	2
10-12	6
13-15	6
16-18	3
Did not remember	5
Reactions from other people	
Positive	11
Negative	5
None	5
Did not remember	1

gave the information, and the majority of the participants were satisfied with that. Teenagers felt in retrospect that they should have given the information themselves in school at an earlier age, preferably together with an adult, although they had not had the courage at the time. The first time an individual informed a group of peers was described as the most difficult, but it had also given them great satisfaction.

All participants had experience of reactions from the classmates, which varied from being positive in the form of admiration, to negative, such as saying it was childish (with regard to the diapers) and disgusting (with regard to the insertion of the catheter into the urethra).

The 10 who were not confined to wheelchairs experienced different reactions from the 12 in wheelchairs. The former were not believed about the self-CIC and 2 of 5 participants even wished they had been in a wheelchair so they could have been identified as disabled.

Problems with the teachers' knowledge about self-CIC were reported. The teachers were often regarded as badly informed, having negative attitudes and being uninterested in the bladder-emptying method and its medical and psychosocial impact.

The most difficult situation to cope with was when the medical staff showed ignorance of self-CIC. The participants expected this group to know more about CIC than they did themselves.

Never being asked about the disability created insecurity and allowed for the individuals' own, often negative fantasies about the reactions of others. The participants wanted to inform their close friends themselves to be able to control what information was given and how much. They stressed that they gave the information in confidence, and that if friends violated this confidence, it was taken as

Table IV. Aspects of integrity ($n=22$).

	<i>n</i>
Reactions when CIC was performed by another person	
Pain, discomfort	18
No comments	4
The helper they preferred as an assistant	
Mother	15
Another competent person	14
Assistant of same gender: females	10/15
Assistant of same gender: males	1/7

CIC = clean intermittent catheterization.

gossip and a breach of trust. To avoid gossip, it was essential, especially for individuals in a wheelchair, that everyone in the group knew about their self-CIC.

B. Aspects of integrity (Table IV)

Although all of the 22 interviewed subjects were able to perform CIC themselves, all of them had experienced recent situations when another person had catheterized them. It was evident that they did not like being catheterized by someone else and consequently preferred to perform self-CIC even at medical appointments. However, only 2 had explained that they would prefer to insert the catheter themselves and they were usually interrupted by the medical staff with comments such as, "Oh, I've done it so many times. It will be so quick and easy". In situations where the subjects are not able to perform self-CIC, e.g. when they are sick, the mother would be the natural helper. However, a few of the parents had never learned CIC.

C. Attitudes to other disabilities (Table V)

To analyse the extent to which the individuals perceived their own problems as a burden, they were asked to grade the severity of specific disabilities. The problems associated with MMC were not considered the most severe. The attitudes did not differ between those who could walk and those who

Table V. Attitudes towards different disabilities ($n=22$).

Type of disability	Mild	Severe
Urinary incontinence	15	7
Faecal incontinence	11	11
Paraplegia	12	10
Infertility	1	21
Blindness	3	19
Aphasia	5	17
Deafness	3	19
Quadriplegia	1	21

Table VI. Attitudes towards friends, relationships, sexuality and fertility.

Subject	Females <i>n</i> = 15	Males <i>n</i> = 7
Friends		
Easy to make friends	13	2
Have a best friend	15	4
Relationship		
Living apart	6	2
Living together	1	0
Married	1	0
Ended relationship	0	2
Aspects of sexuality		
Erection and/or ejaculation		6
Don't know (erection/ejaculation)		0
Orgasm, lubrication	0	
Don't know (orgasm, lubrication)	15	
Pregnancy	1	
Parenthood	1	0

were confined to a wheelchair. A few individuals declared that all disabilities are severe.

D. Attitudes toward friendship, relationships, aspects of sexuality and fertility (Table VI)

This subject area was perceived as affecting the participants emotionally. A total of 8 participants had no friends at all. Two talked about friends, who only turned out to be people they had sporadic contact with, e.g. in a club, or even somebody employed as a personal assistant. Twelve participants had peers they could call a best friend.

A total of 15 individuals thought that it was relatively easy to make friends and believed that this was due to their smiling face and open attitude. The problem was in keeping a friend for a longer period. Of the 22 participants, 5 spoke of problems in making friends and gave the reasons as being their inability to run, their use of crutches or their need for diapers. Twelve participants were presently involved with a partner. Finding a partner was strongly desired by 17 participants, but it was difficult for them to make this wish come true.

