

ORIGINAL REPORT

PROBLEMATIC ASPECTS OF FAECAL INCONTINENCE ACCORDING TO THE EXPERIENCE OF ADULTS WITH SPINA BIFIDA

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Objective: To describe problematic aspects of faecal incontinence according to the experience of adults with spina bifida.

Design: Qualitative interview study.

Subjects: Eleven adults with spina bifida and bowel problems.

Method: Semi-structured open-ended interviews and qualitative analysis.

Results: Problematic aspects were related to participation in terms of time consumption, communication, social isolation, love and sexuality, and accessibility. Also, to a sense of helplessness in terms of panic and worry, to a sense of shame in terms of impurity, social acceptance and self-image, and to bowel function in terms of decisions about colostomy, voluntary constipation, and changing patterns.

Conclusion: The results reveal aspects relevant to supporting clinical practice and suggesting issues for questionnaire studies.

Key words: bowel function, interview, myelomeningocele, participation, patient's perspective, qualitative, rehabilitation.

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INTRODUCTION

Spina bifida (SB) represents a group of malformations of the spine and spinal cord, with a worldwide incidence of approximately 1:1000. It affects a slightly greater number of females than males (1). The spinal cord defect, which is often anatomically irregular, is related to a number of manifestations, such as impairments of motor function, sensory function, urinary bladder function, and bowel function, and, among associated conditions, hydrocephalus and specific cognitive impairments are common (2, 3). Before the 1960s few people with SB survived to adulthood, due to complications, but today the life expectancy is better. Thus, an increasing number of adults with SB need a range of services from the healthcare system with respect to different aspects of disability (4), and bowel function is now regarded as one of the most important problems (5–8). Voluntary control of defaecation requires rectal sensation,

peristalsis and anorectal sphincter function. Spinal cord defects may affect these functions, resulting in different combinations of faecal incontinence and constipation. According to Krogh et al. (9), faecal incontinence has a considerable impact on social activities in children with SB, and this impact becomes more severe as they grow older. McDonnell & McCann (6) reported that, among their adult clinic attendees, 68% had abnormal bowel function, with symptoms ranging across the spectrum from constipation, through urgency, frequency and occasional accidents to the use of incontinence pads, anal plugs and stomas. According to Verhoef et al. (8), 34% of young adults with SB have faecal incontinence and most of them perceive this as an important problem, and several strategies are used in efforts to manage the incontinence (7, 10). Thus, the general magnitude of the problem is recognized, but data about the perspective of adults with SB with respect to faecal incontinence is scarce, which might imply that some aspects of the problem are neglected in clinical practice.

The aim of this study was to describe problematic aspects of faecal incontinence according to the experience of adults with SB, i.e. qualitative aspects of the problem.

METHODS

Theoretical considerations

The theoretical framework chosen for this qualitative interview study was pragmatism, as discussed by Patton (11), i.e. recognizing the variety of philosophical perspectives that inform qualitative inquiry, we practiced the described method without allegiance to any single epistemological perspective. Pragmatism was considered to be relevant to inter-disciplinary integration of knowledge (12) and integrative applied rehabilitation research (13).

Sample

A total of 197 persons with SB from all over Norway were registered at the National Resource Centre at the time of the study. Inclusion criteria for the study were: age over 18 years, and some degree of paraplegia (14) due to SB, and no medical diagnosis of mental retardation. With regard to travel distance, the study included a preliminary selection of 54 persons who fulfilled these criteria, with a possibility of an extended study if necessary. All were native Norwegian speakers. They were asked if they currently or previously had had bowel problems, a main inclusion criterion, and if so, if they wanted to participate in an interview study on this topic. A total of 12 persons agreed to participate. We wanted a sample with some variation regarding each of the 7 *a priori* considered variables reported below, such as age and gender, and to include subjects until we reached a sense of qualitative

saturation of data according to analyses performed in parallel with interviews. According to all these sampling criteria, 11 subjects were included consecutively until interviews were stopped. The included subjects were 6 women and 5 men, age range 24–45 years. Six were either employed full-time or part-time, or were students, while 5 were neither employed nor students. Two lived with a partner, while 9 lived alone. Six had at least some ability to walk with or without crutches, while 5 were dependent on wheelchairs for any ambulation. The upper vertebral level of the cele ranged from T11 to S1. Two had a colostomy because of their bowel problems. A criterion of saturation of data was that the 2 last interviews did not result in any new descriptive category.

