The Experience of Finding an Effective Bowel Management Program for Children With Spina Bifida: The Parent's Perspective

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Many families who have a child with spina bifida identify establishing an effective bowel program as one of the major challenges they face; yet, we know little about a family's experience with this process. The purpose of this qualitative study was to describe the parent's experience. Seven parents were interviewed by telephone. Content analysis yielded four themes: (a) long complicated journey, (b) the impact of the journey on the child, (c) the family struggle, and (d) the promise of the future. The major contribution of this study is a compelling description of one of the most difficult areas for these children and their families. A better understanding of this issue enhances the health care providers' ability to deliver optimal health care.

Key words: Bowel management; Spina bifida; Children; Family struggle

SPINA BIFIDA (SB) IS a congenital impairment of neural tube closure that takes place between 24 and 26 days' gestation and occurs in 7 out of 10,000 live births (McLone & Bowman, 2005; Stevenson et al., 2000). There are several forms of SB, with the least severe involving only the vertebral column that surrounds the spinal canal to myelomeningocele, the most common and severe form that involves the protuberance of the meninges and spinal cord through the vertebral defect. Depending on the location of the lesion on the spinal cord, children may have altered motor and sensory function, musculoskeletal impairments such as club foot or scoliosis, urinary and bowel impairment, and latex allergies (Lazzaretti & Pearson, 2004). Almost all children with SB, even those with sacral lesions, have impairments of bowel and bladder status from infancy. Associated problems that occur from impairments in central nervous system development may include Chiari II malformation, hydrocephalus, seizures, visual or perceptual difficulties, and learning disabilities. In this cascade of potential problems these children face, many families and providers have identified establishing an effective bowel program and thus "bowel continence" as one of the major challenges families face (Andren & Grimby, 2000; Leibold, 1991; Leibold, Emark, & Adams, 2000). In fact, bowel incontinence is reported to be significantly more stressful than impaired motor function (Lie et al., 1991). However, we know little about how parents work with providers to find an effective bowel program. The purpose of this study was to describe parents' experience in finding an effective bowel program for their child with SB.

BACKGROUND

Review of Literature

Bowel continence remains a problem for children, adolescents, and adults with SB or spinal cord injury throughout the world. The frequency of bowel incontinence differs across studies in part due to different definitions of incontinence. King,

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Currie, and Wright (1994), defining bowel incontinence as more than one bowel accident per month, identified bowel incontinence in 90% of the population with SB. Danish authors (Krogh, Lie, Bilenberg, & Laurberg, 2003), defining bowel incontinence as bowel accidents weekly or daily, studied children 2–18 years old and found that 28% of children over 4 years old are incontinent. A national study in the Netherlands defined incontinence in SB as weekly accidents and identified 34% of adolescents and young adults in this category (Verhoef et al., 2005). In the United States, a random sample of the members of the Spina Bifida Association and a comprehensive study of all persons with SB in a southern state documented that more than 50% of children and adolescents had not achieved full bowel continence (Lazzaretti & Pearson, 2004; Malone, Wheeler, & Williams, 1994), whereas a recent study of young adults with SB found 35% of bowel incontinence (Verhoef et al., 2005). Regardless of definition, bowel incontinence is a powerful predictor of social competence and quality of life (QOL) for children and adults (Hicken, Putzke, & Richards, 2001; King et al., 1994; Rendeli et al., 2005; Westgren & Levi, 1998). In addition, Hambley, Lovering, Dimmock, and Taylor (1989) reported a wide range of medical (e.g., chronic constipation, mega colon, inadequate bladder emptying, urinary track infections, or shunt malfunction) and psychological problems (e.g., psychosocial trauma, damage to self-esteem, negative impact on social interaction, or delayed psychosocial development) associated with unsuccessful bowel programs.

A variety of interventions to achieve bowel continence such as timed toileting, digital stimulation or evacuation, suppositories, enemas (King et al., 1994), medications, biofeedback, behavior modification (Whitehead et al., 1986), retrograde colonic enema (Eire, Cives, & Gago, 1998; Scholler-Gyure, Nesselaar, van Wieringen, & van Gool, 1996), and electrical stimulation (Marshall & Boston, 1997) have been evaluated. In general, each is effective for some and not others. Authors from the United States (Leibold et al., 2000) have developed a stepwise algorithm for optimal personalized continence programs. The algorithm, which is primarily based on expert clinical opinion and principles of bowel function, (a) progresses from least invasive and simple (e.g., fiber or medications) to more invasive and complex bowel programs (e.g., cone enemas or large volume enemas); (b) delineates interventions that include diet, medications, suppositories, small-volume and large-volume enemas, and surgical options; and (c) includes need for caregiver assistance. Although the algorithm assists the health care providers (HCP) and the child and family in considering options, it is not based on a synthesis of evidence and has not been tested.