All but 1 subject in this study group attended or had attended regular schools where general sex instruction was part of the curriculum. Much of this information concerns aspects that are of importance for everyone, e.g. love and relationships. However, the part concerning the physiological aspects of sexuality was of little value to them, because they did not understand whether the information also applied to them. Neither the participants nor the teacher knew enough about the effects of the neurological disability on sexual function. Consequently, the participants wanted and needed

more specific information regarding their own situation, and thought that a physician or nurse should provide it.

Some of the subjects could not imagine a future without children of their own. Nineteen individuals said that they were sometimes occupied by thoughts of becoming a parent in the future, but 9 of them did not know whether they would be able to do so because of their disability. Of the 3 female adults living with partners, 1 had given birth to a healthy baby and another was pregnant, but it was difficult for them to understand questions about lubrication or orgasm. At the end of the interview, the participants were asked whether they wanted to add anything: "How am I going to find someone to marry?" was a question asked by 2 males and 2 females.

Discussion

The participants in this study shared a unique experience as pioneers of CIC, which they started at a median age of 10 years. Today more than 95% of all children with MMC in western Sweden are started on CIC during the neonatal period. In general, all participants were satisfied with self-CIC; none would have liked to return to their previous voiding technique. Thus, after more than 5 years' experience of CIC, the technique itself was not a problem in daily life. This study did not find any negative psychosocial influences with CIC, since all answered that they had been dry or drier since starting of CIC [2]. However, all the participants revealed psychosocial problems related to their disability, despite their positive attitudes toward CIC.

The participants comprise a group that is special because of the high frequency of hydrocephalus and concomitant cognitive dysfunction. On the one hand there are difficulties in interviewing since common words need to be used, but on the other hand the participants are often spontaneous and outspoken. A prerequisite for interviewing is that good contact is achieved, which is not always easy. Therefore, the urotherapist in charge of the participants was chosen to perform the interviews to achieve optimal contact rather than risk missing in-depth penetration of the questions. This approach may be discussed, however, and the best method remains to be shown.

Informing others about CIC was especially important for those who were in a wheelchair with no possibility of hiding the disability and who, therefore, wanted to be in control of the information. The positive effects were a reduced risk of misunderstanding and improved self-confidence. For those

with a less evident disability, one of the problems could be the disbelief they met when catheterization and the incontinence were discussed. For some individuals this was so much of a problem that they even wished that they had a more visible disability.

That teachers, classmates and relatives had too little knowledge about the emptying method and its consequences was acceptable, but if medical staff disclosed a similar lack of knowledge, it was terrifying. Furthermore, the medical staff often underestimated the ability of the participants to perform self-CIC at examinations. Everyone should be allowed the integrity of choosing the help they feel is needed. An additional reason for allowing self-CIC at medical procedures is that, when performed by staff members, the procedure was often regarded as embarrassing and even painful. Today, the knowledge of medical staff at hospitals is better, but most of those young adults have more contact with outpatient clinics with less experienced staff.

There is interdependence between an individual's identity and her or his attitudes towards personal disabilities and those of others. For most people the well known and experienced may be easy and surmountable, while the unknown and not experienced may be perceived as unsafe and difficult to manage. In this study, quadriplegia and infertility were considered to be major disabilities. The participants judged urinary incontinence as a minor disability, with the explanation that "I know what can be done about it" [11]. It is interesting to note that in this patient group infertility was regarded as a major problem. Family building is central in life, and not only to non-disabled women and men [12]. Specific knowledge about infertility and MMC needs more research and teaching [13].

How a person is seen is important for his or her identity [14]. If he or she is judged as a patient and only as a patient, while sitting in a wheelchair, it is easy to accept that role and to rely on professional care. The experience of friendship will also influence a person's identity. Am I worth being friends with? Dare I try to be a friend with anyone? In previous studies, as in this one, it was obvious that the definition of a friend was unclear and it was not certain whether the participants had a friend or had experience of friendship [15,16]. Börjesson and Lagergren described great problems with friendship, but more than 50% dreamed about marriage and a family life [17]. Having a partner was an expressed wish in another study group, although it was difficult for them to discover how to contact members of the opposite sex [10].

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