Interviews

The interviews, which comprised open-ended questions, were semi-structured, i.e. with support of an interview guide: an empty matrix with space for making notes, and the key-words past, present, and future along 1 axis, and events, thoughts, and feelings along the other axis (11). Entry questions were general and neutral, such as: How was your bowel function when you were a child? Follow-up questions aimed to explore all relevant problematic aspects, such as experiences from different time periods, and events, as well as related thoughts and feelings. All interviews were performed by the first author (VJ), a rehabilitation nurse trained to use this type of interviews, and clinically experienced but not involved with the group of subjects. The interviews were observed by an assistant (AA). The subjects chose the location for the interview, and most of the interviews took place at their homes, and some at the centre. The interviews, which lasted between 1.5 and 2.5 h, were recorded and transcribed *ad verbum*. Regarding the entire transcribed text, the senior author (MT), a Swedish specialist in rehabilitation medicine (15) teaching disability research (12), and familiar with Norwegian vocabulary, checked and approved the methodological quality of the interviewer's questions, i.e. open-ended, neutral, exploring, singular, and clear (11).

Data analysis

The transcribed text was analysed by the interviewer and the senior author. The analysis started as soon as the first interview was completed and was performed in parallel with the rest of the interviews. Firstly, the transcripts were read repeatedly in order to become familiar with the text. Secondly, the content of the text was identified via descriptive codes. With respect to each interview text, that step was performed first by each author independently, and later together, and by alternating between reading the material as openly as possible and actively asking questions about it. The codes were discussed until agreement was reached. After that second step, the program QSR NUD*IST version 4 (QSR International Pty Ltd 2007, Victoria, Australia) was used for practical handling of the coded and sorted text. Thirdly, the content was discussed and interpreted in terms of descriptions, issues, and more general issues. The suggested descriptions and issues were checked and adjusted repeatedly against the transcribed text. After that, the assistant who had observed the interviews read the descriptions and approved that they corresponded with what had been related by the subjects. Finally, a member of the project group (ES) who had SB and who was appointed by the Norwegian Association for Spina Bifida and Hydrocephalus scrutinized and approved the validity of the descriptions and issues, by comparing it with the original transcribed, coded, and sorted text.

The study was approved by the Regional Committee for Research Ethics in Norway.

RESULTS

The reported problematic experiences related to bowel function were interpreted to represent 13 specific issues, and these were related tentatively to the more general issues of participation,

a sense of helplessness, a sense of shame, and bowel control. Several issues were derived from the same type of events, but interpreted to represent different aspects, such as social and physical aspects. Citations are used, when suitable, with consideration for the privacy of the subjects.

Participation

The experiences related to participation were interpreted to represent time consumption, communication, social isolation, love and sexuality, and accessibility.

Time consumption. Many subjects spent a lot of time trying to control their defaecation. This was described as a considerable loss of time that could have been spent on other activities. Some spent many hours per week carrying out toileting procedures, and one person spent 9 h a week on this before a colostomy improved the situation. One subject stated that, on days that defaecation occurred, it was not possible to do anything else because one could not be sure if more faeces would come after carrying out toileting procedures. "In fact the day is ruined; I've missed being with friends and being sociable for 24 h, which I feel everyone else has." Several subjects experienced that a considerable part of their holidays had been wasted due to lengthy irrigation and defaecation procedures.