In the last decade, surgical options have been added that create a catherizable stoma or device (Hensle, Reiley, & Chang, 1998; Rivera, Kugathasan, Berger, & Werlin, 2001; Van Savage & Yepuri, 2001; Webb, Barraza, Stevens, Crumb, & Erhard, 1998). Originally, the most common procedure was the appendicocecostomy, a surgery that used the appendix to create the stoma and channel to the intestines. The cecostomy (a tube similar to a G-tube, sometimes called a "button" or a "trapdoor" due to its configuration and inserted into the cecum) was introduced in Canada in the late 1990s and is now available in the United States. These options allow for an "antegrade enema" or enema from "above" to clean out the colon and achieve a predictable and effective bowel program. However, these surgeries are not without their complications. Even with the surgical options, many children and adolescents continue to find achieving bowel continence in a timely and efficient manner a challenge. However, the path to finding an effective bowel program is not a linear or singular one. To assist families in this journey, it is helpful if the HCP can share with children and families the experiences of others on this journey. However, the literature remains relatively silent on the experience of finding an effective bowel program from the perspective of children or parents. Because in childhood this journey is orchestrated initially by parents, the current study focused on their experience. This study was undertaken to better understand the process of finding an effective bowel program for children with SB and to hear, from the parent's perspective, the important aspects of their journey.

Conceptual Orientation

The underlying theoretical orientations for this study are the Ecological Model of Adaptation in Spina Bifida (Sawin, Buran, Brei, & Fastenau, 2003) and Orem's self-care theory (Orem, 1995, Renpenning & Taylor, 2003). The ecological model depicts the relationship of two different types of risk factors primarily attributable to central and spinal nervous system structure and function (neurological severity and neuropsychological function) and two types of protective factors (adolescent resilience and family resourcefulness) to these adaptation outcomes (Table 1). This study will facilitate understanding of bowel continence outcomes, a central component of physical health, and the impact of adolescent, family, and HCP on this outcome. Further, the model suggests that there are risk and protective factors associated with positive outcomes. Clearly, SB is a risk for poor bowel outcomes. However, other risk and protective factors have not been identified. In addition, Orem's self-care theory proposes that the parent is the self-care agent for the child until the child becomes capable of self-care activities. In this instance, the parent is the initiator and developer of the bowel management plan for their child and is the individual most involved in finding an effective bowel program. The journey to find an effective bowel program continues throughout childhood. Although children, as they develop, may develop skills in managing the program, the parent often remains heavily involved in decisions about changes in the program or the adoption of a new program. Yet, we know little about that experience. This study addresses the parent's experience in working with their child and an HCP to find an effective program. Both the Ecological Model of Adaptation in Spina Bifida and Orem's self-care theory informed the general approach to this study and the qualitative interview guide.

Table 1. Risks, Protective Factors, and Adaptation Outcomes in the Ecological Model of Adaptation in SB

Concept	Exemplar Variables
SB context	
Characteristics of the sample	Age, gender, socioeconomic status
Risks	
SB condition factors	LOL, hydrocephalus, mobility, clinical history
Neuropsychological impairments	Executive functioning, working memory, processing speed, attention language
Protective factors	
Adolescent's resilience	Decision making, household responsibility attitude, hope, communication efficacy
Family's resourcefulness	Family satisfaction, cohesion, mastery, family activities
Health care adequacy	FCC, SB needs
Adaptation outcomes	
Physical health	Functional status which includes bowel and bladder continence, self-management, secondary conditions
Mental health	Developmental competence, absence of depression or behavior problems
Social competence	Full participation in social life
Academic achievement	Parent's and teacher's perception of academic achievement and child academic achievement
QOL	HRQOL, overall QOL

Note. FCC = family-centered care; HRQOL = health-related quality of life.

METHOD

Research Method

This was a qualitative descriptive study. Data were collected using a semistructured audiotaped telephone interview which followed an interview guide created for this study.

Sample

The study was conducted using a purposive sample of seven parents of children with SB. Recruitment sought "parents of children with SB for an interview about bowel management programs used for their children." Inclusion criteria also included the ability to speak in English and willingness to participate in a telephone interview about bowel management programs used for their children. The sample was obtained by referrals from HCPs at a large eastern medical center, a children's hospital, and community agencies. The parent responsible for most of the child's care was interviewed, who in this study was the mother in all cases. Data were collected until sufficient agreement was identified in the data to generate an understanding of the experience to answer the research question. Participants in this sample showed considerable similarity in their experiences and, thus, have a great deal to offer to improve understanding of complex and important situations regarding bowel management.

Instruments

The interview guide was reviewed by three pediatric experts for its relevance to the goals of the study. The focus of the interview guide was on having the parents share the experience of their journey through the process of finding an effective bowel program. The interview began with a general question about the child's bowel program, "Tell us about your experiences in finding the right bowel program for (child's name)," and had a list of probes if additional information was needed. General probes, such as "tell me more about that," were also used (Gorden, 1987). Specific follow-up questions were used if the issue did not come up as the participants were sharing their experiences. Specific questions in the interview guide included the following: “Tell us more about your current bowel program and how you chose it?” “What are the aspects of a bowl program that are important to you?” “What influence has this had on your child’s self-care, how much of the bowel program can your child do for him/herself?” “Tell us what impact finding an effective bowel program has had on your child and family?” “What do you think professionals need to know about this issue when working with children who have SB and their families?” Demographic (age, gender, school placement, and parent interviewed) and select clinical data (shunt status, level of lesion [LOL], mobility, and type of bowel program) also were collected. The study was designed using a telephone interview format to include potential participants living at a distance from the medical center. Although this limited the interview’s ability to observe nonverbal behavior, there are data to support the use of telephone interviews to collect qualitative data (Waterman, Leatherbarrow, Slater, & Waterman, 1999; Ziebland, Graham, & McPherson, 1998). Further, multiple investigators have used telephone interviews to address sensitive issues (Charron-Prochownik et al., 2006; Kornblith et al., 2006).

Procedures

Human subjects’ review and approval were obtained from the parent institution’s institutional review board. Informed consent was obtained in a two-step process. The consent forms were sent to participants before the interview for review. In addition, at the start of the interview, the interviewer read the consents verbatim for each participant, queried for any questions, and obtained verbal consent. This process was audiotaped. Participants were informed that (a) their telephone interview was being audiotaped, (b) all identifying information in the transcription would be removed, (c) their interviews would be confidential, (d) the transcripts would be identified only by code number, and (e) all tapes would be destroyed after the interviews were transcribed. Parents agreed to participate without compensation. Interviews lasted from 30 to 45 minutes. Participants had the option of ending the interview at any time or not answering any question that made them feel uncomfortable, although none chose to end the interview early.

Trustworthiness

Trustworthiness was addressed first by audiotaping interviews and having them transcribed verbatim to ensure that the participants’ words were captured accurately and providing a thick description. An expert in qualitative research not related to the study provided peer debriefing during the interview and data analysis phases of the study. Debriefing is a valuable technique to promote interviewer’s objectivity and prevent bias (Lincoln & Guba, 1985). Further, the data analysis was conducted by each author independently. Ongoing discussion among the investigators provided an important opportunity to develop an audit trail, verify the rigor of the process, and thus ensure a complete and comprehensive approach to data collection and analysis. Ultimately, these strategies enhance the credibility of the results, ensuring that the conclusions of the researchers were an accurate reflection of the experiences reported by the participants.

Data Analysis

Descriptive statistics were conducted to summarize the characteristics of the sample. Thematic analysis (Boyatzis, 1998; Morse & Field, 1995) was used to identify key themes from the stories. After reading each transcript several times and listening to the audiotapes to identify sentences, phrases, or anecdotes relevant to the study questions, each author identified themes and subthemes independently. In the rare instances when discrepancies existed, the investigators discussed salient findings to reach a consensus.

RESULTS

Characteristics of the Sample

Parents had children whose ages ranged from 18 months to 23 years (see Table 2 for a descriptive summary of the sample and the SB condition factors). Three of the children were females and four were males, and grade in school was appropriate for age. Their educational level ranged from early intervention to the completion of high school. The children’s educational placement ranged from one child in early intervention, one child in head start, two in special education classrooms, one in private school mainstreamed classes, and two in public mainstreamed classes. The SB condition variables included LOL, mobility, and history of bowel surgeries. Two of the children had unspecified lumbar lesions, and five had lumbar lesions from L3 to L5. One child was unable to sit up or walk, and six children were ambulatory with assistive devices including orthoses, walkers,

Table 2. Characteristics of the Sample and SB Condition Variables

Characteristics				SB clinical factors	
Age	Gender	Grade	LOL	Mobility	Bowel management
1. 3 years	Female	Preschool	L3–4	Household ambulator	Surgical
2. 12 years	Female	12th	L3	Wheelchair ambulator	Surgical
3. 16 years	Male	10th	L3–4	Community ambulator	Surgical
4. 6 years	Male	1st	L4–5	Community ambulator	Suppositories, enemas, and medications
5. 18 months	Male	0	Lumbar lesion (unspecified)	No ambulation	Suppositories, enemas, and medications
6. 23 years	Female	Finished 12th	Lumbar lesion (unspecified)	Community ambulator	Suppositories, enemas, and medications
7. 14 years	Male	7th	L5–S1	Community ambulator (AFOs)	Suppositories, enemas, and medications