Communication. Several subjects had experienced problems in communicating with the visiting nurse. Such communication problems were described as causing difficulties in using assistance in situations related to bowel function. In contrast, some subjects described their experiences from childhood, characterized by immediate care by their mother, in some instances without any verbal communication about the bowels. "When I was small, my mother was very aware of it, and she would take care of me very quickly if she noticed any smell; then I got used to it too; almost only she and I noticed it, before anyone else." "My mother supported me in a very natural way, sort of accepted it as a part of me; we never talked about it." Several subjects stated that they had not contacted their general practitioner concerning faecal leakage or constipation. When they had a medical check-up, they hesitated to ask about this issue. The reasons for not discussing the problem with physicians were that the physicians did not seem to be interested or that they believed physicians would not be able to give any helpful advice. "I did not mention it, because I knew they have no solution to give me." Some subjects expressed the view that their doctors might be able to discuss a colostomy, but not to discuss any other aspects of bowel function. It was also common that subjects stated that they had not received much information about the effect of different diets, and several expressed a wish for more such information.

Social isolation. Most subjects had experienced involuntary faecal leakage in different social situations. It was common to describe situations in which faecal leakage had occurred in public spaces, among friends, or in intimate situations. They immediately noticed the smell of faeces, and they had experienced that other persons had noticed the smell at the same

time. Due to problems with physical sensation it was sometimes difficult for subjects to know immediately whether the smell represented faecal leakage or just gas. Due to leakage, most subjects had been forced to leave social activities they were in the middle of; they did not go back afterwards and they felt that the rest of their day had been ruined. Several reasons were expressed for not going back to the social activity; one was the long time required to go home and change clothes, and some subjects had to call for assistance in such situations. Another reason was a strong sense of shame. With some close friends, these problems were less pronounced, while other situations were described as traumatic experiences. "Then I have to hurry home and change, call the visiting nurse in order to get help to shower and change clothes, then my day is ruined; I can't go back to where I left off." According to several subjects, the experience of leakage in social situations had consequences, in the sense that they no longer participated in activities in which they had previously experienced faecal leakage. It was mentioned by several subjects that this contributed to social isolation. Most subjects had experienced faecal leakage in school, and as a consequence they would go home in order to change and wash. They related that, after such an episode, they would not return to school that day. Some of the subjects had spent most of their breaks in the toilet, and thus had little social contact with classmates. Bowel problems were also mentioned as a direct reason for being harassed in school.

Love and sexuality. Some subjects had never had a sexual relationship, a close romantic relationship, or a partner. One reason was that they did not feel secure letting anyone get physically close due to fear of faecal leakage, smell, or other fears related to the bowel problems. They said that they believed that if they had had a partner the bowel problems would have affected their sexual life. Some of the subjects told about faecal leakage in relation to sexual activities. One subject stated the advantages of constipation in relation to this issue. One with sexual experience stated that there had been times that they felt that it would not be possible to engage in sexual relationships because of the bowel problems, while at other times the risk of faecal leakage had been ignored in sexual situations.

Accessibility. Much of what the subjects chose to participate in during their leisure time was guided by access to an appropriate toilet. They checked the availability of appropriate toilet facilities before they went anywhere. Holidays to exotic destinations were often not considered because of the risk of diarrhoea, which meant that they would not be able to participate in any activities. Those with a colostomy did not have such problems, while some others defied the fear of diarrhoea and went for long holidays abroad. One subject stated that a holiday of more than a week was difficult because of the need for assistance with defaecation or because the necessary equipment was too bulky to carry in the luggage. Several subjects described how they felt secure when they could spend their holiday in a cabin owned by their family, because facilities had been arranged to meet their needs, and because they could store necessary equipment, such as incontinence pads. Because of

the connections between faecal leakage and shame, access to a wheelchair and a car of their own was described as a valuable means to conceal leakage when forced to leave a social situation suddenly. "I chose to bring along the wheelchair, even though I'm able to walk, because then it wouldn't matter so much if things went wrong. In such cases I'd be able to wheel out to the car; there I'd have my own confined space, so to speak". Some subjects described a work situation that had been made possible because conditions had been properly arranged with regard to toilet facilities, the creation of a tolerant attitude, and persons that could offer assistance when faecal leakage occurred.