Note. Ambulation status: no ambulation = does not sit, crawl, or walk; household ambulator = can walk with walker or braces including AFO in house but uses wheelchair for most ambulation outside the home; community ambulator = can walk with crutches or braces including AFOs (may use wheelchair for long distances). AFO = ankle–foot orthotics (a type of brace).

braces, crutches, and wheelchairs for long distances. Sixty-seven percent of the sample (4/7) used either suppositories, enemas, or medications to manage their bowel program, and 43% had had surgery to create a mechanism for an antegrade enema. All children, adolescent, and young adults were Caucasian and lived in two-parent homes. Six of the seven children had a history of hydrocephalus and currently had a ventriculoperitoneal shunt. Secondary medical problems included symptomatic Chiari II, tethered cord, orthopedic surgeries, and a bladder augmentation.

Themes and Subthemes

Analysis of the transcripts yielded four themes and 10 subthemes. The four major themes included the following: a long complicated journey, the impact on the child, the family struggle, and the promise of the future (Table 3). In the section that follows, each of the themes will be presented with a short description of the central components of the theme and the subthemes identified. Further discussion will address each of the subthemes in sequence.

Table 3. Study Themes and Subthemes

Theme 1: a long complicated journey

Subtheme (a): uncertainty of accidents
Subtheme (b): problems in relationships with HCPs—not being heard
Subtheme (c): timing: lack of information regarding when to start a bowel program

Theme 2: the impact of the journey on the child

Subtheme (a): universal embarrassment and assault to self-esteem
Subtheme (b): school issues

Theme 3: the family struggle

Subtheme (a): overwhelming stress
Subtheme (b): parents' role negotiation
Subtheme (c): advice to other families

Theme 4: the promise of the future

Subthemes (a): the joy
Subthemes (b): the frustration

Long Complicated Journey

The long complicated journey involved the family frustrations with the many trials of establishing and maintaining an effective bowel program. These frustrations were grounded in the uncertainly of accidents and included daily issues such as medications, diet, mobility, and relationship with HCPs. Subthemes included (a) uncertainty of accidents, (b) problems in relationships with HCP, and (c) lack of information regarding when to start a bowel program. One mother summed up the frustration of her child's bowel program as an ever-changing "bowel du jour."

The journey was not a smooth one, and the uncertainty was a major issue. One mother indicated, "We use to go from one extreme to the other (constipation to diarrhea)." Another parent discussed her misdiagnosis of liquid stool seeping out around the impaction as "diarrhea" and the problems caused by treating these symptoms as diarrhea.

> We would go for several weeks and everything would be fine and then he'd have an accident and I think [when I saw the liquid stool], 'Oh, gees, its diarrhea'… and you give 'em Imodium and then they become even more impacted. So…we start over…and just never seemed to achieve any kind of [satisfactory] bowel continence.

In addition, mobility contributed to the uncertainty of accidents. Children with SB who have lower level lesions are more likely to be walking but also are more likely to have flaccid rectal tone. This mobility combined with flaccid rectal tone for children of some participants made involuntary leakage of stool more likely and added additional challenges.

> Because he was moving and had an uneven gait, it was just sheer gravity. He would have accidents come out, whereas if he was just sitting still he didn't seem to have problems. But we wanted him to walk and that's what he wanted.…

Often, diet changes and medications are first-line interventions to establish effective programs or treat bowel problems. Diet changes were a constant frustration for these families and resulted in uncertain outcomes. Although diet manipulations often reduced constipation, participants reported the long-term inadequacy of common diet interventions in addressing the complex bowel continence issues.

> When he was little we used to give him cereal with fiber. He's a real good eater. I used to add the, uh, fiber flake things. He knows he has to eat fruits and vegetables….But all of his life he has had stains [in his underwear]. I would like to find a better program.

Mothers also reported feeling that unreasonable expectations were placed on them by the HCP regarding daily care and bowel management. One mother said she "wanted to scream" when the physician gave her another bran muffin recipe to help with fiber in the diet when adding fiber was just not sufficient to deal with the lack of intestinal motility caused by her child's neurogenic bowel.

The effective use of medications seemed to be a particular challenge for these mothers, and they reported trying many medications, often with little lasting success and lack of predictability.

> We started out with medicines by mouth when she was six months old. We tried softeners, Colace, Lactulose, Castoria just to keep her moving. Just to try to keep her from getting impacted. I used whatever was on sale.

In this long journey, parents experienced several problems in their relationships with HCPs, especially primary care providers, but also some specialists dealing with SB. These parents felt that frequently they were not being heard when they discussed bowel problems or that HCP did not see bowel problems as a priority. Parents felt that HCPs were just grateful that the children were alive and did not think about the future. One mother indicated about her daughter that "Kids need to have jobs, go to school and they're not going to achieve any of these things if they don't have bowel control." Parents were particularly concerned that bowel problems were not seen as a priority by HCP:

> It wasn't like the issue was taboo; it just wasn't a priority. It seemed like the emphasis was placed on shunts, bladder, and any kind of orthopedic problem. These seemed more pressing than any kind of bowel status. As a parent, I feel that if the health care provider isn't actively involved in treating kids with SB, they can't understand. I don't think most HCP understand how constricting bowel and bladder incontinence can be, especially for bowel. Nobody wants to walk around smelling bad.

Relating to HCPs, particularly HCPs who do not specialize in SB, around these issues remains a problem for many. One mother indicated,

I feel like physicians in general don't want to even talk about it. Doctors feel like it's never going to be an achievable thing for our kids so why bother. I felt like I had to do everything on my own.

In contrast, when HCPs who were knowledgeable and sensitive to bowel issues interacted with the parent, it had a powerful impact. One mother discussed a nurse's impact:

> I wish I had known her [nurse] when [child] was a baby, cause maybe the outcome would have been different….I always felt like she understood what families were going though, especially the patient, and worked hard to achieve bowel continence….I found her to be extremely helpful and sensitive in an area where it could be very uncomfortable to talk about.

Parents thought it was possible that this lack of "being heard" by HCPs was influenced by the HCPs' low expectations for kids with SB.

> If I took my 8 year old without SB to my pediatrician and he was incontinent of bowel, they'd be sending me to John Hopkins or Duke. But with our kids with SB they say 'it just a part of the condition you have to live with.'

The mothers indicated that the timing of initiation of bowel programs was another issue in their relationship with HCP. Many said that they did not have anyone initiate the discussion of bowel continence with them unless they brought it up. One even reported that they had not heard about bowel management until her child was in middle school. Another parent contributed,

> Everybody has their own pace and schedule [but] I am utterly amazed when I run into children that are 5 or 6 years old that have not been started on a bowel program. The earlier, the better. You are training the system, not the child.

None of the parents felt like that there was one best time for HCP to discuss bowel management. However, almost all parents discussed starting early.

> I think professionals, they should always tell you the pros and cons but they should also tell you down the line. I wish I had realized that the younger I started her it would become a normal part of life for her and it would still be a normal part of life today. By the time it came into her life, it was one more hassle and one more thing and she was rejecting it.

Impact on Child

Mothers indicated that the psychological impact on the child was tremendous. The impact of the journey on the child included two subthemes: (a) universal embarrassment and assault to self-esteem and (b) school issues.

All parents talked about universal embarrassment and assault to self-esteem. One mother indicated, “It’s acceptable to be in a wheelchair, it’s not acceptable to have bowel accidents and I cringe when I think how many years my kid has suffered with this.” Another mother of a teen was discussing embarrassment and the interviewer indicated, “It matters when you are sixteen,” the parent responded:

> It matters when you’re four, you’re five or in the second grade. I think the self-images of our kids are greatly reduced at a very young age by this lack of bowel control. [It] is just a detrimental thing socially and those bad feelings and those impressions from your peers hang in there. And those are the things you carry with you.

Mothers reported worrying about the social events their children will miss or the embarrassment they will experience if they have an accident in a social situation. Typical was the parent response “I know it has got to be the most frustrating thing they have ever had to deal with in their life.” Many mothers indicated that this problem was much harder on their child than mobility issues. Social isolation was common. Many parents said that their children had a few friends but very few sleepovers. “It’s just sad when your kid’s not able to spend the night anywhere, they’re not able to go on dates, and they’re not able to sit through biology class without having an accident. That’s no life you know.”

Parents also see problems as adolescents begin to manage their care. Often, when the parent is no longer as closely involved, they fear that adolescents may make decisions that compromise their health. One mother commented,

> At one point when he became a teenager, he finally told us he couldn’t understand why we had to do the bowel program. He decided to do the bowel program himself, which meant he didn’t do anything. He thought if he didn’t do it, it would eventually happen on its own. But it doesn’t work that way.

However, it was encouraging that parents also saw growth in the area of responsibility and self-esteem, even if the teen had problems in that area in the past. One mother reported this area of growth:

> I think [in the past] she has really isolated herself because she was concerned about continence. But as she gets older…like this weekend she took a friend to the game. I don’t think she would have done that a few years ago. She got up in the morning and did the bowel program so she could be extra safe.

School issues were also reported as “ever present” and were an important source of ongoing stress to the child. One participant said that her child goes to school worried that she smells bad or she is going to have an accident because she ate a Greek salad for dinner last night. If she smells something, she dashes out of the classroom to get to the nurses’ office. Parents also worry about how overwhelmed school personnel get with their child and the school personnel’s assessment of the family:

> School people get tired of it. You know and school nurse conveys: ‘What’s wrong with this family?’ and ‘Why can’t they get it together?’ you know they’re burned out with it. So it’s just a real vicious cycle of bad vibes.