Sense of helplessness

The experiences that were related to a sense of helplessness had been interpreted to represent panic and worry. Several subjects described a circle of panic and worry. They felt panic when smell or leakage occurred, and worry that similar situations would happen again seemed to affect their lives to a great extent.

Panic. Several subjects had experienced a strong sense of panic when they became aware of leakage, or the smell of faeces, in different social situations. One subject related the feeling of helplessness when leakage of faeces had occurred in a public swimming pool. Others described the sense of panic they felt when they were out with friends and suddenly noticed the smell of faeces. "You are out with friends; we sit there and have a good time, and then comes this incredible stench of something that has leaked."

Worry. Several subjects stated that uneasiness governed their lives and a great deal of energy was spent on worrying about gaining control over defaecation and avoiding a sense of shame. They experienced that a circle of panic and worry had consequences, in the sense that they no longer participated in activities in which they had previously had faecal leakage. The smell of faeces seemed to be an important issue in their worry. "The smell of faeces is the worst, and you do all you can to avoid the smell, try to control defaecation as much as possible; I feel, however, that this constitutes a permanent stress factor". Several gave detailed descriptions of the worry and sense of helplessness related to the unpredictability of smell and leakage in different social situations. They seemed never to feel certain that they were in control. "I started to become more and more uncertain about what I could eat, and how to behave, to be afraid of going to parties, to be with friends because, at the same time, you think that this could happen at any time and that I'm not in control." The 2 subjects who had a colostomy stressed that a sense of control was important.

Sense of shame

The emotional experiences related to bowel function were also interpreted to represent aspects of shame. These aspects were described in ways that had been interpreted in terms of impurity, social acceptance, and self-image.

Impurity. Many subjects described a strong sense of impurity related to the appearance of faeces on the surface of the body. This was interpreted to reflect a cultural aspect of the notion of impurity. The smell of faeces was also related to this sense of impurity, and many subjects were mentally occupied by the problem of how to avoid the smell. Some who hesitated to get a colostomy described similar connotations to colostomy bags, because it meant faeces were hanging outside the body. Although they knew it was possible to apply for a visiting nurse to help with the defaecation procedure, some subjects were still assisted by their mothers because they felt it was a private thing. Some subjects who did not have any sexual relationship said that problems with the faeces made it impossible even to imagine having a partner. On the other hand, one subject who had experienced a sexual relationship said that, although this emotional aspect was very problematic, it had been a reason for valuable discussions, and this had led the partner to reveal thoughts about taboos and weaknesses, resulting in a feeling of closeness.

Social acceptance. When the subjects recalled the transition from early childhood to adolescence, several remembered how they began to perceive the leakage of faeces as socially unacceptable, and in some these memories evoked strong emotions. The words used to describe such events were expressive, such as catastrophe, accident, gigantic mishap, blow-out, explosion, gruesome, and walking through a minefield. If faecal leakage made it necessary to withdraw from a social situation, many subjects had experienced that they had to leave suddenly without any explanation, or to find some other explanation that would be socially acceptable.