The Family Struggle

Problems with the child’s bowel function affected the whole family. This family theme included the (a) overwhelming stress, (b) parents’ role negotiation, and (c) advice to other families. Mothers reported overwhelming family stress, “Lots of stress.” Some families found adolescence the most stressful. “These kids reach adolescence, which is a particularly rebellious time anyway, they’re going to rebel even more. And, so, it’s lots of friction going on between mom and daughter, or dad and daughter.”

Multiple participants reported that family’s life revolves around bowel management. “You find yourself winding your whole life around this bowel program or fear of the accident. That just grinds away at our families.” All families in the study had examples to share regarding the family struggle on vacations. One mother reported,

> We were going to see a show in New York City one year. He had diarrhea like you wouldn’t believe. We had to stop and buy clothes and diapers. We were late for the show. It was horrible. When we plan a vacation, we make sure we have a prescription for medicines and extra supplies. I keep spare supplies in the car always.

Another mother said that she was always concerned that her son would have an accident.

> When we went on vacation, we would have horrible experiences where he would get diarrhea and the vacation wasn’t a good one for the family. These were not his fault, but the accidents happened and it was frustrating and embarrassing when you are on the beach with other families and friends. Nobody wants to sit on the beach and have a big bowel accident.… How embarrassing for us all.
>
> Finding the right bowel program was a life filled with stress for the whole family. We’ve used suppositories, enemas, everything you can think of orally: Senekot, Milk of Magnesia, Perdiem, we have an enema

> continence catheter kit, we've used extension tubes for enemas, we've played around with just about everything. We've done different doses, different times of day, we've worked very hard on diet. We've restricted some foods. You know we had done everything. And it's not that these things are bad, or that they're completely unsuccessful, they're not one hundred percent reliable. And one accident is one too many.

Parents' role negotiations were a key factor for many parents. In study families, there were conflicts regarding bowel management between the marital partners and between parents and the adolescent striving for independence. It was hard for the parents to take a less active role in their child's bladder and bowel management. Parents were worried that it would not be done often enough and that complications would occur.

Parents balanced the role of parents who provided independence opportunities and those who provided a safety net for their children. If no stool was seen in a certain number of days, then the parent would step in and help with diet, medications, and enemas. One mother reported,

> Sometimes he has a little sometimes a lot. It's hard to quantify it because I am not in there anymore. Sometimes he comes out [of the bathroom] too fast and I send him back because I know he couldn't have gone. You know, it was easier when I was in there. But I do ask him, he rolls his eyes at me but does not answer.

Mothers who had experienced this overwhelming stress were also very interested in giving advice and support to other families. These mothers wanted to help other families prevent these struggles, to pass on the "lessons learned," and to keep them from experiencing the overwhelming stress. Advice from one mother is as follows: "It's trial and error and don't expect it to work all the time. As they get older you have to change what they are doing. Also give them the opportunity to learn themselves." Another commented: "we lost some valuable time by not having the issue addressed early on—they've come a long way treating children with SB by addressing this issue from the beginning—don't wait." A third recommended:

> My advice for new parents is that there are so many other issues for a new parent anyway that bowel doesn't seem to be a priority in the beginning, but don't ignore that....Consider all options and be proactive. It all goes back to 'We're our child's expert' so in conjunction with a nurse make decisions but make sure they are informed decisions.

Parents had a specific advice about diet,

> Do not fiddle and fiddle with [diet]....Diet is important. It's important for anybody, but I think that when your talking to [an HCP] and they're just constantly preaching that stuff to you, you're the one living with it and don't be down on yourself because those things aren't working. If it's not working—my advice is to get a cecostomy and get it done as young as you can.

One mom warned that you have to put the bowel management, indeed all SB management, in context, making sure that you have the child and not the condition topmost in your attention:

> I talk to new parents all the time and I say to them 'You have to treat this child like any of your other children. This child is a child. This is not a handicapped child. The child is a child first who happens to have a physical disability.'

Promise of the Future

This theme focused on a future free of bowel accidents because of the surgical options available and included two subthemes that described their experience: (a) joy and (b) frustration. The promise of surgery has given many families and children hope that a future free from accidents may be attainable. The appendicocecostomy (a surgery that uses the appendix to make a catherizable stoma on the abdomen) and the cecostomy (a tube placed in the abdomen that connects directly into the colon) brought joy to some participants. This procedure allows for a full "clean out" of the large intestine. If this antegrade enema is done frequently enough (every 1–3 days), it minimizes or eliminates accidents as there is no fecal matter to "leak out." Families report serious consideration before the surgery.