Self-image. Most subjects had experienced a close relationship with their mothers. They felt accepted, that the bowel function was accepted as a natural part of them. In contrast to the relationships with their mothers during childhood, some subjects described that being connoted to faecal leakage made them think it was not possible for them to be accepted in a close physical relationship. In different situations, e.g. with a friend, with a group of friends, or in school, most subjects had experienced that leakage had forced them to withdraw from their peers. After such situations, they had a feeling that it was not possible to join their company again because of shame for themselves. Being connoted to faecal leakage, smell, equipment for handling incontinence, or lengthy toileting procedures, was described as a reason for being excluded and harassed in school. The 2 subjects with a colostomy described that they perceived the colostomy bag like a natural part of their body; they did not experience themselves as impure as long as the faeces were inside the bag. The sense of security achieved by a colostomy was mentioned as a factor for thoughts about the possibilities to get close to other persons. "Now I feel that as long as the bag doesn't leak, I'm clean; now I'm able to sit and chat with people, and have them close to my body without feeling that I smell."

Bowel control

The experiences that were related to bowel control had been interpreted to represent decisions about colostomy, voluntary constipation, and changing patterns.

Decisions about colostomy. Some subjects were concerned with the problem of whether or not to request a colostomy. The 2 subjects who had a colostomy described this as a positive change in their lives, and that they would have had it long before, had they known what a relief it would provide. "Because of my colostomy I am able to do much more, commit myself to things; before I had to say that I would have to consider my condition, meaning loose bowels; now I'm able to make appointments and be certain that I can be there." A desire to start working and feel safe at any workplace was described as a reason for wanting a colostomy. Reluctance to wear a bag containing faeces was described as a reason for not wanting a colostomy.

Voluntary constipation. According to several subjects, worry about leakage in social situations was a reason for trying to develop protracted constipation. For some, such voluntary constipation could last up to a month. These subjects were at least partially aware of the long-term disadvantages of that strategy but they could still not resist using it, because of the short-term advantages. "I can do anything; I can go to the cinema; I can even dream about a partner; I'm well aware, however, that the constipation is not permanent, and then, of course, it becomes impossible to imagine getting a partner anyway." All subjects tried to use diet to avoid loose bowels, but some experienced that they had not received much dietary information. Most subjects stated that they had experienced nausea and pain in their stomach. It was common to describe that such symptoms affected their general well-being, school attendance, and other social activities. Several had tried irrigation with water and had stopped, because they did not obtain the desired effect or had got ill. Some thought it was too time-consuming, and some did not get the assistance they needed from the visiting nurse.

Changing patterns. All subjects stated they had experienced changes in patterns of defaecation over time. Some had developed a tendency for looser bowels over the years and hence less control. Some had experienced an increased tendency to constipation. Several subjects had experienced alternating periods of constipation and loose bowels. Some were able to relate the change to specific events, such as the discovery of a tethered spinal cord, while it had sometimes been difficult to understand why the pattern of bowel function changed.

DISCUSSION

In interpreting these results, it is important to be aware of the limitations implied by the specific aim of the study, but also of the strengths of the method with regard to that aim. The aim was not to describe the whole situation, or a particular group with SB, or differences between certain periods of life, but to describe qualitative aspects of the problem exactly. The problematic aspect of bowel function was perceived to be important (8), and we wanted to explore qualitative aspects of that problem in order to identify possible needs for rehabilitation (15). The quantitative words in the results give some indication of the

number of subjects contributing to the description of certain issues, but the frequency of certain problems was not studied with this sample. The 13 specific issues presented in the results reflect relevant aspects of the problem, and the method represents a systematic way to capture such aspects (11). The issues are closely based on the experience of the subjects, and interpreted in terms that are not very abstract compared with ordinary language. The terms are relevant to the communication between persons who experience the problem and professionals working with it (16). The tentative general issues, such as participation, are interpreted in somewhat more abstract terms, deliberately more influenced by the perspective of the researchers (15, 17, 18). They are relevant to rehabilitation professionals in organizing their clinical awareness and knowledge.