> We went through a lot before we decided to do this surgery (appendicocecostomy). It wasn't a surgery we took lightly. But we felt like (child's name) kept having so many bowel accidents and had such a reactive GI system that after several incidences at school where it was just totally humiliating, you know, something had to be done and other bowel programs weren't working and it was making (child's name) anxious. This gives a little more confidence.

For some, the surgery brought joy:

> Since my daughter got the cecostomy, she is totally independent in managing her bowel program. She irrigates every other day before she goes to bed. She irrigates through a trapdoor device. The enema comes through and then the stool comes out. She plans for about an hour for this. She has had no accidents in a whole year! This procedure was the best thing that could have happened for my daughter. It has boosted her self-esteem. If only she could have had this done sooner. It was worth it!

However, others report a different experience, one filled with frustrations. The surgery is not without its complications. Skin breakdown, stoma problems, long bowel programs, excessive gas, and pain were mentioned by participants in this study. Families discussed those frustrations:

> If he eats certain foods (they're like trigger foods)—he will have an accident. Now, the good news is that after all this torturous treachery is that if he does get loose stool he can just flush it out of him, whereas before it would just come and come and come. (It was like, 'When is this ever going to end').

Another family discussed the complication of pain, "It caused her so much pain. And then, she would have diarrhea for a long time afterwards. It was too much, so we stopped that."

Some families indicated that due to these complications that they had experienced, they would not choose to have the surgery again. However, other families conveyed a sense of confidence that their frustrations could be managed and that the surgery had "changed their life" and was worth the "trade-offs." The families that formed the latter opinion had fairly minor complications.

Discussion and Implications for Practice

The major contribution of this study is a fuller understanding of one of the most difficult areas for these children and their families, finding an effective bowel management program in the context of this complex condition. The results provide information on a critical outcome variable in the Ecological Model of Adaptation in Spina Bifida and an increased understanding of the parent's impact on this outcome. Further, the study data give insight into the parent's experience as a self-care agent.

This study has the potential to raise awareness in HCPs regarding this critical issue. As with individuals in the study of Lie et al. (1991), participants in this study reported that bowel incontinence "bothered me more than anything in the world with SB." The data from this study can help children with SB, their families, and HCP move bowel continence up the priority list for assessment and intervention. These mother's stories illustrated the frustration the families felt when they were "not being heard" by HCPs and the positive power of sensitive providers.

Most of the families reported that unreasonable expectations were placed on them by the HCP regarding daily care and bowel management. King, King, Rosenbaum, and Goffin (1999) reported higher parental satisfaction when given ultimate control over decision making. It is important for the HCP to support family-centered care (FCC) where there is a partnership between the parents and the HCP. This involves supportive and respectful treatment and information exchange. Central to FCC is active involvement of families in identifying and prioritizing problems. Clearly, bowel continence is a high priority for these families and needs to be an area of focus for the HCP. Today, many children with SB are cared for in interdisciplinary SB programs where bowel continence is addressed. However, not all families have access to such programs, and families interact with a wide variety of HCPs who are less knowledgeable and sensitive than HCPs who specialize in SB. It is important for all interdisciplinary HCPs who they encounter to be sensitive to the needs of these families.

The families universally reported a difficult and long journey finding an effective bowel program for their children with SB. They had encountered major barriers to achieving continence. They were overwhelmed by the daily management of their children, found interactions with HCP problematic, and found timing issues in bowel management a concern. Many appointments with multiple specialists placed financial constraints on them as well as the differing opinions of each specialty as to the best care for the children. The daily bladder and bowel routines consumed the whole family unit. Vacations and trips were difficult for everyone.

With all the medical advances which have been made for children with SB, their future looks much brighter. The algorithm developed by Leibold et al. (2000) and the materials on bowel management available from the Spina Bifida Association (Leibold, Braun, & Cole, 1995) are important resources for the parent–HCP partnership. The physiology of the gastrointestinal (GI) system is complex. Parents may need reorientation as the child develops, and the bowel program may need to be changed. It may be hard to initially understand that the same neurological impairment that yields better mobility function (i.e., more likely to be a community ambulator) may have a more negative impact on the GI system. Lower level lesions that produce flaccid response mean that the child is less likely to have muscles that spasm but also more likely to have flaccid sphincters, a major risk for rectal sphincter incompetence and ongoing bowel incontinence. The parents and children need to be provided the support and information necessary to succeed in a bowel management program (Erickson & Ray, 2004).