To clinicians, our study is a complement to the information provided by questionnaire studies (19–22) because it is valuable to know what aspects of faecal incontinence might be important to an individual patient. In rehabilitation, such knowledge is crucial because there are so many aspects of disability, and a complex repertoire of interventions to manage different problems (15). A relevant comparison to our results was published recently by Kinavey (23), using somewhat different methods in late-stage adolescents. Her results highlight a concept of *experiencing self as dissimilar other*. According to our interpretation, that concept relates to some of the issues revealed by our results: especially social isolation, sexuality, worry, and shame with respect to social acceptance and self-image. The study by Kinavey (23) is more focused on new concepts, in contrast to our approach that provides a list of aspects in terms that are close to the perspective of patients and rehabilitation professionals. Our issue about time consumption may be important to many patients with SB, and variables such as the time needed for defaecation have been used in quantitative studies (8, 9). The aspect of subjects using most of their break time on toileting procedures indicates that even a short period of time might be critical for the possibility of engaging in social activities. Our issue about communication highlights a need for professionals to be aware that some patients may experience such problems. The issue about social isolation exemplifies that formal belonging to, for example, a group of students, does not necessarily imply an experience of informal participation in the same group. Related intervention issues span from cultural attitudes to faeces, through the psychology of coping, to the physiology of achieving continence. The issue about love and sexuality (21, 24) is somewhat similar to the problem of perceiving oneself as a sexual person, as reported by Kinavey (23). Such perceptions may be related to the psychological concept of self-esteem (25). To improve participation in love and sexuality, it may be useful to support self-esteem by psychological interventions as well as measures to improve continence (26). Our issue about accessibility highlights environmental influence on participation with regard to work and leisure (18, 27). The issues about panic and worry may be related to the psychological concept of self-efficacy, i.e. beliefs and feelings about personal control in challenging situations (28). Self-efficacy is influenced by the response of the social environment; a positive response will encourage the individual to explore and master different

situations. Although dependent on the perceived expertness and trustworthiness of the supporting person, verbal support may also enhance self-efficacy (28). Our communication issue is related to trustworthiness, and verbal support is a common intervention in rehabilitation practice. The results of our study may be used to improve professional knowledge, and thereby the conditions for a constructive dialogue about faecal incontinence. The issues about different aspects of shame are related to findings that urinary continence is associated with higher self-image in children with SB (26). Our findings reflect cultural as well as psychological dimensions of self-esteem (25). To support participation in social relationships, it may be necessary to pay attention to the cultural dimension as well as to the discussed psychological and physiological dimensions. It may be useful to relate the issues of voluntary constipation and changing patterns to the issue of communication. If people believe that professionals will not be able to offer solutions, they may choose to struggle with their problems alone. In addition to communication per se, cognitive functions, such as memory, have to be taken into consideration in the SB group as a whole (3). Decisions about different types of interventions are complex and, although 2 subjects were satisfied with their decision about a colostomy, the less invasive alternatives should be evaluated (7, 10), and our results identify possible aspects of a broad approach to such evaluations.

Rehabilitation in SB is complex, with many related issues (4). Paying attention to our results and our research question, we focus on clinical awareness about the range of the described aspects, and the roles of rehabilitation professionals. The issues about participation are related to the interaction between the individual and the environment. To manage such aspects, the expertise of social workers and occupational therapists is valuable. The related rehabilitation strategies are focused on enabling and disabling factors of the environment, and how a person can master specific situations and activities (15). The issues about a sense of helplessness and shame are related to social psychology. To manage such problems, psychologists may use knowledge about, for example, self-efficacy (28) and self-esteem (25). The issues about bowel function are related to the specialized knowledge of nurses and physicians. These issues deal with a specific body function, and interventions may aim to improve that function (7, 10), although a number of related aspects have to be considered (4, 15). It is clinically important to be aware of the wide spectrum of issues and related enabling strategies. The corresponding area of knowledge is extensive, but possible to approach within a multi-professional rehabilitation team provided there is a common basis for communication with the patient and within the team (15, 18); the results of this study may contribute to this.

In conclusion, the results of this study reveal aspects relevant to supporting clinical practice and to suggesting issues for questionnaire studies.

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