In the last 10 years, several bowel surgeries have added other options for some families. Current data indicate that for many this is a "life-changing option," and several articles reported high patient satisfaction (Van Savage & Yepuri, 2001; Van Savage & Yohannes, 2000; Webb et al., 1998). Families reported that there is less mess and more predictability, it is esthetically more appealing, and there is the potential for more independent management of the bowel program by the child. However, both surgeries also have risks. Evaluations of these procedures have identified complications such as rectal soiling, skin necrosis, stomal granulations, stenosis of the stoma (which frequently required sequential dilation in an outpatient setting), cecostomy tube dislodging, and obstructive volvulus (occurring with malrotation and requiring surgical revision; Chait, Shandling, Richards, & Connolly, 1997; Hensle et al., 1998; Shandling, Chait, & Richards, 1996; Van Savage & Yohannes, 2000). These surgeries are not an option for all children. In a clinical interaction, one teen indicated, "I just do not want one more hole in my body." In addition, not all individuals continue to use the stoma after the surgery nor are all individuals independent after the surgery (Hensle et al., 1998). Further, there are little data in the literature that describe the experience of the child, adolescent, or young adult's experience living with this surgical option. In addition, emerging data suggest that electrical stimulation used to increase bladder control might also be useful in reducing refractory incontinence for children with SB (Han et al., 2004).

Health care providers may find several books developed for individuals with SB and their parents useful to review (Table 4). Providing a lending library or giving books like *SPINAbilities* (Lutkenhoff & Oppenheimer, 1999) to preteens at clinic visits as they enter adolescence would be useful. A successful strategy used by several clinicians is to ask the preadolescents or adolescents (and potentially the parent) to review the chapter or book for the HCP to see if they would feel that it would be useful to others. This also sets up the expectation that the child and family will discuss their review of the book with the HCP. This gives HCPs feedback about what was most useful to that individual and tends to open up discussion of other topics or areas of interest. Several children asked to review books for these authors have actually volunteered to review others, indicating that they carefully evaluated the content and enjoyed the "assignment."

Developing strategies for effective bowel management remains a research priority for the Center for Disease Control's National Center on Birth Defects and Developmental Disabilities (NCBDDD). NCBDDD, via a collaborative agreement with the Association for University Centers on Disability, recently identified bowel and bladder continence among children with SB as one of their four focused research opportunities. Clearly, there is a need to continue to seek more effective management strategies for developing effective bowel program options for this population. These mothers indicate that these new strategies would be welcome. Their stories also indicate the importance of supportive relationships with HCP as families travel this complicated journey.

Limitations

The sample included a small number of mothers of children with SB from one geographical location who volunteered to be interviewed. However, as Sandelowski (2000) argued, descriptive studies, even those with small samples, can be very useful in providing a better understanding of a targeted sample. In this study, all children with SB had lumbar lesions. Although the themes generated are consistent with clinical practice, we cannot generalize these themes or exemplars to all mothers of children with SB or to those whose children have higher (thoracic) or lower (sacral) lesions. Further, we cannot assume that these findings accurately

Table 4. Resources for Individuals With SB and Their Parents

Bowel Continence and Spina Bifida (Leibold et al., 1995)	An excellent book aimed at anyone trying to attain bowel continence with sample menus, bowel tracking charts, and glossary of terms.
Children With Spina Bifida: A Parents' Guide (Lutkenhoff & Oppenheimer, 1999)	This book provides parents with information, guidance, and support to help meet their child's needs through childhood. It has a very good chapter on bowel management by Mason, D. B., Santoro, R. D., and Kaull, A. (pp. 87–106).
SPINAbilities: A Young Person's Guide To Spina Bifida (Lutkenhoff & Oppenheimer, 1999)	An extremely user-friendly book for preteens and teens. It gives practical tips and suggestions for becoming independent and managing health care. It is useful for parents as well.
An Introduction to Spina Bifida (McLone & Bowman, 2005)	
SBA Editorial Review Board (Eds.). (2005). *Health guide for adults living with spina bifida.* Washington, DC: Spina Bifida Association.	This book provides health information and resources to help adults manage their health and prevent further complications.

Note. All can be obtained from the Spina Bifida Association website (www.spinabifidaassociation.org).

portray either the experiences of fathers, siblings, or the individuals with SB.

This study did not address the transition to self-management of bowel program by the child. Nonetheless, these findings can be very valuable in sensitizing the HCP about potential family's perspectives and issues and are likely to be "transferable" (Lincoln & Guba, 1985) or relevant to HCP from multiple disciplines and settings. Future research should include interviews with other family members, especially the children themselves. Their perspectives are critical to understanding effective self-management of this complex condition. Of special interest would be interviews of individuals who choose to have one of the surgical options now available.

CONCLUSION

This study has resulted in the identification of four themes and 10 subthemes that describe the participants' experiences of finding an effective bowel program for their children. It is clear that this component of SB is a major stressor for both child and his or her family. This long complicated journey was made problematic by HCPs who were either unfamiliar or insensitive to the family's need for bowel management counseling and information. Surgical options have brought joy for some families but frustrations for others. Additional studies are needed that describe the experience of finding an effective bowel program from the child's or adolescent's perspective. Especially interesting would be the experience of those who choose to have one of the surgical options now available.

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